Advance Care Planning
An evaluation of engagement in Gippsland

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Research Project by
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1. Executive summary

The awareness of and practical engagement with Advance Care Planning throughout the community is generally low. Few consumers have heard of the expression or taken practical actions to plan for issues surrounding their death. Most healthcare professionals have a general awareness however lack of confidence and doubt about the detail, and, when combined with high existing workloads, has meant that any practical action is relatively small. This lack of engagement is not due to a lack of resources generally available but a lack of meaningful and useful resources capable of encouraging consumer demand and being implemented at a local general practice level.

Recent hospital initiatives to measure the number of people arriving at emergency departments possessing an Advance Care Plan is to be commended. Some have reached out very effectively to their wider communities, however it is generally recognised that this is a reactive approach and sustainable initiation should occur in the broader community and the primary care and aged care environments.

General practices lack support to build skills or to promote Advance Care Planning. Increased awareness is not required. Federal Government initiatives to provide a claimable item for time spent on Advance Care Planning are required. Simple initiatives like providing a centralised resource for General Practitioners (GPs) and Advance Care Planning nurses to gain practical support and to provide appropriate forms and patient communications suitable for local adaptation are high priorities. Generally, the Gippsland community is receptive to Advance Care Planning but do not receive triggers to initiate the conversation or guidance to lead into action.

The goal that was drafted in the design of this evaluation “to achieve the offer of Advance Care Planning to all patients over 50 years of age by 2020” may need modification. While this is generally considered to be a positive aspiration, it will be limited through the practicalities of reaching this number of people when Advance Care Planning is still in its early stages of being offered to people over the age of 75 years.

Community awareness should improve during 2017 due to recent Victorian Department of Health and Human Services (DHHS) initiatives in Advance Care Planning and the recent passing of the Medical Treatment Act due for implementation in March 2018 but there is still a need for clear and simple processes at the primary care level. There is no commonly agreed trigger to initiate an Advance Care Plan. It has been suggested that the 75 year assessment is an appropriate catch-all whereas some believe that is too late. There was no evidence of using the question ‘would you be surprised if this person died within the next year?’ There was also no reference to using the diagnosis of a life limiting condition to initiate the Advance Care Planning discussion. In most circumstances it appeared to be the insights of a nurse or a GP that less formally raise the issue of ‘getting your affairs in order’. There generally seemed to be very little discussion in the community or in the usual healthcare interactions in a pragmatic sense of what might happen during the period leading to death.

The notable exceptions to this was with those consumers who had memorable negative insights into the experience of death and some GPs that led initiatives for Advance Care Planning. The consumers were people who had worked in health environments, had family members who were health care workers, or, most significantly, had experienced a deeply unsatisfactory trajectory to death by someone they had cared for. This latter situation deeply shapes their views on how they wish to approach their death. The GPs that innovated made headway that needed broader support.
An example of the need is exemplified by the following scenario, which is one type of care situation. Approximately 10% of the interviews with consumers describe situations of the interviewee caring for an ageing parent, most commonly a daughter caring for a mother. In these situations, the daughter felt a high degree of obligation to the mother but also a degree of helplessness. While these are certainly loving situations, there was evidence of a lack of communication from the mother to the daughter about their wishes. This situation could benefit from the use of an appropriate facilitator and improve the situation for all.

While Gippsland may be similar to other geographic areas, significant anxiety and trauma were described in the evaluation interviews. Opportunities to initiate discussions and Advance Care Planning were not addressed in any systematic manner. Generally weak processes were in place in general practices and little coordination between primary care, aged care and acute care was evident.

Palliative care played a role but allied support services and ambulance were generally out of the loop. The working hypothesis that primary care has a fundamental role in initiating and coordinating the engagement of Advance Care Planning is supported from this evaluation. Most other services, particularly hospital emergency and aged care facilities, interact with their consumers in times of stress or in a situation where an Advance Care Planning would be extremely helpful but is now too late. These are reactive situations whereas the primary care environment provides the ability for preemptive and proactive initiations of Advance Care Planning.

As the role of general practice is to maintain health, it is logical to work with consumers to help prepare for a good death. This opportunity is supported by all interviewed, some passionately and some with caution due to competing priorities and the perceptions of various barriers. While goodwill exists, the practical steps to improve Advance Care Planning engagement need clarification and support.

There were examples of exciting initiatives in supporting volunteers and coordination in some of the smaller communities where the GPs also serve primary, aged and acute health services. The elements that appeared to make the most significant differences were the operation of an Advance Care Planning nurse employed by the general practice and a GP or nurse that took a personal interest in driving Advance Care Planning. Attendance at professional development workshops provided education and some practical steps to tentatively start the implementation of Advance Care Planning. The Practice Manager has a significant administrative role.

Less is happening than may have been hoped. Some communities were yet to consider Advance Care Planning whereas others had taken significant self-initiated steps. 2017 presents an opportunity to take advantage of other Victorian initiatives and a growing interest in the community to establish a leadership role across Gippsland that improves the coordination across stakeholders and increases the engagement of the community. Gippsland PHN has an opportunity to lead. Nine recommendations are made to improve the level of community engagement in Advance Care Planning.

Improved engagement in Advance Care Planning will help reduce the pain and suffering surrounding death experienced by those dying, their families and the supporting healthcare professionals. There are other benefits in better aligning the wishes of people when they approach death but the most significant one is in the social cohesion developed when a community works together to support its members when someone dies. We do it in birth; we should do it in death.
Recommendations

1. Advance Care Planning needs central and localised resourcing:
   a. Advocate for a specific Medicare Benefits Schedule item number for Advance Care Planning.
   b. Centralised coordinator to facilitate Advance Care Planning throughout Gippsland.
   c. Funding for general practices to appoint an Advance Care Planning nurse.

2. Set a goal for all patients above the age of 75 years old to be offered Advance Care Planning by 2020.

3. Establish key performance indicators with simple measures so that general practices can utilise the POLAR GP data extraction tool for reporting and monitoring.
   a. Percentage of patients above the age of 75 offered Advance Care Planning.
   b. Percentage of patients above the age of 75 with an Advance Care Plan in My Health Record.

4. Lead a collaborative activity to standardise processes and forms throughout the general practice community and health services, and support their acceptance in the aged care and hospital environments.

5. Create a Gippsland-centric, professionally produced and locally tailored, simple consumer handout brochure to be made available to all general practices.

6. Embrace the Lakes Entrance Last Chapter community volunteer initiative and advocate for a shared approach with other Gippsland communities.

7. Support presentations about Advance Care Planning and this evaluation throughout the Primary Health Networks to continue the promotion of Advance Care Planning.

8. Produce a comparative review of Advance Care Planning in the health services.

9. Advocate for the inclusion of Advance Care Planning the Royal Australian College of General Practice (RACGP) in the Standards of General Practice.
Key messages

- Growing community awareness.
  - Ongoing awareness raising events required.

- Low confidence and patchy uptake in primary care practices.
  - Documentation and process support required; initiate a common template through 2017.

- Poor quality promotional/communication materials.
  - Patient information materials need to be provided.

- No consistent trigger.
  - Inclusion of Advance Care Planning in the assessment of people 75 years and older to be standardised as a catch-all when other triggers like patient request, chronic care plan, life-limiting condition diagnosis do not emerge.
  - Promote integration with hospital and Aged Care admissions.

- Discussion with GP is a bottleneck.
  - Spread the load - ‘it’s everyone’s job’, support materials, Advance Care Planning nurse funding is required.

- Further family discussion needs to be supported.
  - Give time, follow up alert, support resources.

- Finalise of Advance Care Planning in General Practice.
  - Needs follow up alert in general clinical software, needs measure of initiation and completion.

- Storage and distribution of Advance Care Planning.

- Promote My Health Record, share with ambulance service.

- Annual evaluation of Advance Care Planning and this strategy.
2. Background

Project Overview

Advance Care Planning (ACP) involves many stakeholders in discussion and preparation for the event of death. Its outcome is respect for the preferences of the dying person and the understanding, support and collaboration of family, carers and healthcare providers. It should lead to a better death for all concerned.

ACP is the process of planning for future healthcare, whereby the person’s values, beliefs and preferences are made known, so that these can guide medical decision-making in the future, if that person has lost the capacity to make or communicate their decisions. There is a strong suggestion that ACP should be happening in the community with the involvement of General Practitioners (GPs), however there is little evidence for this occurring to any great extent generally across the Gippsland PHN. This research project aims to evaluate the current practice of ACP in the Gippsland community, examine residents’ perceptions of it, and determine what resources are needed to enable ACP to occur.

Gippsland PHN needed to understand and plan for the support of its own community, while recognising developments like:

- The consultation by the Victorian DHHS, “Greater say for Victorians, improving end of life care”
- Other relevant initiatives.

This applies still and perhaps even more with the development and release of Victoria’s end-of-life and palliative care framework and the passing of the Medical Treatment Planning and Decisions Bill in November 2016. While these provide good strategic guidance, there is still a large gap between what is planned and what actually happens in our communities. This has maintained the relevance of this evaluation.

The appropriate focus is on individuals articulating their needs within their community and general practice is well placed to initiate and support this discussion. Resources are available but their use and the match to the needs of the stakeholders were not known. The experiences and attitudes of general practice personnel and consumers were also not well known.

To assist the Gippsland PHN support ACP and develop programs to support its community, it needed to evaluate the current status of ACP and identify the gaps and priorities including the perceptions and attitudes of people and GPs about ACP.

The evaluation of this project explored the areas articulated in Victoria’s end of life care framework of enabling genuine choice, supporting individuals, families and carers, responding to diversity, helping people to die well and supporting our workforce. It also listened for other areas that may be unique or particularly relevant to Gippsland.
Output Requirements

The expected outputs of this project were:

- An agreed evaluation plan, including key milestones and ethics approval.
- Delivery of the evaluation plan within budget and timeframe.
- Regular progress updates through the project.
- Documentation of a summary of findings and case studies to support further development.
- Recommendations for further support for ACP.
- Presentation and feedback to the community and clinical councils.

Activities

The anticipated program included:

- Obtaining ethics approval. This was a lengthy process and eventually granted via the Austin Hospital ethics committee. Although it took far more work than anticipated, it did not delay the program in any substantive manner.
- Selection of, and invitation to 10 communities - Yarram, Bairnsdale, Lakes Entrance, Sale, Wonthaggi, Foster, Leongatha, Heyfield, Cowes and Neerim South. Ultimately, Neerim South was unable to participate. The selection was based on a geographic range and representation of smaller and larger communities.
- Undertaking a series of interviews with each community. It was initially estimated that this would be involving up to 30 people per community, centred on one General Practice to cover all stakeholders, which would continue until the situation was fully scoped. These commenced with the GPs in each community and then consumers, other practice members and then into the general community to provide an overview.
- Providing feedback to the participating practice, initially to the key person or sponsoring group and then at a practice meeting. To date this has occurred at Leongatha, Yarram, Foster and Sale, with offers made to the others.
- Distributing an online survey widely throughout Gippsland in February 2017. The plan was to include those results as a baseline measure in the final report and to present the findings to a community meeting and facilitate discussion and creation of their plan.
- Agreeing on a measurement of outcomes to track.

It was planned to have a final report by December 2016, however the recruitment of the practices delayed completion. A number of obstacles emerged that meant some replacement practices needed to be nominated and then various issues within the practices delayed engagement. These included lack of available GPs, lack of commitment, personal issues and other priorities.

As part of the ethics submission, it was important that coercion was not used for either practice participation or for consumer interviews. Gentle persistence was used to gain the commitment to interview and ultimately it was up to the practice whether to participate or not. Those practices that had already acted upon ACP were likely to engage more readily. This was due to the existence of a GP champion, an effective practice manager, existing ACP activity and the presence of an ACP nurse.
One practice manager used the opportunity to participate as a mechanism to raise awareness within their practice. Another practice that had limited activity, had a strong teaching ethic and saw this as part of their obligation for professional development.

3. Research objectives

The objectives of this project were to:

- Document community experiences and needs regarding Advance Care Planning
- Record the support resources currently in use in the community
- Measure attitudes to Advance Care Planning from GPs and consumers
- Provide a base line measure of the existence and communication of Advance Care Planning
- Identify key enableurs of Advance Care Planning
- Provide recommendations to achieve the agreed Advance Care Planning goal.

An emerging goal was ‘to achieve the offer of ACP to all patients over 50 years of age by 2020’.

4. Terminology

In an area like ACP which is an emerging and maturing consideration, terms will be used interchangeably, be ill-defined and be blurred. For example, an individual can be called terms like a patient, client, resident, consumer, partner, parent amongst others, but they are all meant to refer to the person who is receiving the care.

This report will occasionally use terms to be specific to reflect the context and will attempt to use the word consumer to describe those people in the community for whom the system and the healthcare professionals are working to provide value; in this case better care as they approach death.

Consumers also have many terms for describing death. They sometimes actively seek to avoid the word as if it’s going to be insulting or bring bad luck. So the terms passing, end-of-life, going, kick the bucket and other euphemisms are often employed.

The term ACP is also a difficult and meaningless term to most consumers. Indeed, it is a term that emanates from clinicians in a hospital environment and although it attempts to encapsulate the fact that it’s a premeditation and communication of the care wished for in the future, it does receive blank looks when raised with an uninformed consumer. Indeed, more than one general practice had produced documentation for ACP that included a “d” at the end of the word “Advance.”

It became easier through the interviews to use the term particularly if initially described as the “decisions you might make as you consider end-of-life.” It is worth discussing whether “end-of-life planning” might be a better term to employ. Although the latter may evoke the scenario of suicide or euthanasia, it is much better comprehended at first encounter.

There are also Advance Care Directives, substitute decision-makers, persons responsible and support persons. The details of these and the subtle distinctions are not addressed in this report. Suffice to say the legislative changes and pending introductions in March 2018 will provide further detail and
explanations as the implementation plans become introduced. There is benefit if Gippsland PHN is actively contributing and participating in the consultations leading to the finalisation of these plans.

5. Methodology

The methodology used to conduct the review is based on a qualitative approach and so consequently the themes surrounding ACP practices were explored, see Figure 1. Methodology used in the review of Advance Care Planning engagement.

Primary Themes

1. General public knowledge and attitudes towards ACP.
2. Enablers and barriers to ACP.
3. What resources are available for ACP conversations?
4. Process and support gaps for ACP conversations.

Secondary Outputs

1. Recommendations for ACP guidelines.
2. Analysis of ACP practice in Gippsland.

Figure 1. The methodology used in the review of Advance Care Planning engagement in Gippsland.

Qualitative Approach

The data was gained through multimodal interaction, depending on the preference of the community engaged. Where available, there were interviews with GPs and practice staff, ambulance and hospital services and discussion with consumers and carers.
The contacts with patients and carers were through individual discussions. In all cases, the discussion followed the associated discussion guide and proceeded as follows:

1. Consult to gain Gippsland PHN Project Reference Group direction and alignment with plans. Significant discussion was held with Dr Scott Fraser, who was the principal investigator appointed by the Austin Hospital who facilitated the ethics approval and to refine communications to ensure there was no coercion to attract involvement. The plan was further refined through discussion:
   - Clarifying program objectives and goals
   - Developing evaluation questions
   - Confirming evaluation methods
   - Confirming a timeline for evaluation activities.

2. Evaluation instruments were developed – based on the structure of “Advance Care Planning: have the conversation, a resource for doctors” produced by the Australian Medical Association and DHHS and the Framework for End of Life care being produced by DHHS. Based on the discussion guide, the interviews moved from the topics that the consumer wished to discuss as this best informed the evaluation.

3. Evaluate nine communities, starting with the General Practitioners where possible and gaining a baseline appreciation for the state of engagement with ACP as follows:
   - Process measures - what is happening in ACP?
   - Outcome measures - what are the outcomes?
   - Observational system - what is observed by the researcher?

4. Analyse and report to Gippsland PHN.

5. Develop direction and actions in response.

6. Communicate back to the communities.

7. Follow with an online survey to gain a quantitative measure from consumers.


Recruiting of the communities was initiated by a letter of introduction from Marianne Shearer, Chief Executive Officer of Gippsland PHN. Follow-up was then initiated by the researcher, Tom Holman. The researcher found the recruitment a challenging and protracted process. The initial contact was with the practice manager and invariably they required guidance from one of the GPs. In some general practices, this communication worked extremely well and was matched by a GP who was already aware of and supportive of ACP. The practices were also very busy and some of the communication pathways were prone to fail.

Three additional general practices were added to the contact list after three rejected participation. In one case it took eight months of regular contact to gain initiation of the evaluation. This inefficient communication is a significant impediment to the initiation of any new matter at those general practices. It is indicative of the burdens of a busy general practice, and also indicative of an effective system in some practices.
Those general practices that engaged readily and effectively usually had a very effective practice manager and were in some way progressed along the development of ACP. In some cases, it required persistent visitation to initiate the program. It is likely that a similarly matching visitation will be required to continue the development of ACP across all general practices in Gippsland.

The learning from this situation is that engagement with healthcare professionals and the community requires significant resources. These resources are likely to be a combination of individuals talking directly to stakeholders and the provision of consumer oriented hardcopy resources. It is likely that strategic resources will be developed throughout 2017 by the DHHS and bodies like Advance Care Planning Australia but the effectiveness of uptake at the local level will depend on local activity.

The evaluation activity included:

- 18 planning and preparation meetings
- 145 interviews
- 9 communities
- 89 consumers
- 11 GPs
- 9 practice managers
- 14 nurses (two ACP nurses)
- 7 hospital-based health professionals
- conference attendance
- 15 other interviews/discussions
- 6 presentation meetings including Gippsland PHN Community Advisory Committee.

**Quantitative Approach**

An online survey was developed and distributed to gain baseline measures of the communities’ attitudes and experiences with ACP. The survey was made available from 27 January 2017 - 21 March 2017 through Qualtrics, a professional online survey tool and could be accessed via this link: [http://tinyurl.com/z33wqen](http://tinyurl.com/z33wqen)

The online survey has been less successful than anticipated. The survey was distributed to all participating practices and through print and online media in Gippsland. There is a great impediment to engagement when moving from print to online and the target audience invariably is not as engaged in the online environment. Whereas the lack of response to the online survey is disappointing it is extremely indicative of how resources should be developed to support ACP. Too many of the resources at present are online only.

**6. Ethics**

**Approval**

LNR/16/Austin/326 Evaluation of Advance Care Planning Activity within Gippsland PHN was received on 20 December 2016.

The Austin Hospital ethics approval relates only to the qualitative phase of the work, which was the bulk of the project. The online survey was conducted under ESOMAR Code of Ethics.
Discussion

While some interviewees found aspects of the discussion emotional, it was observed and reported to members of the general practice that most found the discussion a rewarding and a positive experience, with the opportunity to talk with someone eager and with the time to listen. Only one interviewee displayed behaviours of concern and this was reported to the practice manager.

The recruitment of consumer interviewees varied between communities. Some general practices recruited people independently, easily and with little support. Others experienced a lack of engagement and more help was required.

The ideal process for recruitment proceeded as follows:

- Discussion with practice manager to outline the project and gain their support.
- Brief discussion with receptionists and provision of notes.
- An article appeared in the local newspaper offering the opportunity for an interview which was then initiated by the consumer phoning the general practice and making an appointment.
- Preparation of handout for patients attending an appointment who after reading would express their interest to the receptionist who would make an appointment.
- On the day of the appointment, the researcher Tom Holman, would be allocated a consulting room.
- On attending, the interviewee would be handed the patient information sheet by the receptionist to read while waiting prior to the interview.
- The researcher would invite the interviewee into the consulting suite and review the patient information sheet, answer any questions, confirm permission to record and then proceed with the interview.
- On the completion of the interview, the interviewee was thanked, information about the use of the evaluation was explained, the commitment to report back to the community was noted and a small thank you gift of a coffee cup with a notation about the value of a discussion of death was offered.

All interviews were at least 30 minutes and most ran between 30 and 45 minutes. When time allowed and the patient remained interested, the interview continued past the hour.
7. Findings

The method used to generate the sample for qualitative interviews and the online survey responses is a convenience-based process which inherently creates a bias in their availability and propensity to respond. Nevertheless, the evidence offered by observation of practice activity, interviews with key healthcare professionals, interviews with patients/community members and responses to the online survey should provide confidence in the findings of this report.

Qualitative – Interviews

Summary of the data received from the interviews

1. All practice based personnel and healthcare professionals interviewed had an awareness and basic understanding of ACP.
2. Reception staff were less comfortable with the topic.
3. Of the 11 GPs interviewed:
   - All were supportive
   - 45% were advanced in their understanding and active in ACP administration
   - 82% voiced concern about the lack of a comprehensive approach to ACP throughout the practice
   - 27% expressed doubts about the enforceability and legal aspects of ACP.
4. No general practice produced any measure of ACP adoption although one GP estimated it had about 60% of those in the age bracket 75 years old plus.
5. Practice managers expressed concern about practical resourcing and ongoing support for ACP.
6. Of the 89 consumers interviewed:
   - 60% were female
   - A diverse range of backgrounds and ages presented
   - Half attended the interview dominated by an interest to know more
   - 40% had a specifically poor experience with a death and were active in considering how to avoid that circumstance for them and/or their immediate family
   - 15% attended the interview with a partner
   - 20% of females interviewed on their own outlined situations of isolation when caring for their ageing mother
   - 12% took the opportunity to discuss euthanasia
   - A quarter of single males outlined their approach to euthanasia
   - Seven had attended relevant community events of which five of them were from
the one community

- Four brought along newspaper clippings
- No-one brought along an Advance Care Plan
- Four reporting having had an Advance Care Plan
- Nine referred to a specific resource (the Bud Tingwell video) from one community and a local resource from another community
- Eight Advance Care Plans were in development
- No-one mentioned the political consultations, Andrew Denton or any local leading discussants
- 10% had arranged a prepaid funeral and had a medical power of attorney
- Half who recognised themselves as being in a position where a discussion about death was appropriate, had initiated that discussion with the wider family group
- Five individuals were brought to the discussion by their partners on the basis of needing to have the discussion regarding death
- Four couples were well advanced and mature in their planning and demonstrated open and effective communication
- Most demonstrated curiosity and a requirement for further information
- 82% had no working understanding of advance care planning (the exception to this were patients in two practices which had ACP nurses and a reasonably well developed approach to ACP)
- All demonstrated a positive disposition to the topic, once they understood its nature and role
- Some demonstrated difficulty in understanding the role of ACP.

Selected comments and insights from the patient interviews

“I am so cross about how badly it went” - (Consumer)

Experience of death is the greatest pre-determining factor that encourages people to engage in ACP. In this case a bad experience produced a very strong emotional drive to prevent a bad experience from occurring again. The observation was how impotent the person felt when embraced by the system that took over and failed to respond or respect the needs of the family and the patient who was now unable to express their needs. Needless pain and hospitalisation without the comforts of home and convenient access was the driving memory of the death of this person’s loved one.

“People do want help with this” - (Healthcare Professional)

The process of ACP is not a routine consideration by most people. When it is initiated it is normally through a trigger and most people find the considerations confronting and the process
bewildering. Therefore, it is highly appropriate to have the process guided by an experienced healthcare professional. This not only provides comfort but it explores options otherwise unlikely to be considered and enables negotiation through the difficult questions. The forms for ACP are particularly bureaucratic and foreign to consumers. They clearly have an origin in clinical and hospital situations and failed to be presented in a way to give laypeople better access. This is being addressed to a degree in online processes however many of the population in Gippsland will prefer a facilitated hard copy ACP.

“Ignorance is not bliss” - (Consumer)

This comment was made by a consumer who appeared to be a successful and well-planned person in their business and private life. Now being confronted by a life-limiting illness, he wanted to apply the same degree of control to his end-of-life. Part of his motivation to attend the interview was to learn and he was seeking to remove his ignorance about ACP. He contended that if he puts things in place he will find more comfort.

“It’s just Mum and me – and I don’t know what to do. The rest of the family just don’t get it.” - (Consumer)

The isolation that some people experience is probably more extensive than appreciated. This particular person observed that she had never discussed this issue with anyone before. Most health professionals observe the issue of the helicopter children and the negative interruption that their appearance can cause. While ACP is helpful in alleviating the stress involved in these situations, the situation in itself makes the development of an ACP a challenge. The mediating and continued support of a healthcare professional is very important in this situation as is the identification of the need, particularly in these isolated situations. If for no other reason, this particular comment highlights the importance and priority of engaging the community in ACP.

“I just want to get things in order. My friend is my Power of Attorney as I can’t trust the children.” - (Consumer)

Some people have taken the initiative without understanding or knowing about an ACP. They often approach a lawyer who guides them to get their financial affairs in order, but the question remains of how informed the friend is about the decisions to be made around death. Most people refer to their funeral and what to do with their assets when they consider getting their affairs in order. Most don’t consider the period leading up to their death, unless they have actively considered euthanasia. People who are disposed to getting things in order are relatively easy to guide with the appropriate information.

“I wouldn’t treat an animal that way.” - (Consumer)

Much of the community have rural connections. This leads to a pragmatic disposition and a high degree of self-reliance. Almost half the interviewees made comparisons between the ways they care for their livestock with the way people should be cared for. There were also strong preferences to not be a burden to anyone and this generally was incompletely thought through, although one person had an elaborate plan to take their own life when the situation demanded. This observation creates more stress, not less, in the carer. This particularly exists where the extent of available healthcare options is unknown.
“I just can’t talk with her about this. She shuts me down each time I try and bring it up. - (Consumer)

This situation exists between mother and daughter. These discussions can be difficult and are more likely to exist in the current dying generation. While it can be argued that ACP will require a generational change, the need for people in this current situation exists and requires the intervention of a healthcare professional. Most of the more elderly interviewees had an extremely pragmatic view of their death but many of the middle-aged females that were interviewed were concerned about the challenges in communicating with their mother. On a more positive note, the handful of couples that presented to be interviewed together demonstrated how joint communication and open discussion about these issues both strengthens the relationship and should lead to a better death.

Discussion

Of the health professionals interviewed, all demonstrated a keenness to improve the level of community adoption of ACP. But matching this was a recognition of the challenges involved in coordinating an approach across the health community, particularly in the aged care sector and the difficulty in moving from an awareness through conversation to the development and completion of an ACP that can be effectively shared. Most identified the initiatives that they were taking and were keen to know what others were doing.

The larger communities that had separate management of their hospitals demonstrated greater separation between the health facilities. In some cases, it was hospital-based personnel taking the lead, sometimes in cooperation with primary care, sometimes in consideration but also occasionally unilaterally. In particular, the documentation that originates from hospitals follows state-wide templates that appear to be not consumer friendly. The design of these forms warrants much more detailed and further consideration and questions whether they were developed through guidance and consultation with consumers. While the smaller communities suffer from the same issues with documentation, there is much clearer coordination of services. In the main it’s because general practitioners are shared across facilities, are geographically closer and serve smaller tighter knit communities.
Quantitative – data received from the online survey

The data used in the graphs are from consumers unless otherwise identified. Results from six enquiry questions asked in the survey are summarised in Graphs 1 - 6 as follows:

Graph 1: How well do you feel you understand what Advance Care Planning is?
Graph 2: Which of the following have you thought about?

- Talking with people about death
- Writing down the things that are important to you in your life and end of life
- Sharing what’s important in your life prior to your death
- Planning for your funeral
- Having a Medical Power of Attorney
- Having an Advance Care Plan
- Sharing your Advance Care Plan with your doctor
- Uploading your Advance Care Plan to "My Health Record"
Graph 3a: Which of the following have you actually completed?

- Talked with people about death
- Written down the things that are important to you in your life and end of life
- Shared what’s important in your life prior to your death
- Planned for your funeral
- Have a Medical Power of Attorney
- Have an Advance Care Plan
- Shared your Advance Care Plan with your doctor
- Uploaded your Advance Care Plan to ‘My Health Record’
Graph 3b: Which of the following have you actually completed?

- Talked with people about death
- Written down the things that are important to you in your life and end of life
- Shared what's important in your life prior to your death
- Planned for your funeral
- Have a Medical Power of Attorney
- Have an Advance Care Plan
- Shared your Advance Care Plan with your doctor
- Uploaded your Advance Care Plan to ‘My Health Record’

Comment: This shows that healthcare professionals also require support in engaging with ACP.
Graph 4: Which of the following people have you talked with about the care you wish to receive in the time leading to your death?
Graph 5: At your next routine appointment with your general practitioner if they raised the topic of Advance Care Planning, how would you feel?

Comment: This should encourage healthcare professionals in initiating discussions with consumers.

Free form answers received: Why if 1-3 were answered as follows:

Please explain why to the above answer.

“*It doesn’t seem relevant to me right now*”

“*Issues with not having a consistent available doctor at the practice*”
Graph 6: Do you think it would be helpful for you to have an Advance Care Plan within the next year?

Comment: This shows that progress with an ACP is likely to be context specific and so be best judged at a more intimate level possible in primary care.

Free form answers received in explanation to their answers:

Please explain your answer to the above.

I am still rather young so it hadn’t been on the top of my list of things to do. Although, I recognize ACP would be beneficial for all ages and therefore think I should be more proactive on my discussion and thinking about my death.

I don’t plan on dying anytime soon, but I guess who does... So I probably should get something on paper.

Who knows when it might be "good night Irene".

In case of sudden dementia or a debilitating terminal illness.

One never knows what’s going to happen. Having things organised is helpful for those left behind.

Although healthy at present I am fully aware that anything can happen at any time, and to have an Advance Care Plan would be helpful for all concerned if anything were to happen to me. I have a will which covers funeral arrangements only, however my feelings re: death and dying are well known to my partner and family.

Probably should do it sooner than later.

I feel comfortable with my life and death plans at the current stage of my life.

I am only 54 years of age and are healthy.

I’m 23 years of age and healthy, the last thing I am thinking about is my death.

I don’t think my health is bad enough to warrant doing any planning yet.
Summary of findings

- There is a low level of community experience regarding Advance Care Planning. Around 10% have some level of engagement but it is mainly those with experience in the health system that are better informed.
- Hospitals have taken initiatives but remain hospital-centric, reactive and poorly coordinated with the wider health community.
- No active monitoring of ACP is evident.
- Resources suitable for consumers were old and of low quality.
- There is no compelling ‘call to action’ for GPs.
- My Health Record is not used.
- ACP activity is initiated in an ad hoc manner, there is not one paramount enabler. The enablers that work in concert to achieve an environment that is supportive of ACP include:
  - At least one GP or nurse passionate about ACP raises attention.
  - Inclusion of ACP on the checklist for the 75 years’ assessment gains action.
  - A clear process for initiating discussion and following through the development of an ACP is required.
  - Supportive community promotional events raises consumer awareness.
  - Funding and the work of an ACP nurse.
  - Respected centralised guidance and resourcing.
  - A community network that brings health services together for a common approach.

Observations relating to the objectives of this project

- Community experiences and needs regarding Advance Care Planning:
Some general practices have taken initiatives but in general the engagement is low and slow with more confidence and dedicated personnel required at practice level and clearer communications required to be available to patients to initiate discussions.

- Support resources currently in use in the community:
Forms and support materials commonly originate from the now outdated respecting patient choices program (which has been championed by the Austin Hospital and is now rebranded as Advance Care Planning Australia). Some materials dated back to 2005 and are generally poorly reproduced via local photocopying. ACP forms are held in computer systems and downloaded but there is little integration with systematic storage and no upload to My Health Record. While there is plenty of resources available, in some ways there is too much to choose from and consistent standardised approaches would assist in the implementation at practice level.
Measure attitudes to Advance Care Planning from GPs and consumers:

Better measures were hoped to be available with the online survey however response rates were low. As there was bias in the self-selected group that presented for interview, no firm measures of adoption can be made at this point. Nevertheless, a strong willingness to discuss these issues is apparent in the community. This view was gained through discussion with community members, interest in the articles in the local media, events and initiatives that have previously taken place and the attendance of GPs and practice staff at conferences. GPs are both busy and have higher and more immediate health needs to address. The strongest drive appears to come from the practice nurses, particularly those charged with the implementation of ACP and given the title ACP nurse. There is also a drive in the community and it comes from those individuals that have experienced a bad death in their family or who currently carry the burden of caring for an ageing parent. The measurement of attitudes may well require a more comprehensive and systematic survey.

Provide a base line measure of the existence and communication of Advance Care Planning:

Agreed KPI need to be established and a data extraction tool utilised to give the general practice a simple measure. There is debate about this baseline and it could simply be the number of uploaded ACPs for registered patients 75 years and above, expressed as a percentage. Two other measures could include the existence of information brochures in the waiting room and a file notation of the offer or communication of ACP for those 60 years and above. In this evaluation project to date no firm measure could be obtained. It is possible that an online population survey may give a measure of the awareness and attitudes of the community surrounding the participating practice.

Identify key enablers of Advance Care Planning:

There is not one paramount enabler. The enablers that work in concert to achieve an environment that is supportive of ACP include:

- At least one GP or nurse passionate about ACP
- Inclusion of ACP on the checklist for the health assessment of people 75 years old
- A clear process for initiating discussion and following through the development of an ACP
- Useful and used hard copy communications
- Supportive community promotional events
- Funding and the work of an ACP nurse
- Respected centralised guidance and resourcing
- A community network that brings health services together for a common approach.
- Achieve the ACP research goal of all patients over 50 offered an ACP by 2020:

It is recommended the research goal be relaxed and the age of 50 be replaced by an age goal of 75 years old. While a positive aspiration, it is limited through the practicalities of reaching this number of people when ACP is still in its early stages of being offered to people over the age of 75 years.
Consumer and healthcare professional perspectives

- ACP is relatively unknown
- The concept is welcome
- Experience in death forms opinions and supports action
- In isolation, this experience is not enough and guidance is required to have action taken
- At the moment, guidance comes mainly from lawyers, funeral directors and GPs
- The process of ACP is unfamiliar
- The paperwork is not easy
- It is appropriate for GPs and nurses to take the lead
- The relationship and trust in the GP/Nurse is critical.

A commentary on the identified groups

Practice Principals engagement varied. Some demonstrated leadership in quickly accepting an appointment to provide direction for the evaluation in their practice. One appropriately delegated to a trusted lead GP. Others remained unavailable. The high number of competing interests in running a small business requires the provision of clear value for engaging their practice in ACP.

Practices Managers were pivotal in the engagement of ACP. As the coordinator and business manager of the practice, they can establish processes, support activities and allocate resources to ACP. Although their general role is to support the clinical activities, ACP requires good business practice. Things like having current forms accessible through the computer system, triggers reminding GPs and nurses about the presence or absence of an ACP and the establishment of measures of progress are within the role of the practice manager. It is clear from this evaluation, that the practice manager has a great influence on the level of engagement.

General Practitioners are the obvious initiator and facilitator of ACP. But they are also the busiest and most distracted by other priorities. As the patient normally presents with other pressing health needs, the facilitation of an ACP often gets overlooked, even if the intent is there. Working in harmony with a nurse can allow the outcome to be achieved through a lower time allocation from the GP. They remain the obvious driver for increasing the engagement of ACP. As a leader in their practice, they should not underestimate the impact of their own behaviour and the asking of questions that promote the uptake of ACP through the rest of the practice.

The acceptance of ACP as a reimbursable Medicare item would enhance uptake as the existing activity is mainly driven by a focus on patient welfare. The exception to this is in the smaller communities where the GPs also provide hospital-based and residential aged care and so they see a holistic view. Although reimbursement is possible, the lack of a specific Medicare item fails to provide obvious support for engagement in ACP.

Nurses are generally interested in ACP. This is particularly notable in the nurses that visit patients at home and are active in chronic care. Some naturally gravitate to ACP activity however they generally feel less equipped to initiate the discussion and would welcome local skill development training and a contact to provide support. While reference was given to some visiting support, the fly in fly out
nature of the support doesn’t engender a stronger community.

**ACP Nurses** have a vital role but this is also a challenging situation as there is no clear funding or business proposition. The two general practices that have an ACP nurse were clearly more developed and mature in engaging the community with ACP than those that did not but it also produced a frustration in that their time allocation was extremely low for ACP activity. While they remained active in the community through other nursing activities, at this time of building momentum, there was an obvious need that outstripped their availability. The nature of the ACP nurse is generally one that supports people and therefore they are best placed alongside another leader within the practice. They are also relatively isolated and because of their limited time allocation are difficult to engage. Nevertheless, it is a priority to provide the ACP nurses with a greater sense of support and engagement with other ACP nurses. Gippsland PHN is well placed to coordinate a network of ACP nurses.

**Hospitals** are currently reporting on the numbers of patients presenting at emergency departments with ACP’s. This has resulted in the development of forms and processes that are naturally hospital centric. Some have reached out to general practices to coordinate community approaches in the development of ACP, but this has run the risk of isolating the general practices due to the hospital-centric nature of their development.

**Support personnel** do have a role. In one of the general practice presentations of the findings, the theme was “it’s everyone’s job”. This was to engender a feeling of teamwork towards the initiation of ACP. In some cases, the slowness of recruiting patients to interview was due to the hesitation of the reception team to raise the issue with attending patients. In one case, and following further explanation, there was a marked change in patient attitude when compared before the interviews with after the interviews on their enthusiasm and support for ACP. In many cases, an observation of need for the discussion regarding ACP can be made by any member of the practice team or ancillary health provider (e.g. podiatrist, transporter, ambulance officer or Royal District Nursing Service (RDNS)) and their action could be simply to pass on a note for the GP to raise it with the patient on the next visit. If this orientation to ACP is not encouraged, it can become seen as just the role for the ACP nurse and not everyone’s responsibility.

**Community awareness** is growing but it is also in a state of confusion. This confusion is due to the interplay between care for those with cancer, the misunderstandings of palliative care, the hospital centric nature of the previous developments of healthcare, the hotter topic of euthanasia and zealots who have a particular view to promote. This is due to the developing nature of ACP however also concerning due to the vulnerable nature of the people who could engage. It is likely that 2017 will see an increase in the level of public discussion due to the passing of the Medical Treatment Bill and the developing policy that will be promoted by DHHS. Implementations deployment by DHHS is unknown, however there could be a strong role for Gippsland PHN.

**The funding trail** it is not clear and could present some barriers. As general practices are commercial businesses, there needs to be a clear business proposition for further engagement. Waiting for a Medicare Benefit Scheme item number will not address the emerging needs in the community and desire by healthcare professionals. The concern is that there will be duplication of effort and parallel funding that does not support the direct activity of general practices. Where primary care is consumer and a federally funded activity, the clear need is to have funding available to resource a general practice based ACP nurse led model.
8. Discussion

- Initiating the conversation:
  Further work is required to have the conversation initiated with consumers. It is unlikely that consumers will initiate the conversation enough on their own and so the intervention of a healthcare professional is required and continued promotion of this issue should occur. More skill development needs to occur with healthcare professionals to enable more people to feel comfortable with this topic and have the skills and confidence to initiate the conversation.
  Rehearsal in supportive local groups would be welcome.

- Resource availability:
  Gippsland PHN promotion of core resources can also reassure people that using other approaches is okay. The tailoring of approaches to local communities should be encouraged, however this needs a more professional and consumer friendly product through having templates that facilitate this. The human desire to adjust materials to their local situation should be recognised. The key is to strike a balance between localisation and the standardisation of forms that can be easily recognised in any situation. It is likely that documentation that emerges from Advance Care Planning Australia will provide that standardisation.

- Quality of documentation:
  In general, the quality of the documentation seen at general practice level was poor. Version control did not exist with well out of date documents still being photocopied and used. It appears that once uploaded into the practice support computer system, they are not easily updated. Furthermore, many examples were obviously obtained at conferences and remain in use via photocopy of photocopy long after they should have been updated. Apart from retaining inappropriate, dense text formatting, the visual appeal is very low presenting another barrier to engagement by a consumer. Large font and visually appealing brochures regarding ACP should be developed centrally as a high priority.

- Strength of process:
  The process of development of an ACP is fragile. The pathway to completing an ACP can be interrupted at many points. While it is recognised that it is valuable to simply have a conversation, ultimately it should result in documentation being shared to support the decision-making when required. The process can be strengthened by the general practice software having triggers and alerts through the progress of the system. For example, having triggers at 75 years, next visit after initiating the conversation, next visit after drafting documentation, six months after initial trigger and annual thereafter are required.
  A delayed step should retain the reminder and an investigation into the cause of the delay should occur. If there are not strong system reminders, the status quo will be maintained and consumers are likely to leave the considerations until too late.
  The process may look like and include:
    - As part of the 75 years assessment, a nurse initiates the discussion and hands over standardised yet localised hardcopy for consideration and family discussion
    - A discussion with GP
Further family discussion
Finalisation of ACP with GP
Storage and distribution of ACP; uploaded into My Health Record
Annual review.

**Idealised Advance Care Planning pathway – a confluence of minds**

Josie and Barry just celebrated their 75th birthdays. They had been and remained in relatively good health. In their circle of friends there had been some light discussion about funeral arrangements and what might happen to their assets when they “passed”. They had their wills in place but had not had any detailed discussions with their children. They had recently read a few feature articles about death and dying and Barry’s brother had recently died. The local newspaper was promoting a local event called “death over drinks” that they were thinking of attending.

A nurse at their local medical clinic called them to discuss a routine health review which they offer to everyone who turned 75. They accepted and the nurse visited their home to commence the review. One of the items on the checklist, Advance Care Planning, was raised and gently introduced. A clear and helpful brochure was left that outlined ACP and encouraged discussion between themselves and the family. Supporting paperwork that would ultimately build to an ACP was left for their review. They like the fact that the paperwork was easy to follow and was specifically referenced to their local community. The nurse placed an ACP reminder into their practice software that would trigger a review of progress in three months.

They arranged an appointment with the ACP nurse who spent time exploring the things important to them as they approached end-of-life and dispelled some misconceptions. This greatly helped in understanding their options and shaping their preferences. It resulted in a simple draft plan but more importantly comforting clarity in their minds about the decisions that could be made if they themselves were unable to voice them.

Follow-up appointments for the assessment were made with their GP. When they attended that appointment, the GP asked how they found the information about ACP and asked if they had any questions. A few practical questions were discussed and the GP talked about the important role of their nominated support person. Josie and Barry were grateful for this guidance and continued their deliberations, discussions with the family, they selected one person as their medical treatment decision maker and support person and started completing the documentation. About three months later, the nurse phoned to ask how things were going and specifically raised ACP. She was told the family was visiting in two weeks’ time and they anticipated finalising their plans then.
Josie and Barry made a joint extended appointment with the GP to review their ACPs and were comforted by the attendance of the ACP nurse. The GP asked some clarifying questions and the documentation was signed off.

Immediately after the appointment, the nurse made copies; one to be placed with Josie and Barry’s care plan folder attached to their fridge, one each for themselves, one for their support person, one for all family members, one for their clinic record which was also uploaded to My Health Record by the nurse.

At a routine medical appointment just after their 76th birthdays, the GP asked how they found the ACP process and whether there was anything they would like to review.

At 80, while visiting friends on his own away from home, Barry suffered an acute onset of chest pain and was taken by ambulance to a hospital. His ACP was accessed from My Health Record and noted at triage and during the subsequent short stay at hospital. He recovered.

Barry died at 85 without warning in his sleep. Josie was being cared for Barry at the time due to her increasing dementia. Josie moved to an aged care facility and her ACP was duly noted. A period of time later she fell and fractured her hip. To determine her care, her ACP was referenced by the nursing staff and the attending doctor, with the guidance of the support person and the agreement of the family. Josie died comfortably in the aged care facility three days later.

- **Support:**

As with any change of behaviour, additional energy must be applied to any existing system otherwise the inertia of the current practice will prevent any change. This means that despite the best of intentions, general practices will find it difficult to make meaningful change without external support.

Gippsland PHN is well placed to coordinate and facilitate ACP throughout the Network. This would provide practice based, localised, annual workshops facilitated by an experienced health professional and suitable for all practice personnel. It could also coordinate the availability of online resource links.

9. **Community reporting**

Each participating practice will be offered the delivery of a report and follow up discussion similar to the PowerPoint presentations used at Sale and Leongatha. As part of that presentation, encouragement is given to participating in a community event during 2017. It is proposed that these be reflective of the needs of each community and be open to the public, contain some general practice representation, present the background and process of ACP and facilitate open discussion.

Investigation and consideration has been given to a touring event sponsored by a consumer advocate such as Health Issue Centre to promote greater discussion about death.

These events could be partnered with a number of different agencies which include the Palliative Care Consortium, Gippsland PHN and local community bodies.
10. Recommendations (with explanations)

1. ACP needs central and localised resourcing:
   
   a. Advocate for a specific Medical Benefit Scheme item number for ACP

   This is a challenging recommendation but one that is worth advocating is a national recognition of the importance of ACP. As general practices are businesses, revenue or cost savings need to be associated with activity to support sustainable behaviours.

   b. Centralised coordinator to facilitate ACP throughout Gippsland

   General practices require development support and a consistent and knowledgeable reference point from someone who understands general practice. The implementation of ACP requires new procedures, changing attitudes and the ability to argue for it being a priority.

   Behaviour change requires an advocate and the provision of practical advice. Without coordination, those GPs and nurses implementing ACP feel isolated. Phone and online support like DecisionAssist are adjuncts but are not the catalyst for change.

   c. Funding for general practices to appoint an ACP nurse

   ACP nurses are able to reach into the community by receiving referrals from many sources. This works particularly well at Barwon Health. Those practices in Gippsland that have an ACP nurse are leading the way in the implementation of ACP.

   The suggested time allowance is small but if external funding to a practice was achieved at this level it is likely be matched and improved by the practice. Without the allocation of additional time and resource there is no consistent motivator or point person to run ACP in the practice. This comes with the risk of ACP being seen as the responsibility of one person but it is the practical recognition that ACP does require extra work.

2. Setting a goal for all patients above the age of 75 to be offered ACP by 2020

   The most practical trigger to ensure effective ACP is to include it in the checklist of items in the health assessment of every 75-year-old person. The year 2020 provides three years of activity to achieve this relatively modest and reachable goal. If this process is established in all general practices, natural extensions will occur to offer ACP more frequently to other consumers identified at need; for example those in chronic care, cancer diagnosis or other life limiting conditions.

3. Establish Key performance indicators (KPIs) with simple measures so that general practice can utilise the POLAR GP data extraction tool for reporting and monitoring:
   
   a. percentage of patients above the age of 75 offered ACP

   KPIs encourage activity by providing simple and unambiguous goals. Measurement allows evaluation of progress and benchmarking of performance. Without a measure monitoring of improvement become subjective.

   b. percentage of patients above the age of 75 with an ACP in My Health Record

   For the reasons outlined above, this KPI is recommended. It can be argued that the conversation involved in ACP is the most important aspect, not the documentation. On the other hand, the sharing of a person’s preferences is one of the important aspects of care at end-of-life. My Health
Record provides a national and universally accessible point of storage and retrieval of an ACP. Some practices and health services have their own electronic records, however this is inadequate in our more mobile society.

4. **Lead a collaborative activity to standardise processes and forms throughout the general practice community and health services, and support their acceptance in the aged care and hospital environments.**

No acceptable common form appears to be used. Some ACP forms in use were dated 2005 and the more modern ones are extremely hospital centric and unfriendly to consumers. Palliative care has a role here but again positions ACP as a reactive process. As general practice extends across the region and is much more closely aligned with consumers in their day-to-day healthcare, it is the logical group to lead the collaboration to standardise processes and forms.

5. **Create a Gippsland-centric, professionally produced and locally tailored, simple consumer handout brochure to be made available to all general practices.**

This is a high priority recommendation. The quality of handout information available to consumers is extremely low. Most observed were poor quality photocopies, poorly formatted with huge amounts of text begging for a more graphical presentation and some marketing smarts. While there is good online information, the consumers most in need of information regarding ACP require hard copy and not direction to a website. This handout should be produced centrally to maintain production standards and also be capable of having templates that could be adapted locally if required. This may seem like a frivolous recommendation however it would make a significant difference and give everyone ‘something to hang onto’.

6. **Embrace the Lakes Entrance Last Chapter community volunteer initiative and advocate for a shared approach with other Gippsland communities.**

This was a most exciting local development championed by Gippsland Lakes Community Health. The model has high potential to be utilised effectively in other communities. Concern about governance needs to be resolved and negotiated with the DHHS and Palliative Care Victoria but it would be logical that Gippsland PHN takes on that governance and coordinating role. It is suggested that Heyfield, Foster and Leongatha are communities likely to be ready to test the first stage of a roll out.

7. **Support presentations about ACP and this evaluation throughout the PHN Networks to continue the promotion of ACP.**

As part of the evaluation process, offers were made to share the results of this evaluation back into the communities. This report should be made widely available and supporting presentations should be offered back to communities. Already interim presentations of draft stages of the reporting have been made at participating practice meetings and continuation of this is recommended. Some local community agencies have expressed interest to hold community events. Gippsland PHN’s Clinical Councils and Community Advisory Committee have expressed interest in this work.

8. **Produce a comparative review of ACP in the health services.**

One of the complicating features of Gippsland is that it covers 10 health services. The simplicity of implementation of ACP at Barwon Health is because of the singularity of health service. This evaluation focused on the general practices in nine communities and it is recommended that a simple and quick comparative review of the 10 health services be initiated as part of the...
collaborative development of a standardised approach.

9. **Advocate for the RACGP to include ACP in the Standards of General Practice.**

The RACGP Expert Committee – Standards for General Practices (REC- SGP) have considered the issue of ACP for inclusion in the Standards. Currently under consideration is the inclusion of ACP as an unflagged (non-mandatory) Indicator in the 5th edition Standards. While this is a positive move forward that will see the accreditation agencies introduce it into their training and evaluation continued support for the prioritisation of ACP in the RACGP Standards should occur.

11. **Resource Material**

**General Practice**

Although there is a growing number of global, national, state and local resource material there is relatively little uptake at the general practice level. The most common situation is for an individual to attend a workshop or a conference and utilise the resource made directly available at that time. As a consequence, some of the hard copy material being used is of low quality and aged. The most common resource used was the respecting patient choices materials, now being rebranded as Advance Care Planning Australia via the Austin Hospital team.

The situation with resources in Victoria is now in a state of flux with the Medical Treatment Planning and Decisions Bill 2016 passed by Parliament on 24 November, 2016, enshrining advance care directives in law. This means that there should be a hiatus for producing materials and training until further details are clear.

In the interim, support materials remain current and further development would be a waste of resources. The best approach would be to remain in touch with Advance Care Planning Australia and monitor developments. The one exception would be better information to consumers.

While there are excellent unique and peripheral resources to assist people better engage with death (like Molly Carlile [http://www.deathtalker.com](http://www.deathtalker.com) and her books specifically to assist children) the only consistent resource that stands out is the leadership and materials emanating from the Austin Hospital.

This has been characterised from the leadership of Bill Silvester (now on sabbatical) and Karen Detering. It seems likely that the Department of Health and Human Services, with ACP being championed by Jackie Kearney, is forming a very productive relationship with the Health Issues Centre [http://www.healthissuescentre.org.au](http://www.healthissuescentre.org.au) rejuvenated by Danny Vadasz. It is worth watching the materials and events available from this group.

Existing resources to frame the development of an Advance Care Plan will remain acceptable up until March 2018. It is likely there will be continued development of templates for which localisation will be acceptable.

Collaborative activity, led by Gippsland PHN, could standardise processes and forms throughout the general practice community and generally support their acceptance in the aged care and hospital environments.

It appears likely that hospitals and aged care facilities will continue to either develop their own or have specific requirements that work against this harmonisation.
It would be appropriate if NURSE-ON-CALL was able to answer routine questions and provide access to further information. At the moment their only advice is to refer to the GP.

It is likely that the momentum for standardisation will be best supported by an approach that meets the needs of the consumer. If this is met in the primary care environment and uploaded into My Health Record, it is likely to gain common acceptance. But in regard to resources, these forms and processes are not the area of greatest need. The greatest need is an appropriate communication to initiate the conversation so a patient can quietly reflect about the issues surrounding an advance care plan.

A Gippsland-centric, professionally produced and locally tailored brochure could be created and made available to all general practices.

**Consumers**

Consumers were almost completely lacking access to resources. The exception to this is those who had actively volunteered and engaged in a program that then better equipped them. A few brought in newspaper cuttings of articles but invariably these articles referred to euthanasia. A few referred to debates on the SBS program Insights. One said she still held the materials that the general practice gave her on the passenger seat in her car. No one talked about using the Internet to gain access to informational resources.

It is clear that the main source of information for consumers will be the general practice.

One community recently engaged in actively promoting ACP had its consumers refer to the video of Bud Tingwell which is on Utube [https://www.youtube.com/watch?v=Yvg1_VS_28Y](https://www.youtube.com/watch?v=Yvg1_VS_28Y) and the Advance Care Planning Australia site (refer Image 1 – screen capture of Advance Care Planning website).

When watched in collaboration with the ACP nurse, this seemed particularly successful. Although the video is now a little bit dated, its presenter and the information is well-placed to be effective with consumers.
Some consumers had initiated discussions with their lawyer and subsequently had a power of attorney and when this occurred about half had a medical power of attorney in place.

There is evidence the conversations are initiated by social workers, aged care nurses, hospital emergency department personnel (usually through a checklist) and, in two communities, activities promoted to initiate discussions. Due to the relatively small sample size, these were not commented on in any of the consumer interviews.

**Primary care personnel**

**Advance Care Planning Australia:**

Advance Care Planning, Austin Hospital, ex- Respecting Patient Choices, is currently the most recognised and comprehensive website: [http://advancecareplanning.org.au](http://advancecareplanning.org.au)

This group is now rebranding and is taking some of the materials developed for DecisionAssist into a National Advisory Helpline - 1300 208 582 - that will be also available to consumers. It seems the most appropriate service from which to take direction and to standardise approaches across Gippsland.

Their interim branding appears to be - Be open. Be ready. Be heard.
Other resources

- Australian Medical Association – training modules
  https://amavic.com.au/page/Member_Services/Policy_and_Media/Current_Issues/Advance_Care_Planning_Have_the_Conversation

- Advance: an online training resource for practice nurses

Useful resources – mentioned once or separately sourced:

- Alfred Health – downloads of forms and information:

- Palliative Care Australia resource, dying to talk:
  http://dyingtotalk.org.au
- End of Life Essentials – hospital oriented information

- Royal Australian College General Practice – yet to be current or leading

- health.vic – comprehensive, very useful for strategic positioning - *Victoria's end of life and palliative care framework* was released in July 2016

- My Values - an online interactive tool developed by Dr Charlie Corke of Barwon Health
  https://www.myvalues.org.au

- Northern Health – a well-resourced multicultural approach, workshop

- Palliative Care Victoria – a very well connected and useful resource. Their Friday Newsflash is the best review of activity in this space.
  http://www.pallcarevic.asn.au/library

- Gippsland Regional Palliative Care Consortium - an enthusiastic and supportive group
  http://wwwgrpcc.com.au

- The consortium clinical practice group has produced ACP guidelines effective from June 2016. Contacts include Carol Barbeler and Anny Byrne – phone: 56226482

- DecisionAssist: a federally funded resource that may produce some useful information although it is aimed at the aged care sector

- The Peninsula Model – an online planning tool

- Office of the Public Advocate - take control, a guide to making enduring powers of attorney, with forms

- ACP SIG: a special interest group for nurses
  http://www.anmfvic.asn.au/interest-groups/advance-care-planning-sig
Local hospital contacts

Local contacts with knowledge of ACP are:

- Robert Gresham - Bass Coast Health
- Sue Shadbolt - Central Gippsland Health Service
- Kirsten Amis - Leongatha
- Irene Murphy – Latrobe Regional Health
- Meredith Davey - West Gippsland.

Local initiatives

- **The Last Chapter:**
  Through funding from Palliative Care Victoria and leadership and support from Latrobe University palliative care unit, a program of empowering volunteers was initiated at Gippsland Lakes Community Health and coordinated by Barbara Phillips. The program was active and effective in the early stages and produced a professional and highly effective video. The volunteers were trained and then helped deliver presentations to existing community groups like Rotary and University of the third age. Concerns were raised that there was a feeling that once presented, the groups were ‘done’. Also the complexity of the topic and potential for distress and discussions to go into areas for which the volunteers were not trained and therefore ill-equipped - the boundaries had the potential to be exceeded - caused the health professionals to draw back on promotion. This is an understandable and fairly common experience as experts release control to the community.

  It also does present some risks, for which health professionals are generally adverse. There is a strong feeling of protection displayed by those who know best. This is particularly evident in those who have a background in palliative care. It is likely, with greater maturity that the best outcomes sit between complete freedom and expert control. Straddling these two extremes and producing an acceptable middle ground would be the role of an ACP coordinator.

  This program could be shared with other Gippsland communities such as Heyfield, Foster and Leongatha with a centralised, governing resource from Gippsland PHN. The elements in common with these three communities is that they have a strong community spirit and likely local coordinators who simply need ongoing central support.

- **Advance Care Volunteer Ambassadors Program, East Hume and Border:**
  This is a very comprehensive program which exists in hard copy and soft copy. It has an orientation in using volunteers to initiate discussions by taking ACP information to the community through existing groups and meeting places. For example, these included retirement villages, chronic health support groups, service group, Country Women’s Association, Men Sheds, University of the 3rd Age, Victorian Farmers Federation, Red Cross and RSL’s. The project manager is Tricia Hazeleger on 0409 299 371. The material is freely available and placed in dropbox.

  It has an agency readiness checklist which was developed from the DHHS strategy. This is pertinent as it recommends a strong framework from which to embark upon increasing ACP initiatives.