



Waterloo Wellington  
Advance Care Planning Education Program

# EVALUATION REPORT

## November 2015

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# Waterloo Wellington Advance Care Planning Education Program Evaluation Report November 2015

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## Introduction

The Waterloo Wellington Advance Care Planning Education Program (ACPEP) is designed to build system capacity and enhance the quality of palliative care and patient/family experience for the general public of Waterloo Wellington. It aims at raising awareness, increasing knowledge and skills, and ensuring advance care planning<sup>1</sup> practices are consistent with Ontario legislation. It is unique in that it reaches both community and health care settings as critical sites for engagement and education. The ACPEP is a three year initiative hosted by Hospice Waterloo Region in partnership with Hospice Wellington and funded by the Waterloo Wellington LHIN.

The ACPEP provides leadership, coordination, and support in working towards meaningful and achievable change within the Waterloo Wellington health care system and the community. The project launched officially in April 2015 with the establishment of a steering committee comprised of stakeholders from the community and health care sectors across the region. The first few months included significant outreach with a keen focus on making the connections and building the relationships that would be needed to move the project forward and meet objectives over the next three years.

The intended long-term outcomes of the ACPEP include:

- **Increased health system capacity to ensure consistent and appropriate advance care planning policies, procedures and practices**
- **Increased community capacity to encourage and normalize advance care planning**
- **Increased quality of palliative care**
- **More effective and efficient use of resources within the health system**

Evaluation is a critical component of the ACPEP. The evaluation is designed to support the development and growth of the program, as well as to assess implementation and outcomes. This report shares the findings from the early evaluation activities. It begins

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<sup>1</sup> Advance Care Planning (ACP) is a process of reflection and communication to let others know what kind of health and personal care one would want in the future if one were to become incapable of providing consent for health care. ACP involves having discussions with family and friends, including one's potential Substitute Decision Maker (the person who would provide consent or refusal of consent for care and treatments if one is not capable of doing so) as well as communicating with health care providers.

with an overview of the evaluation approach and methods, then shares a summary of the findings. The report concludes with a summary and considerations for next steps.

### ***Target Groups***

The ACPEP is designed to engage and support improved practice among three main target groups:

1. **Health care providers:** this group includes the various providers and professionals who are connected to the health care system along the continuum of care; this group includes physicians, nurses, family health teams, palliative care teams, hospital administration, long-term care homes, the CCAC, CHCs, the WWLIN, Hospice Waterloo and Hospice Wellington. The interests and priorities of this group in relation to ACP include attention to standards for professional and ethical practice around decisions for treatment, communication and informed consent in health care settings.

2. **Community professionals:** this group includes community leaders and influencers who are in a position to play a role promoting ACP and connecting their clients to ACP resources. It includes professionals who offer services that are connected in some way to planning for the future and for end of life, such as lawyers, financial planners and advisors, insurance brokers, funeral directors, etc. Their interests and priorities in relation to ACP concern serving their clients and meeting community needs. For lawyers, their interests also include attention to standards for professional and ethical practice in advising their clients and drawing up Powers of Attorney for Personal Care (POAPC).

3. **General Public:** this group includes community members who do not necessarily hold ACP, end of life or health care consent top of mind; it also includes patients and family members, as well as those in the possible role of substitute decision maker. The interests and priorities of this group in relation to ACP concern the quality of health care experience and having the ability to make informed health care decisions.

### ***Activities to Date***

Following the establishment of a project team and a steering committee in the spring of 2015, the ACPEP has been focused on outreach and engagement within the health care sector and the community. The first step was to complete a baseline assessment (described in the next section) that would be used to confirm project indicators and targets. The summer months were spent building relationships and making contacts across each of the target groups. To date 173 contacts have been logged by the ACPEP team.

Over the last few months, the ACPEP team has encountered a great deal of interest and enthusiasm for the project from their contacts within the health care sector and the

community. There is a clear sense that the timing is right for this project, and there has been a level of momentum and engagement that has exceeded expectations. This momentum led the ACPEP team to design and offer programming earlier than expected to establish fundamental and consistent understanding of ACP and health care consent in Ontario. In the fall, ACPEP hosted a number of information sessions to respond to both the demand for greater engagement and to meet the needs/challenges identified by the baseline assessment.

### ***Report Overview***

This report shares the findings from the evaluation efforts to date. It is presented in the following sections:

**Evaluation Approach and Methods** – shares our approach, purpose, questions and methods, including for the baseline assessment and an assessment of early outcomes.

**Baseline Assessment** – this section shares the findings from the baseline assessment, presenting these for each of the target groups: Health Care Providers; Community Professionals and General Public.

**Early Wins** – presents the evaluation findings from the fall information sessions, highlighting their contribution and early outcomes.

**Moving Forward** – concludes the report, sharing a summary and considerations for next steps.

## Evaluation Approach and Methods

In the early stages of the initiative, we are applying a formative evaluation approach with attention to program design, implementation and emerging outcomes. The purpose of the evaluation is to assess the value and contribution of the ACPEP to the health care sector and broader community.

Evaluation questions are primarily outcome-focused, and include:

1. To what extent are key people and players within the health system and community engaged with the project?
2. Has the ACPEP fostered stronger coordination and consistency with Ontario-legislation?
3. To what extent does the ACPEP build capacity within the health system?
  - a. In what ways, and to what extent, is there more consistent and coordinated practice within health and social care organizations.
4. To what extent has the ACPEP built capacity within the broader community?
  - a. In what ways, and to what extent, have key influencers and connectors within the community become engaged in promoting ACP and sharing resources?
5. To what extent have community members become engaged in ACP?
6. To what extent has ACP changed practices within health care interactions?
7. To what extent has ACP improved end of life and patient/family experiences?

The first phase of the evaluation was to complete a baseline assessment. This assessment was designed to characterize current understanding of ACP, current ACP practice within health care settings, attention to ACP within community settings, as well as identify priorities and considerations for developing the program. The baseline assessment was also used to confirm indicators and targets for the next three years of the program.

### ***Evaluation Methods***

To date, the evaluation includes a baseline assessment and an early outcomes assessment.

Methods used to complete the **baseline assessment** were:

- **Environmental scan.** The environmental scan included key informant interviews (77) and focus groups (4), which were completed with 177 health care providers and community stakeholders. Community stakeholders included professionals such as lawyers, estate planners and financial advisors, insurance companies, funeral home directors, senior centres, and other community leaders. Key informant interviews were completed in person by ACPEP engagement leads. The scan focused on local understanding, perspectives and practices related to ACP. Key informant interviews and focus groups were also used as an early outreach strategy to connect with potential partners and contributors to the ACPEP. The scan was completed between April and September of 2015.
- **Physician Survey.** 45 physicians completed an online survey that focused on physician practices related to ACP, including whether they had ACP conversations with their patients, what those conversations included, and barriers to having ACP conversations. The physician survey was completed in June and July of 2015.
- **Community Survey.** 369 members of the general public completed an online survey. The survey asked participants about their awareness, attitudes and experiences with ACP. The survey also asked participants about their interests and needs, other community supports as well as and challenges or barriers to ACP conversations. The survey was distributed to individuals who had registered for fall ACP general public information sessions hosted by Hospice Waterloo. It was also shared through the Leadership Waterloo Listserv, which has a membership of 400 individuals, the ACPEP steering committee and through Hospice Waterloo's network of contacts. The community survey was launched in September, and remained open until mid-November.

The average age of survey participants was 57 years with a range of 21 to 88 years. Most participants (61%) were over 50 years of age. The majority of participants (78%) identified as female.

**Early outcomes** were assessed based on feedback from 10 community information sessions held in late September. The information sessions were hosted by ACPEP and facilitated by Judith Wahl, LL.B., a leading expert and advocate for advance care planning and health care consent. Feedback on the sessions was collected through a hard-copy survey distributed to attendees at the end of the sessions. The survey focused on short-term outcomes, including gain in understanding and intentions to change practice.

There were 517 attendees across all sessions. We received 324 completed feedback forms, which reflected an average response rate of 62%.

<b>Cohort</b>	<b># of Feedback Surveys</b>
Health Care Providers	102
Health Care & Community Leaders	144
General Public	85
<b>Total</b>	<b>324</b>

The evaluation methods and tools were developed in collaboration ACPEP. They were reviewed and approved by the Community Research Ethics Office (CREO).

### ***Analysis***

A thematic analysis, using a system of open-coding, was completed for all the qualitative data, including the key informant interviews, focus groups and qualitative survey data. The thematic analysis, which identified dominant themes and issues according to topic and by frequency of responses. Quantitative analyses included frequencies and distributions of responses for all participants.

### ***Limitations***

Though every attempt was made to ensure a diverse range of participants in the baseline assessment, participation was voluntary. It is possible that those already with an interest and positive attitude towards advance care planning (ACP) were more likely to agree to engage in the key informant interviews, focus groups and surveys. The results should thus be considered a snapshot of the experiences and perspectives of those who may have a readiness to learn more about ACP and a willingness to engage in the education program.



## Baseline Findings

This sections presents an overview of findings related to ACP understanding and practice for each of our three main groups of interest: Health Care Providers; Community Professionals and the General Public.

### *Health Care Provider Understanding & Practice*

When asked during key informant interviews what came to mind when they heard the term “Advance Care Planning”, health care providers responded in a variety of ways, though many were fairly close to the formal definition in terms of emphasizing the conversation about wishes and decisions.

The following table shows the range of definitions used by key informants along with the frequency of mention.

Definition/description of ACP by key informants	Health care
Planning, decision-making and/or communication re: future health decisions and care options	52%
Specifying desired treatment(s) at end of life	16%
ACP conversations are situational/fluid/evolve over time	11%
Legal and/or financial considerations related to end of life	7%
Health care consent	5%
Planning specific to/occurring at end of life	3%

Over the course of the interviews, there were 26 health care providers who referred to “directives” when discussing ACP. These key informants often explained that this was the common language used on their forms, in their policies, or as part of their practices. Some recognized that this wording needed to be changed. Others believed that there were gaps in the system because there wasn’t adequate continuity or communication around what was incorrectly referred to as “Advance Care Directives.”

*“In ER - First, we do want to know if there’s a document. We see this most often when they are coming from a LTC facility and they send their Advance Care Directive.”*

*“We don’t get Advance Directives early enough and a lot of patients get interventions they shouldn’t.”*

The requirements for health care providers regarding health care consent were referred to frequently. The focus on health care consent appears to be a natural entry point to

educating health care providers about enhancing practices around ACP. It is worth noting that ACP legislation was rarely referred to by key informants.

### **Comfort with ACP Conversations**

The majority (88%) of the 45 physicians surveyed reported having ACP conversations with their patients. As well, about a third of health care key informants reported that they do have ACP conversations with their patients and clients. However, these conversations are happening within a range of understanding and misunderstanding around ACP.

Though health care providers recognized the importance and value of ACP, there was some division around their level of comfort and confidence with having advance care planning conversations. While there were those that expressed confidence, many were not fully confident or comfortable. 62% of key informants reported that they were somewhat uncomfortable having ACP conversations. Similarly, half of the physicians surveyed reported they were not comfortable with ACP conversations.

*“Conversations around here (the oncology unit) happen easier than other places. Physicians are very comfortable...Sometimes people avoid it but we deal with death all the time – it’s the setting. These are natural conversations and our physicians are very comfortable. This doesn’t represent the general community. It’s about setting, personality and training.”*

*“There is a fear factor in having that conversation – difficult conversation. They may start it but don’t know how to continue it. They are trained to say, “Here’s an intervention and we’ll check on it in a few weeks”. It’s out of their scope of thinking to ask, “What interventions don’t you want?” They don’t see ACP as an intervention.”*

*“Not everyone is comfortable, especially if not experienced with death but even then some are not. It helps to know the person and the family. Even in long-term care at the day of admission, some people are just not comfortable having that conversation – they don’t want to influence anyone’s choices.”*

### **Policies and Procedures**

Less than half (48%) of health care providers who participated in the key informant interviews reported that their institution/ organization had documented policies to guide ACP. 20% reported they had policies, but these were undocumented and inconsistent. Close to a third did not know or believed they did not have ACP policies. Inconsistent policies were a particular concern across long-term care homes.

*There's a real patchwork of policies right now. Different homes have different policies. So we need to look at overall policies at the higher level. Advance Directives are common place in LTC. They all use the same forms. They are using Ontario's DNR form and they think it guides ACP...some homes do not complete the Advance Directive, they just document wishes.*

Less than a third of health care key informants reported they had evaluation or continuous improvement processes in place to review ACP policies and practices. One key informant reported they had just updated their ACP policy for the first time in 10 years, while a few others reported their policies were currently under review.

### ***Community Professionals Understanding & Practice***

For some community professionals (e.g. lawyers and estate planners), ACP was most frequently associated with Power of Attorney for Personal Care (POAPC). Other professionals (funeral directors, insurance providers, business owners, etc.) thought of ACP more generally with sharing one's end of life wishes, making treatment choices, preparing living wills, funeral planning, and financial planning. Some noted the wide misunderstanding that surrounds ACP, and strongly supported better education for the general public and community professionals.

#### **Role in Promoting ACP**

For lawyers, the connection to ACP conversations was clear:

*"Lawyers are the best place to distribute this information to their clients"*

Their role pertained to preparing wills and POAPC. They raised some concern about how to best represent client wishes through POAPC, with one explaining he was not a medical expert and could use more information/education. Others explained lawyers often leave POAPC to the end of their conversation with clients because they don't know what to include.

Community professionals associated with health and social care services, (e.g. Alzheimer's Society, Community Care Concepts, ACCKWA) also saw a clear role for themselves in educating the general public about ACP. They saw themselves as having a unique connection to the general public that could be leveraged to clear away misconceptions about directives and living wills, as well as to raise awareness about health care consent and the role of SDMs. They strongly supported education for their staff and the sharing of resources with the families they serve.

For others, such as funeral directors and financial advisors, the role was less clear. These community professionals were less aware of ACP and what role they might play in

promoting ACP. For some, there was discomfort and uncertainty about what an ACP conversation would look like between themselves and their clients. However, they were willing to learn more and play a role in supporting the ACPEP initiative.

In exploring what their role might look like, community professionals reported they would be comfortable with participating in training and getting more educated about ACP. They were also open to seeing ACP become more connected with the role they already held. Community professionals recognized their support role in the community as well as their position to connect the general public to information as well as other services. Many of the community professionals expressed willingness to share information with their clients/customers, as well as connect ACPEP to professional associations. They supported greater education and awareness amongst professionals and the community.

### ***General Public Engagement with ACP***

The majority of community survey respondents (65%) reported they felt familiar with the term ACP. They noted that when they hear this term, they think about their wishes for end of life. Some explained that ACP means documenting and sharing your wishes and what you would want for health and personal care with those who are important in your life. Others spoke very generally about ACP, believing that ACP relates to funeral and estate planning, wills and burial or cremation options. Others noted that ACP relates to proactive planning for aging parents and other seniors whose mental and physical health are affected.

### **Attitudes**

Overall, community survey respondents relayed positive attitudes towards ACP. They agreed that having an ACP conversation makes good sense and makes it easier for their loved ones. The majority also reported being comfortable talking about death and with the subject of ACP.

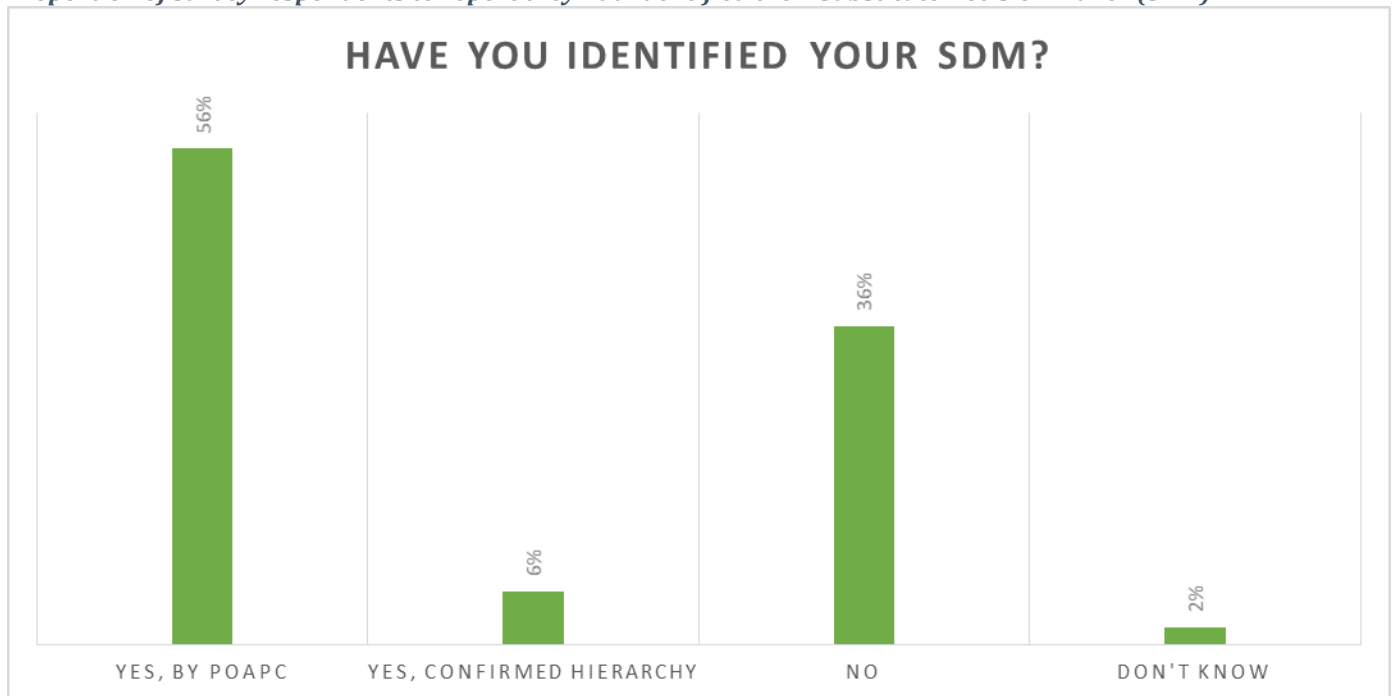
<b>Attitudes toward Advance Care Planning</b>	<b>% Agree</b>
It is important to have an Advance Care Planning conversation with my Substitute Decision Maker	95%
Identifying a Substitute Decision Maker will help ensure my wishes are honoured	94%
Having an Advance Care Planning conversation makes good sense	93%
Having an Advance Care Planning conversation makes it easier for my loved ones	92%
Having an Advance Care Planning conversation will help ensure my wishes are honoured	89%
I am comfortable with conversations about death	76%
I am comfortable with the subject of Advance Care Planning	74%
I trust that doctors and nurses will make good health care decisions for me, without me needing to express my wishes	24%

## Behaviours

After reading the definition of ACP, community survey respondents were asked if they had ACP conversations with a significant other. The majority (70%) reported they had a conversations about their wishes with their significant others.

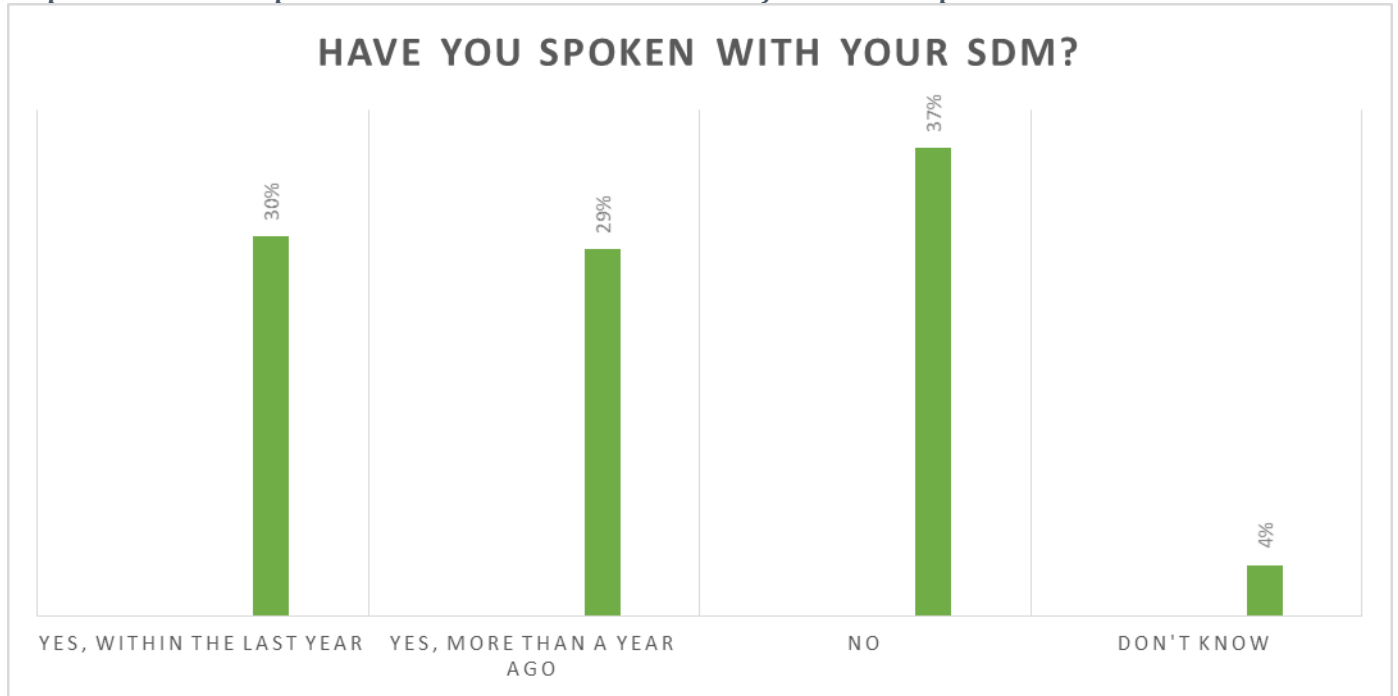
When asked if they had identified the person who will make health and personal care decisions for them if they are not able, about half (56%) reported having completed a POAPC and 6% reported they had confirmed the automatic Substitute Decision Maker from the hierarchy. About a third (35%) reported they had not identified an SDM.

*Proportion of survey respondents to report they had identified their Substitute Decision Maker (SDM)*

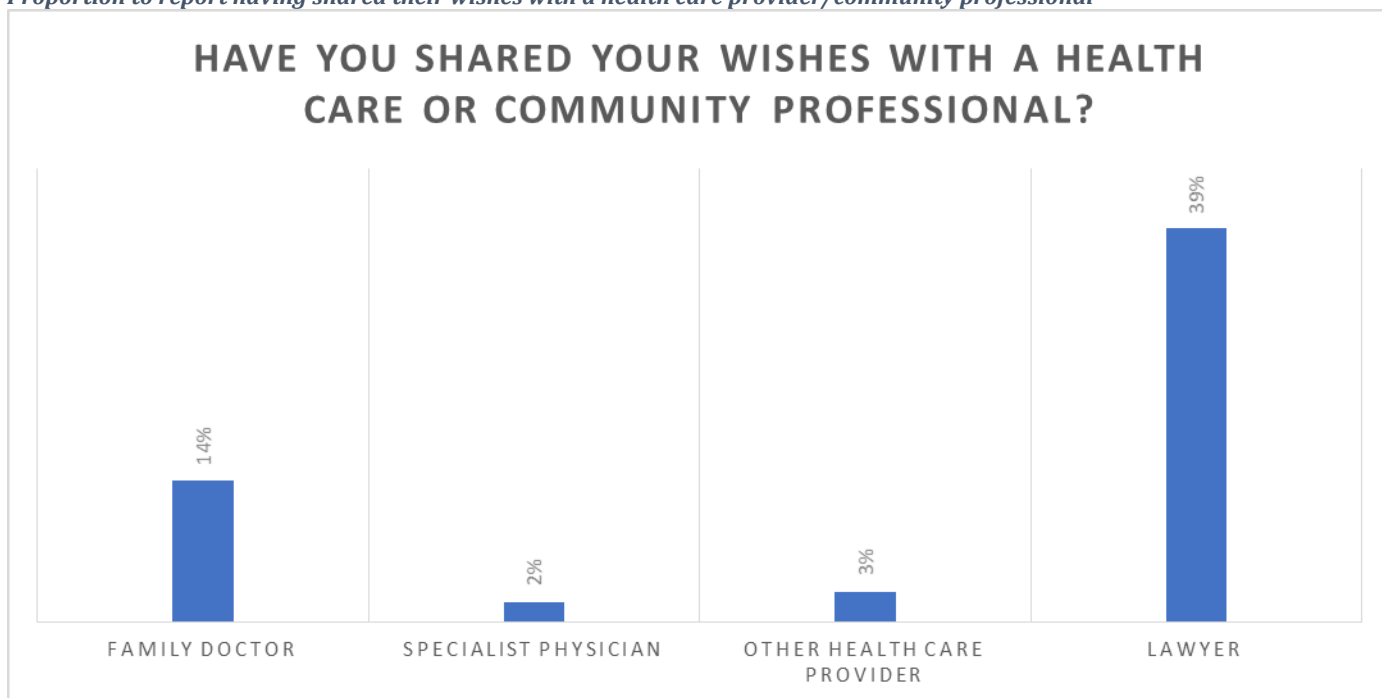


While many of the survey respondents reported having identified their SDM, they were split as to whether they had spoken to their SDM

*Proportion who have spoken with their SDM about their wishes for health and personal care*



More respondents have shared their wishes for health and personal care with a lawyer than with a health care providers. Only a small number of participants have talked with a family doctor, specialist physician or other care provider regarding their wishes for health and personal care in the event they cannot make decisions for themselves. The majority (92%) of respondents reported they have not been asked about their SDM by their health care provider.



### ***Barriers and Challenges***

Participants in the baseline assessment consistently reported a number of challenges that hindered effective ACP conversations and practice.

#### **Health Care**

Health care providers reported common challenges to having ACP conversations including lack of training, tools and common protocols for having the kind of conversations that were relevant to their own practices.

Physicians surveyed reported that it was difficult to have ACP conversations when their patients were not interested in talking about it; when their patients had unrealistic expectations about their prognosis, and when family members were resistant to the conversation. They found that ACP conversations were too stressful for patients and families. Some physicians reported they did not know how to have the conversation, or who should be having the conversation. They also noted working in very busy environments and having other priorities.

Health care providers who participated in the key informant interviews also noted barriers to effective ACP practice, including the lack of understanding, not knowing who should be having the conversation, when or how.

*“Our providers have multiple things to address already and don’t have the right tools for ACP.”*

*“Emergency room/hospital in crisis is common place to have to have the conversation and it’s the worst spot/timing.”*

Identified barrier/challenge	Health care
Difficulties understanding and adhering to patient / family member’s wishes even when ACP is in place	15
Staff need training/resources/support regarding how to have the conversation	7
Need a base of trust and the right timing to do ACP conversations well	7
Need support / tools to navigate family dynamics	6
Health care providers find ACP conversations difficult / uncomfortable	4
Concerns about liability	3
Other issues take priority over ACP conversations	-

Other challenges to effective ACP practice identified by health care providers included:

- The lack of updated, accurate, consistent forms that support coordination across organizations
- The inability to share information and electronic records across health care providers to assist decision-making and inform responses
- Conversations being initiated during crisis, and the challenges to navigate decisions with family members when there is no ‘roadmap’ to follow
- Unrealistic expectations from patients, families and/or SDMs, children demanding “the works” for their parents when health care teams have different understanding about appropriate interventions
- Isolation of vulnerable patients who are estranged from their families and living alone

### **Community Professionals**

Community professionals also reported that the lack of education and informational resources was a challenge to having ACP conversations. Many identified the need for one-page resources that could be shared with their clients/customers. As well, some of those who provide health and social care services identified the lack of training for their staff as a barrier to supporting ACP education for the individuals/families they serve.

Another challenge for some community professionals (e.g. insurance brokers, funeral directors) was their positioning of ACP information as “bonus information” for their clients. They made it clear that they would have to “*run things through legal*” before committing, or explained that they would not be able to mandate the sharing of resources. A few also noted a concern that sharing ACP information might be off-putting to clients, and they wouldn’t want that to disrupt their core business. There would need to be a clear link and value add.



There were also community professionals who raised concern about the complexities of ACP including community members who were marginalized, isolated and who lived with limited means. In the words of one key informant, *“Poverty makes everything, even dying, more difficult.”* The cost of professional advice and support, as well as Powers of Attorney and other legal services, are prohibitive for many.

These key informants shared their concern for people who are living alone, are estranged from their families, do not have someone to act as an SDM on their behalf, and who are homeless or live in an isolated area. This situation was described as being very difficult both for the patient/client and for the health care and social care system trying to support them. As one explained, *“the majority of [our] tenants have very strained, if not, non-existent relationships with their family members...”,* and *“often we see that the POA has been estranged or doesn’t know (that they are the POA).”*

### **General Public**

Community survey respondents identified a variety of reasons for not having had the conversation with their SDM and other loved ones. Some commented that they have not shared their wishes with others because they feel too young, they are just beginning to think about it for themselves or because no one has broached the conversation with them. A few commented that they would need an occasion or “trigger” to initiate and motivate an ACP conversation. These events may include the loss of a spouse, experiencing a medical crisis, caregiving for others or if the topic was raised by a family doctor. Some noted that they or others may be reluctant, scared or uncomfortable with an ACP conversation.

*“My children don't really want to hear me talk about it. I'm sure they think it is so far in the future and it won't happen to me but in my experience with my own parents [I] know it will and it happens before you know it. When I speak about it they think I am being negative when in fact I am just being realistic. Being the decision maker for my mom, I wish she would have had that conversation with me so I would have a better idea of what she really wants me to do or not do for her.”*

Many respondents noted that a lack of time prevents them from having ACP conversations. As such, they suggested that reminders and raising awareness of the need and importance of ACP could help them prioritize and find time for these conversations.

A lack of “accurate and comprehensive information” perpetuates tendencies to put off an ACP conversation. Respondents noted they hold back from ACP conversations because they do not know what decisions need to be made, where to get information and are unsure of their personal wishes and possible decision makers. A few noted they would like to know who to talk to when there is no family support.

## ***Overcoming Challenges to Effective ACP Conversations and Practice***

### **Health Care Providers & Community Professionals**

The need for education, training and resources topped the list as a key need to support more effective ACP conversations and practice.

Health care providers described many different information resources, forms and other tools available to support ACP practice. However, there was no single resource that they agreed was useful in most situations, up to date, user friendly, or supportive of coordination between professionals and/or organizations. Two thirds of the key informants who mentioned Speak Up resources described them as being too long and difficult to read.

Both health care providers and community professionals recommended the following to support them in their roles related to ACP:

- A toolkit containing items such as forms, templates, best practices, sample scripts, a workbook, etc.
- Training/presentations/speakers. Suggestions included team meetings, in-service training from an adult education approach, and online learning
- Standardized, coordinated resources, such as a consistent form used region-wide and properly, validated and supported by a range of practitioners, with standard protocols to support quality and consistency
- Conversation starters, scenarios and questions to get patients/clients thinking
- A “one-pager” that is accessible to all patients/clients.
- Resources that are brief, simple to understand and available in multiple languages

Some health care providers also emphasized the need to offer training specific to SDMs, who can find that role stressful and challenging.

*“Education and information of SDM is critical....this can be very confusing for the SDM if not updated. People assume they have it covered, but SDM doesn’t understand the role, or they are named but didn’t know it, or aren’t fulfilling their duties, or in some cases have even passed away.”*

### **General Public**

Community survey respondents indicated they would like to get information about ACP from a variety of sources, primarily including lawyers, doctors and Hospice Waterloo Region or Hospice Wellington.

<b>I would like to get information about ACP from:</b>	<b>n</b>	<b>%</b>
A lawyer	78	46%
A doctor	78	46%
Hospice Waterloo / Hospice Wellington	71	42%
Family health team	52	31%
A financial / estate planner	47	28%
Community health centre	39	23%
A nurse	36	21%
A funeral director	34	20%
A social worker	30	18%
Other (i.e. government, employers, family, friends, libraries and banks)	24	14%
A member of clergy	14	8%

When asked what would help facilitate ACP conversations, most respondents reported they need information on how to have a productive and open ACP conversation. For example, one noted

*“I’m overwhelmed by what seem like lots of things to consider. The Advance Care Planning that my parents completed was what we thought [was] very thorough [but] still left us...worried that we were interpreting their wishes incorrectly. You can’t anticipate all possible scenarios.”*

Respondents also indicated there is a need for clarity and guidelines for discussion about one’s own care and planning for others. They explained that they need a better understanding of the intricacies of possible scenarios to help them prepare and make decisions in advance. As one suggested,

*“[It would help to have] a guide which would outline all the things I should consider in terms of my health care if I was in an accident or had a sudden illness that incapacitated me i.e. feeding tubes, respirators, paralysis, chronic pain.”*

Some suggested an ACP guide, which could include:

- Conversation starters
- Strategies to minimize stigma and fear
- Strategies to build trust
- Specific questions that should be asked in an ACP conversations
- Implications of ACP decisions
- Legal issues
- Responsibilities of SDMs

**Summary**

Across all groups, the predominant understanding is that ACP conversations equate to “end of life.” There is discomfort, and even fear, associated with these kinds of conversations.

End of life conversations are difficult to have, requiring time, thoughtfulness and grace. Discomfort, reluctance and feelings of being ill-prepared are associated with end-of-life conversations, and act as significant roadblocks to ACP conversations.

Over the last few months, it has become increasingly clear to the ACPEP team that there is no one-size-fits-all ACP conversation. What that conversation needs to be depends very much on who is having the conversation, at what occasion, and what each party needs to know to ensure that the conversation will support effective practice, health care consent and a less stressful patient/family experience.

To improve ACP conversations, there is a clear need for greater awareness and understanding, including consistent use of language. For all stakeholders, this understanding needs to be aligned with Ontario legislation, and make clear the connection between ACP and health care consent.

Education and training can support improved conversations between the general public, patients and families, community professionals, and health care providers. Greater understanding and awareness can also support improved practice within health care settings. At the same time, consistent forms and protocols that accurately reflect Ontario legislation are needed (with priority on long-term care homes and hospitals). Supporting policy development and quality improvement are also needed to improve practice within health care settings.

## Early Wins

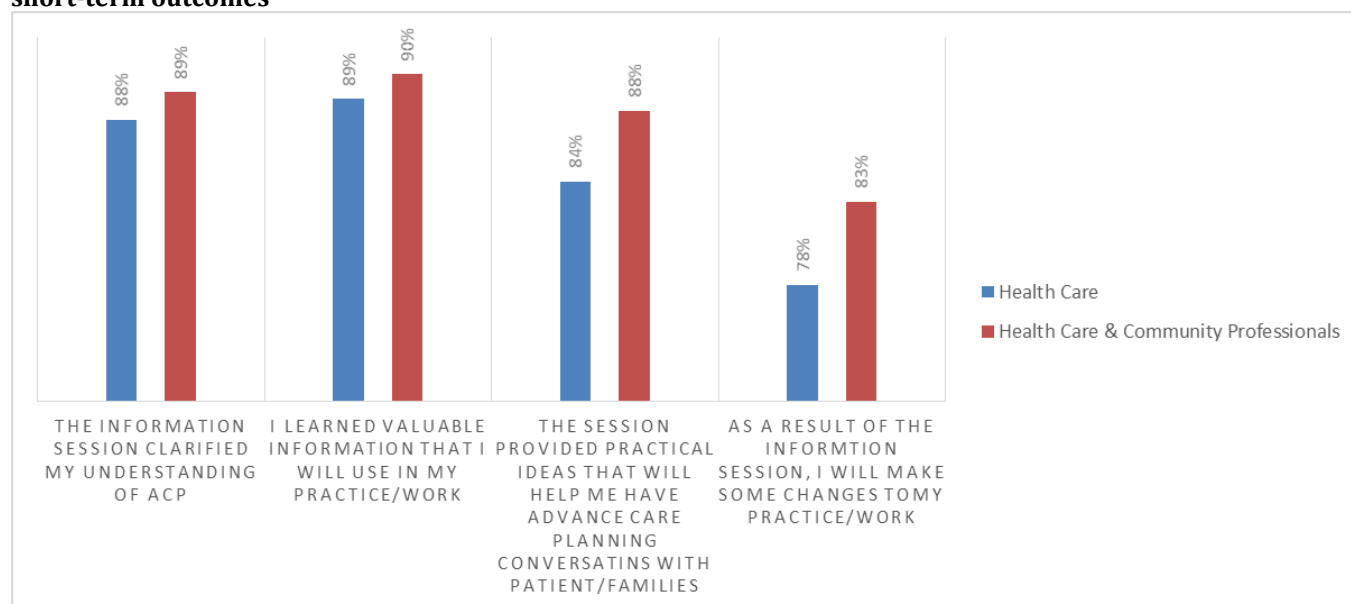
In response to the interest and clear need to launch programming as soon as possible, ACPEP hosted a series of information sessions with Judith Wahl in the last week of September. Ten events were hosted across the region with tailored sessions for health care providers, community professionals and the general public with over 500 attendees.

These information sessions were ACPEP's first steps towards addressing the needs and challenges that were identified in the baseline assessment described above. They were designed to meet the need for greater clarity of ACP, of the link between health care consent and ACP; and clarification of Ontario legislation. The sessions also pointed participants towards the use of correct language while also providing concrete ways to improve their practices. The highlights from these sessions are shared below.

### ***Contribution and Short-Term Outcomes<sup>2</sup>***

Overall, feedback indicates that the information sessions were very effective at increasing understanding of ACP, providing valuable and applicable information, providing practical ideas to support ACP conversations with patient/families, and helping health care professionals to make changes in their practice/work.

#### **Proportion of feedback survey respondents by cohort to Agree or Strongly Agree session had achieved short-term outcomes**



Across all sessions, participants came away with a better understanding of the link between health care consent and ACP. Many of the participants reported that they hadn't

<sup>2</sup> See full report on Community Information Session Feedback for a more detailed discussion

been aware of Ontario law, and that learning more about the law was a valuable aspect of the sessions.

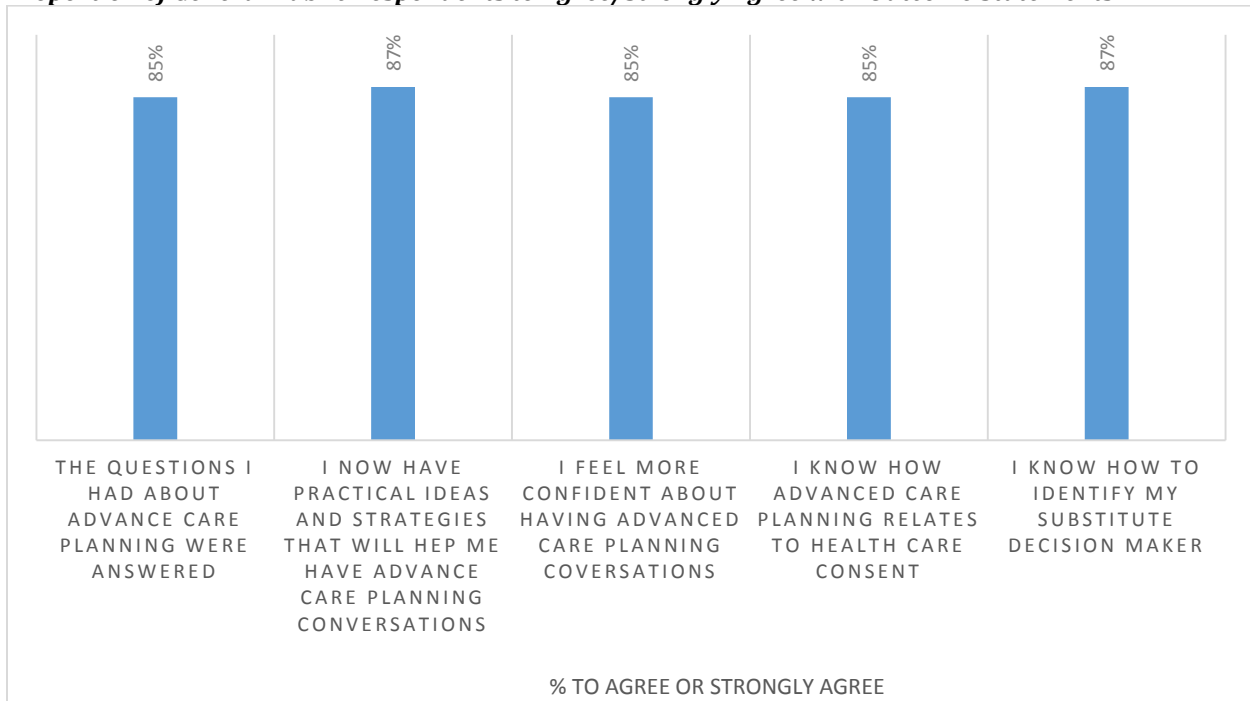
Health care providers reported that they would focus more on improved communication and asking the right questions. They also noted overall that they would be more intentional following the correct procedures around informed health care consent, such as:

- confirming whether the patient is capable to provide consent before asking an SDM; determining who should speak for the patient if they are unable;
- basing decisions on the current context and/or conversations with patients/SDMs rather than forms or past written wishes;
- confirming that the SDM understands their role; and
- ensuring correct information; and terminology are being used.

Health care and community professionals reported that their understanding of ACP had changed through the clarification of SDMs and POAPC. They found the hierarchy helpful, and for a few community professionals, the information sessions emphasized the importance of a POAPC. Some highlighted that they better understood the importance of wishes and that wishes can change. A number also commented they would have the conversations themselves with their own loved ones.

For those who attended the general public sessions, the majority reported that they had a better understanding of ACP and would feel more confident having ACP conversations. They valued having gained greater clarity around health care consent, including understanding that wishes are not consent and that consent has to be given by a person. Many noted that as a result of the session, they will have a conversation with their loved ones.

### **Proportion of General Public Respondents to Agree/Strongly Agree with Outcome Statements**



When asked about their engagement with ACP before attending the information session,

- 51% of general public survey respondents reported having had an ACP conversation with a loved one prior to the session
- 65% reported having identified their SDM; of these two-thirds reported having had a conversation with their SDM about their wishes
- Less than 10% had shared who their SDM was with their doctor

### **Summary**

Overall, the feedback from these sessions is positive. Participants reported a high level of engagement and found the sessions to be informative and useful. Both those in the health sector and in the community reported they had learned important information that will help them improve their practice. Nearly all respondents to the feedback survey reported now having greater clarity and understanding about ACP, in particular around its connection to health care consent.

These sessions are a good example of the kind of intervention needed to support change within the health system and community, demonstrating the value of connecting each sector with high-level expertise.

## Moving Forward

The baseline assessment confirmed many assumptions about current understanding and practice related to ACP. As well, the findings from the baseline assessment have highlighted priorities and leverage points for shifting ACP awareness, understanding and practice.

Within the health care sector, the baseline assessment showed:

- Though the majority reported having ACP conversations with their patients, there is inconsistent understanding and use of language
- This inconsistency leads to a gap between expectations, practice and compliance with Ontario legislation for health care consent
- About half of health care providers report not being fully comfortable or confident having ACP conversations
- Less than half reported documented policies to guide ACP practices
- Less than a third reported quality improvement processes for their ACP practices and policies
- Less than 10% reported they were aware of ACP training
- Language used on forms and in practice is inconsistent with Ontario legislation

For community professionals, the baseline assessment showed:

- Inconsistent understanding and use of language
- Openness to developing their role in promoting, sharing resources and clarifying misconceptions about ACP
- The positioning of ACP with POAPC
- The lack of resources/supports for members of the community who are isolated, marginalized and who live with limited means

For the general public who participated in the community survey, the baseline assessment showed:

- Inconsistent understanding and use of language
- The majority of respondents reported having conversations about their wishes with a significant other
- They also reported they had identified their SDM
- A third had a recent conversation with their SDM about their wishes and a third had not discussed their wishes with their SDM at all
- The most frequently shared their wishes for health and personal care with a lawyer; less than 20% had shared these wishes with a health care provider
- Very few (5%) reported having been asked who their SDM is by a health care provider



The first information sessions to be offered through the ACPEP demonstrated the value of building awareness and understanding of ACP and health care consent with each stakeholder group. Moving forward, the focus now needs to be on tailored engagement and education/training opportunities for those in the health care sector. The community, including both the leaders/professionals and general public, also need ongoing education and engagement opportunities. There is also a need for community professionals to have access to resources and protocols that will help them have an appropriate ACP conversation, avoiding perpetuating misinformation and misunderstanding.

In reflecting back on the original work plan, the ACPEP is right where we expected it to be after six to nine months of program funding. This report marks its transition from doing the ground work (phase 1) towards full activation (phase 2) of the program. Two strategic questions have emerged from the baseline assessment that will inform the next phase of the program:

1. How do we develop and sustain momentum, so that we can motivate individuals, groups and systems to engage in the ACPEP and initiate change (new knowledge, attitudes, practices)?
2. How do we make clear the translation from ACP to health care consent, so that:
  - The general public understand their rights, and inform/empower their SDM
  - Health care providers can understand, support and provide information; and fulfill their responsibilities
  - Community professionals can understand, support and provide information; and fulfill their responsibilities
  - SDMs understand their roles & responsibilities (e.g., how to advocate for their loved one and get more information for themselves)

Both the ACPEP team and the steering committee have been engaged in answering these questions. The most immediate step will be to develop a detailed action plan that will guide the work of the ACPEP for its activation phase. The activation phase is starting in a good place, advantaged by the momentum gained through the ground work and outreach that has been accomplished to date.