Initiating advance care planning in New South Wales general practices using a structured conversation guide

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Background and objective
General practitioners (GPs) are encouraged to discuss advance care planning (ACP) as part of routine care of older adults, but initiating these conversations can be difficult. The aim of this study was to explore GPs' perspectives on current ACP practice in New South Wales, Australia, and on an existing ACP conversation guide.

Methods
Three focus groups were held as part of an existing initiative, 'Ask, Share, Know: Rapid Evidence for General Practice Decisions'. Data were analysed using an inductive thematic approach; themes identified informed adaptation of the conversation guide.

Results
Five key themes were identified: 1. general practice provides the optimal context for ACP discussions; 2. ACP priorities differ between GPs; 3. healthcare professionals' roles in ACP vary; 4. confusion exists regarding ACP practice; and 5. the adapted conversation guide provides a useful structure for ACP.

Discussion
ACP practice varies between GPs. GPs preferred the adapted conversation guide, but further evaluation is required prior to implementation into practice.

ADVANCE CARE PLANNING (ACP) is a process of ongoing communication between a patient, their family and healthcare professionals to clarify the patient's goals, values and wishes for future healthcare should they lose decision-making capacity.[1–3] ACP may sometimes result in a written document such as an advance care directive (ACD). There is variation in ACP terminology and legislation of ACDs between different jurisdictions within Australia.[4]

General practice is the ideal setting for ACP discussions, and evidence supports patient preference for initiation of ACP while they are still healthy in the community.[5–7] The Royal Australian College of General Practitioners (RACGP) recommends that general practitioners (GPs) discuss ACP as part of routine care for older patients during the annual 75 years and over health assessment.[8] The COVID-19 pandemic highlighted the need for GPs to have these conversations, and there have been calls for ACP to be an integral part of pandemic health planning responses.[9]

Evaluating the prevalence of ACP conversations is difficult, with most studies focusing on the more tangible assessment of ACD completion. A 2017–18 multicentre Australian study found the prevalence of ACDs within the general practice group was only 3.2%.[10] While ACDs are only part of ACP, it highlights limited community uptake. Some barriers to GPs initiating ACP include difficulties in defining the right moment to discuss the topic, a perceived lack of knowledge in the ACP process and concern regarding the potential time-consuming nature of ACP discussions.[11,12]

Strategies to increase initiation of ACP in general practice have focused on workshops and communication skills training for GPs and general practice nurses (GPNs), which are time and resource intensive.[13–15] Some studies have shown that discussion guides and question prompt lists can improve the frequency of ACP discussions with patients, but these have been limited to palliative care settings.[16–18] Most doctors believe it is their responsibility to initiate these discussions but struggle with timing.[19]

More evidence is needed to understand how to help GPs facilitate these conversations in a way that is acceptable and meaningful for older patients and their families. This study aims to understand: 1. New South Wales (NSW) GPs' experiences with ACP conversations; and 2. their feedback on an existing ACP conversation guide developed for GPNs.[20]

Methods

This was a qualitative focus group (FG) study with GPs in both metropolitan and regional NSW, Australia. The three FGs

that took part in the study were pre-existing GP groups involved in the Ask Share Know Centre for Research Excellence (ASK CRE) funded through the National Health and Medical Research Council (NHMRC; refer to Box 1). The three FGs participated in two rounds of data collection.

ED, in consultation with LT, JMC and JR, developed eight questions to prompt FG discussion (Appendix 1; available online only). The existing conversation guide was handed to participants for review during the first round of FGs (Appendix 2; available online only). Initial analysis informed revision of the existing ACP conversation guide and revealed the need for a concise supporting glossary, which was developed by ED in consultation with LT (Appendix 3; available online only). A second round of FGs was then conducted, focusing on evaluating the revised conversation guide as well as the supporting glossary.

The consolidated criteria for reporting qualitative health research were used to report this study.[21]

Data collection

Primary researcher ED (general practice registrar at time of study) facilitated the FGs, which ranged from 13 to 51 minutes in duration (mean 29.8 minutes). FGs were held between April and November 2017. All FGs were audio-recorded and transcribed verbatim using a professional transcription service.

Data analysis

Data were analysed using thematic analysis.[22] Data were coded independently by ED and LT (experienced GP academic), with regular meetings to ensure concordance of emergent codes and themes. These were then discussed between all authors and informed the adaptation of the conversation guide.

Box 1. Description of Ask Share Know Centre for Research Excellence

The Ask Share Know general practitioner network (https://askshareknow.com.au) was established under a five-year National Health and Medical Research Council Centre for Research Excellence grant between 2016 and 2021. Participating practices held monthly meetings to discuss the evidence from clinical questions and to test and refine resources and decision-making tools.

Results

Twenty-five GPs participated in the first round of FGs, with 21 GPs in the second round (Table 1). All GPs worked in practices with GPN support and represented a broad range of experience, gender balance and practice setting.

Five key themes emerged from the data after the first round of FGs, which were then consolidated after the second round. These perspectives allowed us to adapt the existing conversation guide into a more user-friendly resource.

General practice provides unique contextual opportunities for ACP conversations

There were some key areas identified by respondents regarding the process of ACP in general practice. The triggers for initiating ACP were often related to chronic disease care plans, health assessments or admission to a residential aged care facility. GPs identified the benefits of discussing ACP with patients over the age of 60 years, as well as those with chronic disease, before they develop a terminal illness or lose cognitive capacity.

> *So I think we are very much, you know, the ideal person to implement this as opposed to when the person is unwell and unable to participate.* [Male GP, FG 1.3]

Respondents reported that for most patients it is not an isolated conversation. It usually involves ongoing discussion, potentially over many years, between the patient and their healthcare team. On occasion it will result in preparation of a formal document such as an ACD.

> *But it's an evolving process, isn't it? I mean, it's something I think that is valuable for patients to know that when and if they are wanting to talk about that then there is a process that we can offer them.* [Male GP, FG 1.1]

Differing priorities of ACP in general practice

An important priority of ACP raised by participants was communication between patients and their families.

> *I think the thing is that it really has to be the discussion with their family; the doctor can only do so much about introducing this. In the end, it's the family that's really going to make the decision. If a patient has gone off and done an advance care plan that they haven't discussed with their family, it's really not even really worth the paper it's written on anyway, because in that circumstance they're going to make the decisions.* [Female GP, FG 1.1]

Some GPs preferred to focus on clinical decisions such as cardiopulmonary resuscitation (CPR) as the main subject of the conversation, while others preferred to broaden the discussion to general healthcare goals.

> *They're sort of like, 'Oh yeah-yeah, I've got that in place, like I'm not for resuscitation'. I'm like, 'Yes, but what about all the other things before that?'* [Female GP, FG 1.2]

In addition to topics such as CPR and healthcare goals, an important aspect discussed by many participants was the need to normalise ACP discussions and remove any stigma or discomfort associated with raising the topic.

> *And something I found with the patients is that they're almost relieved when you ask them actually. So essentially there's a lot more acceptance that this is part of what we do really.* [Female GP, FG 1.2]

Healthcare professionals' involvement in ACP is practice dependent

There was variation between GPs in terms of how they viewed their role in initiating ACP. The structure of the practice and experience of colleagues had an impact on their degree of involvement in the ACP process. Many GPs saw their focus as starting the ACP conversation and allowing patients to return at a later date for a more in-depth discussion when they felt comfortable and ready. The 75 years

and over health assessment was identified as a useful trigger for the discussion.

> *But the benefit of having it in the over 75 health assessment so it's almost just a prompt to make them think about it so it might not be a big long discussion. It might be, 'Have you ever thought about this?' and then just to get them to think about it and then to bring it up another – You might not necessarily need to go through all of this kind of stuff in that environment.* [Female GP, FG 1.1]

In some cases, the GPN played a more active and larger role, especially if they had further training or a special interest in ACP.

> *I don't think we've had a nurse who has been as interested in it, as she has been. So – and you know, if I were – if someone wanted to talk about it more, I would refer them back to her.* [Female GP, FG 1.2]

Other GPs felt that despite different professionals' levels of experience and training, GPs were better placed because of their relationship with the patient.

> *I personally would want to do this myself, because they're all – I feel like the nurses would not be familiar with the patient, so it could go completely wrong.* [Female GP, FG 1.1]

Confusion exists regarding terminology, current resources and documentation required in ACP discussions within the general practice setting

Communication barriers mentioned by GPs included language and legal jargon used in the ACP conversation, as well as difficulty in documenting and disseminating ACPs and ACDs. Ensuring both the GP and patient have a shared understanding of terms used is important.

> *And simplifying the form as well because all that legal talk is quite confusing for me and for the patients ...* [Female GP, FG 1.1]

Most GPs could not identify a targeted, concise resource to support ACP discussions, particularly if they had minimal experience or training in the area. They identified the need for a simple resource to support such discussions.

> *And that's where it would be absolutely essential for this to be backed up with the resources, because I think that's where we all get ourselves in tangles trying to talk about the difference between guardianship and enduring powers of attorney and all that sort of stuff.* [Female GP, FG 1.1]

The supporting glossary developed was reviewed by participants in the second round of FGs (Appendix 3; available online only) and was viewed as useful by respondents.

> *... this could be one of the little suite of goodies you give someone at that appointment to think about and then make a note to then discuss it more formally when they come back.* [Female GP, FG 2.1]

Appropriate documentation of either a formal ACD or the ACP conversation was raised as a potential issue with for successful implementation of the plan in the future. GPs reported a variety of ways this currently happens in practice, including within the general practice clinical software, uploaded to MyHealthRecord as an ACD by the patient or within their health summary uploaded by their GP, in the medical records department of their local hospital or with family.

> *Um, and then once they've actually done an advance care arrangement, we scan it into their notes and we usually put in*

Table 1. Characteristics of participating general practitioners within each focus group

Characteristics	FG 1.1 (n = 8)	FG 1.2 (n = 8)	FG 1.3 (n = 9)	FG 2.1 (n = 5)	FG 2.2 (n = 9)	FG 2.3 (n = 7)
Practice location	Urban	Urban	Rural	Urban	Urban	Rural
Sex						
Male	2	2	6	2	2	3
Female	6	6	3	3	7	4
Number of years in general practice						
1–9	2	4	4	0	5	4
10–19	1	1	1	1	1	2
20–29	2	3	3	2	3	1
≥30	3	0	1	2	0	0

FG, focus group

> *the comments that'll come up on the front page of their note that they've had one done.* [Female GP, FG 1.2]

The conversation guide provided a useful structure to address many of these issues

The existing ACP conversation guide reviewed in the FGs needed a number of changes to better suit GPs. The original version was four pages long with 'Yes/No' questions as well as space for freehand answers. The participants overall commented that any tool that is used in consultations needs to be simple and succinct, ideally one page in length.

> *So it's just so easy for elderly people to get confused with the documentation. I think the simpler the better.* [Male GP, FG 2.1]

The main appeal of using a tool was giving the conversation a structure and a way to direct patients to reflect on their healthcare goals and discuss this with their families. The focus is not on making a formal document but encouraging discussion.

> *Because that's just an introduction, it doesn't actually answer the question as to what their advance care directive is. It's just introducing, a nice way of getting people to start to think about advance care directives.* [Female GP, FG 2.3]

Preferred use of the tool varied between GPs, with some reporting they would use it as an aide memoir, others as a paper document to go through with patients. Many respondents said they would like it to be incorporated into the clinical software, with options for autofill or electronic prompts, and a link to the tool within the 75 years and over health assessment template.

> *I mean I think if – if you're working through your checklist with your – say a health assessment, if – do they have an advance care directive, it should rather, or have you asked about an advance care directive, 'Yes/No'. It would be good if that could that then be exploded [expanding a section within an electronic document].* [Female GP, FG 1.1]

After analysis of the initial FG data, the existing conversation guide was adapted, streamlining it into a one-page document (Box 2). This adaptation incorporated the aforementioned findings and was then reviewed in the second round of FGs.

Box 2. Adapted advance care planning conversation guide after the initial round of focus groups

Starting the conversation about preferences for future medical care

This conversation guide is for use with healthy people to open up a discussion about advance care planning. For people with more serious or advanced illness, it may be more appropriate to have a more detailed discussion and complete an advance care directive.

In the next 5–10 minutes, is it ok if I ask a few questions about your future health wishes? Is this something you would feel comfortable discussing today?

1. Have you heard about advance care planning? What is your understanding? Would you like more information on it?
2. Is there anything specific about your future healthcare you would like us to know? What is important to you in terms of healthcare goals?
3. Have you ever thought about who you would like to make medical decisions for you in an emergency if you were too unwell to speak for yourself? (Refer to glossary)

   If so, who?
4. Have you spoken to them about your wishes, values and beliefs about medical treatment and care?
5. Have you ever signed a document with a lawyer to appoint someone to make health decisions on your behalf if you were unable to? This is called an Enduring Guardian in NSW. If you don't appoint one, your substitute decision maker will follow a hierarchy (starts with spouse).
6. Have you ever written down your wishes, values and beliefs about medical treatment and care (such as an advance care directive or living will)?

Where to now?

- *Provide information on Enduring Guardian and Power of Attorney*
- *Provide relevant resources*

Discussion

This study is unique in its focus on exploring NSW GPs' perspectives on initiating a conversation about ACP with healthy older adults in general practice via a conversation guide. While the data were gathered in 2017, the need for time-efficient ways to initiate ACP remains highly relevant to general practice.[23] Furthermore, the findings remain relevant as there have not been any significant reforms or structural changes to Australian general practices in the intervening years other than the formal addition of telehealth consultations. This study highlights a number of key features of ACP practise, including the goals of ACP, the roles of the GP and GPN, communication strategies to strengthen ACP conversations, the importance of resources and education, and the nature of the ACP process. It also informed development of an adapted conversation guide comprising six simple questions that GPs can integrate into routine care (Box 2). The brevity of this tool enables patients who are ready to discuss ACP to be identified in a routine health assessment or consultation, and a follow-up consultation to be arranged to have a more detailed ACP discussion if appropriate.

Most participants felt that the primary focus of ACP should be enabling a discussion between the patient and their preferred substitute decision maker regarding the person's values and goals for their future healthcare. This is much broader than simply clarifying resuscitation status, which was raised by a few participants. Enabling the patient to have the conversation with those important to them was perceived to strengthen the

likelihood that the person's preferences would be honoured. This has also been identified in a Belgian study exploring GP perspectives on ACP in practice.[24]

This study found the GP's role in ACP depended on the experience of other colleagues (both GPs and GPNs) within the practice, as well as the practice process of health assessments and care planning. This variation in practice is important, as any intervention will not be a 'one size fits all'. Despite the variation in role delineation, there was consensus that primary care is the ideal place to initiate these discussions. This is in line with current evidence, which shows it is preferable to initiate ACP when a patient has capacity and is not acutely unwell.[5–7,25,26]

Given the heterogeneous nature of general practice, it is difficult to develop a tool that all GPs would find useful. This study suggests that any tool needs to be flexible and adaptable in order to suit different GPs. There were varying perspectives regarding the focus of questions included, similar to the discord seen in existing literature.[6] Most GPs agreed it should not be limited to patients aged over 75 years but also include younger adults with chronic disease. The adapted ACP conversation guide was seen as a beneficial tool to use, either as an aide memoire or as a checklist to work through with patients in a consultation.

Interestingly, most of the GPs involved in this study reported confusion regarding the ACP process, in particular the terminology, legality and choice of ACD forms. There is a wealth of educational resources and online courses available for GPs in Australia,[27] but these were not used by many of the study participants. This suggests the need for a careful and coordinated approach in the development and marketing of educational resources for GPs. The supporting glossary developed in this study received positive feedback when compared with existing resources.

There is established evidence of the barriers facing GPs in initiating and implementing ACP, including difficulty defining the right moment to initiate those discussions, as well as concern over the potentially time-consuming nature.[11,12,28] There is a limited number of studies showing effective and simple interventions for use within primary care.[15,29,30] Respondents in this study appreciated the simple one-page layout of the adapted conversation guide (Box 2). The brevity of this guide is ideal for a busy general practice setting, allowing initiation of ACP, which can then be followed up in more detail at later consultations. The adapted guide has since been used in a national Australian Government–funded program for general practices, The Advance Project (www.theadvanceproject.com.au). The Advance Project provides a suite of resources and multicomponent training to enable a team-based approach to initiate ACP and palliative care needs assessment in general practice.[23]

Study limitations

The data were gathered in 2017 but are still relevant to current general practice. Given the small sample size and the nature of the study, the findings cannot be generalised to all GPs. This study involved GPs from NSW, Australia, so terminology regarding ACDs and ACP is relevant to this jurisdiction only. Patient perspectives were also not studied. The conversation guide would benefit from wider review in different general practice contexts for implementation into practice.

Conclusion

Focusing ACP solely on the creation of a formal document such as an ACD risks missing the core premise of ACP, which is to encourage patients to reflect on their values and healthcare goals. There is significant variation in the current ACP process within NSW general practice, so resources and tools that are developed to support the conversation need to be adaptable and able to be integrated into different patient record systems. Simplifying the process and delineating roles will enable improved initiation of ACP and subsequently greater patient uptake. The adapted ACP conversation guide appears an acceptable way for NSW GPs to initiate ACP discussions.

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