


# BMJ Open Australian general practice experiences of implementing a structured approach to initiating advance care planning and palliative care: a qualitative study

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## ABSTRACT

**Objectives** Initiation of advance care planning (ACP) and palliative care (PC) assessments in general practice is key to quality end-of-life care. The Advance Project promotes a team-based approach to initiating ACP and PC needs assessment in general practices through training, resources and practical support for implementation from local primary health networks (PHNs). This paper aims to understand: (1) general practice participants' experiences of undertaking Advance Project training and implementing the Advance Project resources in their practices; (2) barriers and facilitators to implementation of Advance Project resources; and (3) PHN staff experiences of supporting general practices through training and practical support for implementation of the Advance Project resources.

**Design** Qualitative study using semistructured interviews and thematic analysis.

**Setting** Twenty-one general practices and four PHNs from three Australian states were recruited between June 2019 and May 2020.

**Participants** General practitioners (GPs), general practice nurses, practice managers (PMs) and PHN staff.

**Results** 45 participants comprising 13 GPs, 13 general practice nurses, 9 PMs, 3 allied health staff and 7 PHN staff were interviewed. The general practice participants generally agreed that the Advance Project training/resources led to changes in their own behaviour and increased their awareness of the importance of ACP/PC discussion with their patients. Participants reported the following benefits for patients: increased awareness of ACP; engagement with families/carers and peace of mind. Key facilitators for successful implementation were a team-based approach, the role of the PHN, the role of practice champions, training facilitators' ability to influence peers and facilitate change, and mentoring support. Barriers to implementation included issues related to workplace culture, cost, time/workload, patients and health system.

**Conclusion** Findings suggest that the Advance Project approach facilitated successful implementation of ACP and PC needs assessment into usual care in general practices that encouraged teamwork among GPs and general practice nurses. The ability of the practice to make the best use of practical support and guidance available to them through their local PHN both before and during

## Strengths and limitations of this study

- This study explored the experiences of general practitioners, general practice nurses, practice managers and primary health network staff of implementing a national training programme and suite of resources (the Advance Project), which promotes a team-based and systematic approach for initiating advance care planning and palliative care needs assessments in general practices.
- There was diversity among interview participants, including multistate representation, varying levels of experience working in general practice sector and employment type.
- While the study reports on experiences of implementing the Advance Project resources across 18 general practices within 3 Australian states, it has limited rural representation in the participants sampled, which limits transferability of findings to such settings.
- Follow-up interviews regarding practice change post implementation were limited due to project timelines and impact of COVID-19 pandemic, and hence we cannot confirm that changes were sustained.

implementation was a key factor in integration of Advance Project resources into routine practice.

## INTRODUCTION

Australia's ageing population and the growing prevalence of chronic and complex health conditions makes primary care settings an ideal setting to initiate early advance care planning (ACP) and palliative care (PC) discussions.<sup>1 2</sup> The important role of ACP in facilitating quality end-of-life care has been well established<sup>3 4</sup> and emphasised through health policy at various levels.<sup>5 6</sup> However, barriers including time, cost and system issues continue to inhibit initiation of ACP/PC within primary care.<sup>3 7-9</sup> Numerous strategies have been proposed to address these barriers; however, the impact of these remains

**Box 1** Definitions of key terms used in the study

Advance care planning is a 'process of reflection, discussion and communication that enables a person to plan (in advance) for their future medical treatment and other care, for a time when they are not competent to make, or communicate, decisions for themselves'<sup>16</sup>

Palliative care can be defined 'as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems—physical, psychosocial and spiritual'<sup>17</sup>

Supportive care is care that eases the symptoms of a disease or the side effects of treatment for a disease. Supportive care does not cure the disease. It is aimed at improving quality of life and it addresses the psychological, social and spiritual needs of patients and their carers<sup>18</sup>

to be seen. For example, while recent studies suggest that general practice nurses (GPNs) are well placed to initiate ACP and palliative and supportive care needs assessment, further research is needed to evaluate this in routine practice.<sup>10–15</sup> Definitions of key terms<sup>16–18</sup> used in this paper are provided in [box 1](#).

The Advance Project ([www.theadvanceproject.com.au](http://www.theadvanceproject.com.au)) sought to enable earlier attention to ACP and palliative/supportive care, and more efficient management of patients' and caregivers' needs and concerns in general practice. The training also aimed to enable practice staff to implement the ACP/PC assessments into routine practice.

In phase 1, a suite of resources and multicomponent training (online modules and face-to-face workshops) was developed to enable GPNs to initiate ACP during routine health assessments with older people and those with chronic conditions, and to assess patients' and carers' palliative/supportive care needs.

In phase 2, a systematic and team-based approach to initiating ACP and assessing PC needs in general practice was implemented to address barriers from phase 1. Resources were developed for general practitioners (GPs), GPNs, practice managers (PMs), patients and carers; and an adaptable model for resource implementation in usual care was produced (see online supplemental appendix 1). Resources included a toolkit (see online supplemental appendix 2), online training modules and training videos, which provided an explanation of the Advance Project team-based approach to initiating ACP and PC needs assessment in general practice and demonstrated how to use the assessment tools in consultations with patients and carers. This phase extended the education to include GPs and PMs. Additionally, four champion primary health networks (PHNs) and their staff led programme implementation in their region, including local trainer development, workshop delivery and practice support. Mentoring from the Advance Project team supported PHNs and individual GPs/GPNs/PMs.

This paper reports on the findings of one component of the phase 2 evaluation, focusing on exploring participant's experiences of the Advance Project. This paper

aims to understand: (1) general practice participants experiences of undertaking Advance Project training and implementing the Advance Project resources in their practices; (2) barriers and facilitators to implementation of Advance Project resources; and (3) PHN staff experiences of supporting general practices through training and practical support for implementation of the Advance Project resources.

**METHODS**

This qualitative study was part of a larger mixed methods study evaluating the Advance Project. Study reporting is based on the Consolidated Criteria for Reporting Qualitative Health Research.<sup>19</sup>

**Participant selection and setting**

PHNs were recruited to the Project in response to a call for expressions of interest from all Australian PHNs.<sup>20</sup> Included PHNs then sought local practices to participate. GPs, GPNs and PMs from the 21 participating general practices and staff from the 4 champion PHNs in 3 states of Australia were recruited to participate in this study. Three allied health (AH) participants who were in a similar role to GPNs conducting annual health checks at two general practices were also recruited. An email invited potential participants to take part in an interview. Interested participants contacted the evaluation officer (SVN; with no direct working relationship with the participants) and a mutually convenient time was chosen for the interview.

**Data collection**

Semistructured individual or small group interviews were used to collect data. A literature review and input from the project's expert advisory group were used to develop the interview guide (see online supplemental appendix 3). A total of 25 interviews (12 individual and 13 group) were conducted face-to-face or via telephone, given the geographic distribution of participants and COVID-19 pandemic, by a single interviewer (SVN). All interviews were audio recorded and transcribed verbatim using a transcription service. Field notes were made by the interviewer to capture their perceptions during data collection.

**Data analysis**

This study used a qualitative descriptive approach.<sup>21 22</sup> Qualitative descriptive studies are useful in situations where information is sought directly from participants who experienced a phenomenon or an event under investigation, and researchers seek to capture various elements of an event. Seeking an insight into the life world of the participants is seen as a key benefit and can be part of a mixed-methods approach to understand a phenomenon more deeply. The goal is not theory generation, but development of comprehensive summary of participant experiences by staying close to the data and using quotes

to illustrate meanings participants attribute to events or facts.<sup>21 22</sup>

Generic principles of thematic analysis<sup>23</sup> such as familiarisation with data, coding to describe content, looking for themes or patterns across codes from different interviews were employed. Each interview was read and re-read and coded to identify key concepts by an experienced qualitative researcher with non-clinical background (SVN). Higher-level themes were then generated by combining codes and consolidating all data relevant to each potential theme. Then a selection of transcripts was reviewed collaboratively by other researchers (with expertise in general practice (JR), primary care (EJH, VL) and PC (JMC)) and themes were discussed. Data saturation was discussed as no new themes emerged after the last interview. Themes were then organised into categories that addressed key implementation related topics. No member checking was conducted with interview participants due to tight project timelines.

### Patient and public involvement

There was no patient or public involvement.

## RESULTS

### Participant characteristics

Of the 45 people who participated in the interviews, 13 (28.9%) were GPs, 13 GPNs (28.9%), 9 PMs (20.0%), 3 AH staff (6.7%) and 7 staff from the PHNs (15.5%) (table 1). This included 12 individual and 13 group interviews (with most groups having 2–3 participants). Three of the twenty-one general practices did not participate in the evaluation interviews, citing lack of time and staff turnover issues. Most participants (n=35; 77.8%) were female. Of the 10 male participants, 9 were GPs and 1 was an AH professional. Over a third of general practice participants (n=15; 39.5%) had been employed in general practice for less than 5 years, while just under a third (n=12; 31.6%) had worked in general practice for over 20 years. Most participants (n=36; 94.7%) were employed in a metropolitan area and just under half were from the state of New South Wales (n=19; 42.2%). Interviews ranged from 25 to 60 min.

Data analysis revealed six categories: (a) training/resources; (b) impact of training; (c) perceived benefits for patients, carers and practice; (d) facilitators to implementation; (e) barriers to implementation; and (f) strategies to facilitate implementation. Each category is described below with exemplar/example quotes from participants identified by role.

### Training/resources

Overall, the training was highly rated by participants. Several participants described the usefulness/relevance of the training and resources, the simple and easy to understand language used in the patient/carer booklets and use of practical demonstration videos during training.

**Table 1** Interview participant characteristics

Characteristics	Participants (n)(%)
<b>Sex</b>	
Male	10 (22.2%)
Female	35 (77.8%)
<b>Role</b>	
GP	13 (28.9%)
GPN	13 (28.9%)
PM	9 (20%)
AH	3 (6.7%)
PHN	7 (15.5%)
<b>Experience working in general practice</b>	
≤5 years	15 (39.5%)
6–10 years	6 (15.8%)
11–15 years	4 (10.5%)
16–19 years	0 (0)
≥20 years	12 (31.6%)
Unknown	1 (2.6%)
<b>Employment</b>	
Full time	25 (65.8%)
Part-time	13 (34.2%)
<b>Location</b>	
Metro	36 (94.7%)
Rural/regional	2 (5.3%)
<b>State</b>	
New South Wales	19 (42.2%)
Queensland	17 (37.8%)
Western Australia	9 (20%)
<b>Advance Project training completion</b>	
Workshop and online training	32 (84.2%)
Online training only	1 (2.6%)
Workshop only	2 (5.3%)
Brief training session	2 (5.3%)
Brief training and online	1 (2.6%)

AH, allied health; GP, general practitioner; GPN, general practice nurse; PHN, primary health network; PM, practice manager.

I found the modules very helpful because I don't come from a background that I had any understanding of advance care planning. So being able to explain to the patients from a reception point of view and having resources that can back up what I'm trying to say, I found very helpful. Just like the modules to explain exactly what advance care planning was, was very helpful for me. (PM)

I think the resources themselves were user friendly. .... I found that the language was very specific and very easy for patients to identify with, which is good. I'm glad that it's not something that's above them. It's at a level that they can understand. (PHN)

GP/GPN participants found that the resources assisted with overcoming discomfort of raising the topic and the training increased their confidence to have discussions with patients.

I think it [training] gives us better understanding, better understanding of what exactly it is, and how we can provide the information and all the useful resources to our patients. Give us more confidence in having the discussions with them as well. (GP)

I've got a better understanding and knowledge around why it's important and how to talk about it and how to answer questions that patients might have, and what questions to expect and those kinds of things. I think it's really - it really helps me. (GPN)

Most GP/GPN participants found face-to-face workshops helpful for providing opportunities to network with peers, discuss peer feedback and perspectives, clarify questions, and brainstorm challenges and strategies to overcome barriers.

I really liked the primary health network workshop where we talked about - we had a little discussion. There were a lot of practice nurses as well as GPs there. We had a little discussion about wording, about what you actually say to people. Everyone had slightly different ideas about how to broach the topic, and that is quite a big barrier for me. I've always been a bit cautious about that, so it was really interesting to hear other people's experience about it. So, I really enjoyed that. (GP)

Some GP/GPN participants stated that online training was not as useful if they had prior experience in ACP/PC or already initiated ACP/PC. Such participants preferred their own approach to such discussions but used selected resources to give to patients/carers to complement discussion.

All PHN staff and one GP asserted that brief training sessions, from 30 to 45 min, were more suitable than longer workshops for general practice staff. Such shorter sessions could be delivered at the practice and the volume of information was not overwhelming.

...practices are time poor and they're coming to a three-hour workshop after being at work for eight hours is really asking a lot of them. I feel like having those lunch-and-learn sessions are just a much better way of getting that short, sharp delivery of good information that is practical for them to actually use. (PHN)

In addition, some PHN staff felt this may be a more sustainable way for PHNs to deliver training in the future. However, other PHN staff noted that such onsite training sessions limited opportunities for participants to ask questions and did not offer peer networking with participants from other practices that occurred in workshops.

Some refinements to the training and resources were suggested.

I really enjoyed the online [training] and when we went to the workshop. That was great. I was just thinking, maybe, we could do some role play. I know that we watched the role play in the video. But I thought that in the workshop it would've been good if we could do some role play. Because I was saying I felt a little bit nervous approaching patients and maybe a bit of practice at it, before would've been good. (GPN)

I felt that they (the patient/carer booklets) were quite lengthy. Could they have been any shorter? I'm not sure if they could've been. (PM)

#### Impact of training and resources on participant behaviour and awareness of the ACP/PC topics

Most participants stated that the training led to changes in their behaviour or at practice-level and increased their awareness of the importance of ACP/PC. For those GPs and GPNs who had already been initiating ACP and PC conversations, the training provided reassurance regarding their approaches and provided additional resources for patients/carers rather than prompting practice change.

The first thing it has done is to encourage us to systematically hand out advance care planning information when the nurse does the 75 plus health assessment, not necessarily (the Advance Project) information but certainly advance care planning information. The second thing it has done is alert the nurses and the GPs to the need for this so that they're open to it when patients ask them. The third thing it has done is, I think for me anyway, made me more aware of the full range of advance care planning components that there are. (GP)

Other GPs/GPNs/PMs reported that they have made substantial changes to their practice in ACP and/or their assessment of patients' PC needs as a result of participating in the project. Examples included: more frequent initiation of ACP discussions, routine use of resources during annual health assessments or chronic disease management consultations, more discussions with patients and carers documented in records and promotion of the resources to other GPs and patients.

Having the forms [patient/carer booklets] here that we could give to the patients, so that they had an avenue that they could take into the doctor and say, I've been sitting in the waiting room. I've been reading this. Can you tell me, what do I do next?... I made sure that there were always copies of those at reception so patients would be able to take them themselves if they wanted to just have a look and see. (PM)

It's changed from basically saying this patient requires some supportive or palliative care and doing

a referral to actually identifying issues that they may have, or at least opening up the discussion...So it's actually allowed us to make an earlier referral, so that they're able to be assessed at a stage where we can work towards the future rather than waiting for a crisis to occur and then requesting for an urgent assessment and management. (GP)

Palliative care...in this practice ...we haven't done in a methodical way before taking up this Advance Project.... Now we are implementing these materials and resources on daily basis. So the answer is previously we weren't doing this much amount of resources and care to the patients focused on palliative care, but now we are doing more. (GP)

### Perceived benefits

Those GPs and GPNs who had initiated conversations about ACP using the Advance Project resources reported that patients generally responded positively, and that most patients appreciated an introduction to the ACP booklet.

I find the biggest benefit is for the patients. I think it explains it for the patients a lot more in a lot of simpler layman terms, I guess. Patients feel like, I think they feel a lot more comfortable using the booklet because it's not such an official thing, I guess you could say. As compared to the actual advance health [directive] ..., you know they actually feel a little bit more comfortable sitting down by themselves, going through that booklet, writing their wishes before approaching their family and things like that. (GPN)

While most patients were reported by GPs/GPN to have appreciated receiving the patient resources, some participants reported that some patients were reluctant or showed limited interest. In addition, not all patients made a follow-up appointment to discuss the booklet.

It's a topic, sensitive topic that people try to avoid, or they never talk about it, and we just have to be very technical in dealing with it. It's just hard to initiate a conversation even. Or some people they are avoiding it too, they don't want to know about it. (GP)

Several examples of positive outcomes for patients, carers and general practices were described by participants. GP/GPN participants perceived the following benefits for their patients: (a) increased awareness of ACP; (b) an ACP discussion resulting in advance care directives (ACDs) or review/revisions to existing ACDs; (c) engagement with families and carers regarding the patients' healthcare wishes, patient satisfaction (peace of mind); (d) feelings of being in control, not burdening families; (e) referrals to specialist services; and (f) follow-up visits with GPs after completing booklets with their thoughts/responses. Perceived benefits for carers included feelings of being supported, reassurance/knowledge regarding loved ones' wishes and managing expectations when dealing with multiple carers. Practice outcomes described included consideration of a systematic way for

implementing the resources, supporting holistic patient care beyond just clinical care, and helping the practice to be aware of a patient's wishes and relevant information uploaded to practice records.

I suppose there are various outcomes. There's an outcome for the practice in terms of getting us to think about it and systematically handing it out with the 75-plus health assessment, handing out some information about advance care planning. So, that's an outcome. There was an outcome for my patient who wanted an operation and had already written the document. That was helpful because she felt that she had written everything in there about what she wanted done and how she didn't want to be resuscitated and so on. That was helpful for her. Other people have found it helpful to have it for similar reasons, particularly people who really didn't want to be resuscitated. They really wanted us to record that. (GP)

Well, probably the most important outcome is that it has allowed the carers to make contact with supportive and palliative care. That's the main one. It has triggered in some of them the ability to look for what sort of home care support they can obtain, with regard - because sometimes the younger families are workers, so they're not constantly available (GP)

### Facilitators to implementation

Five main facilitators for successful implementation were reported namely: a team-based approach, the role of the PHN, the role of practice champions within the practice, facilitators' ability to influence peers and facilitate change and mentoring support.

### Team approach

The team-based approach was described as a catalyst for practice staff to collaboratively plan and implement a systematic and structured approach to using the resources in their routine practice. Adopting a team-based approach to implementation of resources meant not relying on one staff member to initiate ACP/PC conversations.

So one [way to initiate the conversation] would be that I would do a referral to the care plan nurse and giving them the preparing for discussion pamphlet, and say, have a look at this pamphlet, and when you see the care plan nurse, hand it to her. Sometimes, if I haven't thought of it at the time, then the care plan nurse may very well say, look, we're doing the health assessment, and as part of the health assessments, I'm going to give you this document, so that when you do go back to the doctor, can you go through it? So it's a bit of back and forth that can occur, but so long as either of us is triggering that discussion. (GP)

Well, when I undertake a health assessment I've got to follow up with a GP anyway, so we write notes and the GP can see them...It's documented in the patient file



that we've had that conversation. If there's anything that gets flagged in here that I feel like that should be followed up with a GP, then I'll have a verbal discussion with them as well...These are my concerns, should we get like an OT [Occupational Therapy] assessment or should we have a referral to ACAT [Aged care assessment team], or whatever...I would knock on the door and say, can I have a chat. (GPN)

#### *Role of PHN*

The PHN's established relationships and experience working with general practices was another key facilitator. PHN staff's ability and willingness to provide on the ground practical support to practices were critical factors that facilitated successful implementation.

Whenever we are in doubt [PHN staff name] was there to help us out at every single step. In fact she recently came across both locations... We have two branches so she kept some displays on the patient board, information board (GP)

[PHN staff name] was amazing. She was fabulous. She was always just sending through emails and updates, checking in with how we were going, offering her support. A couple of weeks ago, before all of this Coronavirus took off, she actually came down to the practice again and sat with the rest of our nurses and spoke to them about the Advance Project and what it was and how we could really implement it and, ... she was really supportive and really great (PM)

It was nice to have someone that understands as a Practice Manager you are busy, and you are juggling a lot of things and a lot of projects, and she [PHN staff] was really understanding of that. It was great for someone to be able to come into the practice and talk to the nurses and GPs. Because sometimes I think in my role, our staff can just – if I'm telling them we're involved in this really great project, sometimes they can just think of it as, oh, it's another project and just me nattering at them. Whereas it's good to have, I guess, like an external person come in and speak to them. I feel like they tend to take that on board a bit more. So, that aspect of the overall training and support was really great (PM)

#### *Practice champion*

In practices where a champion GP/GPN or PM had a passion for the topic, motivation and was influential in making necessary practice-level changes, implementation seemed more successful.

[Facilitator name] and I presented at a whole practice, when I say the whole practice they had the nurses and the GPs all there. So there were about 15 people there and that came about because two of the GPs had actually come to the workshop that we had here. They took it back and were talking to the GPs and they wanted to know more. So we were able then to come in and actually do the big after hours workshop

in the practice, a smaller version of what we would have presented. Now from there, I think it was really successful because a couple of days later the practice manager and the head GP actually did a presentation at [XXXX]. They actually used some of the [Advance Project] resources down there and they did their own little PowerPoint on what we had actually presented and showed them at the [XXXX]. There was like 80 people, so that was something I would say was actually quite successful. To see it going on further, they were so passionate about what they were doing and they're continuing even now. (PHN)

#### *Workshop facilitators' ability to influence peers and facilitate change*

Many participants also reported that knowledgeable workshop facilitators who provided local examples and explained how the resources could be used in their region assisted with building confidence to implement the resources at their practice.

I think what supposedly helped us is we had two or three really good presenters that were passionate. We had [Facilitator name], who was like the ACP whiz here on the <region>, [Facilitator name] 's taught me so much. We had [Facilitator name], who is ... the specialist palliative care and then we had Dr [Facilitator name]. Now [Facilitator name] is a GP but she's also a visiting medical officer at <name> Hospice. So very passionate about palliative care, very passionate about advance care planning. I think their passion made it easy then to be able to do the workshops. (PHN)

#### *Mentoring support*

Mentoring support from the Project clinician mentor or PHN staff was also facilitators for successful implementation.

I did benefit from the online learning but I benefited better from the face-to-face learning, and [PHN staff name] coming in and re-educating when she came in and going through it again and again. I've benefitted a lot more from that encounter than I did from the online learning, but that's me personally. I can't speak for other people. (GPN)

#### *Perceived barriers to implementation*

Several barriers to implementing the Advance Project assessments were described by participants, including workforce issues, cost, time/workload, patients and health system issues.

#### *Workplace issues*

Staff turnover, staff shortages, lack of supportive GPs willing to work collaboratively with GPNs were reported by participants. In some practices, although the GPN and/or practice manager were interested in initiation of the ACP discussions, the GPNs did not feel supported

and were unsure about the next steps once the patients received the ACP booklet. Lack of privacy, inadequate private space in the practice for GPNs to have discussions with patients and constant interruptions from others were also noted as workplace contextual barriers.

Sometimes our staff has the attitude of, oh, another project that we're involved in. So, when I got to them and have a discussion about the resources and what we're doing with these, sometimes there's a bit of resistance because they, yeah, just perceive it as, oh, another thing that we have to do. I guess, yeah, in terms of that attitude, would be a bit of a barrier. (PM)

PHN participants reported specific barriers related to GP attitudes regarding topics related to death, some GP attitudes towards patient care (financial/business focus vs patient care), and overseas-trained GPs' lack of knowledge about local systems and referral process. The transient nature of the workforce in some areas and practices was also perceived to be a barrier.

In one practice that ended up dropping out of being one of our champion practices, there was a turnover of staff. So ...that absolutely turned a very, very good practice on its head. Sometimes, because in some of these areas people do move around. (PHN)

We tried to get some feedback around what are the barriers for you as a practice in addressing advance care planning. The majority of the comments that were coming out of it was ... the financial implications, because practices now run as a business. It's not like your traditional historic GP service. The other one is the message they gave to us, well we are here as a profession to keep people alive, so we don't like saying to them we can't do anything more for you, you need to think about death, so to speak. (PHN)

#### *Cost-related barriers*

Cost-related barriers were raised by both practice and PHN staff. All participants reported printing costs associated with providing booklets to patients and carers. General practice participants also described how the lack of ACP/PC focused medicare benefit schedule (MBS) item numbers challenged implementation.

Well, if it had its own MBS billing code there would be a bit more of an incentive. I think you'd probably get more GPs on board with it then, even if it's nurse led. (GPN)

I just think that it's pretty poor if there's a patient that has a chronic illness, you get the \$12 when our conversations could be half an hour or 45 minutes I had with some; an hour conversation with some of these patients. (GPN)

Additionally, PHN participants reported that lack of funding for designated support roles to embed the change in practice poses a risk for sustainability.

I think basically it comes down to the fact of change management. Realistically the Advance Project for us has only been over nine months, change management can take up to 18 months to two years. What really concerns me is now that we're coming to the end, if the money is not there to be able to support general practice in this, then it might just get dropped. So I think the financial gains and as you said, we're looking at MBS item numbers and things like that, I think that will certainly help. But from a PHN perspective, we need people on the ground that can actually be talking advance care planning with the practice. (PHN)

#### *Time and workload*

All participant groups reported time barriers. GP/GPN participants described being time poor and that other patient priorities at times took precedence over implementation.

I was doing the 75-plus health checks, but the problem with that...there was so much other stuff to be done that advance care planning was just a five-minute conversation in that one hour of assessing and identifying. (Allied Health professional)

The minute another patient comes into the room, it means the conversation is ended. We're just so busy in our day already that we don't have the necessary time to discuss it. (PM/GPN)

On the other hand, other practices found it feasible to use the existing annual health check appointments for ACP assessments.

I would say it was quite easy to implement into our practice, because like I said, advance care planning was something that we had already talked about with our patients about the health assessment. It's something that we've always talked to them about. It's one of the things that we tick off as having done a health assessment. So it was quite easy to bring these booklets in and say to the patients, well you don't have to make a decision now, you can take this booklet, have a read through it. See what you decide. Come back in about two weeks, have a chat to us, see where you stand. (GPN)

Some GP/GPN participants indicated that they believed that the Project resources created unnecessary additional workload. Some stated that other approaches they used previously worked better for them and their patients. Nevertheless, others explained that the increased workload was unavoidable as there was a need to plan for having these important patient conversations and a behaviour/practice change was necessary both at an individual and practice level for routinely conducting these discussions.

From the GP, from my point of view, it increases it [workload]. Obviously because you are entering, you are dealing with - I mean it's a formalised process and



you've got to think about it and put the time aside and dedicate that time to go through it. So it is an additional impost, but I mean it's an important one. I mean, so that boils down to an individual doctor's decision whether they want to go down that path. (GP)

### Patient barriers

General practice participants reported barriers including patients not making follow-up appointments, lack of health literacy, challenges associated with multiple GPs, patients' reluctance to discuss ACP, and challenges raising the topic with new patients before rapport was established.

Sometimes [patient] level of literacy and understanding was a bit of a challenge as well. So, even though they might not be opposed to it, some of them are just really, quite simple folk. Quite hard to just engage, I guess. They'd come back with a document and you sort of know that they struggled to even read and fill it in. (GP)

### Health system barriers

Some general practices also reported lack of clarity regarding sharing the information after their ACP discussions. Other general practice participants reported barriers to accessing services to meet the patients' identified support needs. For example, one rural practice reported that lack of access to PC services was a major barrier to making referrals, even if they identified patients who might benefit.

We don't have any palliative care or oncology down here. Our patients travel a long distance to receive that. A lot of them will move out of the region when they become palliative. (GPN)

There is - there does seem to be - my - the impression that I had, rightly or wrongly, in terms of palliative care services in the community, was that it - yes, people got advice and they got consultancy services, but in terms of the actual services available for people who were dying - the actual, hands-on, nitty-gritty of looking after someone who was dying in their own home, there's not a huge amount available...ACAT would try and get them packages that would enable people to have services, but that didn't always happen, and in reality, yes, a level four package would give you - what is it - 12, 15 hours per week, of care, but when someone's dying, that's not enough. (AH)

### Strategies to facilitate implementation

Participants described strategies to facilitate implementation of the project (boxes 2 and 3). General practice participants advocated strategies such as increasing patient and carer awareness about the programme through advertising/forums, enabling greater collaboration between GPs and GPNs, campaigning for adequate funding, and ensuring staff at the practice accessed the

## Box 2 Strategies used or proposed by general practices to facilitate implementation

### Strategies

- ▶ Increasing patient and carer awareness about advance care planning (ACP) and project resources through advertisements on practice notice boards, making booklets available near waiting rooms and education evenings (general practice nurses (GPNs), practice managers (PMs))
- ▶ Providing GPN-led assistance for patients to complete assessments (GPN, PM)
- ▶ Ensuring general practitioners (GPs) acknowledge and support GPN-initiated assessments with a follow-up GP appointment (GPs, GPN, PMs)
- ▶ Having information ready regarding local palliative care services and resources (GPN)
- ▶ Providing additional information to the patients using patient forums or dedicated telephone numbers for additional support post ACP discussion with a GPN (GPNs)
- ▶ Ensuring GPs/GPNs are trained in using Advance Project resources (PMs)
- ▶ Advocating for funding to support GPs/GPNs to engage in ACP (PM)
- ▶ Using primary health networks for training and support focused on the local context when needed (GP, GPN, PM)

training and support for conducting Advance Project assessments. PHN participants advocated strategies such as influencing GP attitudes using champion GPs, enabling sustainability through ongoing train-the-trainer support for education, and practical support for general practices to embed Advance Project resources into their existing workflow.

We had to put in basically a few statistics around the <Region>. We had to bring in things that would be of interest to the GP and it could be what's in it for you, that kind of approach, because honestly that's what they wanted. (PHN)

That if we invest in a potential train-the-trainer model within a larger practice model, like the one across the road here that we had to say no to, they're a company of

## Box 3 Strategies used or proposed by primary health networks (PHNs) to facilitate implementation

### Strategies proposed/used by PHN staff participants

- ▶ Influencing general practitioner (GP) attitudes using champion GPs as examples to showcase successful implementation
- ▶ Educating GPs on the local context such as local statistics to engage practice staff and increase their awareness
- ▶ Keeping focus on 'initiating' and not getting distracted by legal or local issues during training sessions
- ▶ PHN support for practices to identify and use appropriate Medicare benefit schedule item numbers to bill for consultations
- ▶ Incorporating resources as part of practice-based quality improvement projects
- ▶ Training practice support staff to promote sustainability
- ▶ Use of train-the-trainer approaches to meet future demand for training



GPs and have multiple practice surgeries across not only the <region> but <city> and wherever, that it becomes a bit of a train-the-trainer. So we're not having to go in and train everyone within the practice, or we might train up one person who's [a] champion. (PHN)

## DISCUSSION

This paper reports on general practice and PHN staff perspectives of implementing a novel team-based approach to initiating ACP and PC in general practice. Overall, the training and resources were well received by participants with some areas of improvement identified for the future. A team-based approach to initiating ACP/PC, presence of champion staff who are experienced, reputable and able to influence peers and facilitate practice-level change, practical support from PHN staff for implementation and mentoring were identified as important facilitators for successful implementation. Barriers to implementation included issues related to workplace culture, cost, time or workload, patients and health system. Many of these barriers are common to implementation of new projects or practice change in general practices.<sup>7 24</sup>

In our study, the champion was not necessarily a GP but often a GPN or a PM with leadership skills and good rapport/trusting relationship with staff members. Research has demonstrated the importance of practice champions in high functioning general practices,<sup>25</sup> and affirms our strategy of identifying and supporting practice champions. The important role played by PHNs and practice facilitators in quality improvement of general practices is well recognised in the literature.<sup>26 27</sup> In our study, the PHNs helped to influence staff attitudes to initiating ACP/PC and provided practical assistance to practices. Unfortunately, this was sometimes not enough, as some practices struggled with lack of commitment due to issues with inadequate funding or negative attitudes by key staff members in initiating topics related to death.

Our findings confirmed the importance of practice investment in upskilling staff in ACP and PC assessments. The knowledge and confidence gaps in primary care health professionals in ACP and PC are well known.<sup>3 28</sup> The current findings suggest that the Advance Project training and resources are effective in addressing those gaps. But what has not been previously explored is our finding that the small number of practices who engaged in nurse mentoring appeared to be more successful in creating substantive change. Nurse mentoring has been shown to improve the confidence, sense of autonomy and motivation of nurses,<sup>29 30</sup> but little is known about the benefits of mentorship around specific clinical issues such as ACP and PC assessments. Further research is required to explore how nurse mentoring around specific clinical issues can bring about practice change.

Participants perceived that the Advance Project had a mostly positive impact on patient and carer outcomes, as well as on the practice. However, there were many challenges as well, including the transient nature of staff in

some practices and lack of GPs having an established relationship with patients. This is unfortunate, as continuity of care and established relationships with patients are an important reason for why ACP is well suited to general practice.<sup>3 31-34</sup> Continuity of care also facilitates the involvement of GPs in PC, as they are more likely to provide this type of care to patients with whom they already have an established relationship.<sup>35</sup>

Lack of adequate funding was identified as a significant barrier by many participants, despite information being provided on Medicare funding options to undertake these activities. Issues with funding have previously been identified as a challenge to the implementation of general practice interventions.<sup>27 28</sup> This finding highlights a need for continued advocacy for flexible funding models that allow health professionals to deliver evidence-based general practice care as required by patients.

Future work should focus on understanding the implementation of Advance Project training and resources in regional and/or rural general practices, as the current study included practices predominantly from metropolitan areas. Our study focused mainly on Advance Project training programme evaluation aspects and participant perspectives on selected domains of interest were gathered. Detailed in-depth interviews with general practice participants to further explore their experiences of implementation was not feasible due to limited project time and resource constraints. Patient and carers' experiences of using the project resources were not explored through interviews. This would enhance our holistic understanding of how ACP and PC assessments could be better integrated into primary care. Follow-up with general practice participants is also necessary to ascertain whether the practice-level or individual-level behavioural changes were sustained post project funding period.

## CONCLUSION

The Advance Project approach of initiating ACP and PC seemed to work well in general practices that demonstrated teamwork among GPs, GPNs and PMs, encouraged GPN-led initiation of Advance Project assessments and which effectively used support available through the local PHN to plan and facilitate integration of Advance Project resources into their routine practice. Successful strategies to implementation included proactively overcoming any challenges by either coming up with their own strategies or taking up support from the local PHN or project team nurse mentor for practice-level or individual-level GP/GPN behaviour change. The findings highlighted that the implementation of new routines/change take time and ongoing practical support for general practices is essential for sustainability in the short-term and long term. Findings from this qualitative evaluation will inform future refinements to the Advance Project training programme and help prepare future PHNs interested in supporting general practices with successful implementation of the Advance Project training programme.

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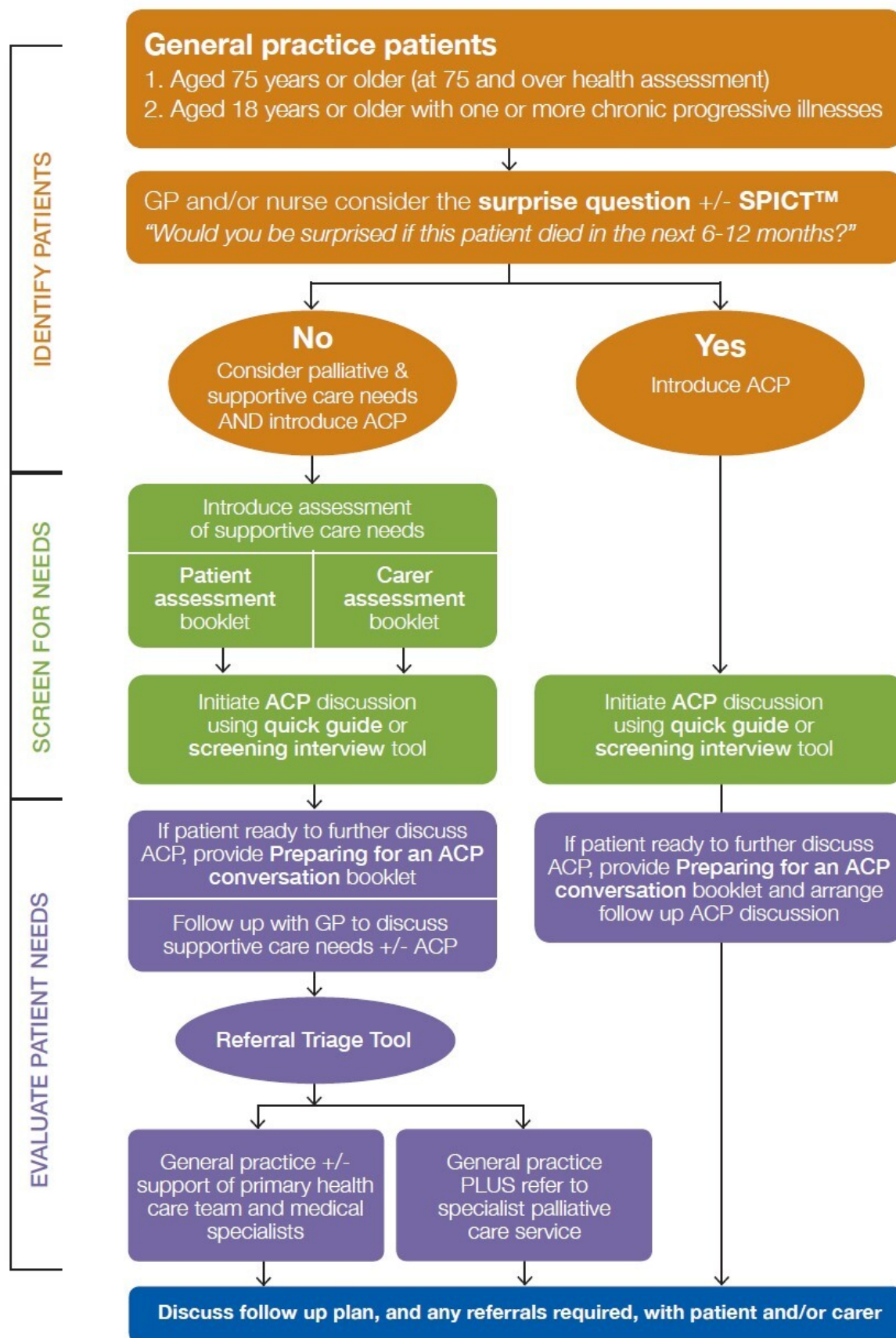
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# The Advance Project™ Guide

Initiating advance care planning (ACP) and palliative care in general practice





## Appendix 2 Screening and assessment tools in the Advance Project Toolkit

Assessment tools	Brief description
Advance Project Guide	<ul style="list-style-type: none"> <li>“The Advance Project Guide: a model for initiating advance care planning and palliative care in general practice”. This guide explains how to implement the various resources in the toolkit in everyday clinical practice.</li> </ul>
<b>Advance Care Planning<sup>a</sup> (ACP) Tools</b>	
ACP screening interview tool	<ul style="list-style-type: none"> <li>A step-by-step guide for general practice nurses (GPNs), with exemplar questions and prompts, for initiating conversations about ACP during routine health assessments</li> <li>Promotes patient awareness of ACP, identifies any prior ACP and the patient’s preferred substitute decision makers, any wishes the patient may have already thought about regarding their future care should their health deteriorate, as well as the patient’s readiness to further discuss ACP</li> <li>There is space within the tool to record the patient’s responses to interview questions, and it can be uploaded into general practice software as a record of the initial ACP discussion</li> <li>Developed initially for acute care settings<sup>1</sup>, then adapted and piloted for use by GPNs.<sup>2</sup></li> </ul>
The Advance Project: Quick guide for introducing advance care planning in routine consultations or health assessments in General Practice	<ul style="list-style-type: none"> <li>This quick guide supports general practitioners (GPs) to initiate conversations about ACP. It complements the more structured interview for initiating ACP that was developed for nurses in Phase 1 of the Advance Project. It includes similar prompts as the ACP screening interview tool but does not provide spaces within the guide to record patient responses.</li> </ul>
The Advance Project: “Preparing for an advance care planning conversation - A guide to help you prepare for a conversation with your family or health care team about your wishes for future health and personal care.”	<ul style="list-style-type: none"> <li>A patient resource that guides patients through the next steps in ACP and helps them prepare for further discussions about ACP with their family or GP or nurse. It prompts reflection about the person’s values and preferences for future care and encourages the person to share their responses with their family and health care team.</li> <li>It fills an identified gap between the conversation being initiated by a nurse or GP, and the person being prepared for further discussions about ACP or considering completing a formal advance care directive.</li> </ul>
The Advance Project patient resource: “Who will speak for you if you can’t speak for yourself?” A guide for choosing a substitute decision maker for health care decisions.	<ul style="list-style-type: none"> <li>A guide for choosing a substitute decision maker for health care decisions.</li> </ul>
<b>Palliative Care<sup>b</sup> and Supportive Care<sup>c</sup> needs assessment tools</b>	
Surprise question and/or the Supportive and Palliative Indicator Tool (SPICT <sup>TM</sup> )	<ul style="list-style-type: none"> <li>A screening process to identify patients who may benefit from a comprehensive assessment of their unmet palliative and supportive care needs.</li> <li>The surprise question is “Would you be surprised if this patient died in the next 6 to 12 months?”</li> <li>The SPICT<sup>TM</sup> tool identifies patients who may be at risk of deteriorating and dying and was developed by Boyd et al<sup>3</sup></li> </ul>
The Advance Project Patient Assessment Booklet: “Supporting you to live well with a chronic illness.”	<p>A patient and clinician resource to assess patients’ palliative and supportive care needs. This booklet includes an introduction regarding the purpose of the assessment and instruction for use, so that the assessment can be self-administered if appropriate. It includes the following:</p> <ul style="list-style-type: none"> <li>Integrated palliative outcome scale (IPOS)- a well validated tool for assessing common physical and psychological symptoms in patients with life limiting illnesses. The nurse or GP can assist the patient to complete this, to inform the GPs’ consultation with the patient. Alternatively, patients with good health literacy may complete this tool on their own after it is</li> </ul>

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	<p>introduced by the nurse. The IPOS provides a two-page summary of the patient's symptoms.<sup>4</sup></p> <ul style="list-style-type: none"> <li>• Patient concerns and questions checklist (NAT-CC patient): this tool was adapted from the NAT-CC carer version<sup>5</sup> and informed by a question prompt list previously developed and evaluated in specialist palliative care settings.<sup>6,7</sup> The original prompt list was significantly shortened and simplified as part of the Advance Project for use in primary care. The tool helps patients to identify the questions and concerns they want to discuss with their GP about their illness, practical issues and future care planning.</li> </ul>
The Advance Project Carer Assessment Booklet: "Looking after you while you care for someone with a chronic illness."	<p>A carer and clinician resource to assess carers' supportive care needs. It includes an introduction regarding the purpose of the assessment and instructions for use, so that the assessment can be self-administered, and:</p> <ul style="list-style-type: none"> <li>• Carer needs and concerns/questions assessment tool (NAT-CC carer): This tool was adapted from the NAT-CC (Needs assessment tool for cancer carers) to be relevant to carers of patients with other life limiting illnesses, and for administration by practice nurses. The NAT-CC was previously developed by one of the Advance Project consortium members<sup>5</sup> and adapted to be relevant for carers of patients with a chronic condition (not only cancer). It was also informed by a question prompt list previously developed and evaluated in specialist palliative care settings.<sup>6,7</sup></li> </ul>
The Advance Project Referral Triage Tool	<ul style="list-style-type: none"> <li>• A guide for determining the need for additional supportive care services for people at risk of deteriorating and dying, including clear triggers/indicators for considering early referral to specialist palliative care services. This tool was informed by a literature review and developed by a subgroup of the Advance Project advisory group team.</li> </ul>
<b>Other</b>	
The Advance Project and Medicare Benefits Schedule (MBS) Items Fact Sheet.	<ul style="list-style-type: none"> <li>• This fact sheet outlines Medicare items that can be used to fund initiation of ACP and/or palliative and supportive care needs assessment in general practice in Australia. It was released after review by the Medical Benefits Division of the Australian Government Department of Health.</li> </ul>

<sup>a</sup>**Advance care planning** is a "process of reflection, discussion and communication that enables a person to plan (in advance) for their future medical treatment and other care, for a time when they are not competent to make, or communicate, decisions for themselves"<sup>8</sup>

<sup>b</sup>**Palliative care** can be defined as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"<sup>9</sup>

<sup>c</sup>**Supportive care** is care that eases the symptoms of a disease or the side effects of treatment for a disease. Supportive care does not cure the disease. It is aimed at improving quality of life and it addresses the psychological, social and spiritual needs of patients and their carers<sup>10</sup>

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## Appendix 3

### Interview guide – qualitative interviews with GPs, Practice Nurses and Practice Managers from Champion General Practices

#### Basic demographic details

<b>Sex:</b>	<input type="checkbox"/> Male	<input type="checkbox"/> Female		
<b>Role in the General Practice:</b>	<input type="checkbox"/> General Practice nurse (GPN)	<input type="checkbox"/> General Practitioner (GP)	<input type="checkbox"/> General Practice Manager (GPM)	<input type="checkbox"/> Other
<b>Number of years you have been working in General Practice:</b>				
<b>Number of days per week working in General Practice:</b>				
<b>Location</b>	<input type="checkbox"/> Major city	<input type="checkbox"/> Inner regional	<input type="checkbox"/> Outer regional	<input type="checkbox"/> Remote and very remote
<b>If a GPN/GP/GPM, which components of training have you completed (tick multiple boxes if applicable)</b>	<input type="checkbox"/> Online training	<input type="checkbox"/> Workshop	<input type="checkbox"/> Brief face-to-face training session at your general practice (<1 hour)	<input type="checkbox"/> Tele-Mentoring

These questions are a guide only and cover the range of questions that might be asked, not all questions will be asked with all participants. For example, questions about costs will mostly be directed to general practice managers (GPMs) or GPs who are the practice owners. Questions about clinical experience will be directed to the GPNs and general practitioners (GP)s. If questions were already answered by prior responses during the interview, questions won't be repeated.

#### Semi-structured interview questions

- 1) Prior experience providing advance care planning and palliative care  
GPs/GPNs: Prior to taking part in the Advance Project training please describe your or your general practices experience and how frequently you had:
  - Discussed advance care planning with your patients
  - Provided palliative care for your patients
- 2) Experience taking part in the Advance Project training  
For ALL: What was your overall experience in taking part in the advance project training (online and workshop)?
  - What aspects did you find most helpful?
  - What could be improved about the training?
  - Had you previously had training in advance care planning and/or palliative care? How did the Advance Project training differ or value add in addition to your previous training (where applicable)?
- 3) Experience implementing the Advance Project resources and assessment tools
  - a) ALL: Did the training change the way you approach advance care planning in your practice, and if so, how? If not, what were the barriers?
  - b) ALL: Did the training change the way you approach palliative and supportive care assessments in your practice, and if so, how? If not, why? What were the barriers?
  - c) ALL: Which Advance Project resources and assessment tools were used in your practice?
    - Which specific tools or resources did you use most often?
    - Approximately how many times have you used any of the Advance Project resources for initiating advance care planning?
    - Approximately how many times have you used any of the Advance Project resources for assessing patients' and/or carers' palliative and supportive care needs?



- Do you have any suggestions for improvements to any of the Advance Project resources? (prompt: capture resources name and description of future improvements)
- d) For ALL: What was the role of different team members within the practice in implementing the Advance Project resources and assessment tools? For GPs/ nurses: What was your experience in introducing the Advance Project assessment tools/resources to patients? What was it like having consultations with patients/carers after they had completed the Advance Project Assessment tools?
  - e) What were the benefits in using the Advance Project assessment tools and resources?
  - f) How were the Advance Project assessment tools and resources received by your patients and their carers? What impact did the Advance Project Assessment tools have on outcomes for your patients and carers? (prompts – impact on advance care planning within the practice? impact on provision of palliative or supportive care? Impact on referrals for additional support for patients, including referrals to specialist palliative care services)
  - g) What impact did using the Advance Project Assessment tools have on your workload and workflow in the general practice? How feasible was it to implement the assessments into your practice?
  - h) What were the barriers to using the Advance Project Assessment tools in your practice? What helped you to overcome these barriers?
  - i) Are you likely to continue using the Advance Project resources and tools in your practice?
  - j) What do you think would help you to continue using the Advance Project assessment tools in your practice?
  - k) What additional support would you like to receive to enable ongoing provision of advance care planning and palliative care within your General Practice?
- 4) [About the costs or billing for implementation/practice change](#)  
The next section of the interview is about the costs of implementing advance care planning and palliative and supportive care assessments into your practice.
- a) What Medicare items were most commonly used in billing for the assessment/consultation where the Advance Project assessments were implemented?
    - Probes: initiation of advance care planning, follow up assessment for advance care planning, initiation of supportive care assessment, follow up for supportive care assessment
  - b) How many consultations are/were required on average to initiate and discuss advance care planning using the Advance Project tools? Which staff members were involved? How much time on average was involved for each staff member?
  - c) How many consultations were required on average to assess and address patients' palliative/supportive care needs using the Advance Project tools? Which staff members were involved? How much time on average was involved for each staff member?
  - d) How many consultations were required on average to assess and address carers' supportive care needs using the Advance Project tools? Which staff members were involved? How much time on average was involved for each staff member?
  - e) What proportion of this time was able to be covered by practice billings?
  - f) Were there any out-of-pocket costs to *patients and their families* to start ACP conversations and screen for palliative/supportive care needs at the GP clinic? What sort of costs were these?
  - g) Were there any other costs *to the practice* in introducing the Advance Project tools?
  - h) What incentives or reimbursements might you need to enable ongoing provision of advance care planning and palliative care within your General Practice?  
Do you think a specific MBS item for ACP and or palliative/supportive care assessments or MBS items for longer consultations for GPNs would increase the feasibility of these types of assessments in GP clinics? If so, how?
- 5) [Confidence and readiness to initiate advance care planning and supportive/palliative care assessments](#)
- a) GP/GPNs: Do you feel the Advance Project Training has increased your confidence to initiate conversations about advance care planning and supportive/palliative care and why?
  - b) What aspects of applying the Advance Project training and resources do you feel least confident in, and why? What would help you to become more confident in these areas?
- 6) [Close](#)
- a) What were the top 2 things you have taken away from participating in this program?
  - b) Is there anything else that you think might be important to add?

## Interview guide – qualitative interviews with Primary Health Network (PHN) Staff

These questions are a guide only and cover the range of questions that might be asked.

Thank you for consenting to participate in this research. In this interview I am interested in your/your primary health network (PHN)'s experiences participating in the Advance Project including providing face-to-face training to general practice staff in your network, supporting implementation of the Advance Project resources in your network, and working with the champion general practices who participated in the quality improvement project.

1. Could you please tell me your first name, the location of your network, how long you have been working in this network, and describe your role in the Advance Project for me.
2. Could you please tell me about your prior professional experience relevant to the Advance Project
  - Probes: clinical experience as a health professional, delivery of education, working with general practices, working on projects in the field of advance care planning and/or palliative care
3. What aspects of the Advance Project training and resources were useful for your PHN and the health professionals in your network who participated in the Advance Project?
  - *Can you give us an example?*
4. What additional training and resources do you think would be needed to support general practices in your network? Why?
  - *Can you give us an example?*
  - *Tell me more about your suggestions*
5. Do you have any suggestions for refining the Advance Project resources, the face-to-face training materials, or the train-the-trainer support? If so, please describe these
6. What factors helped you to implement the Advance Project training and resources in your network?
  - Probe: delivering of face-to-face training, incorporating resources into existing and/or local resources for palliative care and advance care planning, communication/dissemination strategy, liaison and support for champion general practices
  - Provide an example where, as a PHN, you feel that implementation of the Advance Project training and resources in your network was successful.
7. What challenges or barriers did you/your PHN experience to implementing the Advance Project training and resources in your network?
  - Probe: delivering of face-to-face training, incorporating resources into existing and/or local resources for palliative care and advance care planning, communication/dissemination strategy, liaison and support for champion general practices
  - Provide an example where, as a PHN, you feel that improvements or new/better approaches could be used in the future to facilitate successful implementation of the Advance Project training and resources in your network
8. What initiatives has your PHN already used to actively promote Advance Project training and resources?
  - *Can you give us an example*
9. Please describe your ongoing plan to support implementation of the Advance Project resources by general practices in the network. How will your PHN support sustainability of the face-to-face Advance Project training program? What might be the challenges in sustaining the support for implementation of the resources and delivery of education in your PHN? How could these challenges be overcome?
10. What lessons have you learnt as a result of your participation in the Advance Project and from your engagement with general practices who participated in the training, and the quality improvement evaluation of the Advance project resources?