

Research into awareness, attitudes and provision of best practice advance care planning, palliative care and end of life care within general practice

Department of Health

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1. Executive summary and recommendations

The study reported here consisted of large scale qualitative fieldwork undertaken with general practitioners (GPs), allied health professionals and medical specialists in August and September 2016. 20 group discussions, four online boards and 70 in-depth interviews were conducted. Following the qualitative work, an online survey of GPs (n=1,000) was conducted, with fieldwork undertaken in November and December 2016 and January 2017. The primary research was informed by a literature review and stakeholder interviews.

This report adds to the existing literature in a number of important ways. In summary, it has clarified that GPs are doing more palliative care (PC) than previously thought, are especially ready to engage with specialist PC nurses, and that only a small proportion of GPs are outright rejectors of PC.

While the study has identified that GPs would like more resources (both educational and more practical supports), the GP segmentation highlights the importance of tailored interventions that take into account different attitudes towards PC as well as preferences for doing medicine overall.

However, the research has also shown that most GPs would benefit from strategies to make resources more accessible and visible, and from the explicit inclusion of PC in continuing service integration.

1.1. GPs are doing more palliative care than previously thought

While Bettering the Evaluation and Care of Health (BEACH) data – to date the most reliable national data on GP PC practices – estimates that GPs see PC patients at one in 1,000 patient consultations, this study suggests that rates of PC consultations are actually much higher – at approximately one in every 100 consultations. There are a number of explanations for this, including the increased efficacy of a purpose-built survey in measuring GP PC behaviour and a changing patient base.

In addition, our analysis shows it is likely that even more patients with advanced chronic disease would be identified for the introduction of a more palliative approach if the surprise question (*“would you be surprised if your patient died in the next year”*) was more widely used and known.¹²

1.2. What do GPs mean when they report doing palliative care?

While a core cohort of GPs are knowledgeable about PC and end of life care (EoLC), a substantial proportion are not.

GP understandings of PC and EoLC are highly fragmented, and most GPs do not differentiate between the two. Many GPs define PC very narrowly in terms of non-curative care and pain and comfort relief. A much smaller proportion embrace the idea of the whole patient, and hence a wider range of care options – including, for instance, providing emotional support, family advice and negotiation, and helping patients fulfil their ‘bucket lists’. This range of views is reflected in approaches to best practice care.

This study has suggested that a lack of a precise definition for PC is a barrier to best practice. Having said this, while there may be value in a broader community project to

¹ Currently part of the palliative care toolkit.

² Because of the way in which patients with cancer are viewed differently to potentially palliative patients with other chronic diseases, and dementia patients have specific issues again with respect to palliative and end of life care, we have broadly referred to patients with ‘cancer’, ‘dementia’ and ‘chronic disease’ patient in the body of this report, acknowledging that each group technically has a chronic condition.

reframe PC and remove the stigma around discussing death, this study has indicated there would be little benefit in a campaign with the sole aim redefining PC for GPs.

1.3. Is best practice palliative care occurring?

GPs say that the different settings for PC – in-home, in residential aged care facilities (RACFs), hospices and hospitals – place very different demands on general practice, and have different ramifications for best practice PC.

GPs see the in-home setting as being the hardest environment in which to do best practice PC, with best practice being slightly easier to achieve in RACFs and much easier in hospices and hospitals.

While GPs recognise that many patients wanted to die at home, they felt that there are inevitably trade-offs to be made in this setting. The extent to which specialist PC, nursing and allied health services are available, and the coordination of these, as well as the ability of families to provide personal care are all seen as determinants of whether best practice can be achieved.

The services and staff available in RACFs to some extent ‘solve’ key issues GPs have with caring for palliative patients in-home. However, the variable quality of RACF staff, and (often poor) interaction between RACF, locum services and hospital emergency departments are all seen as barriers to best practice.

GPs say they are largely not involved when their patients receive PC in hospital and hospice settings, although they feel that their inclusion would be beneficial for long-term patients.

1.4. Overcoming barriers to best practice palliative care

In this study, the barriers and enablers to best practice PC emerged as dynamic and intertwining. This analysis suggests that GPs who are already interested and engaged in PC weave themselves into something of a virtuous circle, where individual motivation, education/training and exposure drive and reinforce interest and engagement. However, GPs with less interest in, or experience of, PC tend not to have these cushioning structures, which in turn make PC individual episodes more difficult. Structural factors work against both groups, diminishing GP engagement and their ability to provide best practice care.

1.5. Different GP segments have different needs in delivering best practice PC

Statistical analysis revealed four different segments of GPs with respect to PC. The segments differ on the extent to which GPs are interested in doing PC and find it rewarding, and whether they are comfortable with, and knowledgeable about PC. They are:

- *Palliative Care Experts* (25%): are comfortable, knowledgeable, interested and engaged. They do substantially more PC than average, value an holistic approach to patient care, and find PC much more rewarding than other segments.
- *Palliative Care Aspirers* (39%): are interested in doing more PC, but their current skill/knowledge levels and lower exposure to palliative patients hold them back.
- *Palliative Care Indifferent* (23%): will do PC if required, but do not seek it out. They are less comfortable with, and less technically skilled in, PC.
- *Palliative Care Avoiders* (14%): actively avoid PC, and dislike many of the tasks associated with it. They are uncomfortable with the soft skills that other GPs told us are required for best practice PC, including dealing with emotion, talking about death, and liaising with families.

Nearly two thirds of GPs are interested in providing palliative care. However, it is clear that there is no ‘one size fits all’ approach to engaging the different segments and that their different attitudinal and behavioural patterns need to be catered for.

1.6. Advance care planning

GPs vary widely in terms of when they think advance care planning (ACP) should be raised and advance care directives (ACDs) completed – ranging from an issue to be discussed with fit and healthy patients to something done at the end stage of a terminal illness.

It would appear that communicating to GPs that their patients are expecting them to broach the topic, coupled with a community campaign to promote and normalise completion of ACDs at the 75+ health check or on diagnosis of a chronic or life limiting illness, and combined with easy access to forms (and the facilitating involvement of practice managers and/or nurses) would go some way to ensuring more ACDs are in place.

1.7. Tools and training

A majority of GPs are interested in learning more about PC. Above all, they are interested in local sources of information and easily absorbed and applied resources. This suggests that local Primary Health Networks (PHNs) and specialist PC care teams will be invaluable in helping translate interest to engagement, and avoidance to workable strategies for dealing with PC patients (upskilling or referral). Corporate medical practices' education offering will also be a key channel.

Given the way in which early exposure appears to trigger later interest in PC, continuing to focus on PC as part of the medical curriculum and GP training programs will also be very important to building a future medical workforce that is engaged with PC. However, the results of this will be generational rather than immediate.

1.8. Scope for interventions and recommendations

This research aligned with goals two and five of *The National Palliative Care Strategy 2010 - Supporting Australians to Live Well at the End of Life*: 'to enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to PC services' and 'to build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care'.

1.8.1. Goal 2: Awareness

This research has identified that while GPs are more engaged in PC and ACP than previous data indicated, there is still a strong appetite for more knowledge.

Rather than a campaign to reframe PC, GPs are calling for specific information – for instance, on symptom management, use of Medicare Benefits Schedule (MBS) items, pre-emptive prescribing and completing ACDs as well as practical information on local service networks.³ This would enable them to build confidence and provide more PC.

This study suggests that there is a strong role for increasing awareness of existing comprehensive PC and EoLC resources amongst more engaged GPs. In addition, there also appears to be a role for setting goals for best practice PC including as it applies to:

- managing symptoms to minimise impact on activities of daily living
- reviewing unnecessary medicines / treatment
- introduction to a local specialist PC team
- conversations around planning for a good death

³ We note that that different legislation and terminology for ACDs exists across Australia – for consistency and readability we have used the term ACD throughout this report, and refer interested readers to www.healthpractitioners.com.au/advance-health-directives/

- dealing well with families and cross-cultural care
- anticipatory prescribing and care planning at end of life, and
- managing acute deterioration in the community.

The range of attitudes with respect to PC, as outlined above, means that the different segments of GPs are at different stages of readiness to upskill for PC. While some GPs will seek out resources and education (*Palliative Care Experts*), others need to be informed so they know to seek it out (*Palliative Care Aspirers*) while the third and fourth group will need to be nudged to engage with information and better practice (*Palliative Care Indifferent* and *Avoiders*).

1.8.2. Goal 5: Capacity

The study identified a number of areas of capacity that are limiting delivery of best practice PC, both within general practice and in the broader health system.

Firstly, addressing capacity will involve GP knowledge, skills and triggers to engage in PC and ACP

These include:

- creating easy access information on how to manage symptoms and local service networks, including referral pathways for GPs who choose not to engage
- integrating the surprise question for chronically ill patients and completion of ACDs into medical software packages at key points in time (75+ health check, answer to surprise question is yes, dementia diagnosis)
- establishing (clinical) triggers in the chronic disease management framework, promoting GPs to consider/adopt more holistic care, ACP and PC
- encouraging peak bodies, PHNs, local specialist PC services and other relevant organisations etc. to signal that GP have an important role in PC, and
- working with corporate and locum services to ensure that they are structured for best practice (including improve continuity of after-hours care and care of a patient by a GP who is not a patient's usual doctor).

Secondly, there are funding and resourcing needs

These include:

- reviewing funding mechanisms for:
 - practice nurse involvement in ACP/ACDs and care coordination
 - elements of non-billable GP PC work such as consultations with families, service coordination, after-hours calls from RACF staff and over the phone prescribing and consultation with PC nurses
- considering resourcing for in-home equipment and services, and respite care, and
- considering formalising roles for practice managers and nurses (some ACD tasks, case coordination) and specialist PC nurses (prescribing) for patients in community

Thirdly, best practice PC requires better health system integration

The study identified a number of areas where health system integration could be improved, including mechanisms for:

- secure messaging and better sharing of ACP and clinical records across the health system (including e.g. My Health Record)
- specialist-GP shared care for chronic disease patients, and

- GP and after hours locum services shared care for (advanced) chronic disease and palliative patients.

Out of scope areas, affecting, but not specific to general practice

Other areas of capacity identified, but out of scope for this project included:

- the extent to which patients, their families and carers/advocates can also drive change in GP behaviour
- the way in which specialists can better initiate timely palliative pathways (especially for cancer patients)
- increasing access to specialist PC services
- ensuring qualified nursing staff are available in RACFs
- ensuring that RACF staff are trained in palliative care
- the need for innovative solutions to distance delivery, setting transition and episodes of acute deterioration in the community, and continuity of care across silos of care, and
- the need to scale up solutions that have tested well.

1.9. Recommendations

Recommendation 1. Chronic Disease Management Frameworks

Incorporating the surprise question and clinical triggers to a palliative approach into chronic disease management frameworks, especially for those patients with advanced progressive chronic diseases.

Rationale

More patients with advanced chronic disease would be identified for the introduction of a more palliative approach if the surprise question (*“would you be surprised if your patient died in the next year?”*) was more widely used and known.

Chronic diseases are not chronic forever, but progress to advanced disease, a terminal phase and death.

Recognition of this in the chronic disease framework and also the PC strategy will provide the clinical rationale for GPs, specialists and health services to reframe their discussions with patients and communication with each other about when and how to introduce discussion of ACP and PC.

Recommendation 2. Better defining the role of the GP

Defining the role of the GP in PC to encompass a basic clinical level of care (e.g. as might be expected of *Palliative Care Indifferent* and *Palliative Care Avoiders*) and also a more engaged extended person-centred level of care (e.g. as could be done by *Palliative Care Aspirers* and *Experts*).

Rationale

Despite the existence of professional standards such as Good Medical Practice and the AMA standards for EoLC, it is clear that GPs are essentially self-defining their role. Signals as to what is expected of GPs from credible sources would assist in clarifying this situation.

However, rather than using one level of care to define best practice, we are suggesting that a two-dimensional definition avoids deterring either one group of GPs – those who want to do the right thing for their patient without too much personal involvement and those who want to provide person-centred best practice PC.

Recommendation 3. Local Directories

Encourage PHNs to develop and keep up-to-date directories of local PC resources for GPs and other service providers (for instance as part of Health Pathways).

Rationale

GPs have identified the low level of awareness of local resources as a barrier to engaging in PC. PHNs are ideally placed to do this work. Stakeholders identified that it is important that PHNs are appropriately funded to lead this work.

Recommendation 4. 'Cheat sheet'

Developing and ongoing updating of an easy access 'cheat sheet' that enables GPs to quickly acquire and apply information on symptom management (e.g. using or expanding on their existing clinical skillset), use of MBS items and completing ACDs (for instance as part of Health Pathways).

Rationale

GPs have identified lack of easily accessible knowledge to do with a number of aspects of PC. Having a quick look up document – available in hard copy and online – would be well received by GPs, to build confidence and enable them to provide more palliative care.

Recommendation 5. Better promoting the palliAGEDgp app

Promoting the palliAGEDgp so that GPs are able to use it if they would like to.

Rationale

While not as top of mind as a 'cheat sheet', palliAGEDgp was also considered a useful resource, however there was very low awareness of the app. Promoting it in an way that delivered practical uptake would assist in creating access and use.

Recommendation 6. Better integration and communication with other parts of the health system

Improving coordination and communication between practice-based GPs, locum services, RACFs, specialists, ambulance services and hospitals would appear to be beneficial in introducing a palliative approach prior to the terminal stage (where appropriate) and also in ensuring efficient and effective treatment of palliative patients.⁴

A quick win in this area may be the promotion or formalisation of specialist PC nurses as having a general practice liaison and coordination/shared care role.

Rationale

The need for improved health service integration is widely recognised. Despite funding and organisational silos, there is a growing sense of shared responsibility for improved integration by many different practitioners and services. This suggests that there are likely to be many opportunities for improving GP links for ACP and PC.

Examples can be found in service integration strategies by PHNs – for instance, Health Pathways and other local clinical pathways for GPs to share care and refer to other services including for chronic diseases, ACP and PC. To illustrate – a specific example shared with our team was the *Victorian consensus guidelines on integrated emergency care for older persons*. The GP Shared Care Model was also cited as another example in this context.

⁴ We note that each PC setting – in-home, in RACF, hospice – requires further work on how to address service gaps.

Recommendation 7. Encouraging referrals to specialist PC teams or GPs who are Palliative Care Experts

Encouraging referral to appropriate expertise where GPs are not confident in delivering quality PC care.

Rationale

A small proportion of GPs (14%) actively avoid PC while a larger proportion (23%) are indifferent. While GPs within both these segments indicated they would like further training, it is likely that PC training may not receive the same priority as other interests. To ensure patients have access to best practice PC, guidelines for GPs should include referral mechanisms as well as strategies to engage and resource GPs (through building links with PC services, knowledge and confidence).

Recommendation 8. Adjusting medical software to include the surprise question and completion of ACDs

Building the surprise question for chronically ill patients and completion of ACDs into medical software packages, such as 75+ health check, dementia diagnosis, and chronic disease management templates.

Rationale

GPs have told us that medical software can be a good source of behavioural prompts and templates, and this would seem a good way to promote and normalise use of the surprise question and ACP. Ideally these would seamlessly integrate with existing tools and so be incorporated as part of the Chronic Disease Management Framework.

Recommendation 9. Promoting the role of general practice nurses

Promoting or formalising the role of general practice nurses in completing or contributing to ACDs and care coordination.

Rationale

General practice nurses can potentially play a key role for patients who would benefit from discussion around or completing ACDs and accessing other community services, particularly in practices where GPs are too busy or uncomfortable with ACD and some of the care coordination tasks.

We note that these nurses already play a key role in managing the care of chronically ill patients, especially those with co-morbidities, and may be well-placed to be part of a general practice 'team' that ascertains when and whether a palliative approach would benefit patients as their disease progresses.

2. Background and methodology

2.1. Background

The National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life (the Strategy) represents the combined commitments of the Australian, state and territory governments, PC service providers and community based organisations to develop and implement consistent PC policies, strategies and services Australia.

This research aligned with goals two and five of the Strategy: ‘to enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to PC services’ and ‘to build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care’.

Amongst health professionals, GPs had been identified as a service gap, particularly in relation to their level of understanding of their role in the provision of advice regarding ACP and delivering PC in the community. This project was designed to build an evidence base to help guide development of capacity and capability in general practice.

2.2. Aim

The objectives of the research were to understand:

1. the awareness, knowledge, and attitudes about ACP, PC and EoLC within general practice
2. how health professionals in general practice describe their role and scope of practice in relation to ACP, PC and EoLC, and which aspects of best practice PC they are currently providing
3. the perceived enablers and barriers in the provision of ACP and best practice PC and EoLC within general practice and report on the system changes that are needed to support best practice, and
4. the awareness and utilisation of currently available palliative care and ACP tools and training by health professional working in general practice, and perceived barriers to accessing these tools and educational resources.

2.3. Methodology

This comprehensive research program comprised:

1. Review: a literature scan and expert-stakeholder depth interviews which identified issues for exploration in the primary research with health professionals.
2. Explore: large-scale, national qualitative phase with GPs, specialists and allied health professionals – 20 group discussions, four online boards and 70 in-depth interviews conducted nationally.
3. Test: a representative quantitative survey of 1,000 GPs from around Australia.

Ethics approval for the primary research activities (qualitative and quantitative) was sought and granted by the Department of Health’s Human Research Ethic Committee.

A detailed methodology is provided at Appendix 2.

2.4. Reading this report

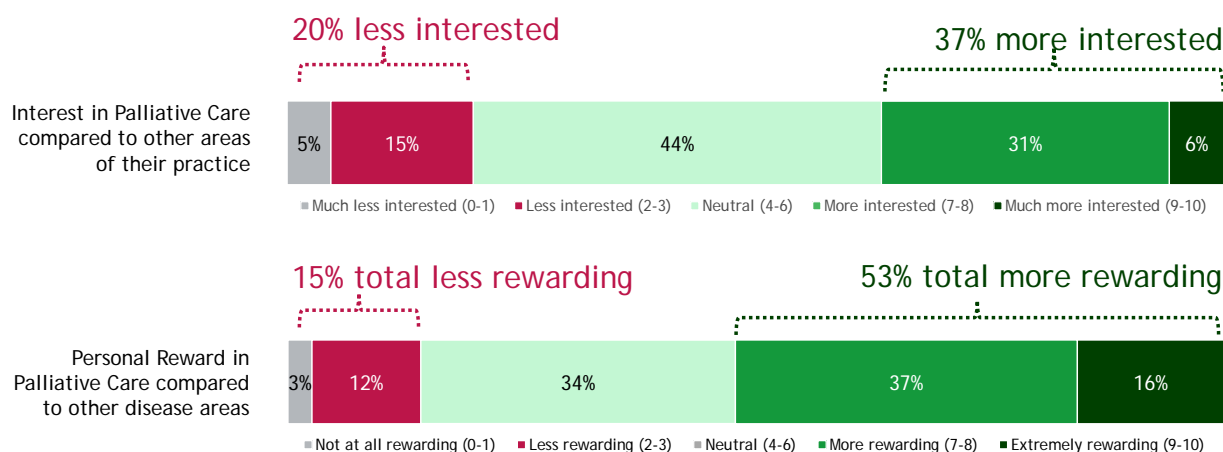
This report reflects both qualitative and quantitative research findings. Where possible we have lead report sections with the quantitative findings and then used the more in-depth qualitative results to provide context and depth. Introducing the four GP ‘segments’

2.5. Interest and level of personal reward in palliative care

The survey data showed that GP interest in PC was polarised. One third of GPs (37%) were more interested in PC compared with other areas of their practice – one in sixteen (6%) were much more interested – while one in five (20%) said they were less interested.

Over half (53%) said PC was at least somewhat more rewarding, while one in six (15%) said they found it less rewarding than other areas of care.

Figure 1: Level of interest and personal reward in palliative care



B8. In comparison to other areas of your practice, how interested are you in Palliative Care? Base: total sample, weighted, n=1000.
 B9: In comparison to managing other disease areas, how personally rewarding do you find the practice of Palliative Care? Base: total sample, weighted, n=1000.

2.6. A palliative-care focussed segmentation of GPs in Australia

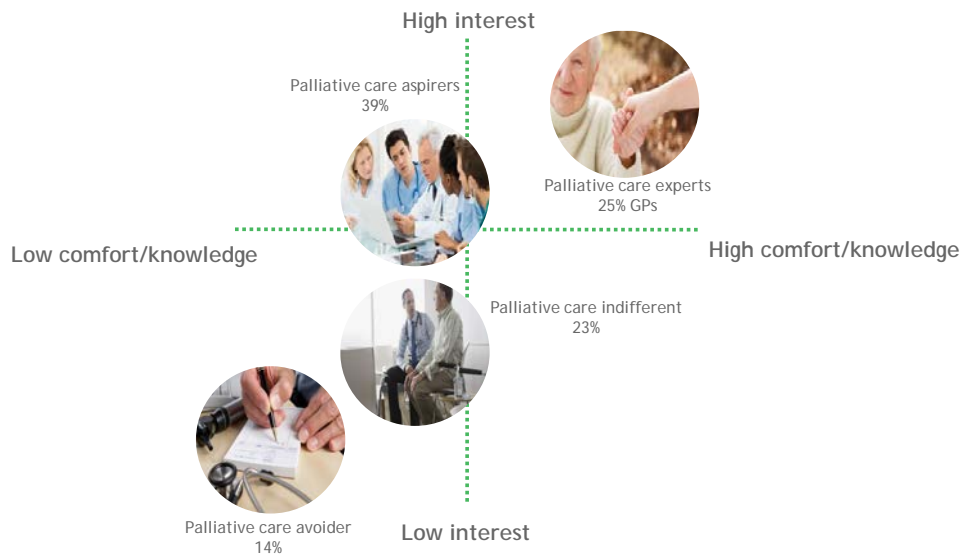
Further statistical analysis (latent class analysis) revealed four different attitudinal/behavioural segments of GPs with respect to PC. The segments differed on two key aspects: the extent to which they were interested in doing PC and found it rewarding, and whether they were comfortable with, and felt knowledgeable about PC.

The four segments are detailed below:

- *Palliative Care Experts* (25%): are comfortable, knowledgeable, interested and engaged. They do substantially more PC than average, value an holistic approach to patient care, and find PC much more rewarding than other segments.
- *Palliative Care Aspirers* (39%): are interested in doing more PC, but their current skill/knowledge levels and lower exposure to palliative patients hold them back.
- *Palliative Care Indifferent* (23%): will do PC if required, but do not seek it out. They are less comfortable with, and technically skilled in, PC.
- *Palliative Care Avoiders* (14%): actively avoid PC, and dislike many of the tasks associated with it. They are uncomfortable with the soft skills that other GPs told us are required for best practice PC, including dealing with emotion, talking about death, and liaising with families.

While *Palliative Care Aspirers* are already motivated to do PC (but might need to be made more aware of the tools and training that would increase the likelihood of them doing better), *Palliative Care Indifferent* and *Avoiders* are likely to require behavioural nudges that do not rely on their intrinsic goodwill.

Figure 1: Segment interest and knowledge in palliative care



Below we outline the segments in more detail.

2.6.1. Palliative Care Experts

Palliative Care Experts are passionate, committed GPs who find PC rewarding. They are very interested in, and much more knowledgeable about PC than the average Australian GP – but nearly all (93%) are keen to understand more. Dealing with conflict in the patient’s family is the aspect they are least comfortable with. They are most likely of all the segments to see the lack of good quality carers in RACFs as a significant barrier to best practice. They are also more likely to emphasise the role of good communication in the delivery of best practice PC.

Their demographic skews are: significantly more likely to practice in regional/rural areas, significantly more likely to be 55+ years-old, and significantly more likely to be a principal/director in their practice.

2.6.2. Palliative Care Aspirers

Palliative Care Aspirers represent the largest segment – nearly four in ten Australian GPs (39%). They are interested in PC, but not as knowledgeable or experienced as the *Experts*. They find PC more personally rewarding than other areas of their practice, and are generally comfortable delivering most aspects of PC. This segment is most likely to say they are seeing an increase in interest for ACP in their community.

They see PC as an important part of a GP’s job, but are also more likely than any other segment to see it as a demanding part of their job.

2.6.3. Palliative Care Indifferent

Palliative Care Indifferent will do PC, but won’t seek it out. They find it less interesting than other areas of their practice, and are have slightly lower self-rated knowledge than average. They are also less comfortable dealing with conflict in patient’s families, doing case conferencing, after hours contact and home visits.

They are among the least likely to see PC as an important part of their job, and least likely to see quality of care in RACFs as a barrier to best practice. This implies that they tend to have lower standards in implementing and managing PC in a ‘best practice’ format.

They are less likely to agree that ACPs are valuable because they give health professionals certainty.

They are relatively unsure about where to access support services – and are more likely to cite this as a key barrier to delivering best practice PC.

They are least likely to be a practice principal/director, and most do less than 1 home visit per month, on average.

2.6.4. Palliative Care Avoiders

Palliative Care Avoiders have less PC encounters than any other segment. They are far less interested and find it far less rewarding than average. They also have much lower levels of self-reported knowledge. This group is likely to only do PC when they really have to, can't get out of it or pass to a colleague – such as a very long-term patient.

They are uncomfortable with the 'soft skills' aspects of PC, they are uncomfortable dealing with patients' families and avoid talking about death wherever they can. They are also less comfortable with pain management and non-pain symptom control aspects of PC.

They see PC as much more demanding as other parts of their work and are much more likely to see doing good PC as very hard. Further, they are much more likely to agree 'it's hard to be sure that your skills in PC are up to date'.

They are also strongly against the idea of doing out-of-hours work or visiting patients in RACFs or at home – 56% haven't done a visit in the past year. PC avoiders are more likely to be found in metro areas, and less likely in country towns, rural and remote areas. They are also more likely to be female (54% vs 39% of all GPs).

They are also much less interested (62%) than average in further developing their skills in PC and EoLC – although clearly there is some scope to offer them knowledge in easily /quickly digestible ways. They are very unclear about ACDs legislation in their state, and only 7% of PC avoiders have heard of the surprise question.

2.7. Summary and key implications

The survey data showed that GP interest in PC was polarised, with 37% more interested in PC compared with other areas of their practice and 20% less interested. Further statistical segmentation of the GP audience revealed a number of GP profiles with respect to PC. These ranged from the segments who wholeheartedly engaged with PC or appeared likely to do so with more support (*Palliative Care Experts* and *Palliative Care Aspirers* – 64% of the GP population) as well as those segments who tended to not to see out or actively avoid PC (*Palliative Care Indifferent* and *Palliative Care Avoiders*).

Establishing these segments represents a key contribution to the evidence on how to encourage best practice PC within general practice. Where the literature review and qualitative studies both articulated hypotheses about the extent to which GPs were motivated to do PC, the segments provide firm evidence. Their key benefit is the way in which they provide a framework for future support and communications – this helps us move from a 'one size fits all' approach to PC engagement and education to a more highly targeted approach.

Importantly, the different segment attitudinal profiles suggests that the extent to which GPs take an interest in PC is in part predicted by their broader approach to practice (a strict medical/technical vs whole patient approach, high vs low communication etc.) One of the themes of this report is to explore the question – *how far can we, or should we, even try to change the behaviour of a GP who is not naturally interested or good at the kind of medicine that best practice PC requires?*

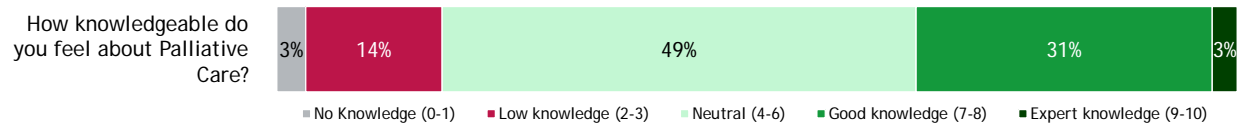
We will further discuss segment differences throughout the report, and use them to shape recommendations.

3. What do GPs say palliative and end of life care are?

3.1. Knowledge of palliative and end of life care

In the survey, very few GPs reported being expert in PC (3%), although a further third (31%) felt they had good knowledge (Figure 2).

Figure 2: Self-rated knowledge in palliative care



B10. How knowledgeable do you feel about palliative care? Base: total sample, weighted, n=1000
B11. Would you be interested in further developing your skills in palliative and end-of-life care? Base: total sample, weighted, n=1000.

Consistent with responses to most self-rated knowledge questions, male GPs were more likely to suggest they had good levels of knowledge (36% rated themselves 7-8 out of 10, compared to 22% of females), while nearly a third of female GPs (29%) rated their knowledge as low (2-3 out of 10) or worse. GPs in major regional centres were more likely to rate their level of knowledge as good (46% rated themselves 7+) and GPs who were principals or directors in their practice were twice as likely (6%) to claim expert knowledge.

The different segments varied widely on self-reported knowledge of PC. Only one in a hundred (1%) of the *Palliative Care Avoiders* and one in twelve (8%) of the *Palliative Care Indifferent* claimed good levels of knowledge. On the other hand, a majority (71%) of *Palliative Care Experts* claimed good or better (7+) knowledge.

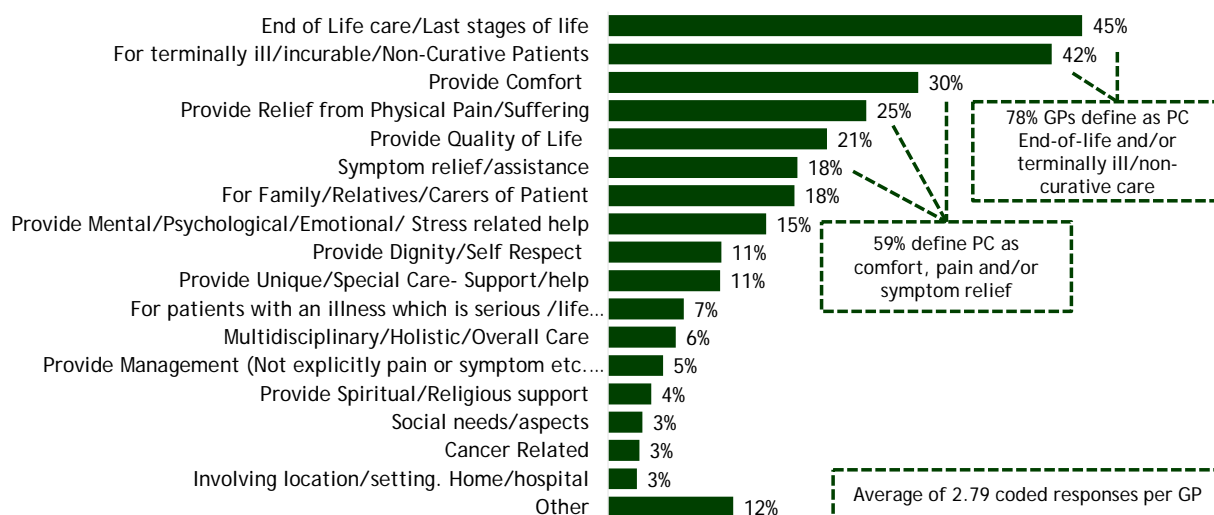


3.2. How do GPs define palliative and end of life care?⁵

3.2.1. Palliative care is end of life care – pain and symptom relief for the terminally ill

Figure 3, below, shows responses to an open-ended question – one of the first in the survey – asking GPs to define PC. In the survey, GPs largely defined PC as EoLC for terminally ill or incurable patients – nearly eight in ten (78%) used these terms in their definition. Six in ten (59%) defined PC as providing comfort, symptom and/or pain relief.

Figure 3: GP definitions of palliative care



B1. Take a moment to think about palliative care, what does palliative care mean to you? Base: total sample, weighted, n=1000.

Far fewer GPs defined PC as providing quality of life (21%), being for the family of the patient (18%), involving psychological help (15%) or spiritual support (4%). Interestingly, only one in sixteen (6%) saw multidisciplinary or holistic care as part of the definition of PC.

3.2.2. GP understandings of palliative care – in more detail

In the exploratory qualitative research conversations GPs resisted defining PC. They said that each palliative patient is different, individual or unique and this made a uniform definition impossible. However, when moderators pressed, and teased out the definition in conversation a number of associations emerged. These are discussed below

Palliative care as the last days of life

Although GPs in the qualitative study had anecdotes about palliative patients who had lived for years, they frequently defined PC in terms of a much shorter timeframe – the last hours, days or weeks of life. They said this was also a time when patients were less able to care for themselves and required palliative or nursing services – and hence formally became palliative patients.

"[PC is] Often just the last days or maybe weeks before death" Melbourne GP

"It is a little bit of a problem. Palliative services limit funding to the last month or so. If it goes on too long they will discharge." Perth GP

"Eventually all people with severe chronic conditions are terminal. You might raise palliative care in the last months when people are at a stage where they can't look after themselves." Perth GP

⁵ For most GPs across the qualitative sample, PC was largely synonymous with EoLC; the only nuance being that EoLC was seen as being the final days or weeks of life (e.g. the last stage of PC). Because of this, in the subsequent report we have only delineated between the two if this is needed to explain a particular aspect of GP attitudes or practice, or to highlight a need for change.

Palliative care as pain and symptom management

GPs across the qualitative sample talked about providing 'comfort' – in the form of physical pain and symptom relief – as central to PC.

"It is about making someone comfortable, making them pain free, giving them some dignity."
Adelaide GP

"It's making sure they're comfortable... pain free" Brisbane GP

A number of explanations for the GP focus on pain relief emerged.

- This narrow approach to PC reflected normal medical practice – seeing patients, making diagnoses, writing scripts, follow-up.
- It provided a clear role in PC for GPs. For patients who were not being seen in a hospital or hospice setting, it was still the GP's responsibility to prescribe, even if care was being coordinated or delivered primarily through a specialist PC service.
- In addition, for the less experienced, palliative pain relief was seen as a difficult area of practice. Unfamiliar drugs, restricted medicines and (potentially unknown) advances in practice as well as fear of being accused of practicing euthanasia could all make it a somewhat worrying area.

Palliative care is the opposite of curative care

The decision not to continue active treatment of a patient's underlying condition was seen by GPs to be at the core of what defines a palliative patient.

"It is about making someone comfortable, making them pain free, giving them some dignity."
Adelaide GP

"It's making sure they're comfortable... pain free" Brisbane GP

"End of life care, relieving symptoms rather than curative. Usually for terminal conditions."
Adelaide GP

When discussing cessation of active treatment, GPs could be quick to clarify the distinction between ceasing active care and euthanasia. This could be a sensitive topic – many had been asked to end lives, and some acknowledged the fine line between comfort care and care that kills.

"Not actively hastening anyone's end." Hobart GP

"I've had quite a few patients ask me to give them something at the end..." Melbourne GP

Others found it difficult to make ethical decisions around stopping active treatment for palliative patients. For instance, they asked – does it also require them to cease *all* life-extending medications (i.e. heart and blood pressure medications)? How should they treat instances of acute deterioration for palliative patients, such as a bout of pneumonia for an advanced dementia patient?

"Knowledge gaps include Prescribing for the relatively well palliative care patient (i.e. cease warfarin and increase their stroke risk whilst they are generally well?)" Rural Victorian GP.

While a very small minority saw the point of the early introduction of a specialist PC team to a patient who has been diagnosed with a life-limiting illness, almost none acknowledged the possibility of parallel curative care and PC – or the benefit of alerting patients to palliative possibilities earlier in a disease progression.

For most, 'palliative' and 'curative' were mutually exclusive terms. This means GPs often found it hard to rationalise the introduction of a palliative approach while there was any possibility of treatment or cure for the patient's terminal condition.

"You don't give palliative care to a stable patient. It is for when they are deteriorating." Perth GP

"It is about care of the dying." Bendigo GP

Powerful emotions

GPs across the qualitative sample talked about the emotion of dying, with varied levels of sensitivity and empathy.

- For some, this was connected to their patient's fear of dying, and their concern that bringing up the topic of PC would cause a patient to lose hope and fall into despair.
- Others viewed emotion in a very mechanical fashion. When faced with difficult emotions their automatic reaction was to diagnose depression and anxiety and prescribe medication.
- Others talked about emotion in a much more nuanced fashion, and about the process of gently and over time helping patients to come to terms with dying, including exploring their fears and hopes, what they would like to achieve before they die and how they would like to die.

"It's difficult for a GP to be better than a social worker." Perth GP

"It's about coming to terms with the disease, getting the patient to release." Perth GP

"Patients will have certain thoughts, what they want to do, fulfilling last wishes. It's important to find out what is important." Perth GP

"It is not just medical, you have to remind patients to consider their financial affairs, putting their legal affairs in place." Bendigo GP

Relating to family

Liaising with a patient's family was seen as a central to, and often the most challenging part of, PC. Ensuring that patients and their families had a common understanding was seen as key to avoiding unnecessary conflict at end of life. GPs who operated as part of a broader family practice, and treated not just a patient but also their extended family, often saw this as a chance to better understand their patient and the family dynamic.

Understanding the needs of carers (including arranging respite where possible) was also seen as very important given the needs of this vulnerable group and their central role in ensuring palliative and end of life patients could receive care in-home.

"This one family were so fantastic... she quit her job to look after her mother in law over the last 6 months of her life, and she was really good at – you could tell – it was keeping her alive and happy...But that was her, that was what she wanted to do." Darwin GP

More about cancer

Cancer was mentioned by only one in thirty-three (3%) GPs as part of the definition of PC in the quantitative survey, while it was a central feature of almost every qualitative discussion. This suggests that the strong association between PC and cancer observed in qualitative discussions was more to do with practice than formal definition.

In the qualitative research, GPs said that cancer patients were top of mind because they expected these patients would become palliative and also because they were referred 'back' to GPs for PC when specialists deemed that curative treatments were no longer appropriate (i.e. there was a clear trigger).

"You are not trying to cure someone. The oncologist is hands off." Perth GP

Patients with chronic illness more rarely defined as palliative

GPs treating patients with chronic illness (alone or in conjunction with a specialist) tended to think of this as symptom relief even if there was no curative intent. They rarely identified these cases as potentially benefitting from more holistic treatment or treatment by a specialist PC team.

"You manage chronic conditions symptomatically. They are palliative really. But people always want to have the latest treatments, managing situations. Who makes the judgement call? You don't want to tell the patient, this is it, you can't say for sure if it won't get better. It is easier with cancer." Bendigo GP

There were rare exceptions. This included patients with heart failure, emphysema, COPD, advanced osteoarthritis, MS, Huntington's, HIV AIDS, transplant patients where their transplant has failed and renal patients who made a conscious decision not to go on to dialysis. GPs who defined non-cancer patients as requiring a palliative approach tended to have greater experience of PC.

While GPs acknowledged that – similarly for palliative patients – there was no cure for dementia, they did not see the use in redefining care for advanced dementia patients as palliative.

"I mean then you'll have two-thirds of the population in palliative care" Sydney GP

In addition, difficulties in estimating prognosis for patients with chronic illness and dementia emerged as a key barrier to GPs defining these patients as palliative. GPs said that the rapid advances in technology and treatment for chronic illness and dementia meant that it was harder for them to decide when treatment was no longer appropriate compared to a specialist in the area.

"Chronic diseases are more difficult to manage. They can go on for a long time. You can't do anything further, you just carry on, repeated acute incidents until you get to the point... this is the last one..." Perth GP

"Not always a discrete trigger [with chronic disease]. They are sometimes treated as an outpatient and the emphasis is more on symptom control. It can go on for a long time." Perth GP

The qualitative discussions suggested that the tendency not to think of chronic disease and dementia patients as palliative was also driven by the patients accepted by PC teams. As GPs reported it, this is more often than not cancer patients, with some specifically specialist PC teams ruling out patients with other illnesses. In addition, specialists other than PC physicians were just as likely to be the 'go to' source of advice for GPs for patients with advanced chronic illness, further defining these conditions as 'non-palliative' in nature.

"I have a patient with end stage emphysema. I didn't think about referring them to Silver Chain." Perth GP

"Dementia patients don't get palliative care. They go into a residential aged care facility and a GP manages." GP Perth

"Palliative care are rarely involved [with people with a chronic disease or dementia] unless they are in hospital." Bendigo GP.

3.3. How do GPs define *best practice* palliative and end of life care?⁶

3.3.1. Pain and symptom control that is more individualised, patient centred

Figure 4, below shows the results of an open-ended question asking GPs to define best practice PC. The top definition (nominated by 40% of GPs) focussed on providing comfort and a pain-free end of life period.

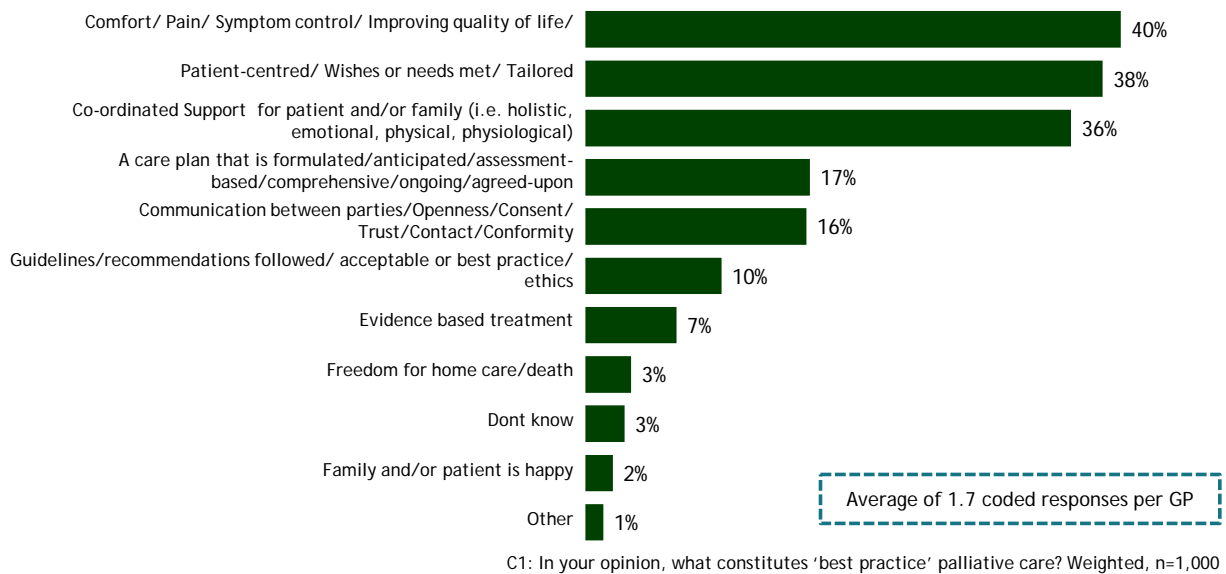
However, close behind this top definition (38% of GPs) was best practice PC as patient centred, meeting a patient's wishes or needs, and providing care tailored to what they want. Female GPs were significantly more likely to cite this definition of 'best practice' PC (48% compared to 32% of males). This was the most common definition among female GPs. Other ideas about what constituted best practice were co-ordinated support (36%), care plans (17%) and communication between trusting parties (16%).

The segments defined best practice PC slightly differently. *Palliative Care Experts* were more likely (23%) to emphasise communication, openness and trust. *Palliative Care Experts* and

⁶ The literature review did not find a strong level of agreement on what constitutes best practice PC and EoLC, or discover a specific and formal definition or measurement of best practice as it applied to general practice.

Palliative Care Aspirers were both more likely (9%, 10%) to emphasise evidence-based treatment.

Figure 4: GP definitions of best practice palliative care



3.3.2. More experienced GPs form a deeper understanding of patient needs

In the qualitative study, even GPs with extensive experience found it difficult to define best practice PC –they said this was because of the individual nature of each patient’s condition, needs and wants. For instance, for some patients, best practice might be an environment with constant nursing care and on-call medical support, while for others it might be being at home with friends and family.

For those with less experience of PC, best practice was defined by control of symptoms (absence of pain and discomfort); and that specialist PC teams or more experienced GPs were in a better place to provide this care.

More experienced GPs had a nuanced view, focussed on the extent to which PC was patient centred – that is, directed by the patient’s informed view of how they wanted to live their life while palliative, and how they wanted to die. They acknowledged that this could involve trade-offs (e.g. additional pain for lucidity, lack of professional nursing if at home).

“Ideally there are no barriers to a 'good death'. It is essential to have a clear understanding of the expectations of the patient and family with regard to all the parameters above. Good communication is the key and then hopefully a palliative care service that can support these wishes.” Rural New South Wales GP

The more experienced were also able to talk about patterns of care – including anticipation of care needs and the frequency of physician visits required to effectively manage their patient’s needs. They also had a more strategic view managing symptoms; that is working to the broader aim of minimise the impact of symptoms on the “activities of daily living”.

While more experienced GPs tended to feel that they were doing PC very well – noting that few were applying objective measures to their work – less experienced GPs were not as confident about their skills and ability to manage palliative patients. Not all in the latter group were seeking help, support and advice, and some appeared unconcerned by their lack of experience or the narrow scope that their care covered.

3.4. Summary and key implications

While a core cohort of feel knowledgeable about PC, a substantial proportion indicate a lack of capability or comfort with these areas.

Variation in knowledge is reflected in the range of GP views on what constitutes GP. Some GPs take a very narrow view of PC (focussing on pain and comfort care at the end of life) whilst others have a more holistic view (considering factors such as emotion of dying and mental health care). It is also reflected in approaches to best practice care, both conceptually (symptom management vs supporting and coaching patients towards as good death) as well as in practice – with the more expert being highly attuned to the required patterns of care and pre-emptive management.

This analysis suggests that definitions of PC help shape what kind of care is provided by GPs, and that a lack of a precise definition for (best practice) PC is a barrier to best practice care. Specifically, this study suggested it does not encourage GPs to think about:

- introducing a palliative approach for non-cancer patients
- introducing PC during active treatment or before end of life
- taking a more holistic approach to PC, or
- required patterns of care and pre-emptive management.

Having said this, while there may be value in a broader community project to reframe PC and remove the stigma around discussing death, this study does not suggest there is value in a project with the sole aim redefining PC for GPs.

GPs did not react well to this more conceptual approach to the topic in group discussions, and appeared more likely to respond to specific initiatives that would broaden understandings through doing. For instance, this could involve projects to encourage adoption of a palliative approach for non-cancer patients or to better equip GPs to manage the psychosocial aspects of dying. In this context, there appears to be a role for modelling best practice PC including as it applies to:

- managing symptoms to minimise impact on activities of daily living
- reviewing unnecessary medicines / treatment
- introduction to a specialist PC team
- conversations around planning for a good death
- dealing well with families and cross-cultural care
- anticipatory prescribing and care planning at end of life, and
- managing acute deterioration in the community.



4. GP views on their own and others' roles in palliative care

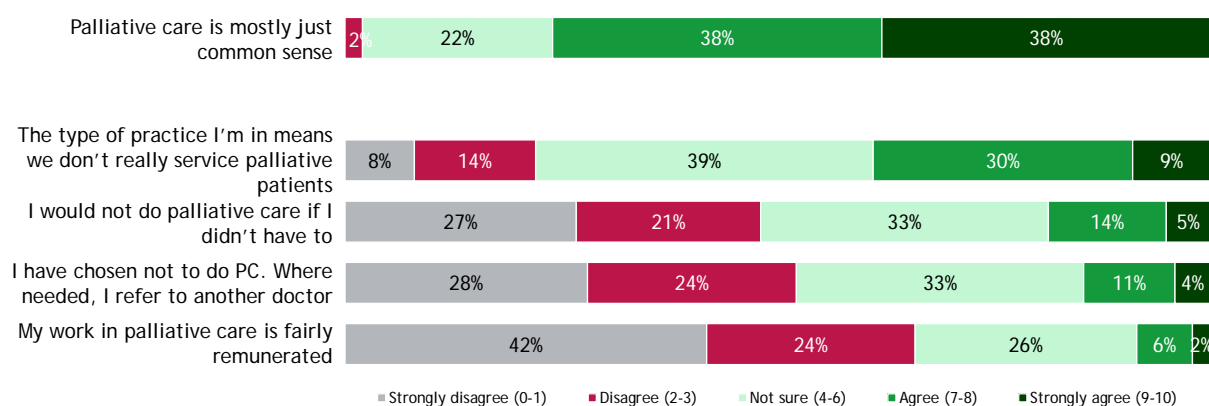
4.1. How GPs see their own role

4.1.1. Most GPs say they do see a role for themselves in PC (although less so in hospital/hospice settings)

A clear majority (76%) of GPs saw PC as an important part of their job. Very few (4%) disagreed with this statement, and only around one in twelve (8%) agreed they had chosen not to do PC and one in six (15%) agreed they would not do PC if they didn't have to. (Figure 5)

Not surprisingly, *Palliative Care Experts* and *Palliative Care Aspirers* were significantly more likely to see PC as an important and rewarding part of their work. Nearly half (47%) of *Palliative Care Avoiders* strongly disagreed (0-1 out of 10) that PC is an important part of the job, and a similar proportion (48%) agreed they would not do PC if they didn't have to.

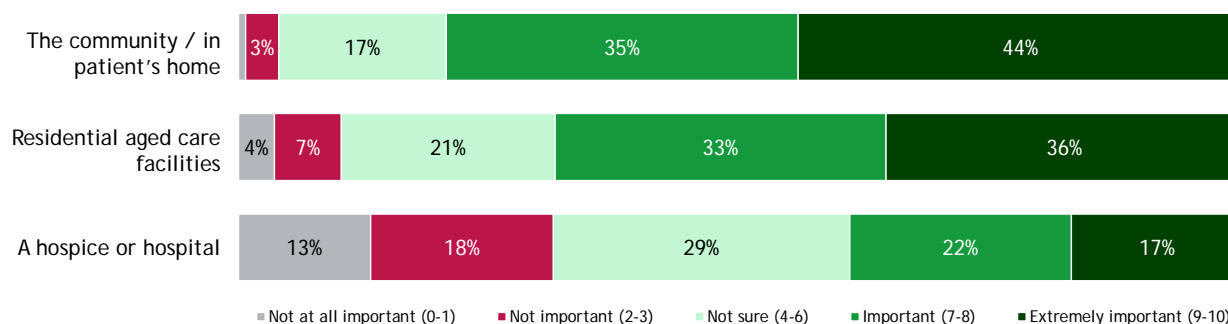
Figure 5: GP perceptions about the role of GPs in PC



Source: D1 - Please use the scale below to indicate whether you disagree or agree with the following statements... Base: total sample, weighted, n=1000.

The survey showed GPs' perceptions of the importance of their role to be setting dependent (Figure 6). 79% of GPs said they were important to in-home care and 69% of GPs saw themselves as important to care of palliative patients in RACFs – compared to the 39% who saw their role as important to hospital or hospice care.

Figure 6: Relative importance of the GP's role in different settings



C6. How important is your role in delivering best practice palliative care in the following settings? Base: total sample, weighted, n=1000. Proportions lower than 2% removed for clarity

Implicit associations show GPs likely to see palliative care as 'not medicine'

Although, as an optional component, and only completed by a small fraction of the final sample (n=52), an Implicit Association Test (IAT) was used to understand whether GPs had an

implicit bias against seeing PC as medicine or not medicine (and hence part of their core clinical role).

GPs were asked to categorise terms representing palliative and curative care as medicine (framed by terms like paracetamol, vaccination, antibiotic, pharmaceutical and prescription) or 'not medicine' (framed by terms like nursing, social work, psychology, counselling and dietetics).

The results shown in Figure 7 demonstrated that, even after completing an extensive survey about PC, on average GPs had a slight implicit bias towards seeing PC as 'not medicine' – that is, they saw it as more related to nursing and allied health. This result implied that GPs were less inclined towards seeing PC as part of their role than they would like to think.

Figure 7: Implicit association shows GPs tend to think of palliative care as more an allied health role

Implicit Association Test - Perception of Palliative Care



4.2. GP views of the roles of others in the health system

In the survey 77% of GPs agreed with the statement that “health professionals need to work together more closely to deliver palliative care”.⁷

GPs reported that lack of coordination between different health system silos, and poor communication on discharge from hospital and between GPs and specialists/specialists PC teams as key barriers to best practice PC. (Figure 15, p37)

However, differences between the segments suggested that these difficulties were at least partly driven by attitudes.

The segments had very different levels of comfort with respect to working with other providers in the delivery of PC. For instance, two-thirds (63%) of *Palliative Care Avoiders* were not comfortable co-ordinating palliative services for patients in the community, while 88% of *Palliative Care Experts* were. A majority of *Palliative Care Experts* (87%) said they were comfortable leading case conferencing, while nearly half (42%) of *Palliative Care Avoiders* were not. *Palliative Care Experts* were much more likely (42%) to see the quality of RACF staff as an issue that made delivery of best practice harder, compared to *Palliative Care Indifferent* (19%).

The rest of the survey responses followed a similar pattern – the more engaged segments were much more comfortable dealing with and managing different providers across the health sector and community.

⁷ Source: D1 – Please use the scale below to indicate whether you disagree or agree with the following statements... Base: total sample, weighted, n=1000

4.3. Exploring roles in depth

The qualitative research conversations enabled further exploration of how GPs felt about, and interacted with, other parts of the health system. These findings are reported below, with some reference to quantitative data.

4.3.1. Specialists and their nursing staff

With respect to cancer, and where they thought that PC applied to chronic disease and dementia patients, GPs in the qualitative study looked to specialists to signal that active treatment was no longer appropriate. However, while many said they disagreed with or distrusted specialists' judgement, few would feel confident enough to challenge their advice.

"It's a brave GP who'd question a specialist!" Rural Victoria GP

"Introducing palliative care at earlier stages is a good idea but the problem is who will declare that the patient should be on palliative care. A GP cannot label or diagnose a patient to be on palliative care. I think specialists should be encouraged to decide this earlier and this will give an ample time to the patients to accept this. This will also help GP to organise other allied health (psychologist and social worker) to ease the life of terminally sick patients." Rural New South Wales GP

GPs also looked to specialists to provide advice on the treatment of patients whose needs extended beyond a GP's expertise or weren't considered relevant to PC physicians.

Communication between specialists and GPs was generally by fax, letter or email. While telephone was preferred, it was acknowledged that making contact was difficult. GPs said that specialists varied widely in their ability to communicate well and on time.

Counterpoint: Specialists also complained about poor GP communication – they felt they did a much better job.

They had little insight or awareness into how specialists viewed GP communications.

The handover and communication between specialists and GPs at the point of transitioning to PC point was a bugbear for most GPs. Specialists did not always: provide patients with a good understanding of their prognosis and options, refer back to GPs, provide adequate notes on referral or do a timely referral (with the result that GP could see patients before specialists communicated back to them), or notify GPs that patients were discharged from hospital.

"The oncologist refers back to the GP and say they are palliative but there are no other directives." Bendigo GP

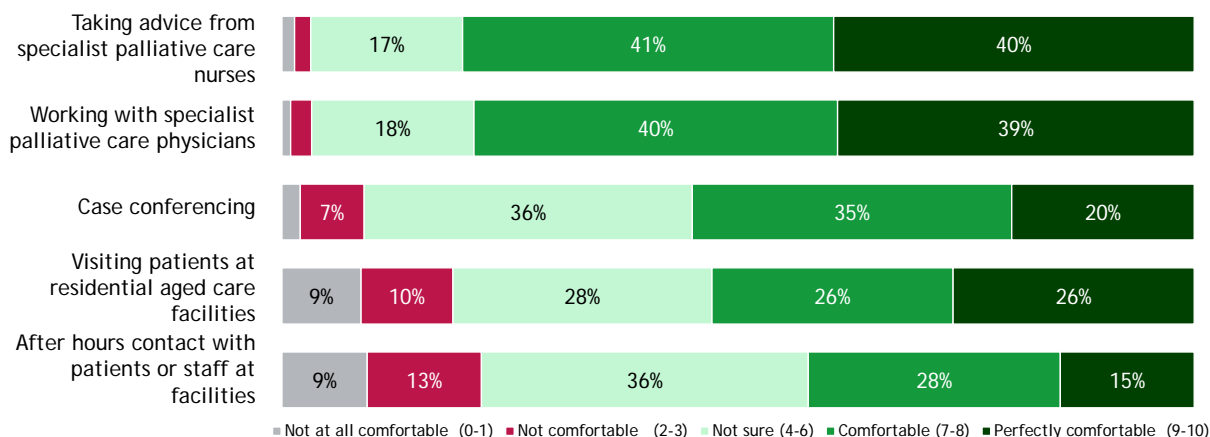
"They might say, I have discharged someone, they need home oxygen, you need to manage them in the community. They have no future in hospital." Perth GP

Some GPs were positive about the increasing role of nursing staff within specialisations in encouraging better communication with patients and GPs.

4.3.2. Specialist palliative care teams

Figure 8 reflects GP respect for, and reliance on, specialist PC physicians and nurses. In the survey, 81% of GPs said they felt comfortable working with specialist PC nurses and 79% felt comfortable working with specialist PC physicians.

Figure 8: Comfort with different aspects of palliative care



B13. Thinking about the range of activities involved in palliative and end-of-life care, how comfortable are you with each of the following aspects of palliative care? Base: total sample, weighted, n=1000. Note: labels for proportion sizes lower than 3% have been removed for clarity

In the qualitative study, GPs looked to specialist PC services to provide: advice on appropriate symptom management, coordination of care and access to services and equipment, and nursing and allied health services. Many GPs with patients living at home said they relied quite heavily on the advice of specialist PC nurses in prescribing.

"[Getting advice] If someone is palliative I wouldn't be in a hurry. We are trained to deal with symptoms. I wouldn't call unless I couldn't manage." Bendigo GP

"I'd be stuck if I had to do coordination [for a palliative patient] the palliative care team do better. They initiate services for the patient, they do the OT review, nursing. They are a good team. Effective." Hobart GP

"We are also lucky as we have a very knowledgeable palliative care nurse and he usually has management ideas I have not thought of when we are in a pickle." Rural South Australian GP

Communication with specialist PC services was variable. Some GPs reported excellent relationships and close contact with services, whilst others struggled to make contact and get advice. Some worked in tandem with specialist PC services, others felt that specialist PC services 'took over'. A few said they had tried to connect with specialist PC services but were refused help.

Counterpoint: PC services also said that they felt that many GPs were ill equipped to navigate available care in the community.

Many GPs said they would welcome a closer working relationship with specialist PC services. They would like:

- an introduction – to know who is who at the PC team
- to better understand what sorts of services are offered by the specialist PC team and which patients are eligible
- how and when to register a patient with the service, and
- quick upskilling when needed in relation to a particular patient (easy access to advice).

Encouraging examples:

A Brisbane-based PC service employed a GP liaison (nurses or GPs) to ensure that their team and advice (provided as outpatient care) were more accessible to GPs: "The public health system can be a mighty beast with so many rules and regulations. It can be very hard for one person to know their way around it."

A Brisbane-based paediatric PC service has a 'pop up' facility that goes out to rural and remote areas to upskill GPs caring for terminally ill children.

4.3.3. Community nursing and allied health professionals

In the qualitative study, GPs saw roles for community nursing and allied health professionals including personal care staff, pharmacists, counsellors, dieticians, physiotherapists and occupational therapists.

GPs with well-established networks or who were able to access these services for their patients through specialist PC services were in stark contrast to the GPs who did not know where to begin looking, or did not have available services due to being in a rural or remote location.

Encouraging example: An Adelaide pharmacist noted that medicines reviews and chronic disease shared care plans were helpful in ensuring better coordination of patient care.

4.3.4. Residential aged care facility staff

In the qualitative study, RACF staff were seen as integral to providing nursing and personal care to residents of nursing homes. Similarly, to domiciliary and PC nurses, they could be seen as a source of expert and up to date information on a patient's condition. The presence of a registered nurse was seen as particularly critical by GPs working as after-hours locums. However, in the opinion of GPs, RACF staff varied in their ability to provide good care to palliative patients and communicate well with GPs.

Counterpoint: Residential aged care facilities said they found it hard to have GPs attend their facilities, and that this was a driver to hospital admissions.

4.4. Whose role is it to trigger palliative and end of life care?

4.4.1. GPs are not responsible

The survey asked GPs about whose role they felt it was to initiate a conversation about PC (i.e. was it theirs or their patient's role). Figure 23 (p49), shows that only one in ten (10%) said bringing up a conversation about a transition to PC was completely their role.

Counterpoint: Some specialists who were treating outpatients in hospitals with specialist PC teams did report linking in PC teams earlier.

As flagged earlier, in the qualitative research, most said that responsibility for triggering a switch to PC lay with specialists, even if they did not think that specialists were good at doing this.

"You have the conversation a number of times." Perth GP

"People deserve the chance to come to terms with their condition." Perth GP

"A lot of oncologists don't have the conversation. They get nurses, social workers, counsellors to have this."

GPs said they worried about raising the issue, citing the stigma around the term PC and the potential for patients to 'lose hope' if they bought up the prospect that active care might not be successful.

The researchers suspected that GPs' own death avoidance and aversion to non-curative care (medical heroism) led them to give primacy to these more negative emotions rather than a patient's need and right to understand and plan for their remaining life. Having said this, GPs uniformly called for more community education around PC and EoLC in order to better prepare their patients and their families.

"The conversation could be triggered during routine clinical care in general practice, or it could be triggered during a specialist review when no further curative treatment is able to be given. The approach I take depends on the patient and how much information they have already been given by

their specialist (may just involve answering more questions for the patient that they didn't think of when at the specialist appointment)." Regional New South Wales GP

"Once again it comes down to better communication between treating doctors so that all are agreed on the next best step. Often everyone seems to run their own race for a long time without much interaction or cooperation early on." Rural Queensland doctor

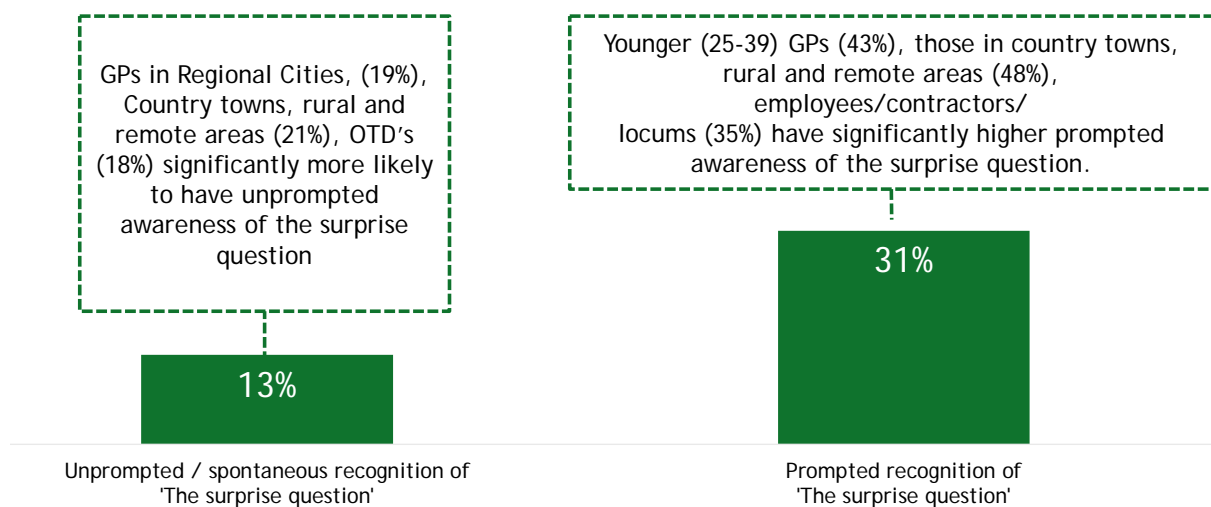
Qualitatively, the minority of GPs who were more involved in triggering or managing the transition from curative to PC spoke of the very practical planning associated with helping a patient and their family come to terms with the likely progression of their disease (i.e. where a palliative approach might be appropriate or at end of life). Those who were broaching the topic with patients were more likely to believe in a patient's right to understand their condition and to come to terms with that condition and hence what they want to do with their remaining time.

"For people with a chronic disease, in the old days a GP could make the decision. Treatment or no treatment, three months or less than three months. You might say your lungs are failing, you are not suitable for dialysis. Now it is falling back to specialists to make that decision." Adelaide GP

4.4.2. The surprise question as a trigger

The quantitative study highlighted the potential power of the surprise question. The surprise question was developed as tool to assist health professionals determine whether there is a need for ACP. It simply asks: "would you be surprised if this patient died in the next year" to trigger GPs to think about whether or not their chronically ill patients were approaching end of life. The survey showed that the question was not widely known – only one in eight (13%) had heard of it, and one in three (31%) recognised it if prompted (Figure 9).

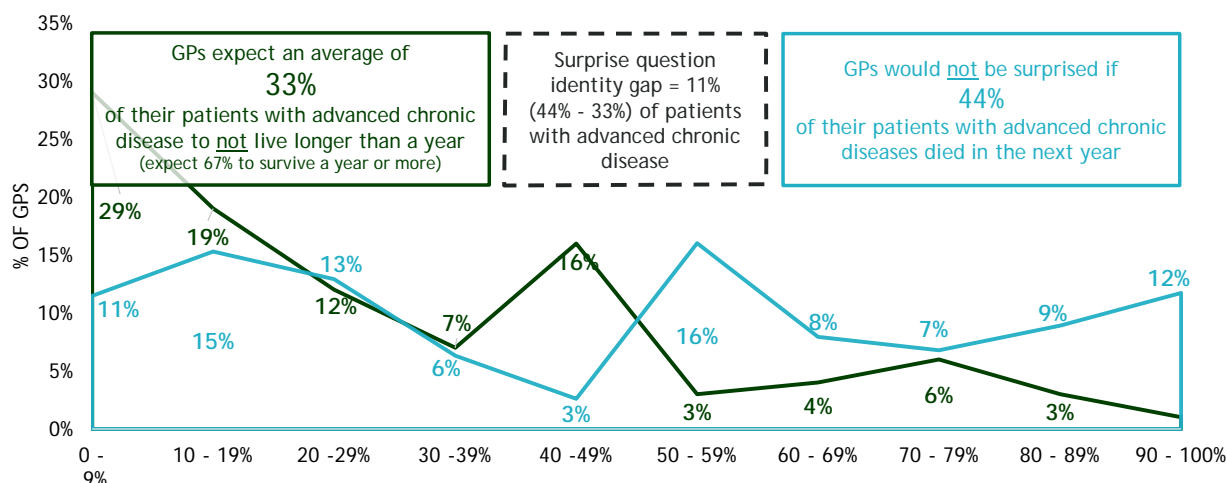
Figure 9: Spontaneous and prompted awareness of the "Surprise Question"



Source: QB4. Decision Assist, in conjunction with RACGP have devised an approach to identifying people appropriate for palliative care called 'The surprise question'. Have you heard of this before?
 QB5. The surprise question is "Would you be surprised if this patient died in the next year?" Have you heard of this before? base: total sample, weighted, n=1000.
 QB6. For what proportion of your patients with advanced chronic diseases would the answer to the surprise question be 'No'. Base: total sample, weighted, n=1000.

The survey asked GPs to estimate the proportion of their chronic disease patients they would estimate would live longer than a year. It also asked "For what proportion of your patients with advanced chronic disease would the answer to the surprise question be 'No'". Figure 10 shows how this re-framing of the patient's journey – from living longer than a year to potentially dying in the next year – changed GP's perceptions of the proportion they think will survive.

Figure 10: The 'Surprise question' Identity gap⁸



Source: QB3. Thinking about your patients with advanced chronic disease, what proportion would you estimate will live longer than a year. (reversed in chart) base: total sample, weighted, n=1000. NB: 290 'don't know'
 QB6. For what proportion of your patients with advanced chronic diseases would the answer to the surprise question be 'No' base: total sample, weighted, n=1000. NB 266 'don't know'

On average, GPs were surprised if the answer to the surprise question was 'no' for 44% of their advanced chronic disease patients, while they would not expect 33% of the patients with advanced chronic disease to live longer than a year. These results implied that using the surprise question framing the average GP may identify one in nine (11%) more of their patients with advanced chronic diseases for the introduction of a palliative approach.

4.5. Summary and key implications

The majority of GPs see a clear role for themselves in PC.⁹

4.5.1. Roles of others

While PC requires GPs to interact with others across the health system, GPs say a lack of communication and cohesion is a key barrier to best practice PC, with 77% agreeing with the statement that "health professionals need to work together more closely to deliver palliative care".

This project did not throw up any clear and easy solutions for solving the issue of health sector silos with respect to PC. However, it did find some encouraging examples of local, innovative programs addressing issues such as distance or unwanted hospital admissions for RACF residents.

Stakeholders said that the need for better health service integration is recognised across the system, and there is a growing sense of shared responsibility for this by many different practitioners and services. This suggests that there are likely to be many opportunities for improving GP links for ACP and PC. Examples can be found in service integration strategies by PHNs – for instance, local clinical pathways for GPs to share care and refer to other services including for chronic diseases, ACP and PC. To illustrate – a specific example shared with our team was the Victorian consensus guidelines on integrated emergency care for older persons.

While health system integration was not a core focus of enquiry, the researchers did wonder if the next logical step is to communicate and 'scale up' strategies that have tested well at a local level.

⁸ The proportion of the chronic disease patients that GPs expect survive longer than a year is reversed in this chart – and so is the implied proportion they would not expect to live longer than 1 year

⁹ It is worth noting that these are enshrined in profession standards such as Good Medical Practice and the AMA standards for end of life care.

4.5.2. Responsibility to trigger

While GPs agree in principle on the benefits of 'triggering' and doing PC earlier, most do not see a role for themselves in driving change or practical strategies to do so.

However, this study suggests that use of the surprise question has clear potential to help GPs identify patients with advanced chronic disease who may benefit from a palliative approach.

Having said this, while *Palliative Care Experts* and *Aspirers* might be easily encouraged to apply the surprise question, *Palliative Care Avoiders* and *Palliative Care Indifferent* will likely require a stronger clinical rationale (e.g. through the Chronic Disease Management Framework and use of clinical triggers such as SPICT).

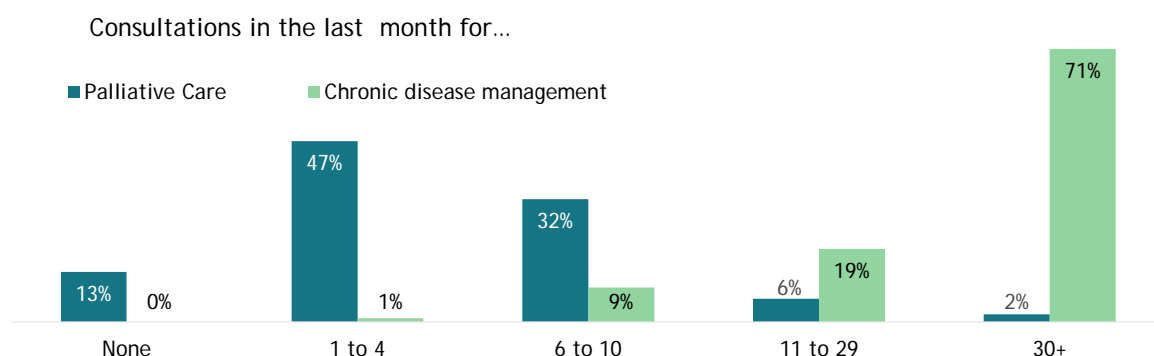
Both groups will would require awareness raising and training around the surprise question as well as more conducive environment to promote its use (e.g. prompting through medical software, practice booking a longer consultation, promotion by peak bodies, PHNs, specialist PC services etc.)

5. Extent to which GPs are doing palliative care and best practice palliative care

5.1. Extent to which GPs are doing palliative care

The survey found that a majority (87%) of GPs had at least one PC encounter in the previous month – see Figure 11 below. The survey data showed that GPs in country towns, rural and remote areas saw a higher than average number of patients per month (7.9) for PC compared with their counterparts in capital cities (5.3).

Figure 11: Number of patients seen for PC and chronic disease management over past month

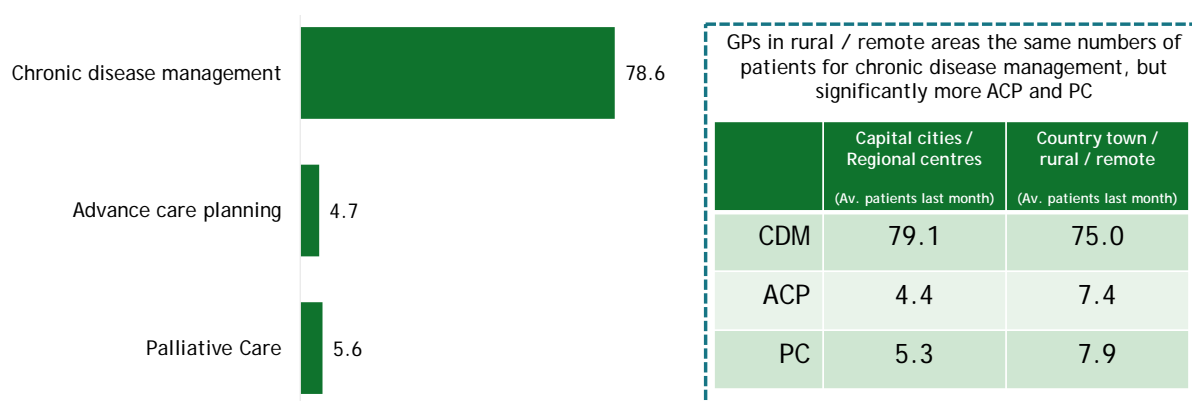


Source: B7. Thinking about your day-to-day practice over the last month, how many patients did you see for...? base: total sample, weighted, n=1000.

GPs reported that they would see, on average six patients a month for PC, and five patients per month for ACP (Figure 12). In contrast, they estimated seeing an average 79 patients for chronic disease management. A crude estimate based on the identity gap demonstrated in the previous chapter suggests that if the surprise question was more widely, known, the number of PC encounters could more than double by classifying around 11% of chronic disease patients as palliative.

This quantitative data also suggests that GPs are probably doing more PC than BEACH data (which estimated PC at around one in 1,000 patient consultations) would indicate.

Figure 12: Average number of patients seen for palliative care, advance care planning and chronic disease management



Source: B7. Thinking about your day-to-day practice over the last month, how many patients did you see for...? base: total sample, weighted, n=1000.

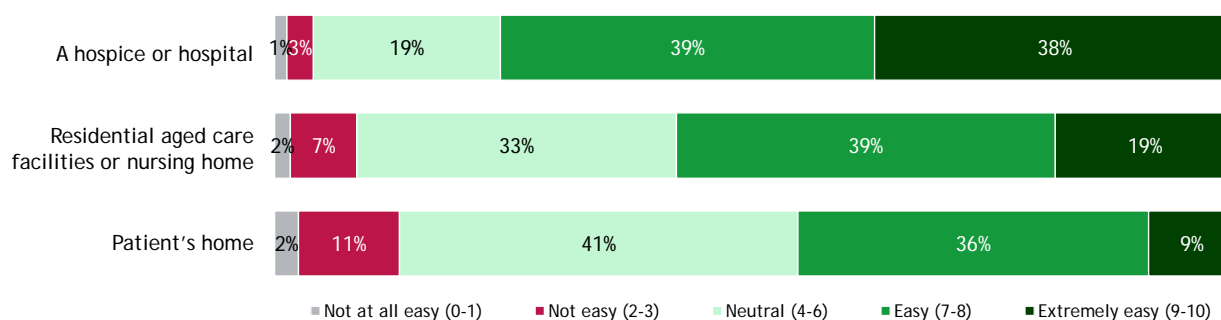
An average full-time GP does an estimated 6,186 consultations per year. Extrapolating from BEACH, a GP would see six patients a year for palliative care (one in 1,000). This survey found GPs are doing PC for 62 patients a year which is an estimated one in every 100 consultations, a rate that is an order of magnitude higher than estimates from BEACH data – approximately one in every 1,000 consultations.

5.2. Settings heavily influence delivery of best practice palliative care

GPs told us that the different settings for PC placed very different demands on general practice, and had different ramifications for best practice PC.

Quantitatively, GPs saw the in-home setting as being the hardest environment in which to do best practice PC. Only 9% of GPs said it was extremely easy and a further 36% said it was easy to deliver best practice care in-home. This compares to 58% of GPs who said it was easy or extremely easy to deliver best practice care in RACFs and the 77% of GPs who said it was easy or extremely easy to deliver best practice care in hospices or hospitals (Figure 13).

Figure 13: Relative ease of delivering best practice palliative care in different settings



C5. In your experience, in which of these settings is it easiest to deliver best practice palliative care? Base: total sample, weighted, n=1000.

This may reflect the greater proportion of work falling to GPs in community settings as well as setting specific barriers to best practice. However, the different segments findings suggest that GP attitude and capability also play a role in driving perceptions.

To illustrate – *Palliative Care Avoiders* were significantly less likely (21%) to suggest that delivering best practice PC in the community setting was easy, compared to *Palliative Care Experts* (63%). The latter group was also significantly more likely to suggest their role was extremely important (9-10) in the community setting (76%), RACFs (70%) and in hospitals or hospices (40%).

Below we explore in more depth how GPs saw these issues in the qualitative study, with reference to the quantitative data where appropriate.

5.2.1. In-home poses unique challenges and complications for GPs and families

While GPs recognised that many patients wanted to die at home, they also felt there were barriers to their receiving best practice PC in-home.

Being cared for in the home involves trade-offs

Qualitatively, GPs debated the idea of whether or not 'best practice' PC, and especially EoLC, can be provided in an in-home setting. The lack of 24-hour nursing care (to anticipate and treat care issues as they arise) was seen as a big trade off against a patient's desire to be cared for in their home. Victorian GPs noted that the state government's commitment to have people be able to die at home if that is their wish (announced during this study) was not backed by sufficient resourcing. Across the sample, GPs said that a push to have more PC patients cared for in their homes would have to be resourced, including for equipment, personal care, allied health and nursing services and availability of medicines in community pharmacies.

Families' willingness and ability to provide care

In the qualitative study, GPs told us that a family's ability to provide adequate support was an important determinant of whether in-home patients received (best practice) care. Some GPs felt that patients were not always informed or realistic in their choice to die at home,

and noted that initial patient wishes could change as patients come to realise the intensity of support required and the impact on their loved ones.

“The biggest barrier to a good death is that it is a lot harder to achieve than patients or family realise; I have had situations where the patient wants to die at home but when they have developed increased pain, family or even palliative care nurses have panicked and transferred them to hospital against their wishes rather than increase their opiates.” Rural Victorian GP

GPs were alert to the burden on families of providing in-home care. They told us that the activities of daily living, like washing, toileting and eating could become very difficult, with carers not always well equipped (emotionally and physically) to deal with basic bodily functions.

They noted that being cared for in-home could lead to (pain) symptoms being dealt with in a less timely fashion than if a patient were in a RACF, hospital or hospice. In addition, patients being cared for at home who had acute deteriorations were seen as being more likely to be admitted to hospital, due to lack of nursing support at home.

“Dying in preferred place e.g. at home may be prevented by care needs which are required through the 24-hour cycle and exhaustion of willing carers may be unacceptable. Palliative care team resources may be inadequate. Comfort and dignity in dying are not achieved with inadequate palliative care resources.” Jack board

5.2.2. Residential aged care facilities solve some issues but are variable in their ability to deliver best practice palliative care

The services available in RACFs to some extent ‘solved’ key issues GPs had with caring for palliative patients in their homes – this included having nursing or care staff and allied and other support services available, and coordination of care. Having said this, GPs talked about similarly intensive visitation patterns in aged care as for in-home palliative patients – once a week (potentially) increasing to once a day at end of life. They also noted visiting multiple patients, taking after-hours calls from the nursing staff and extended family conferences within RACFs.

“In nursing homes people get better care. Certain issues arise when people are being cared for at home [dehydration] that the staff in nursing homes don’t let happen.” Bendigo GP

“The residential facility has waiting lists; the hospital is easiest.” Bendigo GP

“We have a room specifically for palliative care but you have to be terminal.”

However, across the qualitative sample, GPs were also concerned about the variability and quality of care provided in RACFs, particularly by non-nursing staff. For instance, they told us that recent changes in New South Wales where registered nurses were no longer required to be available 24/7 in RACFs meant that no staff would be authorised to administer medications and pain relief after hours. Given that not all after-hours locums in this study were comfortable administering pain relief, this would appear to have high potential to increase unwanted hospital admissions.

In addition, GPs said that while in theory, planning with a patient and family and anticipatory care should mean that patients who have acute deteriorations are able to be cared for in facilities if they or their families had indicated that this was their preference, in actuality, a combination of factors meant that vulnerable residents were often shifted to hospital. This included as a result of RACF staff who didn’t want, or were unable, to care for patients, families demanding that patients be transferred to hospital, and locums and ambulance teams having insufficient information on which to make decisions.

GPs said that ensuring RACFs have staff who are trained in managing routine PC symptoms, as well as better information sharing with ambulance and locum services will be crucial to avoiding unnecessary hospital admissions from RACFs.

Encouraging example: A Sydney-based geriatrician has organised a 'flying team' that can treat patients with acute deterioration in nursing homes, thus avoiding distressing or unwanted hospital admissions.

5.2.3. Hospitals and hospices leave GPs out of the decision making

GPs reported that, depending on the treating specialist, they were often left out of decisions and communications for their patients being treated in a hospital or hospice. GPs felt they should be more closely involved with these patients – they believed their long history with the patient allows them to better understand their needs compared to medical records alone.

They said they could contribute better to continuity of care for their patients (and their families) if they were more involved – or at least informed – in the decision-making process.

5.3. Summary and key implications

While BEACH data – to date the most reliable national data on GP PC practices – estimates that GPs see PC patients at one in 1,000 patient consultations, this study suggests that rates of PC consultations are actually much higher – approximately one in every 100 consultations.

It is harder to measure rates of 'best practice' PC. The different settings for PC – in-home, RACFs, hospices and hospitals – place very different demands on general practice, and have different ramifications for best practice PC. GPs see room for improvement in each setting.

GPs see the in-home setting as being the hardest environment in which to do best practice PC. While GPs recognise that many patients wanted to die at home, they also say there are barriers to them receiving best practice PC in-home (especially as it is defined by 24-hour nursing care and access to immediate symptom relief). The extent to which specialist PC and allied health services are available, and the coordination of these, as well as the ability of families to provide nursing care are all seen as determinants of whether best practice could be achieved.

The staff and services available in RACFs to some extent 'solve' key issues GPs have with caring for palliative patients in their homes. However, the quality of RACF staff, and interaction between RACF, locum services and hospital emergency departments mean that there are still barriers to best practice in this setting.

When a patient is receiving PC in a hospital or hospice setting, GPs report that, depending on the treating specialist, they can feel left out of decision-making and all communications. GPs say they should be more closely involved with their patients in hospital or hospice as their long history with patients allows them to better understand their needs compared to medical records alone.

6. Enablers and barriers in the provision of best practice palliative and end of-life care within general practice

6.1. Structuring the presentation of barriers and enablers

The over-lapping and inter-related nature of the enablers and barriers to best practice PC within general practice have made structuring this section a challenge. It is possible to list out barriers and enablers at the levels of patient, individual GP, general practice, PC team and health system. However, it is our view that this can become something of a laundry list that doesn't suggest priorities or describe the dynamic interaction enablers and barriers.

This study suggests a number of categories that may provide a more useful framework for understanding barriers and enablers:

- GP motivation – intrinsic interest in PC.
- Education/training and exposure – as we describe below, researchers saw these as a trigger for GPs to become involved in a 'virtuous circle', with positively pre-disposed GPs becoming even more eager to overcome structural difficulties to do good PC.
- System factors that deter GPs from practising PC or from doing so well – poor remuneration, lack of time, specialist PC services that do not encourage GP involvement, poor communication and coordination between different health system pillars, distance and quality of RACF staff.
- Practice pressures – that discourage home visits, RACF visits and engagement of practice nurses with patients.
- Patient factors – for instance family and cross-cultural issues.

While individual motivation, education/training and exposure drive GP interest and engagement in PC, structural and patient factors are work against them. Below we discuss each of these areas using qualitative and quantitative findings.

6.2. Vicious and virtuous circles: individual GP factors as enablers and barriers

The quantitative segmentation introduced in section 4 above, outlines four GP segments. Two segments, amounting to 64% of GPs (*Palliative Care Experts* and *Palliative Care Aspirers*) are already doing more PC than other GPs or would like to do more. One segment – *Palliative Care Indifferent* (23%) is relatively disengaged and 14% – the *Palliative Care Avoiders* – actively avoid PC.

6.2.1. The virtuous circle

This study suggested that GPs who are already interested and engaged in PC weave themselves into something of a virtuous circle.

Qualitatively, GPs told us that an early interest in or exposure to PC (for instance as a trainee) as well as prolonged exposure as a rural, regional or remote GP meant they had made an effort to upskill themselves in PC and seek out the support and advice they needed to do it well.

"Who else is going to provide the care?" Rural Victorian GP

"Living in the country it is inevitable that you're involved in palliative care. We frequently receive our patient back from tertiary hospital for palliative management at our local hospital." Remote Queensland GP

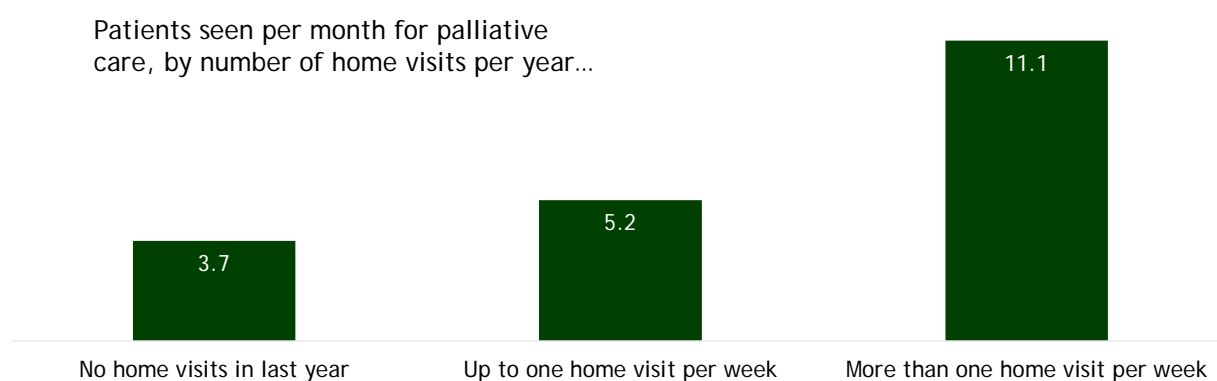
"Being a long-established doctor in a small town [and until three years ago, the only doctor in town] has meant a need to be involved in palliative care. Nonetheless it is not an area of medicine that I particularly enjoy but I do see it as an important and necessary area." Rural South Australian GP

In both the qualitative and quantitative studies, engaged GPs also appeared more likely to have done a registrar round in PC, or rounds with the Program of Education in the Palliative Approach (PEPA).

“Before I had exposure to it I, like many others I feel, thought of it as care in the final stages of life (terminal point). Though now I find it see it in a much broader context. Palliative care is indicated when there is a mental shift in cure to end of life /symptomatic care of the patient. This occurs much earlier, with planning for expected symptoms, education into pathway, patients’ beliefs and wants whilst still communicative and the use of planned medications with heavy emphasis on symptom control rather than longevity.” Rural Victorian GP

GPs with an interest were willing to commit to more intensive patterns of patient care important for best practice, for instance, seeing patients at least once a day at end of life, including in-home and in RACFs. Figure 14 shows that GPs prepared to do more than one home visit a week or more saw three times as many patients for PC in the last month compared with GPs who hadn’t done any home visits over the last year.

Figure 14: Patients seen in last month for palliative care, by number of home visits



Source: B7. Thinking about your day-to-day practice over the last month, how many patients did you see for...? base: total sample, weighted, n=1000. E7: Approximately how many home visits have you done over the past year (No home visits n=258, Up to one per week n=558, More than one per week n=184)

These GPs also tended to have good networks and were connected to local services such as specialist PC, social workers, psychologists and physiotherapists. This meant they could seek advice when needed and ensure that their patients had the services they required. To illustrate, in the quantitative study, *Palliative Care Experts* were significantly less likely than other segments (25%) to say that communication with other health professionals made PC more difficult.

They were also more comfortable with the soft skills involved in PC. For instance, 80% of *Palliative Care Experts* said they were comfortable dealing with conflict and families (in contrast, 81% of *Palliative Care Avoiders* said they were *not* comfortable).

In the qualitative study, some more engaged GPs had also ensured that their practice structure gave them enough time to do PC well and were appropriately remunerated for their time. This included:

- building more case-conferencing into their practice with other specialists and the family present to better remunerate the time involved in coordination
- leaving time open in their schedule to attend to emergencies, and
- doing visits to patients’ homes and RACFs on the way to and from their practice.

6.2.2. The vicious circle

It makes sense that GPs with less interest in, or experience of, PC tended not to have these cushioning structures of education, experience and professional and practice support, which in turn tended to make individual episodes of PC feel more difficult.

In the qualitative study, these GPs saw their lack of (up to date) skills as a potential deterrent to becoming more involved in PC or to doing PC well. They were infrequently doing

PC and were much more likely to express doubt – about the extent to which their knowledge and skills were adequate or up to date.

Counterpoint: "Some GPs have a keen interest in palliative care, they are passionate and know how to treat people. I don't know if most GPs have the expertise in palliative care to manage well."
Specialist renal nurse

Quantitatively, these emerged as the *Palliative Care Aspirers*, *Palliative Care Indifferent* and *Palliative Care Avoiders* – showing that 75% of GPs could be better woven into a more virtuous circle.

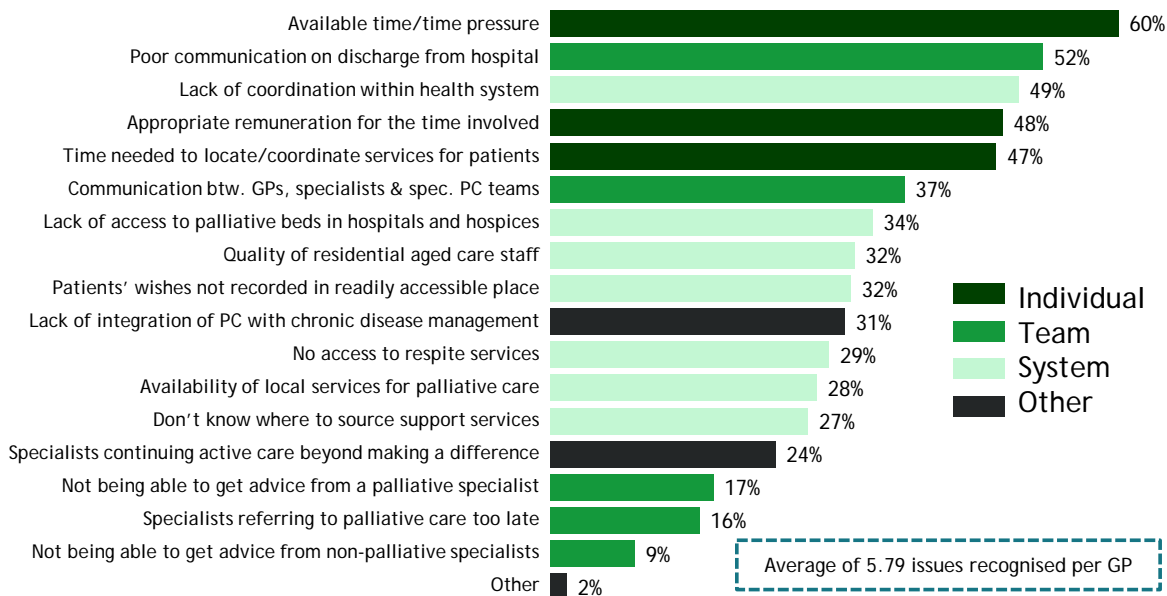
"Subcutaneous pain relief? I don't know how to do that, inserting a catheter I haven't done that in years. Most GPs would need to be upskilled to do palliative care." Perth GP
"A lot of GPs don't have the training; they are not comfortable. They are scared." Tasmanian GP
"When you hardly ever deal with it, it's really hard to do." Toowoomba GP
"Opiate doses can be a bit of a minefield and what I'm most worried about." Rural Queensland GP

6.3. Structural /environmental factors reinforcing GP (lack of) engagement with (best practice) palliative and end of life care

6.3.1. GP priority barriers

Figure 1 below illustrates what GPs saw as the priority barriers to best practice PC. In line with our virtuous circle hypothesis, barriers at the level of the individual – time and remuneration – were the most powerful in preventing the delivery of best practice. But after this, team function – poor communication on discharge from hospital, and a systemic issue – lack of coordination with the health system – were the most important issues.

Figure 15: Issues that create difficulty in providing best practice palliative care



C3. Please examine the following list of resources that GPs have told us, when lacking, make best practice palliative care more difficult. Base: total sample, weighted, n=1000.

On average, GPs recognised close to six different issues that impacted on their ability to provide best practice PC. This highlights the inter-related nature of barriers. For example: poor communication between different areas of the health system makes it more time consuming for GPs to catch-up on patient needs, co-ordinate services or access beds in hospitals or hospices.

6.3.2. Structure of specialist palliative care services

Another trend observed in the qualitative study was that way in which GPs appeared to resent 'too much' involvement by other services (where these took over) or 'too little' (where they were forced to take on a larger role than they had wanted).

GPs told us about specialist PC services 'taking over' patients – this meant they could go from being a primary physician to a bystander, with very little role in their patient's care.

They told us that at the other extreme, where specialist PC were stretched or fragmented, coordinating and delivering services was more demanding of their time and potentially detrimental to patient care. One group of GPs estimated that less than 10% of their in-home patients received best practice PC because of a lack of services.

GPs in rural and remote areas expected to take on a greater role. However, while they tended to have fewer local services, many said that their knowledge and networks meant that they could compensate for this.

"I think the biggest barrier for GPs is getting the time to do house calls. Patients who are palliative are not able to come to the surgery in general. So we rely heavily in Palliative care nurses doing house calls and then keeping us informed as to what is happening. So this leads onto my second point – having enough skilled Palliative care nurses in the community." Regional South Australian GP

In the qualitative study, the extent to which specialist PC services 'took over' particular aspects of PC, or required GPs to operate relatively independently, appeared to be a strong signal to GPs about the extent of their role. The most extreme example of this was found in Perth, and we have provided an illustrative case study below.

Case study Silver Chain in Perth: In Perth, Silver Chain appears to have taken on much of the responsibility for coordinating and delivering PC. Some GPs still do PC work (i.e. although might use Silver Chain as a locum service on weekends). They might also be required to organise some interim comfort care or support until a patient has been assessed and taken on by Silver Chain – at most this delay was reported to last no more than a few days or over a weekend. And GPs are still required to prescribe. Most welcome this lesser involvement in PC, citing the specific skills/knowledge required to do PC, the onerous and thankless task of coordination and frequent home visits needed to do some pain management and end of life care well. However, some resented Silver Chain taking over their patients and would have liked a bigger role in their patients care or better sharing of the patient or better communication with Silver Chain. No one saw themselves as part of a PC 'team'.

"Some GPs do feel like Silver Chain hijacks their patient." Perth GP

"GPs have too much on their plate either way. They are quite happy to pass on the patients."

6.3.3. Practice ownership structure and business model

The survey data did not show a relationship between practice ownership and the number of PC patients seen. GPs working in corporate practices saw significantly less patients for ACP (3.8 per month on average), but about the same number of patients for PC as privately owned practices. They also reported seeing significantly more patients for chronic disease management (98.1 per month compared to average 78.6 across all GPs).

GPs working in practices where patients were either all or mostly bulk billed saw the greatest number of patients for PC – an average of 5.9 in the last month compared to 3.9 for those who work in practices where patients were either all or mostly privately funded.

However, qualitatively, GPs said that corporate and bulk-billing clinics that do not allow a deep relationship to be built up between patient and care giver did not allow for best practice PC. Some GPs felt they were not likely to invest the time needed for best practice PC for patients who weren't 'regulars'. They also talked about the importance of a long-term relationship in giving them insight into a patient's preferences and giving them a sense of reward in being involved in a patient's death. The exception to this was in rural areas where a more corporate model involving rotating GPs was the only way to ensure that a doctor would be available to the population.

"The medical side is easy; they can deal with it no problem. You can't do palliative care well if you don't know the family, don't know about the ex-wife, that the kids are fighting."

This analysis suggests that GPs working in corporate practices may be seeing a lot of palliative patients, or chronically ill patients who would benefit from a palliative approach; however, depending on the corporate policies in place may not be encouraged to develop the relationships or put in the time required to do best practice PC.

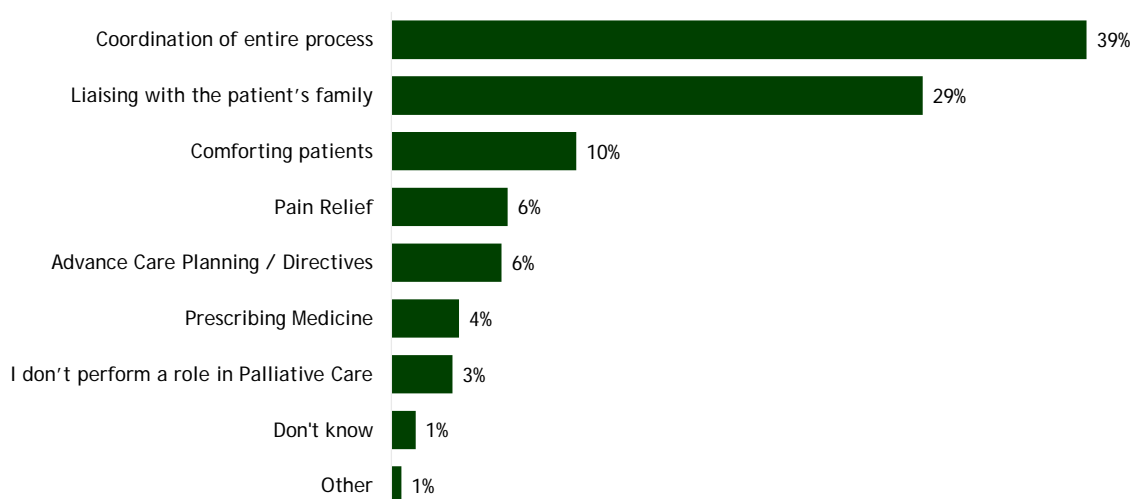
"Look, I think the medical centre model is going to change... The model in Australia is going to shift from bulk billing because of the population shifting in the age groups. You cannot do five-minute medicine on somebody that's really sick." Sydney GP

I don't do home visits or house calls. Once they go off to their palliative care and they've found a GP that does the house calls, they're out of my area. Sydney GP

6.3.4. Time

Quantitatively, 39% of GPs nominated coordination as the PC element that took up most their time. Liaising with families (29%) and negotiating patients' emotional needs (10%) were the next most time-consuming elements.

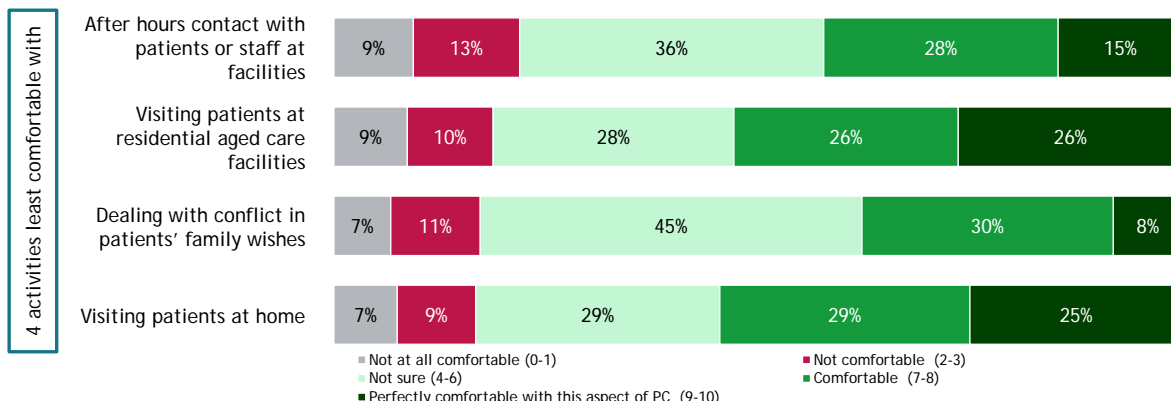
Figure 16: Most time-consuming aspects of palliative care



B16. What do you consider the part of palliative care that takes up the majority of your time? Base: total sample, weighted, n=1000.

Many of the most time-consuming elements – doing home visits, visiting patients in RACFs and after hours – were also the aspects of PC that GPs nominated as being least comfortable with (see Figure 17 below) – and also not remunerated (as discussed in the next section). They saw this as a deterrent to GPs becoming involved in PC or to investing the time best practice PC requires.

Figure 17: Palliative care activities GPs are least comfortable with



B12. Thinking about the range of activities involved in palliative and end-of-life care, how comfortable are you with each of the following aspects of palliative care? Base: total sample, weighted, n=1000.

6.3.5. Remuneration

In the qualitative discussions, with the exception of the few who had specifically structured their practices to achieve this, GPs agreed that 'best practice' PC was not financially viable. They said that most of their interactions with families, service coordination, after-hours calls from RACF staff and over the phone prescribing and consultation with PC nurses were not billable.

Counterpoint: Nurse practitioners argued that they could be given a larger role in community settings (including residential aged care facilities) including with respect to prescribing opioids and other medications to make up for GP's lack of time.

In addition, they tended to feel that rates for in-home visits and RACF visits were low.

GPs reported using standard MBS items for PC (standard consultations, home visits or RACF visits). Some were surprised when shown the range of MBS items that were relevant to PC. GPs – or at least their practice managers – said they would welcome clarity on how to charge for PC, including where they are entitled to charge for case coordination.

"Money and attitudes. make it lucrative and we'll be flocking to it. otherwise, in a predominantly bulk billing service like mine you are asking me to give up a few hours on a home visit for someone many Ks away for less than a rubbish plumber, and denying my other patients appointments whilst I see them."

"It's asking GPs to do a lot of home visits and after hours' work. The Medicare rebates are pitiful."
Perth GP

"Palliative care is very time and labour intensive." Perth GP

"I refuse to do home visits. If I do it, I do it out of loyalty." Perth GP

"Unless the patient is sitting with you, you can't charge for it, so all the phone calls, the coordination, the dealing with the family, the phone calls with specialists... you're doing it for the love of it!" Brisbane GP

"Standard house call. By the time you get in your car and get there, it's not worth it. Plumbers and sparkies charge \$120 just to get there! You do it for the love of the patient." Sydney GP

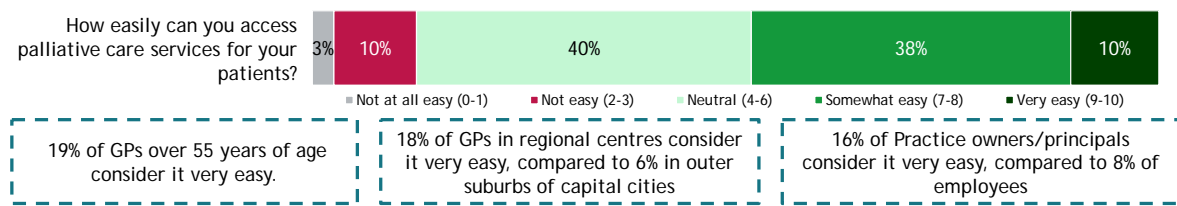
6.3.6. Team / resourcing factors

Team factors identified as barriers to best practice care in the quantitative study included: poor communication and coordination, lack of access to services and resources, lack of knowledge about local services and resources, and issues associated with residential aged care resourcing. Section 7.2 above discusses in detail how GPs viewed the role of other health professionals and perceptions of communication.

6.3.7. Access to and knowledge and availability of services and resources

In the survey, around half of GPs said they found it somewhat or very easy to access PC services for their patients. Only 10% considered it very easy. This figure was higher among those in regional centres compared with those in the outer suburbs of capital cities, and higher among practice principals compared with employees. Older (55+) GPs tended to say they found it easier to access services, indicating that experience with the health system and greater local knowledge helps. Those who never or only rarely service culturally and linguistically diverse and Aboriginal and Torres Strait Islander populations said they found it more difficult to access PC services.

Figure 18: Ease of access to palliative care services



C2. In your opinion, how easily can you access palliative care services for your patients? Base: total sample, weighted, n=1000.

The survey showed that GPs with more expertise in and comfort with PC (*Palliative Care Experts* and *Palliative Care Aspirers*) felt they had much easier access to services than the other segments. The qualitative study illustrated that less engaged GPs seeing fewer palliative patients could feel very under confident and as if they had to re-establish fragmented networks all over again when presented with each new palliative patient. They did not feel as if they were a part of a PC 'team' or that they necessarily had a good understanding of what support was available to them.

"One barrier can be a fear of ending the patient's life too soon by accidental overdose." Rural Victorian GP

"Like many areas keeping up skills may be difficult with each GP perhaps not having many difficult palliative patients each year. Encouraging GPs to get assistance from other GPs with special interest would raise standard. Poor remuneration for time and expertise. Special item numbers or block funding for someone deemed palliative." Rural South Australian GP

6.3.8. Coordinating and resourcing personal and nursing care and equipment in-home

Qualitatively, GPs told us that if a specialist PC service was not coordinating or providing in-home nursing, then patients could fall between funding and resourcing cracks. GPs talked about spending hours trying to track down appropriate care and services – and locating a funded service that a patient would be eligible for. In the qualitative study, the minority of general practices who were doing a lot of care coordination said that the MyAged Care website was a particular source of frustration. They would welcome clearer guidance about what services (including equipment) are locally available to, and affordable for, palliative patients.

"If old enough an ACAT will pick up." Adelaide GP

"Some palliative patients are difficult. They come back to you but you struggle because it's not like a hospital, you don't have the networks [of other services to draw in/refer to]." Bendigo GP

As flagged above, another key barrier to patients being able to die well at home was lack of informal carer support or an undue and unfair burden on informal carers. In particular, a lack of personal and respite care services were seen to 'sink' informal carers. GPs called for additional PC and community nursing and personal care services to support dying in-home, including consideration of the sometimes very strict guidelines for acceptance and retention of patients by PC services.

"The main aim is for people to die at home. If you don't have anyone you have to go into aged care." Rural Victorian GP

"We just had a patient in palliative care and he took too long time to die so they transferred him to a nursing home. It broke my heart because he didn't want to be in a nursing home." New South Wales Practice Nurse

6.3.9. Issues caused by distance

Qualitatively, GPs told us that while many in the health system work valiantly to overcome care issues related to distance, there remains the issue that specialist, allied health and tertiary hospital services are less available in rural and remote areas. They said this can require patients to travel to obtain care, and potentially spend time away from familiar home environments, family and friends at a time when they are most vulnerable, and that

access to after hours or in-home nursing and personal care can also mean that symptom management is less prompt.

"We work in an area where there is a lot of chronic disease, if people wish to be seen at home that can be a 30km trip." Bendigo GP

"If people have no one to care for them at home or need to go into a residential aged care facility it can be really difficult. There might be no places available nearby or they might have to go in half way across the state where their family can't visit."

GPs felt that they could be integral in overcoming these barriers – using their personal and professional networks to get good care for their patients.

The structure of specialist PC services, and how they relate to rural and remote GPs may also determine the extent to which GPs are able to provide good care. We suggest the Queensland paediatric palliative service offers a good model in this context.

6.3.10. Quality of residential aged care facility staff

As flagged above, both the quantitative and qualitative studies pointed to the quality and consistency of RACF nursing and care staff as an issue negatively impacting on the care palliative patients received.

Counterpoint: Staff at residential aged care facilities complained that doctors are not necessarily competent e.g. quite a few examples of doctors not prescribing what they consider to be the right drugs or dosage and nurses have had to follow up with doctor to question their prescriptions and in some cases, have it changed. Some also considered that they are also best placed to trigger conversations about pall care and refer to SPC but often not done because simply don't "think about it".

GPs called for the presence of regular registered nursing staff and education to other RACF staff.

"In RACF regular staff are not always there or employed or there are fill in staff that don't know the patients. They don't necessarily employ a nurse practitioner on the weekends." Perth GP

"Staff are often not qualified; the registered nurses have a limited skill set. The easiest thing is to transfer to hospital. And that's hell, especially for people with dementia. They're on a gurney, no privacy, fluorescent lights, noises. It's a failure in quality of care." Perth GP

"[When a locum comes, you need] a file with a point of contact, how they are progressing, their expectations, the family's expectations." Perth GP

"In a nursing home, they can't look after people in an emergency, depending on their age and comorbidities so they send a patient to hospital." Darwin GP

"Some people do get better care in facilities, they have OTs, physios..." Brisbane GP

6.3.11. Managing episodes of acute deterioration in-home and in residential aged care facilities

Across the qualitative sample, GPs, nursing and specialist staff spoke of the difficulties of managing episodes of acute deterioration for palliative and end of life patients who are being cared for in their own homes or in RACFs, and the resulting patient experience of unwanted or unhelpful medical intervention and hospital admissions.

Key issues included a lack of:

- good quality nursing care in RACFs
- motivation (or ability) amongst RACF staff to manage deterioration
- previous conversations with a patient and their family about the possibility of acute incidents about how they would prefer their care be managed in those eventualities
- documentation of these wishes (including through ACDs)

- available medicines (including in RACFs, and through locum services and community pharmacies)
- information at crucial points (i.e. for after-hours locum or ambulance services, or for emergency doctors and nursing staff), and
- anticipatory prescribing and care planning by GPs.

These issues tend to reflect systems failure and are not necessarily easily solved. They require:

- ACP and ACDs to be undertaken and readily available across different parts of the health sector (addressed in section 9.1 below)
- capacity building for RACF staff, GPs and after-hours locums, and
- the increased ability to provide nursing for palliative patients in the home.

Making recommendations for building capacity for RACF and increasing the ability to provide nursing for palliative patients in the home are outside the scope of this study. With respect to after-hours locums, we note that we spoke to a larger locum service provider who described a full education program and clear opportunities for regular GPs to share information about palliative patients with locum services.

6.3.12. Supporting the transition from home to residential care

In the qualitative discussions, GPs also criticised the options open to patients who were no longer able to be cared for at home. Hospitals (with the possible exception of smaller rural and remote hospitals) were seen as unfriendly and undesirable places to die. Lack of availability of hospice and RACF beds, as well as a cumbersome and expensive entry process into RACFs were seen as barriers to good PC. GPs called for additional hospice beds and a consideration of a streamlined entry process to RACFs for patients in the palliative phase.

"I worked in emergency departments. People come in from residential aged care facilities. They are really in the palliative stage. But there is a lack of information and unless they have brought in their file you don't know." Perth GP

6.4. Patient characteristics

6.4.1. Family

In the qualitative study, GPs felt that delivering PC in the community was difficult or even impossible without family being involved, especially at end of life when people are likely to require higher levels of personal care. However, GPs also reported the potential for high levels of family dysfunction at end of life.

"Family, parents, kids, often say, "Stop there, we want to do everything we can..." and this can create a conflict of interests." GP Melbourne

Decision making in these environments can be complicated, and from a GPs' perspective, where the family is in conflict about how to treat the palliative patient (or often, the potential estate), it becomes much more difficult to approach best practice.

"The family is most important; it can be highly charged." Perth GP

"It's whole of family care. You can give answers that they can't get from a specialist." Perth GP

"You have time to ask. If you are a GP, you will have known them for a long time. You know their partners and their kids." Perth GP

"Support doesn't end when the patient dies... it can be an emotional rollercoaster." Perth GP

Completion of ACDs and broader community education were felt to be important to address this issue.

6.4.2. Cross cultural communication and care

Many of those doing more PC had dealt with people from a different culture to their own. This included those in city practices dealing with migrant populations and Indigenous Australians and overseas trained doctors dealing with Australian multiculturalism.

In the qualitative study, GPs said that in terms of best practice care, there can be a discrepancy between the doctor's view that the patient should be informed and family (and possibly the patient's) view that communication should be with the family on behalf of the patient. It was our sense that rather than offend or create conflict, GPs are avoiding broaching PC and death issues. However, because they tended to assume rather than ask, this may not necessarily be in the patient's best interest. They said that they would welcome resources on this topic. More experienced GPs said that they would also recommend coaching GPs to understand cultural views and their importance (given that part of patient centred care is negotiating and shared decision-making) will likely be important.

"There are a lot of cultural issues [for Aboriginal patients]. Sometimes you don't even know what the cultural issues are. You get health workers in, gender is important. It is difficult when patients are transferred upstate. They come to Fiona Stanley, their records are lying up north. It can be trying. The patient is not well, has cancer, this or that. You don't know the story. You've got a patient's family telling you all sorts of stories, you don't know what to think." Perth GP

"I had an [Aboriginal] patient with pancreatic cancer from Broome, they were not happy with Silver Chain and transferred all the notes. That worked and I think that e health will help sort this further." Perth GP

"We don't do it [at the AMS]. It is a cultural thing not to talk about cancer." Perth GP

"In some cultures the family thinks that everything should be done for a patient. Hospital staff are frustrated because they know it is futile care." Brisbane GP

"When Aboriginal patients are diagnosed sometimes they just want to go home. To do bush medicine." Darwin GP

6.5. Summary and key implications

It is possible to list out barriers and enablers at the levels of patient, individual GP, general practice, PC team and health system. However, it is the researchers' view that this can become something of a laundry list that doesn't suggest priorities or the dynamic nature of how enablers and barriers interact.

This study suggests that GPs who are already interested and engaged in PC weave themselves into something of a virtuous circle, where individual motivation, education/training and exposure drive and reinforce interest and engagement. However, GPs with less interest in, or experience of, PC tended not to have these cushioning structures of education, experience and professional and practice support, which in turn tended to make individual episodes of PC feel more difficult. Other structural factors worked against both, diminishing GP engagement and their ability to provide best practice care.

There are opportunities to better engage and support less resourced GPs —

- promoting exposure to clinical PC practice as an undergraduate, through GP training, and further engagement amongst GPs with the available programs
- building medical knowledge of how to manage symptoms as well as practical information on local service networks, and
- integrating PC into rural workforce strategies as well as engaging with corporate medical practices and their education and training systems.

With respect to specific awareness and education interventions, the different segments will need different approaches. For instance, *Palliative Care Aspirers*, will likely be easily engaged to overcome knowledge barriers to best practice PC — their issue is lack of awareness.

However, *Palliative Care Indifferent*, and even *Palliative Care Avoiders* will need different strategies that emphasise ease of engagement as well as very publicly signalling the importance of GPs taking up a PC role through key influencers such as PHNs and the RACGP. Another strategy for *Palliative Care Avoiders* might be to develop mechanisms for them to easily refer to *Palliative Care Experts* or *Aspirers* or specialist PC teams.

Educational tools and resources for all groups are discussed in section 10 – in addition to these, this study has also suggested a need to review:

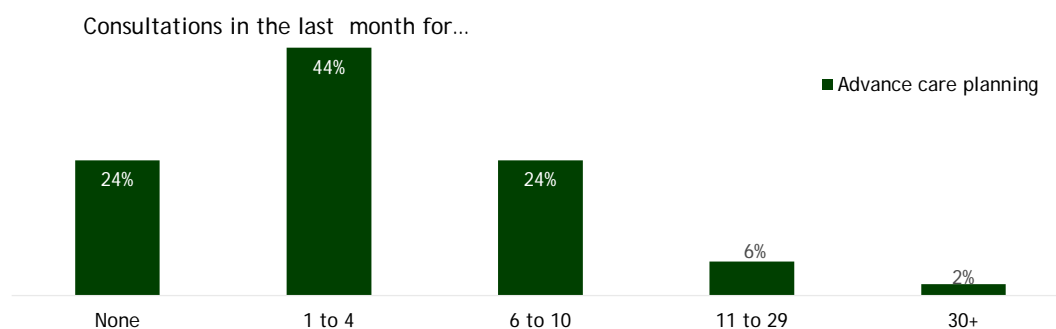
- where practice managers and nurses (some ACD tasks, case coordination) and specialist PC nurses (prescribing) might more efficiently do some PC tasks for patients in community
- lack of GP remuneration for key PC activities
- availability of community resources to support in-home PC
- non-inclusive specialist PC services driving disengagement
- corporate and locum services that aren't incentivised for structured for best practice PC, and
- the need for innovative solutions to distance delivery, setting transition and episodes of acute deterioration in the community, and to communicate these more broadly.

7. Advance care planning and advance care directives

7.1. Advance care planning in general practice

Three-quarters (76%) of GPs completing our survey said that they had seen at least one patient for ACP (Figure 19) in the past month.

Figure 19: Number of patients seen for advance care planning over past month



Source: B7. Thinking about your day-to-day practice over the last month, how many patients did you see for...? base: total sample, weighted, n=1000.

Four in ten (38%) GPs in the survey said they were seeing increased community interest in ACP (Figure 22). A pattern of interest emerged in the survey – 44% of GPs in inner-city areas were seeing an increase in community interest, compared with 33% in outer suburbs, and 12% in regional centres, rural and remote areas. In the qualitative discussions, GPs noted that increasing interest was coming from more educated and affluent patients.

“My practice is in Armadale...I get fit, rich people in their 40s and 50s coming in and asking me about advance care plans” Melbourne GP

7.2. ‘When to plan’ partly defines ‘what’ is planned

In both the qualitative and quantitative studies there was a lack of agreement on the best time to undertake ACPs and ACDs, and hence on what the nature of planning involved (e.g. theoretical advance planning or planning for the end of life).

Some GPs saw ACP as an activity untaken for relatively well patients or patients at an early stage of their disease. In the survey, a proportion of GPs said that ACP should be raised: at the onset of chronic disease (14%), when signs of cognitive decline first become apparent (24%), when a patient is fit and healthy (19%) and at the 75-year-old health check (30%). In the qualitative conversations, GPs described this sort of planning as ‘theoretical’, more of a statement of intent than capturing ideas or actions that might be realistically or practically applied. However, it was also suggested that introducing ACP at these points may pave the way to serial PC conversations as disease progresses.

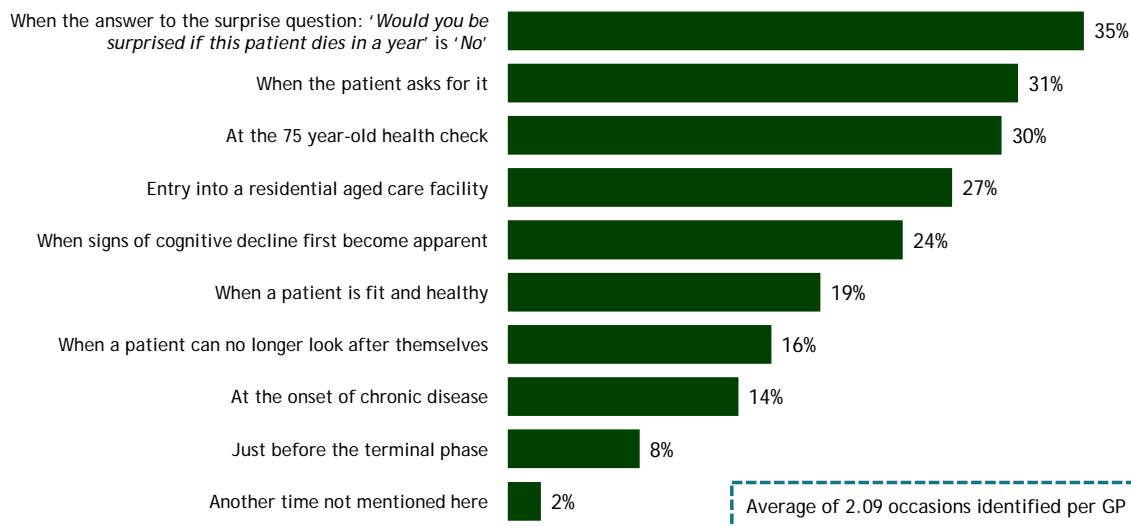
“Advance care planning is easier as it is theoretical and everyone is happy to plan for an unlikely future event rather than a more imminent death.” Rural South Australian GP

A quarter of GPs (27%) in the quantitative study said that the ideal time to do ACP was on entry into a RACF. However, in the qualitative study, many GPs felt entry into a RACF would be too late for dementia patients to be able to effectively provide consent.

Geriatricians especially felt that it would be important to do some sort of ACP close to an initial dementia diagnosis (although did not necessarily see themselves as being responsible for this). Having said this, nurses working in RACFs said that that ACP done upon entry is best practice, but is often ignored as facilities or individuals don’t want to be too “confrontational” when patients arrive and at a hard time for families.

“The feedback from nursing homes is that patients are paranoid, they are scared this means you won’t get treated as well.” Perth GP

Figure 20: Best times to bring up advance care planning



B17. Which of the following is are the best times to bring up advance care planning with your patient? Base: total sample, weighted, n=1000.

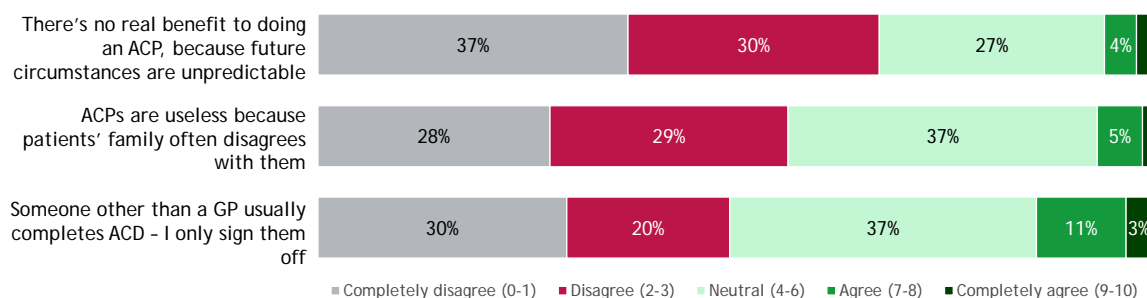
The survey showed that a substantial number of GPs saw ACP as more relevant to end stage terminal illness. Figure 20, above shows that when asked about the ideal time to bring up ACP, 35% suggested that the surprise question indicator should be the trigger, 16% when a patient can no longer look after themselves and 8% just before the terminal phase. Qualitatively, they told us that this is when they can begin to outline specific preferences in plans that might realistically translate into action.

7.3. Advance care planning seen as useful, but plans are less so

The survey showed that a majority of GPs feel there some benefits to ACP:

- 67% of GPs disagreed with the statement: 'There's no real benefit to doing an ACP because future circumstances are unpredictable'.
- 57% of GPs disagreed with the statement: 'Advance care plans are useless because patients' families often disagree with them'.
- Only one in eight (13%) agreed they only sign-off on ACDs after someone else (the examples given were a practice or other nurse) creates them (Figure 21).

Figure 21: Opinions about advance care planning



B18. When it comes to advance care planning, how much do agree or disagree with the following...? Base: total sample, weighted, n=1000. Note: labels for proportion sizes lower than 3% have been removed for clarity

Qualitatively, GPs told us they could see benefits to their patients and their patients' families of thinking through the issues and agreeing these in clear written form. But GPs also cited many instances where an ACP was not available when it was needed – for example on emergency hospital admission – and where this had resulted in unnecessary or futile care.

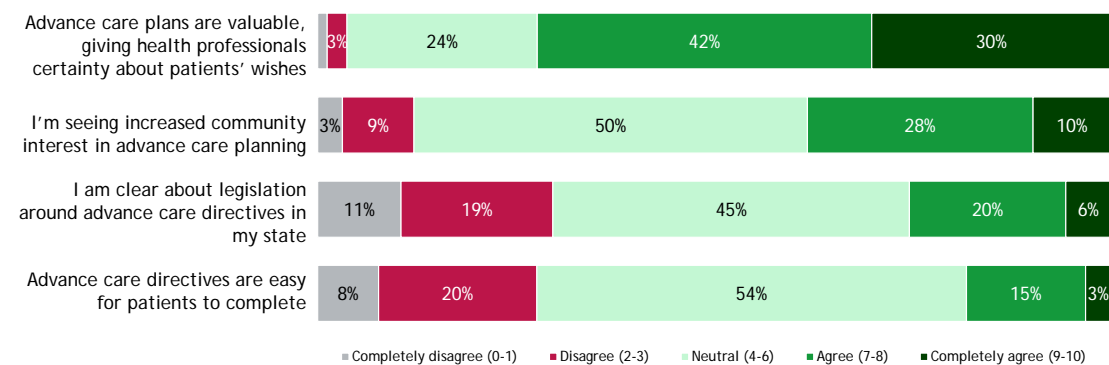
GPs tended not to be aware that ACPs/ACDs could be included in the My Health Record, and sceptical that the adoption of My Health Record will happen at a pace and scope to make this an easy / quick solution.

Similarly, to other areas of PC, the more engaged segments were more likely to be positive about what ACP could achieve. For instance, *Palliative Care Experts* (85%) were substantially more likely to agree (7-10) that care plans gave health professionals certainty and were also more likely to disagree that they only sign off on ACDs (58%) – demonstrating a more active engagement in the planning process.

7.4. Lack of knowledge of legislation and onerous forms a barrier

GPs said that ACDs were confusing and not easy to complete. Only one in five (18%) agreed ACDs were easy, and only a quarter (26%) agreed they were clear about relevant legislation (Figure 22).

Figure 22: Opinions about advance care planning



B18. When it comes to advance care planning, how much do agree or disagree with the following...? Base: total sample, weighted, n=1000. Note: labels for proportion sizes lower than 3% have been removed for clarity

GPs in Queensland and Tasmania were significantly more likely to agree that ACDs were easy to complete (24%, 43%) and that they were clear about the relevant legislation (32%, 31%).

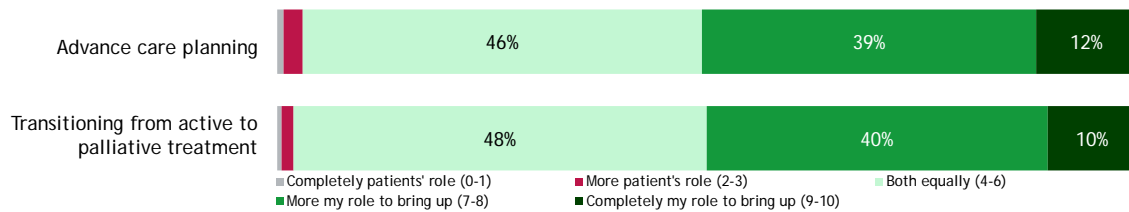
Qualitatively, GPs told us that they didn't have easy access to forms – either they didn't know how or where to source them, or they weren't stored in practices in such a way as to be readily available during a consult.

7.5. GP, patient and other roles in triggering advance care planning discussions

Importantly, as shown in Figure 20, above, the second choice for ACP timing was 'When the patient asks for it' – a third of GPs were waiting for their patients to bring up ACP rather than initiating the conversations themselves. (In the qualitative conversations, GPs were shocked at the idea that their patients were waiting for them to bring up an ACP conversation.)

The survey also asked GPs specifically about whose role they felt it was to raise ACP. Figure 23, below shows that while few GPs felt it was their patient's role, around half (46%) felt it was equally theirs and their patient's role – implying they may be hesitant to initiate discussions. Qualitatively, some mentioned that they believed solicitors were responsible for completing the plans.

Figure 23: GPs perceptions of whose role it is to bring up ACP and transition to PC



B15. When it comes to introducing end of life issues, do you feel it is your patients' role, or your role to bring up? Base: total sample, weighted, n=1000. Note: labels for proportion sizes lower than 3% have been removed for clarity

"Some people come and talk to you or they go to a solicitor who draws up the advance care directive." Perth GP

"2 or 3 years ago, I had a patient with end stage liver cirrhosis, they didn't tell their family, they died and it got messy." Bendigo GP

"I think people would be upset and offended if you offered it at the 75+ health check." Perth GP

7.6. Best practice is an ongoing discussion that GPs can be prepared for

GPs in the qualitative study who appeared to do ACP and ACDs well offered the following best practice 'tips and hints':

- have forms on site
- involve a practice nurse or practice manager who would insert the relevant forms into a patient's file as needed
- integrate forms into software
- have multiple conversations involving family members to ensure the whole family agrees with the direction the ACP is taking
- seeing ACP and ACDs as a way to manage family expectations, as well as ensure the patient receives the care they want
- thinking about ACP as an ongoing series of conversations, rather than a one-off
- That ACDs provide doctors with (more) certainty of how to treat,
- doing ACP while a patient can still consent / before the onset of dementia, and
- allowing enough time – few felt that a decent ACP consultation could occur in less than half an hour - requiring extended consultation times to execute.

"Sitting down to have the conversation takes about an hour." Perth GP

"I wouldn't think about it before a diagnosis." Perth GP

"Sometimes someone gives you one to put on their file." Perth GP

"We bring it up but the nurses do most of the talking. They go through it step by step and then we sign it at the end." Adelaide GP

7.7. Summary and key implications

Three-quarters (76%) of GPs have seen at least one patient for ACP in the past month, and four in ten (38%) say they are seeing increased community interest in ACP.

However, GPs vary widely in when they think ACP should be raised and ACDs completed – ranging from an issue to be discussed with fit and healthy patients to something done at the end stage of a terminal illness.

Both the qualitative and quantitative studies indicated an ambivalence about planning. While the process of planning is seen to be beneficial, documents (whether ACDs or other plans) do not necessarily maintain their relevance or are easily located when they need to be.

In addition, GPs do not feel well-informed about the relevant legislation, say that they find filling out the forms difficult, and do not tend to have easy access to forms. PHNs could work with practices on the practical steps that appear to encourage completion of ACP and ACDs: having forms on site, involving practice nurses and managers and being clear about how a practice can charge for these.

While more affluent sections of the community appear to be taking up ACP, it would also appear that there are further opportunities to prompt GPs to encourage it through building the completion of ACDs into medical software packages at key milestones (e.g. 75+ health check, dementia diagnosis, a 'yes' answer to the surprise question).

In summary, it would appear that communicating to GPs that their patients are expecting them to broach the topic, coupled with a community campaign to promote and normalise completion of ACDs at the 75+ health check or on diagnosis of a chronic or life limiting illness, and combined with easy access to forms (and the facilitating involvement of practice managers and/or nurses) would go some way to ensuring more advance care directives are in place.

Michie COM B behavioural change case study.

An internal behavioural change workshop was run based on the example case of persuading GPs to undertake ACDs as a matter of course for patients with an advanced chronic illness.

The workshop identified a number of behaviour change drivers that would need to be in place for the behaviour to occur. This included the GP's own physical and psychological capability and motivation as well as the social and physical opportunity determined by the GP's external environment.

Capability

- GP is aware of the surprise question
- GP is trained in use of the surprise question during consultation
- Remembers how to apply the surprise question
- Chooses to apply surprise question over competing priorities
- GPs manage biases about predicting prognosis/death avoidance/low communication
- Consciously overcomes lack of habit around applying surprise question (initially)
- GP has a process for doing the surprise question

Opportunity

- Patient comes to see GP
- There is enough time in the consult to review the patient in view of the surprise question
- The surprise question is flagged (software or other)
- This needs to be flagged as important by practice, PHN, local specialist PC team, AMA, RACGP, chronic disease framework, corporate practices etc. as necessary.

Motivation

- Fits with professional standards (Believes applying the surprise question fits with the kind of GP I am/Believes good GPs ask the surprise question in this situation)
- Sense of self-efficacy/professional confidence
- GP trusts as evidence based and helpful for clinical decision making
- GP believes that the benefits of asking question outweighs negatives
- GP intends to ask surprise question of patients in the 'long term chronic disease cohort'
- Self/practice sets goals for applying the question

- GP feels like has been remunerated for time
- GP has feedback loop if doesn't apply
- GP overcomes burnout/stress/overwork

In turn, this analysis led to the identification of a number of interventions and behaviour change techniques needed for more widespread uptake of the surprise question.

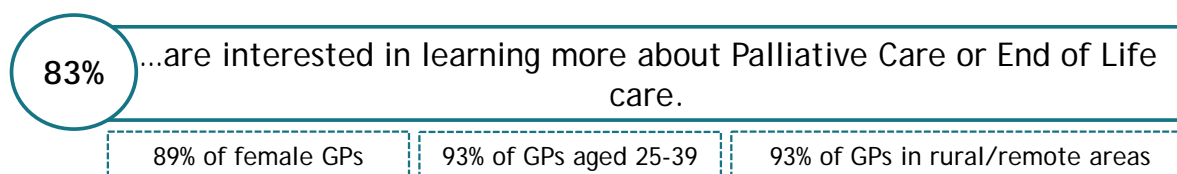
- Education as well as training in how to use the surprise question.
 - Provide information about the consequences of performing the behaviour (potential for surprise question to identify patients who may require different treatment patterns; information on how patients identified at this stage and reviewed for treatment needs have better quality of life / live longer)
 - Training (instruction/demonstration) in how to apply the surprise question
- Enablement for bias regulation.
 - Ask GP to record additional patients picked up over a three month period.
- Environmental restructuring (booking longer consult, question prompted through software & practice structures).
- Education and persuasion to establish that using the surprise question is part of a good GP and that GPs can trust in outcomes).
 - Communication from a credible source (RACGP, PHNs, specialist PC services) in favour of the expectations on GPs, the evidence base and clinical rationale.

8. Palliative care and advance care planning tools and training

8.1. Interest in learning more

Most GPs were interested in learning more about PC and EoLC. Females, younger GPs and those in rural and remote areas were significantly more interested.

Figure 24: Interest in learning more about palliative care, end-of-life care



B10. How knowledgeable do you feel about palliative care? Base: total sample, weighted, n=1000
 B11. Would you be interested in further developing your skills in palliative and end-of-life care? Base: total sample, weighted, n=1000

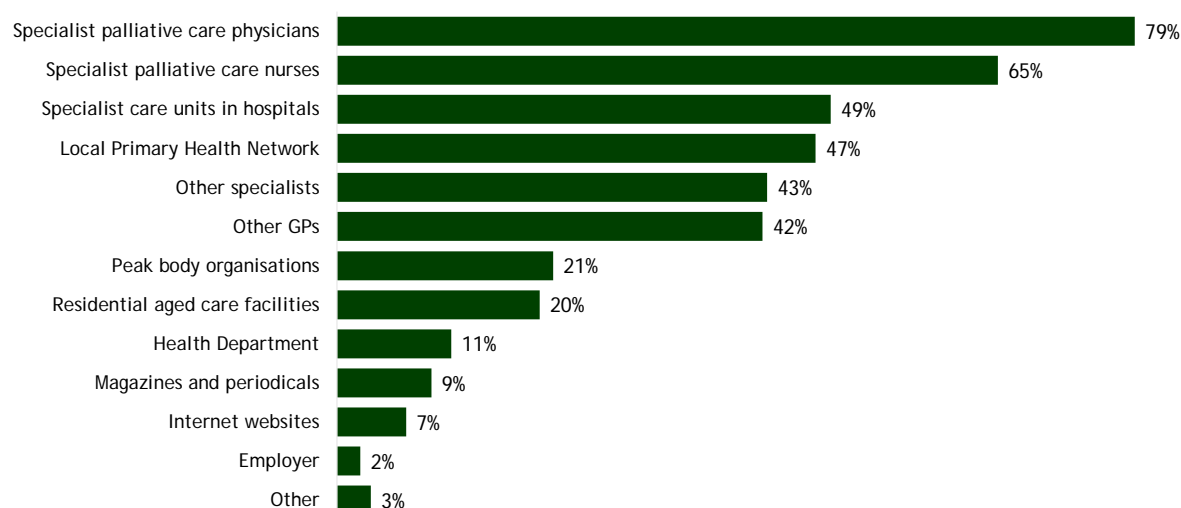
Although significantly less likely to want to further their knowledge compared with the *Palliative Care Experts* (93%), a majority (62%) of the *Palliative Care Avoiders* would still be interested in further developing their skills.

8.2. Where they would like to get more information

The survey results showed GPs' preference for local, personal networks as a conduit for information. Eight in ten (79%) GP's saw local PC services, with specialist nurses the next most credible source (65%). Hospitals (49%) and PHNs (46%) and other specialists (43%) and GPs (42%) were next down the preference list, while peak bodies (21%) and RACFs (20%) round out a third tier of preferences (Figure 25).

This analysis suggests that better connections with local specialist PC teams are valued and – and often required for GPs to feel comfortable managing palliative patients.

Figure 25: Preferences for information about palliative care services in area



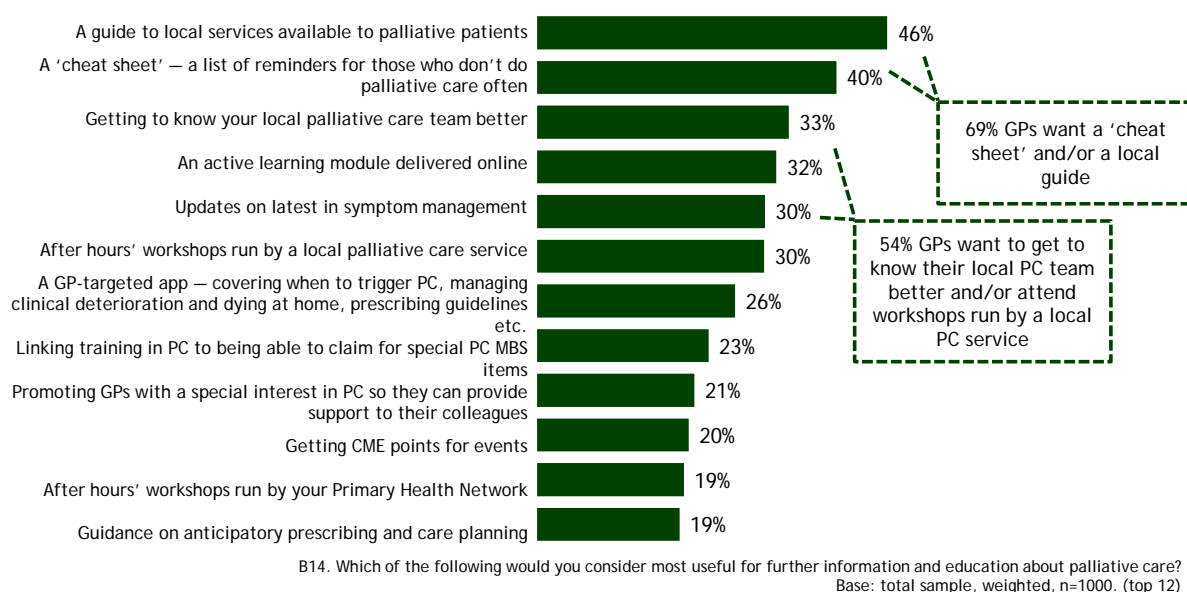
B13. Where would you expect to get information about palliative care in your area? Base: total sample, weighted, n=1000.

8.3. What GPs would like to learn more about / what tools would they like

The qualitative research found use of a wide range of resources and educational tools, but also a lack of knowledge about key tools.

As Figure 26 below illustrates, when asked to prioritise informational and educational opportunities, respondents in both the qualitative and quantitative studies prioritised quick, easy, accessible, local options.

Figure 26: Most useful suggestions for further information and education about PC



- Nearly half (46%) would see a guide to local services available to palliative patients as the most useful information source.
- A 'cheat sheet' — a list of reminders for those who don't do PC too often was selected as a useful source for 40%.
- After these quick, easy informational solutions, some GPs were prepared to put more effort into their own education and would also like to get to know their local PC team better (33%) — potentially via workshops (30%), an active online learning module (32%) and updates on the latest in symptom management (30%).

8.4. Segment preferences for information and education

Across all segments, the order of the top five most useful information and education options was the same as that shown in Figure 26. However, there are some differences in what each segment would like in terms of information and tools.

- *Palliative Care Avoiders* were more likely to pick the 'cheat sheet' than any other segment (47%) and they were significantly more driven by receiving CME points for events (31%) than other segments. Although they responded less favourably to the range of higher-involvement education and training options, they were indicatively (25%) more likely to want guidance on anticipatory prescribing and care planning.
- *Palliative Care Indifferent* were significantly more likely to want a guide to broaching the shift from curative to PC (17%) and a guide to filling out ACDs (18%) — only 11% of the total population wanted these.
- *Palliative Care Aspirers* were significantly more likely to want updates on symptom management (30%), and less interested in getting CME points for events (16%) or guidance on anticipatory prescribing (15%)
- *Palliative Care Experts* were the most interested in linking training in PC to MBS items (30%), and the least interested in a 'cheat sheet' (32%) or a guide to filling out ACD (8%).

8.5. Summary and key implications

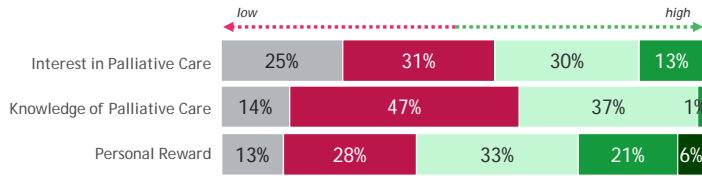
The survey found that 83% of GPs are interested in learning more about PC. Above all, GPs are interested in local sources of information, and quickly digestible information that takes little effort to integrate into their practice. This suggests that local PHN and specialist PC care teams would be invaluable in helping translate interest to engagement, and avoidance to workable strategies (upskilling or referral).

As discussed, earlier, the key role of early exposure to PC in promoting interest in the areas suggests that ensuring a minimum palliative curriculum is available to undergraduates and through the RACGP's specialist GP training and accreditation programs.

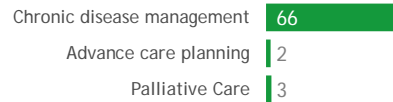
9. Appendix A: Segment profiles



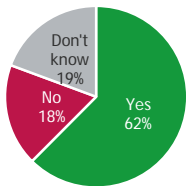
Segment 1 - PC avoiders (14% of doctors)



Patients seen last month for...

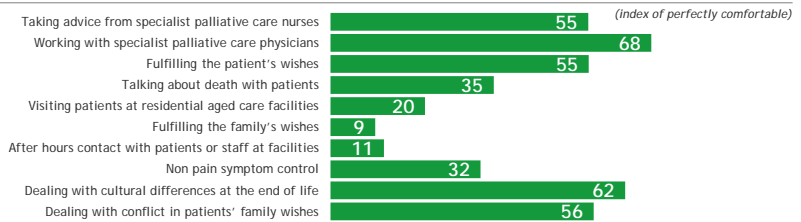


Seeking more Pall Care skills?



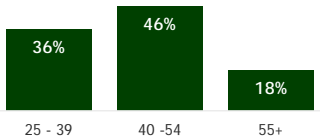
25% have received formal Palliative Care training in the past

Comfort with aspects Palliative Care



Segment 1 - PC avoiders (14% of doctors)

Age group

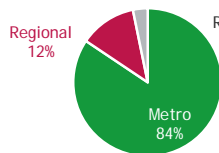


Gender

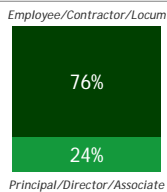


Avoiders are twice as likely to consider their employer as a good source to get more information about palliative care compared to other segments.

Area of residence



Role at practice



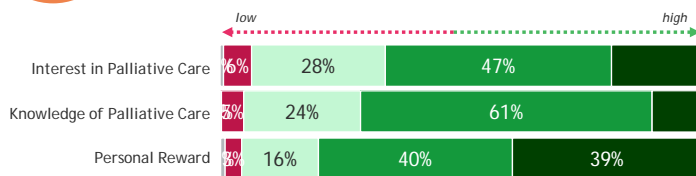
56% don't do home visits

58% don't do RACF visits

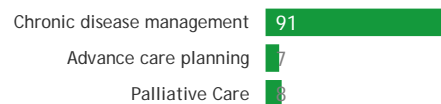
53% have seen less than 10 patients for Palliative Care ever



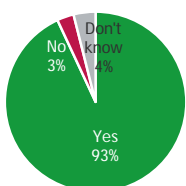
Segment 2 - PC experts (25% of doctors)



Patients seen last month for...

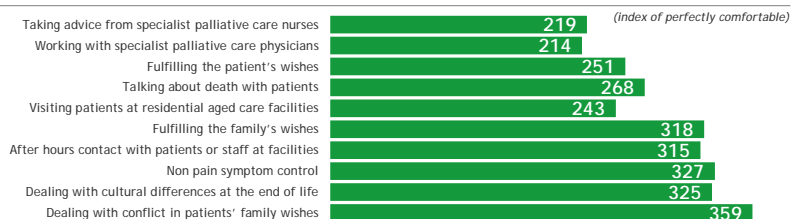


Seeking more Pall Care skills?



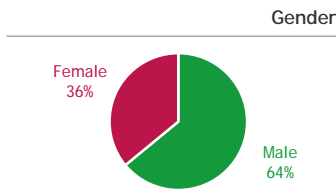
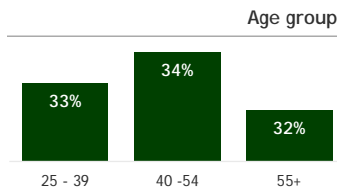
54% have received formal Palliative Care training in the past

Comfort with aspects Palliative Care

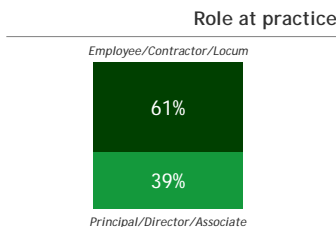
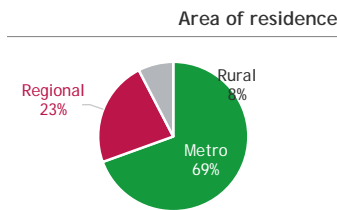




Segment 2 - PC experts (25% of doctors)



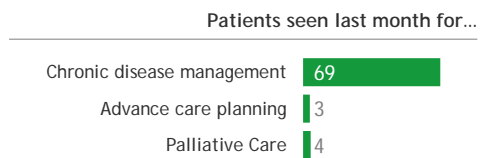
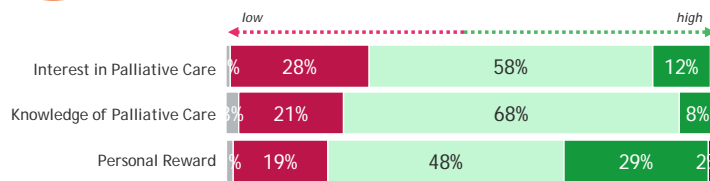
This segment is most likely to consider peak body organisations like "Palliative Care Australia" a good information source for Palliative Care.



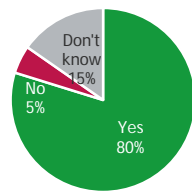
- 27% do more than two home visits a week
- 21% visit RACFs more than twice a week
- 55% have seen more than 50 patients for Palliative Care ever



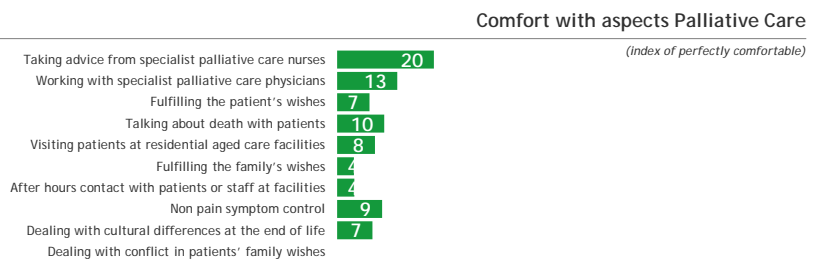
Segment 3 - PC indifferent (23% of doctors)



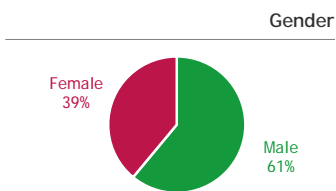
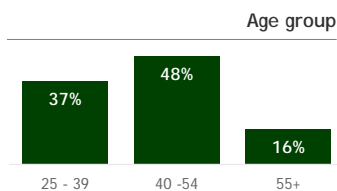
Seeking more Pall Care skills?



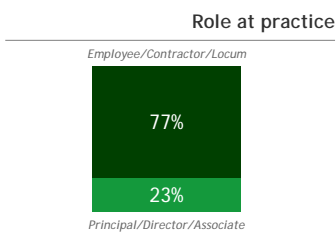
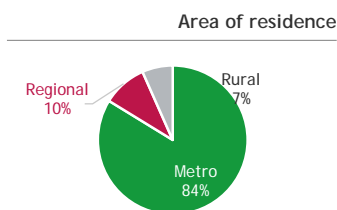
36% have received formal Palliative Care training in the past



Segment 3 - PC indifferent (23% of doctors)



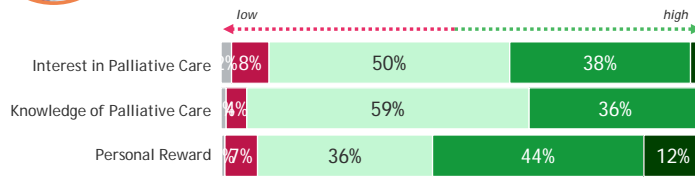
This segment is most likely to expect more information about palliative care from the local primary health network.



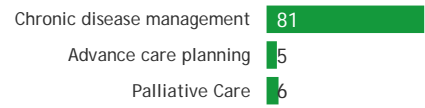
- 40% don't do home visits
- 38% don't do RACF visits
- 9% have seen more than 50 patients for Palliative Care ever



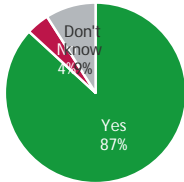
Segment 4 - PC aspirers (39% of doctors)



Patients seen last month for...

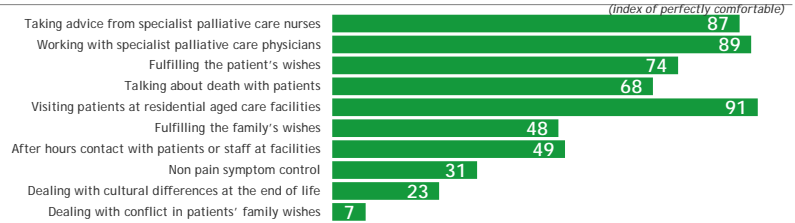


Seeking more Pall Care skills?



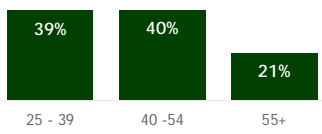
46% have received formal Palliative Care training in the past

Comfort with aspects Palliative Care

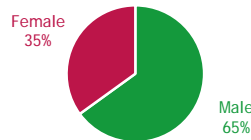


Segment 4 - PC aspirers (39% of doctors)

Age group

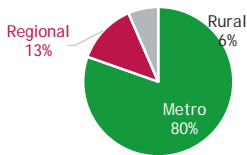


Gender

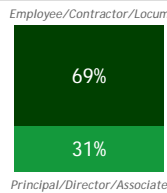


One in four think RACFs to be a good information source to seek information about Palliative Care in their area, although many don't do this kind of visits.

Area of residence



Role at practice



60% do up to one home visit per week

29% don't do RACF visits

27% have seen more than 50 patients for Palliative Care ever

10. Appendix B: Methodology in detail

10.1. Advisers and project team

The research team gratefully acknowledges our two project advisers, Dr Denise Ruth and Mr Stephen Campbell. The *Where to* report authors are Catherine Boekel and Charles Coulton.

10.2. Literature Review and expert-stakeholder depth interviews

The literature review proceeded in three stages:

1. Systematic searches of literature databases ('bottom-up' search). MEDLINE and several other online databases (CINAHL, EMBASE, PubMed) were systematically searched to identify clinical tools utilised in the PC setting. Searches were restricted to literature on adult populations, published in English, and dated from 2000 onwards. The results of these database searches then underwent several rounds of review based on the filters. The objective was to include only articles that focused on PC within general practice in Australia or in jurisdictions with similar health systems (UK, Canada, Scandinavia), or where they added a relevant perspective, and to exclude any articles that were not relevant to PC or EoLC.
2. Supplementary data gathering strategies to identify clinical tools not detected by the 'bottom-up' search (supplementary searches). The systematic or database searches were followed by several searches and data gathering strategies to identify additional relevant perspectives. Searches of grey literature were conducted, including the following resources: The online PC resource, CareSearch; Key organisations: National Palliative Care Research Centre, Palliative Care Australia, Palliative Care Victoria. This design reflected the observation that systematic literature searches are unlikely to identify the majority of clinical tools and practices relevant to Australian context.
3. Synthesis and incorporation of stakeholder interviews. The results of the supplementary data gathering strategies were reviewed by the investigators to identify the range of themes, tools and practices articulated across the literature.

In addition, we conducted 21 stakeholder interviews with state and territory government, professional and peak organisations.

10.3. Qualitative phase

The qualitative methodology comprised discussion groups and online bulletin boards with GPs, and depth interviews with specialist palliative care physicians and nurses, geriatricians, oncologists, respiratory and renal physicians, practice nurses and managers and other allied health professionals. Fieldwork was undertaken in August and September 2016.

The final sample frame is provided overleaf.

Qualitative Sample Frame

General Practitioners (GPs): Face-to-face group discussions (20) and online boards (4)

Research unit	Generation	Other demographics	Palliative care experience	OTD / CALD / ATSI / aged care	Location
Discussion groups 1&2	Baby Boomer (>50) (1) Generation X/Y (40-50) (2)	Owner/partner (1) Employee (2)	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	1 in 10 to be OTD 1 in 20 to service ATSI communities 1 in 5 to be CALD, or serving mostly CALD communities, 1 in 5 to provide services in aged care settings - including locums	Sydney, NSW
Discussion groups 3&4	Baby Boomer (>50) (3) Generation X/Y (30-40) (4)	Employee (3) Owner/partner (4)	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	1 in 10 to be OTD 1 in 20 to service ATSI communities 1 in 5 to be CALD, or serving mostly CALD communities, 1 in 5 to provide services in aged care settings - including locums	Melbourne, Vic
Discussion groups 5&6	Baby Boomer (>50) (5) Generation X/Y (30-40) (6)	Owner/partner (5) Employee (6)	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	1 in 10 to be OTD 1 in 20 to service ATSI communities 1 in 5 to be CALD, or serving mostly CALD communities, 1 in 5 to provide services in aged care settings - including locums	Brisbane, Qld
Discussion groups 7&8	Baby Boomer (>50) (7) Generation X/Y (<50) (8)	Employee (8) Owner/partner (7)	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	1 in 10 to be OTD 1 in 20 to service ATSI communities 1 in 5 to be CALD, or serving mostly CALD communities, 1 in 5 to provide services in aged care settings - including locums	Perth, WA
Discussion groups 9&10	Baby Boomer (>50) (9) Generation X/Y (<50) (10)	Owner/partner (10) Employee (9)	3-4 to have direct, recent experience of palliative care, 1-2	1 in 10 to be OTD 1 in 20 to service ATSI communities	Adelaide, SA

Qualitative Sample Frame

General Practitioners (GPs): Face-to-face group discussions (20) and online boards (4)

Research unit	Generation	Other demographics	Palliative care experience	OTD / CALD / ATSI / aged care	Location
			to have little/ no experience	1 in 5 to be CALD, or serving mostly CALD communities, 1 in 5 to provide services in aged care settings - including locums	
Discussion group 11	Generation X/Y (30-40)	Employee	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	1-2 to be OTD	Wagga Wagga NSW
Discussion group 12	Baby Boomer (>50)	Mix	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	Providing services to ATSI	Wagga Wagga NSW
Discussion group 13	Generation X/Y (30-40)	Employee	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	1-2 to be OTD	Bendigo, Vic
Discussion group 14	Baby Boomer (>50)	Mix	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	Providing services to largely CALD communities including in aged care	Bendigo, Vic
Discussion group 15	Baby Boomer (>50)	Employee	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	1-2 to be OTD	Toowoomba, Qld
Discussion group 16	Generation X/Y (30-45)	Mix	3-4 to have direct,	Providing services to ATSI	Toowoomba, Qld

Qualitative Sample Frame

General Practitioners (GPs): Face-to-face group discussions (20) and online boards (4)

Research unit	Generation	Other demographics	Palliative care experience	OTD / CALD / ATSI / aged care	Location
			recent experience of palliative care, 1-2 to have little/ no experience		
Discussion group 17	Baby Boomer (>50)	Employee	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	1-2 to be OTD	Darwin, NT
Discussion group 18	Generation X/Y (30-45)	Mix	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	Providing services to ATSI	Darwin, NT
Discussion group 19	Baby Boomer (>50)	Mix	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	1-2 to be OTD, 1-2 to provide services in aged care	Freemantle, WA
Discussion group 20	Generation X/Y (30-40)	Mix	3-4 to have direct, recent experience of palliative care, 1-2 to have little/ no experience	1-2 to be OTD	Hobart, TAS
Online board 1	Generation X/Y	Employee	6-8 to have direct recent experience of palliative care, 4-6 to have little/no experience	Half to be OTD	Regional towns across Australia
Online board 2	Baby Boomer (>50)	Owner/partner	6-8 to have direct	Half to be OTD	Rural areas across

Qualitative Sample Frame					
General Practitioners (GPs): Face-to-face group discussions (20) and online boards (4)					
Research unit	Generation	Other demographics	Palliative care experience	OTD / CALD / ATSI / aged care	Location
			recent experience of palliative care, 4-6 to have little/no experience		Australia
Online board 3	Baby Boomer (>50)	Mix	6-8 to have direct recent experience of palliative care, 4-6 to have little/no experience	Half to be OTD	Regional towns across Australia
Online board 4	Generation X/Y	Owner/partner	6-8 to have direct recent experience of palliative care, 4-6 to have little/no experience	Half to be OTD	Rural areas across Australia
General Practitioners (GPs): Face-to-face/telephone/online depth interviews, Specialists (20 Allied Health (20), Site visits (4)					
Research unit	Generation	Other demographics	Palliative care experience	OTD / CALD / ATSI / aged care	Location
General practitioner depths 1-12	6 Baby Boomer (>50) 6 Generation X/Y (30-50)	6 Owner/partner 6 Employee	8-10 to have moderate-heavy palliative care caseload 2-4 to have little/no direct experience	2-3 to be OTD 2-3 to serve CALD communities, 2-3 to serve aged care	Capital cities
General Practitioner depths 13-20	4 Baby Boomer (>50) 4 Generation X/Y (30-50)	4 Owner/partner 4 Employee	6 to have moderate-heavy palliative care caseload 2 to have little/no direct experience	2-3 to be OTD 1-2 to serve ATSI communities, 1-2 to serve aged care	Regional towns across Australia

Qualitative Sample Frame					
General Practitioners (GPs): Face-to-face group discussions (20) and online boards (4)					
Research unit	Generation	Other demographics	Palliative care experience	OTD / CALD / ATSI / aged care	Location
Specialist depths (oncologists (5), geriatricians (3), palliative care specialists (2), kids program (2)) 1-12	6 Baby Boomer (>50) 6 Generation X/Y (30-50)	Mix	Extensive experience	2-3 to be OTD 2-3 to serve CALD communities	Capital cities
Specialist depths (oncologists (2), geriatricians (2), palliative care specialists (1), kids program (1)) 13-20	4 Baby Boomer (>50) 4 Generation X/Y (30-50)	Mix	Extensive experience	1-2 to be OTD 1-2 to serve ATSI communities	Regional towns across Australia
Allied health (nurses) depths 1-5 specialised in palliative care	4 Baby Boomer (>50) 4 Generation X/Y (30-50)	-	Extensive experience	2-3 to be OTD, 1-2 to service aged care	Capital cities
Allied health (nurses) depths 6-8 specialised in palliative care	2 Baby Boomer (>50) 2 Generation X/Y (30-50)	-	Extensive experience	1-2 to be OTD, 1-2 to service aged care	Regional towns across Australia
Practice managers 9-11	As falls	At least 10 years' experience in general practice		1 - corporate practice 1 - partnership practice 1 to work for practice that services aged care	As falls
Allied health (speech, occupational therapists, social workers, Aboriginal Health Workers) with direct experience with palliative care depths 12-17	3 Baby Boomer (>50) 4 Generation X/Y (30-50)	-	Extensive experience	2-3 to be OTD, 1-2 to service aged care	Capital cities

Qualitative Sample Frame

General Practitioners (GPs): Face-to-face group discussions (20) and online boards (4)

Research unit	Generation	Other demographics	Palliative care experience	OTD / CALD / ATSI / aged care	Location
Allied health (speech, occupational therapists, social workers, Aboriginal Health Workers) with direct experience with palliative care depths 18-20	3 Baby Boomer (>50) 4 Generation X/Y (30-50)	-	Extensive experience	1-2 to be OTD, 1-2 to service aged care	Regional towns across Australia

The following qualitative discussion guide was used:

Section 1: Introduction including coverage of privacy issues

Section 2: Overall knowledge, attitudes and behaviours

- **PC and EoLC**

- Top of mind definitions
- What types of patients (i.e. age), illnesses (i.e. cancer, dementia, chronic disease), stage of illness (i.e. diagnosis, deterioration - see diagram at Att 1) and proximity to death are they associated with?
- What are the triggers to initiate PC and EoLC? When is it appropriate to begin to transition from curative to palliative treatment? From PC to EoLC?
- What makes you resist doing PC and EoLC... and question when it is not appropriate?
- What is your experience of caring for patients with respect to PC and EoLC? (i.e. in terms of patient profiles and sort of care required)?

10.4. How would you describe PC and EoLC as a relati

The quantitative phase consisted of a 15-minute survey of 1,000 General Practitioners (GPs) from around Australia. The survey was conducted online, with a sample frame drawn from the Australian Medical Association (AMA) list of all GPs. The survey was conducted between 15th November 2016 and 23rd January 2017.

Data was weighted to ensure that results presented are representative of the Australian population of GPs.

The final achieved sample - including unweighted counts and weighted final proportions — is shown below.

Respondent Specifications	n (unweighted)	% (unweighted)	% (weighted)
Gender			
Male	611	61%	61%
Female	389	39%	39%
Location			
Metro	641	64%	79%
Regional Centre	176	18%	10%
Rural/Remote/Very Remote	183	18%	11%
Overseas Trained Doctors (OTD)			
OTD	356	36%	34%
Australian trained	644	64%	66%
Principal / Director			
Principal / Director	451	45%	30%
Employee	549	55%	70%
Age			
25-39	191	19%	37%
40-54	430	43%	41%
55+	379	38%	22%
State			
NSW	319	32%	35%

Respondent Specifications	n (unweighted)	% (unweighted)	% (weighted)
Gender			
VIC	262	26%	26%
ACT	5	1%	1%
QLD	230	23%	19%
NT	9	1%	1%
WA	80	8%	9%
SA	71	7%	7%
TAS	24	2%	2%
Total sample	n=1,000	100%	100%

The following survey instrument was used:

Introduction Text

Welcome! Thanks for agreeing to take our survey. Important decisions will be made based on what you tell us, so we'd really appreciate it if you can answer the questions we have for you carefully and honestly.

This survey is being conducted by Whereto Research in accordance with the Market and Social Research Privacy Code, which you can read about here. If you have any questions at all about this survey, please feel free to contact Whereto Research on (03) 8648 3418 or via info@wheretoresearch.com.au.

Please read all of the questions carefully and give us your honest opinion. There are no right or wrong answers, we are just really interested in what you have to say.

SCREENING QUESTIONS

Please answer the following questions so we can make sure we are speaking to a good mix of people.

ASK ALL

A.1. In Which state or territory do you currently live?

NSW 1 CONTINUE

VIC 2 CONTINUE

ACT 3 CONTINUE

QLD 4 CONTINUE

NT 5 CONTINUE

WA 6 CONTINUE

SA 7 CONTINUE

TAS 8 CONTINUE

None of these 9 TERMINATE

ASK ALL

A.2. Which of the following best describes the area you currently live in?

Capital city inner suburbs 1 CHECK QUOTAS

Capital City outer suburbs 2

Major regional centre 3 CHECK QUOTAS

Country town 4 CHECK QUOTAS

Rural area 5

Remote / very remote area 6

CODE 1,2 = METRO CODE 3,4 = REGIONAL CODE 5,6 = RURAL/REMOTE

ASK ALL

A.3. Please indicate whether you are...

(SINGLE RESPONSE)

Male 1 CHECK QUOTAS

Female 2 CHECK QUOTAS

Other / prefer not to say 3 CONTINUE

ASK ALL

A.4. Which of the following age ranges do you fall into?

(SINGLE RESPONSE)

<18 1 TERMINATE

19-24 3 TERMINATE

25-29 4 CHECK QUOTAS

30-34 5

35-39 6

40-44 7

45-49 8

50-54 9 CHECK QUOTAS

55-59 10

60-64 11

65+ 12

ASK ALL

A.5. What is your profession?

(SINGLE RESPONSE)

Nurse / nurse practitioner 1 TERMINATE

Medical specialist (e.g.: Surgeon, Anaesthetist, Oncologist etc.) 2 TERMINATE

General Practitioner 3 CONTINUE

Pharmacist 4 TERMINATE

Social worker 5 TERMINATE

Psychologist 6 TERMINATE

Other TERMINATE

ASK ALL

A.6. In which country did you complete your basic medical training

Australia 1 CHECK QUOTAS

Bangladesh 2 CHECK QUOTAS - OTD

India 3

Iran 4



New Zealand 5
Nigeria 6
Pakistan 7
South Africa 8
United Kingdom 9
United States 10
Other country 11
CODE 1 = Australian trained; CODE 2,3,4,5,6 OTD

ASK ALL

A.7. At your practise or service, are you...

(SINGLE RESPONSE)

A Principal/Director 1 CHECK QUOTAS
Associate 2
An employee 3 CHECK QUOTAS
A contractor 4
A locum 5
After hours locum 6

ASK ALL

A.8. In your practise or service, how often do you service patients of a culturally and linguistically diverse background (CALD)?

(SINGLE RESPONSE)

I never service CALD patients (0%) 1
Rarely (0<10%) 2 CHECK QUOTAS
Sometimes (11%-20%) 3
A lot of the time (21% -50%) 4 CHECK QUOTAS
Mainly service patients of CALD background (50%+) 5 CHECK QUOTAS

ASK ALL

A.9. In your practise or service, how often do you service patients from an Aboriginal or Torres Strait Islander background?

(SINGLE RESPONSE)

I never service indigenous patients (0%) 1
Rarely (0<10%) 2 CHECK QUOTAS
Sometimes (11%-20%) 3
A lot of the time 21% -50% 4 CHECK QUOTAS
Mainly service patients of indigenous background (50%+) 5 CHECK QUOTAS

TERMINATE TEXT

Thanks for your participation so far, our client has asked that we speak with a defined sample of the population of general practitioners in Australia and it looks like we have already received an overwhelming number of responses from people like yourself.

QUALIFY TEXT



Great - it looks like you qualify for the survey. The survey will take around 15 minutes to complete. Your responses will remain completely confidential and anonymous.

The study is being conducted on behalf of the Commonwealth Department of Health, and has received approval from the Department's Human Research Ethics Committee.

Please note we are only interested in your top-of-mind opinions and attitudes in this survey and there is no need to look anything up.

Experience/Awareness with Palliative Care

Introduction to section or delete text.

ASK ALL

A.10. Take a moment to think about Palliative Care. In your own words, what does palliative care mean to you?

(OPEN ENDED TEXT BOX)

ASK ALL

A.11. And thinking about Advance Care Planning, what does this term mean to you?

(OPEN ENDED TEXT BOX)

ASK ALL

A.12. Thinking about your patients with advanced chronic disease, what proportion would you estimate will live longer than a year.

(SLIDER 'Proportion of patients with advanced chronic disease that will live longer than a year' 0-100% IN 1% INCREMENTS, RANDOMISE

Also tick box "can't say"

ASK ALL

A.13. Decision Assist, in conjunction with RACGP have devised an approach to identifying people appropriate for palliative care called 'The surprise question'

Have you heard of this before?

Yes 1

No 2

Don't know 3

ASK ALL

A.14. The surprise question is "Would you be surprised if this patient died in the next year?"

Have you heard of this before?

Yes 1

No 2

Don't know 3

ASK ALL

A.15. For what proportion of your patients with advanced chronic diseases would the answer to the surprise question be 'No'

(SLIDER 'Proportion of patients with advanced chronic disease that will live longer than a year' 0-100% IN 1% INCREMENTS, RANDOMISE

Also tick box "can't say"

ASK ALL



A.16. Thinking about your day-to-day practice over the last month, how many patients did you see for...

Please indicate approximate number of patients over last month

A.16.a Palliative Care Enter text box

A.16.b Advance care planning Enter text box

A.16.c Chronic disease management Enter text box

ASK ALL

A.17. In comparison to other areas of your practice, how interested are you in palliative care?

(SLIDER)

Much less interested than other areas Much more interested than other areas

0 1 2 3 4 5 6 7 8 9 10

ASK ALL

A.18. In comparison to managing other disease areas, how personally rewarding do you find the practice of palliative care?

(SLIDER)

Not at all rewarding - Extremely rewarding

0 1 2 3 4 5 6 7 8 9 10

ASK ALL

A.19. How knowledgeable do you feel about palliative care?

(SLIDER)

No knowledge at all - Expert knowledge

0 1 2 3 4 5 6 7 8 9 10

ASK ALL

A.20. Would you be interested in further developing your skills in palliative and end-of-life care?

(SINGLE RESPONSE)

Yes 1

No 2

Don't know 3

ASK ALL

A.21. Thinking about the range of activities involved in palliative and end-of-life care, how comfortable are you with each of the following aspects of palliative care?

(SINGLE RESPONSE TO EACH STATEMENT - RANDOMISE STATEMENTS)

Not at all comfortable dealing with this aspect of palliative care

0

1

2

3

4

Not sure

5

6

7

8

9

Perfectly comfortable dealing with this aspect of palliative care

10

A.21.a Pain management

A.21.b Non pain symptom control

A.21.c Psycho-social aspects of care

A.21.d Dealing with conflict in patients' family wishes

A.21.e Ethical issues

A.21.f Working with specialist palliative care physicians

A.21.g Taking advice from specialist palliative care nurses

A.21.h Coordination of palliative services for patients in the community

A.21.i Supporting the patient's family

A.21.j Fulfilling the patient's wishes

A.21.k Fulfilling the family's wishes

A.21.l Stopping curative or protective treatment when life expectancy is limited

A.21.m Dealing with cultural differences at the end of life

A.21.n Dealing with the emotions of your patient's family

A.21.o Talking about death with patients

A.21.p Case conferencing

A.21.q After hours contact with patients or staff at facilities

A.21.r Visiting patients at home

A.21.s Visiting patients at residential aged care facilities

ASK ALL

A.22. Where would you expect to get information about palliative care in your area?

Please select all that apply

(MULTIPLE SELECT)

Local Primary Health Network 1

Magazines and periodicals (specify) 2

Specialist palliative care physicians 3

Specialist care units in hospitals 4

Specialist palliative care nurses 5

Internet websites (specify) 6

Other GPs 7

Other specialists (e.g.: oncologists, geriatricians) 8

- Residential aged care facilities 9
- Health Department 10
- Peak body organisations (e.g.: Palliative Care Australia) 11
- Employer 12
- Other (specify) 97

ASK ALL

A.23. Which of the following would you consider most useful for further information and education about palliative care?

Please up to select five that you feel would be most useful to you

(SELECT UP TO FIVE RANDOMISE)

- a guide to local services available to palliative patients 1
- after hours' workshops run by a local palliative care service 2
- after hours' workshops run by your Primary Health Network 3
- A 'cheat sheet' – a list of reminders (of areas to cover/ think about) for those who don't do palliative care often 4
- Clinical audit – assessing your practice approach to palliative care and how to improve 5
- A clinical placement with a specialist palliative care service 6
- a guide to cross-cultural palliative and end of life care 7
- An active learning module delivered online 8
- Symptom management podcasts 9
- Practice developing a care plan in a multidisciplinary team setting 10
- MyAged Care' equivalent website for palliative care (i.e. to facilitate entry into the system) 11
- An online evidence base for palliative and end of life care such as [Caresearch](#). 12
- Information booths or sessions at GP conferences 13
- A GP-targeted app – covering when to trigger palliative care, managing clinical deterioration and dying at home, prescribing guidelines etc. 14
- Promoting GPs with a special interest in palliative care so they can provide support to their colleagues 15
- Getting to know your local palliative care team better 16
- Linking training in palliative care to being able to claim for special palliative care MBS items 17
- A guide to broaching the transition from curative to palliative care with patients 18
- Guidance on anticipatory prescribing and care planning 19
- Having face to face education activities available to rural/remote GPs 20
- Getting CME points for events 21
- A guide to filling in ACDs 22
- Updates on latest in symptom management 23
- Something else (Please specify) 97

ASK ALL



A.24. When it comes to introducing end of life issues, do you feel it is your patients' role, or your role to bring up?

(SINGLE RESPONSE TO EACH STATEMENT - RANDOMISE STATEMENTS)

Completely patients' role Both equally Completely my role to bring up
0 1 2 3 4 5 6 7 8 7 10

A.24.a Advance care planning

A.24.b transitioning from active to palliative treatment

ASK ALL

A.25. What do you consider the part of palliative care that takes up the majority of your time?

(SINGLE RESPONSE, RANDOMISE)

Liaising with the patient's family 1
Pain Relief 2
Prescribing Medicine 3
Coordination of entire process 4
Comforting Patients 5
Advance care planning / advance care directives 6
Other (specify) 7
I don't perform a role in Palliative Care 8
Don't know 9

ASK ALL

A.26. Which of the following are the best times to bring up advance care planning with your patient?

(Select up to 3- RANDOMISE STATEMENTS)

When a patient is fit and healthy 1
At the onset of chronic disease 2
When the answer to the surprise question: 'Would you be surprised if this patient dies in a year' is 'No' 3
When signs of cognitive decline first become apparent 4
Just before the terminal phase 5
When a patient can no longer look after themselves 6
Entry into a residential aged care facility 7
When the patient asks for it 8
At the 75 year-old health check 9
Another time not mentioned here (specify) 10

ASK ALL

A.27. When it comes to advance care planning, how much do agree or disagree with the following...?

(SINGLE RESPONSE TO EACH STATEMENT - RANDOMISE STATEMENTS)

Completely disagree Neither agree nor disagree Completely agree



0 1 2 3 4 5 6 7 8 7 10

A.27.a I am clear about legislation around advance care directives in my state

A.27.b Advance care directives are easy for patients to complete

A.27.c Someone other than a GP (e.g.: a practice nurse, or nursing home nurse) usually completes advance care directives - I only sign them off

A.27.d I'm seeing increased community interest in advance care planning

A.27.e There's no real benefit to doing an advance care plan, because future circumstances are unpredictable

A.27.f Advance care plans are valuable because they give health professionals certainty about a patients' wishes

A.27.g Advance care plans are useless because patients' family often disagrees with them

ASK ALL

A.28. In your opinion, what constitutes 'best practice' palliative care?

(OPEN ENDED TEXT BOX)

ASK ALL

A.29. In your opinion, how easily can you access palliative care services for your patients?

(SLIDER)

Not at all easy to access palliative care services Very easy to access palliative care services

0 1 2 3 4 5 6 7 8 9 10

ASK ALL

A.30. Please examine the following list of resources that GPs have told us, when lacking, make best practice palliative care more difficult.

Of these issues that people have mentioned, select up to 7 that you feel create the most difficulty for you in delivering best practice palliative care.

(SELECT UP TO 7, RANDOMISE)

Available time/ time pressure 1

Appropriate remuneration for the time involved 2

Availability of local services for palliative care 3

Communication between GPs, specialists and specialist palliative care teams 4

Don't know where to source support services 5

Time needed to locate/coordinate services for patients 6

Patients' wishes not being recorded in a readily accessible place 7

Not being able to get advice from a palliative specialist 9

Not being able to get advice from non-palliative specialists 10

Lack of coordination between different parts of health system 11

No access to respite services 12

Poor communication on discharge from hospital 13

Lack of access to palliative beds in hospitals and hospices 14

Quality of residential aged care staff 15

Specialists referring to palliative care too late 16



Lack of integration of palliative care with chronic disease management 17

Specialists continuing to do active care beyond the point where it will make a difference
18

Other (specify) 19

ASK ALL

A.31. Please rank the barriers you selected in terms of their impact on best practise
(RANKING, RANDOMISE, SHOW SELECTED AT C.3)

Most impact on delivering best practice

Least impact on delivering general practice

ASK ALL

A.32. In your experience, in which of these settings is it easiest to deliver best practice
palliative care?

(SINGLE RESPONSE TO EACH STATEMENT - RANDOMISE STATEMENTS)

Not at all easy to deliver best practice palliative care in this setting

0

1

2

3

4

Not sure

5

6

7

8

9

Extremely easy to deliver best practice palliative care in this setting

10

Don't provide palliative care in this setting

99

A.32.a In patient's home

A.32.b In residential aged care facilities or nursing home

A.32.c In a hospice or hospital

ASK ALL

A.33. How important is your role in delivering best practice palliative care in the following
settings?

(SINGLE RESPONSE TO EACH STATEMENT - RANDOMISE STATEMENTS)

My role is not at all important in to a patient receiving best practice palliative care

0

1

2

3

4

Not sure

5

6

7

8

9

My role is extremely important to a patient receiving best practice palliative care

10

Don't provide palliative care in this setting

99

A.33.a In the community / in patient's home

A.33.b In residential aged care facilities

A.33.c In a hospice or hospital

Segmentation / Attitudes

ASK ALL

A.34. Please use the scale below to indicate whether you disagree or agree with the following statements...

(SINGLE RESPONSE TO EACH STATEMENT - RANDOMISE STATEMENTS)

Strongly Disagree	Not sure	Strongly agree
0	1 2 3 4	5 6 7 8 7 10

A.34.a Palliative care is an important part of a GPs job

A.34.b I would not do palliative care if I didn't have to

A.34.c Health professionals need to work together more closely to deliver palliative care

A.34.d With reference to palliative care, I feel that communication with other medical professionals is working well

A.34.e Palliative care is more demanding other aspects of my work

A.34.f I feel I have had good training in palliative care

A.34.g I really only do best practice palliative care with long term patients

A.34.h My work in palliative care is fairly remunerated

A.34.i Dealing with the emotions of the patient's family is the hardest part of delivering good palliative care

A.34.j Palliative care is mostly just common sense

A.34.k Palliative care is just a continuation of the normal care I give to patients

A.34.l Doing good palliative care is very hard

A.34.m I have chosen not to do palliative care - where patients need it, I refer to another doctor

A.34.n It's hard to be sure that your skills for palliative care are up to date

A.34.o The type of practice I'm in means we don't really service palliative patients



DEMOGRAPHICS

Almost done! Thanks for sticking with us. We just have a few final questions to understand the range of people we're speaking to a bit better.

ASK ALL

A.35. For how long have you been a GP? / Years practising?

(SINGLE RESPONSE)

Less than 10 years 0

10 to 20 years 1

More than 20 years 2

ASK ALL

A.36. And how long have you been in your current practice?

(SINGLE RESPONSE)

Less than 2 years 0

2- 7 years 1

More than 7 years 2

ASK ALL

A.37. Have you ever had any formal training in palliative care, either as an undergraduate, registrar or as part of continuing medical education?

(SINGLE RESPONSE)

Yes 1

No 2

Not sure 3

ASK ALL

A.38. In which if the following areas have you ever worked as a doctor?

(MULTIPLE RESPONSE)

Major metropolitan centres 1

Large regional cities 2

Country towns 3

Rural areas 4

Remote or very remote areas 5

ASK ALL

A.39. What proportion of your patients are bulk billed (approximately)?

(SINGLE RESPONSE)

0% 1

10% 2

20% 3

30% 4

40% 5

50% 6

- 60% 7
- 70% 8
- 80% 9
- 90% 10
- 100% 11
- Don't know /can't answer 12

ASK ALL

A.40. How much experience, if any, have you had with patients in Palliative Care?
(SINGLE RESPONSE)

- None 1
- Very little (less than 10 patients ever) 2
- Some (10 to 50 patients ever) 3
- A lot (more than 50 patients) 4

ASK ALL

A.41. Approximately how many home visits have you done in the past year?
(SINGLE RESPONSE)

- None-I don't do home visits 0
- None - I haven't needed to in the last year 1
- 1-12 (Up to one per month) 2
- 13-51 (Between one a week and once a month) 3
- 52-104 (one or two per week) 4
- More than 104 (more than 2 every week) 5

ASK ALL

A.42. Approximately how many times have you visited residential aged care facilities (RACF) or nursing homes in the last year?
(SINGLE RESPONSE)

- None- I don't do RACF or nursing home visits 0
- None - I haven't needed to in the last year 1
- 1-12 (Up to one per month) 2
- 13-51 (Between one a week and once a month) 3
- 52-104 (one or two per week) 4
- More than 104 (more than 2 every week) 5

ASK ALL

A.43. And is the practice you currently work in owned by?
(SINGLE RESPONSE)

- Either single or multiple directors who also practice as GPs 1
- A corporation 2
- State government - specialist palliative care service 3
- State government - health clinic 4



ASK ALL

A.44. How many doctors work out of your practice?

(SINGLE RESPONSE)

I work by myself 1

2-5 2

6-10 3

11-20 4

More than 20 5

Don't know 6

ASK ALL

A.1. Is your own personal cultural background similar to that of your patients?

(SINGLE RESPONSE)

Yes, I am of the same or very similar cultural background to a majority of my patients 1

No, I am of a different cultural background to a majority of my patients 2

Unsure / don't know 3

ASK ALL

A.2. In your practise, approximately what proportion of your patients are bulk billed?

(SINGLE RESPONSE)

All bulk-billed 1

Mostly bulk-billed 2

Balanced 3

Mostly private 4

Only private patients 5

Don't know 6

ASK ALL

A.3. Thinking about your patients, roughly what proportion is in each age group?

(FILL OUT % FOR EACH AGE GROUP, MUST ADD UP TO 100)

0-17 %

18-29 %

30-49 %

50-64 %

65-79 %

80+ %

100 %

ASK ALL

A.4. Approximately how many hours do you work per week?

(SINGLE RESPONSE)

Enter number of hours XX

ASK ALL



A.5. Approximately how many patients do you see per week?

(SINGLE RESPONSE)

Enter number of patients XX

SHOW ALL

That's it, you're all done! Thank you for taking our survey - we really appreciate you taking the time out to tell us your thoughts and opinions!

If you would like further information about palliative care specific to general practice please visit the CareSearch GP Hub.

Now, we have an interesting, optional test that is designed to test implicit, subconscious biases. It should take no more than 5 minutes and is completely different to completing a survey. We will also let you know afterwards about what the test says about your own implicit biases

ASK ALL

A.6. Would you be interested in taking this optional implicit association test now?

(SINGLE RESPONSE)

Yes [LINIK TO IAT] 1

No 2

Record as complete

Implicit association test

Wordings that appear for respondents

<item attributeAlabel>

/1 = "Medicine"

</item>

<item attributeA>

/1 = "Paracetamol"

/2 = "Vaccination"

/3 = "Antibiotic"

/4 = "Pharmaceutical"

/5 = "Prescription"

</item>

<item attributeBlabel>

/1 = "Not Medicine"

</item>

<item attributeB>

/1 = "Nursing"

/2 = "Social work"

/3 = "Psychology"

/4 = "Counselling"

/5 = "Dietitians"

</item>

<item targetALabel>

/1 = "Palliative Care"

</item>

<item targetA>

/1 = "End of Life"

/2 = "Advanced Care Planning"

/3 = "Comfort and Pain Relief"

/4 = "Terminal Care"

/5 = "Treatment Options Exhausted"

</item>

<item targetBLabel>

/1 = "Curative Care"

</item>

<item targetB>

/1 = "Heal"

/2 = "Cure"

/3 = "Repair"

/4 = "Make well"

/5 = "Prolong Life"

</item>

<item instructions>

/ 1 = "<%expressions.buttoninstruct1%>Words representing the categories at the top will appear one-by-one in the middle of the screen. When the item belongs to a category on the left, press the left <%expressions.buttoninstruct2%>; when the item belongs to a category on the right, press the right <%expressions.buttoninstruct3%>. Items belong to only one category. If you make an error, an X will appear - fix the error by hitting the other <%expressions.buttoninstruct4%>."

This is a timed sorting task. GO AS FAST AS YOU CAN while making as few mistakes as possible. Going too slow or making too many errors will result in an uninterpretable score. This task will take about 5 minutes to complete."

/ 2 = "See above, the categories have changed. The items for sorting have changed as well. The rules, however, are the same."

When the item belongs to a category on the left, press the left (E) <%expressions.buttoninstruct4%>; when the item belongs to a category on the right, press the right (I) <%expressions.buttoninstruct4%>. Items belong to only one category. An X appears after an error - fix the error by hitting the other <%expressions.buttoninstruct4%>. GO AS FAST AS YOU CAN."

/ 3 = "See above, the four categories you saw separately now appear together. Remember, each item belongs to only one group. For example, if the categories <%item.targetalabel.item(1)%> and <%item.attributealabel.item(1)%> appear on separate sides above - words meaning <%item.targetalabel.item(1)%> would go in the <%item.targetalabel.item(1)%> category, not the <%item.attributealabel.item(1)%> category."

The green and white labels and items may help to identify the appropriate category. Use the left (E) and right (I) <%expressions.buttoninstruct4%>s to categorize items into four groups left and right, and correct errors by hitting the other <%expressions.buttoninstruct4%>."

/ 4 = "Sort the same four categories again. Remember to go as fast as you can while making as few mistakes as possible.

The green and white labels and items may help to identify the appropriate category. Use the left (E) and right (I) <%expressions.buttoninstruct4%>s to categorize items into the four groups left and right, and correct errors by hitting the other <%expressions.buttoninstruct4%>."

/ 5 = "Notice above, there are only two categories and they have switched positions. The concept that was previously on the left is now on the right, and the concept that was on the right (I)s now on the left. Practice this new configuration.

Use the left (E) and right (I) <%expressions.buttoninstruct4%>s to categorize items left and right, and correct errors by hitting the other <%expressions.buttoninstruct4%>."

/ 6 = "See above, the four categories now appear together in a new configuration. Remember, each item belongs to only one group.

The green and white labels and items may help to identify the appropriate category. Use the left (E) and right (I) <%expressions.buttoninstruct4%>s to categorize items into the four groups left and right, and correct errors by hitting the other <%expressions.buttoninstruct4%>."

/ 7 = "Sort the same four categories again. Remember to go as fast as you can while making as few mistakes as possible.

The green and white labels and items may help to identify the appropriate category. Use the left (E) and right (I) <%expressions.buttoninstruct4%>s to categorize items into the four groups left and right, and correct errors by hitting the other <%expressions.buttoninstruct4%>."

</item>

/ items = ("Your IAT score (D) was <% expressions.d %>, which suggests <% values.magnitude %> automatic preference for <% values.preferred %> compared to <% values.notpreferred %> when thinking about medicine.~n~n~nPress the spacebar to complete this session.")

/buttoninstruct1 = if (computer.touch) {"";} else {"Put your middle or index fingers on the E and I keys of your keyboard. "};}

/buttoninstruct2 = if (computer.touch) {"response button ('E') provided on the bottom left of your screen with your left middle or index finger";} else {"(E) key";} }

/buttoninstruct3 = if (computer.touch) {"response button ('I') provided on the bottom right of your screen with your right middle or index finger";} else {"(I) key";} }

/buttoninstruct4 = if (computer.touch) {"response button";} else {"key";} }