HOSPICE WATERLOO REGION

Conversations Worth Having: Advance Care Planning Education Program

OUTCOMES REPORT 2018

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Waterloo Wellington Advance Care Planning Education Program

Outcomes Report

Conversations Worth Having: Advance Care Planning Education Program

From April 2015 to March 2018, Hospice Waterloo Region led a systems-wide education program designed to build awareness and shift practices around advance care planning. Funded by the Waterloo Wellington LHIN, the Advance Care Planning Education Program (ACPEP to start but then later branded *Conversations Worth Having*) was designed to address misconceptions about advance care planning as well as ensure policy and practices within the region were consistent with Ontario legislation.

Context on Advance Care Planning

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. It involves having discussions with 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 with family and other close relationships.

ACP is recognized as critical to health care consent in Ontario. Ontario legislation differs from other jurisdictions with regards to health care consent in that consent must be given by a person in the situation consent is required (written instructions prepared prior to the event does not qualify as consent). If the person is not capable, health care providers must contact the SDM to give consent on the patient's behalf. This standard in Ontario legislation means that there is often confusion resulting from the use of language, tools, training and other resources from jurisdictions where advanced directives or "living wills" are permissible. This confusion then results in practices inconsistent with Ontario law.

Advance Care Planning is further recognized as a core component of quality palliative care and an enabler of patient and caregiver empowerment and capacity. Good ACP practices have been demonstrated to improve client/family experiences with end of life care and help ensure Ontarians receive care according to their wishes.[1]

[1] Detering, Hancock, Reade, and Silvester. *The impact of advance care planning on end of life care in elderly patients: randomised controlled trial.* **BMJ**, 2010; Canadian Hospice Palliative Care Association, *Advance Care Planning in Canada: National Framework*, January 2012, http://www.chpca.net/projects-and-advocacy/projects/advance-care-planning.aspx; Catalonia WHO Project, 2012; AAN Task Force on End-of-Life, *Advance Care Planning as an Urgent Public Health Concern*, **American Academy of Nursing Policy Brief**, April 2010

ACPEP Overview[2]

The Advance Care Planning Education Program was designed to address the intersection between health care and community, achieving wide-reaching engagement of both sectors. Health sector engagement crossed the continuum of care, including acute, primary and long-term care providers. Community engagement included social and community support providers, community professionals (legal, financial, human resource, funeral), and the general public.

The initiative was conceived to help bridge gaps between public awareness and professional/provider knowledge and practice. The aim of ACPEP was to educate and build skills and resources of residents, professionals and practitioners to ensure each could meaningfully participate in quality conversations about advance care planning, substitute decision-making and health care consent that were consistent with Ontario legislation.

The program was innovative and adaptive, and included a wide range of activities such as:

- Building an extensive network relationships and connections to ACP
- Designing and facilitating education sessions for health care, community and social care providers, community professionals and the general public
- Developing an awareness campaign, *Conversations Worth Having*
- Developing new resources, including website, fact sheet, SDM wallet card, and sector-specific tools and guides
- Developing *Time to Talk* with the faith community
- Bringing lawyers and experts together with acute and long-term care to explore various approaches to changes in policy, practice orientation
- Partnering with university gaming students to create a comic style online e-learning module on ACP directed at front line workers,
- Working with local artists and hosting a public event that engaged the attendees with ACP on a visual and emotional level
- Training for providers and colleagues from all sectors to be ACP ambassadors within their own organizations
- Knowledge sharing with broader palliative care/ACP network

Through these activities, ACPEP made positive and significant progress in building capacity within both the health sector and community. This report shares the key outcomes achieved by ACPEP, focusing on its core contributions of increasing capacity in the health system and within the community. The report concludes with key learnings and reflections.

[2] A detailed project description and the evaluation methods are shared in the appendices.

Outcomes Report

The evaluation shows that ACPEP met its short and intermediate outcomes for:

- Increasing health system capacity to ensure consistent and appropriate advance care planning policies, procedures and practices
- Increasing community capacity to encourage and normalize advance care planning

This shares the evaluation results, including the reach of the project along with the findings on project outcomes for the health sector, community professionals/support providers, and the general public.

Reach

The ACPEP team developed over **800** unique contacts with individuals across the health care and community sectors, which supported **1,188** activities and the engagement of **12,303** participants. Almost **112,000** printed resources were distributed, including **59,903** SDM cards and brochures.

Number of Activities and Participants by Cohort, 2015 to 2018

Cohort	# of Activities	# of participants	Subsectors
Community Support /Community Professionals	107	665	Corporate Wellness; Education; Faith; Insurance; Funeral; Legal; Service Club; Agencies serving Older Adults and Vulnerable Populations; Volunteers; Community Organizations
Health Care	568	3,297	Home and Community Care; CHC; FHT; Hospital; LTC; Primary
General Public	405	7,399	Residents
Media	7	6	Media engagement
Cross Sector	18	202	Mixed group
Regional/Provincial	83	734	Legal; Education; Funder
TOTAL	**1,188**	**12,303**	

*Activities include meetings, presentations, teleconferences, focus groups, health fairs, etc.

Top Five Resources Distributed, 2015 to 2018

Resource Type	# of Resources
SDM Cards	40,431
SDM Brochure	19,472
POA Books	13,559
Speak Up Books	14,623
Program One Pager	11,949

Health System Outcomes

The baseline assessment of health care providers completed in year one confirmed a number of barriers and challenges to effective and consistent ACP practice among health care providers. These challenges included lack of knowledge, training and tools, and a lack of understanding and comfort among patients and families. Physicians noted that ACP conversations were stressful for patients and families, with some physicians reporting they did not know how to or who should have the conversation.

Over the three years of the project, ACPEP helped to address these barriers and improved health system capacity for ensuring consistent and appropriate policies, procedures and practices by:

- **Building the network across the health care system to support ACP**

Over the course of the project, the ACPEP team engaged over 260 contacts in the health system and reached over 3,000 health care providers. This network supported the implementation of the education program as well as the hosting of sessions and events, development of sector-specific tools, and the distribution of resources. Network development to this extent required substantive attention to keep the momentum around ACP going and to ensure ACP was recognized for its role in quality care/health care consent.

- **Increasing access to resources**

ACPEP provided over **48,000** printed resources to health care providers, including SDM cards and brochures, and the Conversations Worth Having Fact sheet. These resources were seen as valuable by health care providers, who reported using them with their patients to provide information and to start conversations. These resources also helped health care providers ask the right questions of patients and caregivers.

> *"With the help of the EMR tool, the SDM question gets asked more. Now we are able to guide patients and give them literature that they can take home, have a look, think about different scenarios and we will revisit it at the next visit. The resources have been amazing in stimulating conversations and that was something that wasn't there 5 years ago. Now we are asking the question and it is in a clear place. The conversations are happening more often." Family Health Team*
>
> *"Leaving us with the resources so we can now train the front line is really priceless. Often we are asked to do it but we are asked to invent wheel, but you have really done the work and gave us the resources that we can now use to move forward. " Long-Term Care*

- **Increasing knowledge and awareness of ACP and Ontario legislation**

ACPEP delivered **139** education sessions and trainings to **2,151** health care providers, covering key topics including health care consent, the SDM hierarchy, Ontario legislation, and how to have the conversation with patients.

Health Sector Presentations by Geography, 2015 to 2018

	Cambridge	Guelph	Kitchener	Rural Waterloo	Rural Wellington	Waterloo
# of Presentations	23	18	38	10	22	26
# of Participants	271	216	626	61	194	718

Health Sector Presentations by Sub-Sector, 2015 to 2018

	Acute Care	Community Care	Long-term Care	Primary Care
# of Presentations	13	14	61	35
# of Participants	219	239	597	562

On average, 91% of health care participants in ACP events reported greater knowledge and awareness of ACP. This result exceeds the program target of 80% of participants to report increased knowledge.

Health Sector Increase in Knowledge and Awareness

As a result of this session...	N	Average Out of 5	% Responses ≥ 4
The information session clarified my understanding of Advance Care Planning	256	4.4	89%
The session clarified my understanding of capacity	102	4.6	94%
The session clarified my understanding of the hierarchy of Substitute Decision Makers	103	4.8	99%
The session clarified my understanding of the role of Substitute Decision Makers	132	4.8	95%
The session provided practical ideas that will help me have advance care planning conversations with patients/clients	117	4.2	84%
I learned valuable information about the role & responsibilities of Healthcare Providers in relation to ACP & Health Care Consent	110	4.7	97%
I learned valuable information that I will use in my practice/work	309	4.4	90%
As a result of the information sessions, I will make some changes to my practice/work	308	4.2	83%

Health care providers who were **more engaged with ACPEP were significantly more likely to:**[3]

→ **report confidence** having ACP conversations with patients, as well as in explaining and applying the SDM hierarchy in practice. Eighty five percent of engaged providers reported being more confident with ACP conversations and the SDM hierarchy compared to less than half of providers not engaged. This result hits the program target of 80% of participants report confidence.

"[The training] Added confidence and heighted awareness, giving clarity around POA, SDM, what this means and what is staff's role, and what is the hierarchy. Even myself I had no idea the hierarchy existed to be honest. Education on those things, of ACP vs. consent and what the two look like was an eye opener for everyone." Long-Term Care

"[The project] gave me confidence – like last week I called a lawyer because I noticed on the patient chart that the person had changed their POAPC, I called as I wasn't sure that the patient had the capacity to do that at this time, I would not have done that earlier" Long-Term Care

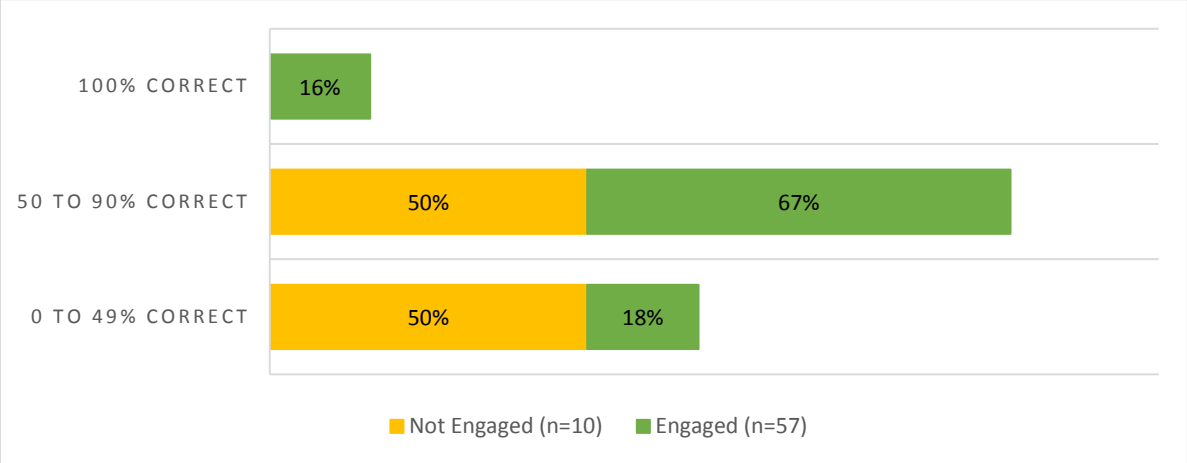
→ **Identify language consistent with Ontario legislation.** Health care providers not engaged in the project more often reported inconsistent language (e.g. advanced directives, next of kin). However, while all engaged participants are more often identifying correct language there are also those still using incorrect language, such that a mix of consistent and inconsistent terms remain in use.

"The project changed people's ideas of Advance Care Planning, SDMs. People were unsure of language when talking to family and residents and now there has been clarification for the staff. I know some homes are also making changes to their forms to reflect their new understanding of language." Long-Term Care

[3] Using the health care provider online survey results from years 2 and 3 we assessed the relationship between level of engagement (low, medium, high) and capacity outcomes, calculating analysis of variance in reported scores and determining significance at $p<.05$. Consistently greater engagement was significantly correlated with positive outcomes.

Health Care Provider % to Report Are Confident with ACP

Health Care Provider % to Correctly Identify language Consistent with Ontario Legislation



While engaged health care providers more often correctly identified language that was consistent with Ontario legislation, there are still those who are unclear. The distribution of results show the need for ongoing attention and reinforcement of consistent language.

- **Changing practices and policy**

More highly engaged health care providers reported they had made a number of changes to their practice over the course of the project, including asking and documenting a patient's SDM, as well as posting and sharing ACP resources. Overall 81% of health care providers who reported being engaged in ACPEP reported making changes to their practice, compared to 58% of providers who reported low engagement. This result hits the target of 80% of ACPEP health care participants reporting positive change in practice

Health Care Provider Change in Practice by Level of Engagement

WITHIN THE LAST YEAR, HAVE YOU…	ENGAGED PARTICIPANTS (n=112)	NOT ENGAGED PARTICIPANTS (n=48)
Started asking about patients' "Substitute Decision Maker"	66%	50%
Documenting patients' Substitute Decision Maker	60%	38%
Shared ACP materials and resources with your patients	58%	17%
Ensured the language you are using is consistent with Ontario legislation	54%	13%
Shared SDM wallet cards with patients	25%	4%
Posted the SDM hierarchy for staff, and family members to see	24%	6%
Made changes to your intake form to identify the "Substitute Decision Maker"	19%	8%
TOTAL % TO REPORT HAVING CHANGED AT LEAST ONE PRACTICE	**81%**	**58%**

Of the health care providers who participated in our survey, 15 sites reported they had developed or adapted the language in their policies on ACP.

"We have developed a clinical guideline that walks through ACP, a policy for code status and developing a code status order sheet…. Once the policy and clinical guideline are complete, there is going to be an education blitz to support those documents. We are going to be meeting with each of the professional practice groups, so physicians, to make sure they understand the direction that we are going." Hospital

"I know homes are now using the resources as part of the family conferences in LTC…" Long-Term Care

"I am bringing up the SDM piece a lot more often, reinforcing need with patients who have change in their health status to confirm SDM/are you aware of SDM and encouraging them to make a POA" Nurse

"Staff are embracing this including practice change; and it is great to see that this does not have to be led by a physician, that it is the clinical nurse that is leading this and the change is a result of her passion and leadership on this. The clinical nurse developed the internal process, she has been the champion and the team rallied" Executive Director

Community Outcomes

A community wide survey completed in the fall of 2015 revealed that while residents report talking to their significant others about their health care wishes, there was confusion around language, Ontario legislation for health care consent and the substitute decision maker hierarchy. This baseline survey also showed that community members were not having ACP

conversations with their healthcare providers, and that there was a need for practical supports on how to have this conversation.

To build the capacity of the community, ACPEP included a two-fold strategy that included engaging residents directly in education as well as building the capacity of key community professionals and support providers to further educate, use correct language, and share correct resources. ACPEP thus achieved success in building community capacity through:

- **Greater engagement of community professionals**

Over the three years, ACPEP engaged over **600** community professionals and support providers, providing education sessions and resources they could share with their clients and staff.

- **Increased understanding and awareness of ACP, and Ontario-specific legislation**

Similar to the outcomes achieved among health care providers, community professionals and support providers reported increased knowledge and confidence speaking to their clients about ACP.

> *"I have gained valuable insights that have been helpful in my professional practice as an estate and financial planner." Community Professional*

According to survey results, those who were more highly engaged in the program were significantly[4] more likely to:

→ **identify language consistent with Ontario legislation**, though there were still those who reported language inconsistent with Ontario legislation (such as advance directives).

→ **understand and be more confident talking to their clients,** including for introducing the conversation to their clients and explaining ACP in the context of health care consent.

→ **report a change in their practice and protocols** which primarily included sharing resources with their clients such as the wallet card, updating client information packages and having conversations about ACP, the substitute decision maker hierarchy and power of attorney for personal care.

> *"We now include the SDM wallet cards in the kits that we give to new clients and our client agreement now contains a paragraph about POA and SDM. And as a result of*

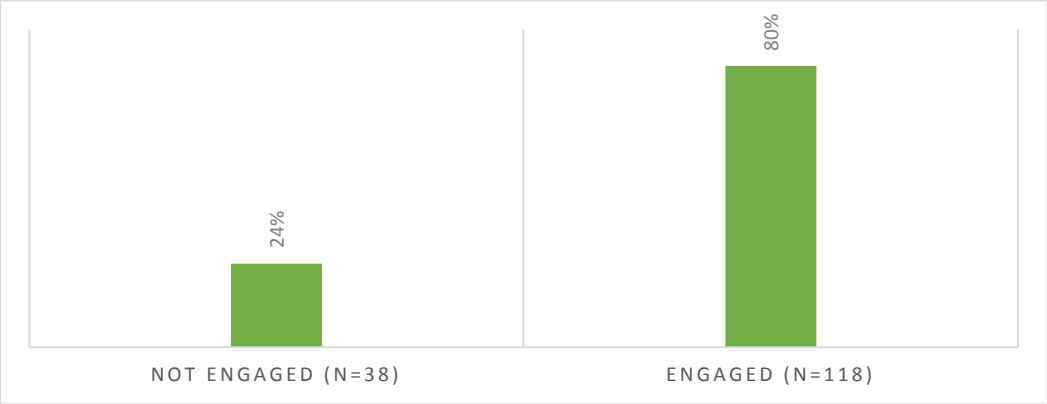
[4] Using the community professional online survey results from years 2 and 3 we assessed the relationship between level of engagement (low, medium, high) and capacity outcomes, calculating analysis of variance in reported scores and determining significance at $p<.05$. Consistently greater engagement was significantly correlated with positive outcomes.

training, staff are now more aware of the SDM hierarchy and what questions to ask to determine the client's legal SDM." Community Support Provider

"Without the learnings from the initiative, I wouldn't have known how to begin to have conversations with clients. I didn't talk about it before and now it is a regular part of interaction with clients. It also made me realize how unprepared I was personally and think that I still needs to have these conversations, especially with my spouse." Community Professional

"I now have more of a focus on POA for personal care. I specifically recommend that people leave these open, no conditions, that it is much more powerful when it is clean… I now talk about this as a two step process – identify your SDM and talk to them and everyone else about wishes, that the wishes will evolve over time so it is important to continue to talk about it." Lawyer

Community Professional/Support Provider % to Report Are Confident with ACP



Community Professional/Support Provider % to Report Have Made Change to Practice

Key informants also reported that ACPEP was valuable to their practice and the community. They noted the value of the resources, as well as of in-person education and

encouragement. Community professionals and support providers emphasized that conversations that connect to death remain difficult to have and resources, while helpful for providing information, are less effective than in person sessions when it comes to building confidence and engagement with the topic.

> *"Having a guest speaker was very impactful, more than just what providing resources would have done. [ACPEP] raised the issue for people but there needs to be a real person for it to be effective. Resources are good but older people especially get inundated with so many resources for everything. The language of ACP needs interpretation and a real person helps to navigate that." Faith Leader*
>
> *"Before this project we didn't talk about it. Now staff actually talk about it… The lunch and learn presentation was most helpful. The resources are helpful, but face-to-face learning is most effective." HR Manager*

- **Greater engagement of residents**

Over **7000** residents were engaged in the ACPEP directly through education workshops and information sessions. General public residents also benefitted indirectly through the sharing of almost **112,000** resources.

Engagement of residents through ACPEP activities and events resulted in positive outcomes including:

→ **Increase in knowledge and confidence:** Education sessions provided consistent results in achieving outcomes. According to workshop evaluations almost all participants reported they had increased knowledge and confidence as a result of the session.

> *I think this is really, really valuable information. I'm glad you are informing people and allowing us to make good decisions for ourselves and our families " Workplace Lunch'n' Learn Participant*

AS A RESULT OF THIS SESSION…	% TO REPORT POSITIVE OUTCOMES (N=1216)
I have a better understanding of advance care planning	93%
I feel more confident about having advance care planning conversations	90%
I know how advance care planning relates to health care consent	93%
I know how to identify my Substitute Decision Maker	94%

When asked what their biggest learning was, participants, for example, replied:

Acknowledging there could be a delay in care if providers are not able to readily determine who my SDM is.

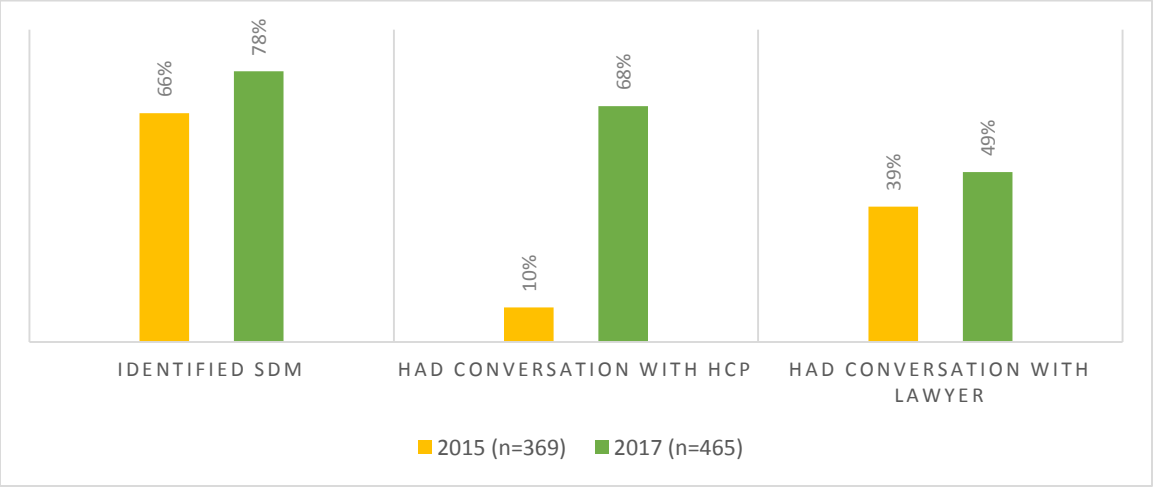
Finding out Advance Care Directives are NOT in Ontario.

Learning that these types of conversations are valuable and important to not only your own life, but to the lives of others around you and your loved ones.

Thank you for giving us the information we need to make our own health care decisions

→ **Increase in ACP conversations and identifying their SDM**: the 2017 community survey showed that more residents were having conversations about ACP. The biggest difference was in residents who reported having conversations with a health care provider, which went from 10% in 2015 to 68% in 2017.

Community Survey % to Report SDM and ACP Conversations



Key Learnings and Reflections

In their seminal work, *Getting to Maybe* (2006), Westley, Zimmerman and Patton disrupted how we approach social change. They called our attention to complexity and emphasized how working in complexity required changemakers to be innovative, adaptive, and resilient. Influencing change in complex systems, they clarified, required changemakers to focus their attention on learning, on adjusting their strategies based on what they learned, and on gaining comfort with emergence. They characterized this approach as "getting to maybe" because their research showed that time and time again, the journey to substantive and

lasting change is neither linear nor easy. Pulling one thread in a complex system can lead to unexpected shifts in another part of that system, and changemakers need to be attentive and ready to shift focus and activities accordingly. Because outcomes and impact take time – sometimes years – to achieve, successful system innovators use iterative processes to prototype and refine interventions. They try ideas out, they learn, they adapt, and keep at it over the long term.

The Advance Care Planning Education Program as it unfolded over its three years reflects the insights of Westley and her colleagues, demonstrating the challenges of working in complexity as well as how being adaptive can move initiatives forward in their purpose and support the achievement of meaningful outcomes. At its core, the program was designed to address the lack of awareness about advance care planning as well as to address the use of practices and language that were inconsistent with Ontario legislation. It was designed to bridge health care and community settings so that the full range of stakeholders could be engaged in both spreading awareness and shifting practice.

In taking an adaptive approach, the team was able to capitalize on emerging learning and course correct when needed. The team developed strategy real-time, nurtured new connections and relationships, all while harnessing momentum where it appeared and finding work arounds when they encountered barriers and disengagement. This led to innovative programming and resources, as well as bringing different stakeholders together.

This approach supported the ACPEP to not only exceed activity and participation targets, but also to realize positive outcomes in building capacity for the health system and community. The achievement of the outcomes noted in the report above reflect the intentional and committed work of the ACPEP team over the last three years. Strategies that facilitated this success included:

- → **Investing in building relationships and connections.** The team invested a significant amount of time reaching out across the health system and the community, making key connections and developing key relationships. Leveraging these relationships served to amplify interest in the project and facilitate the breadth activities and participation. A key reflection of the team over the course of the project was that change cannot happen without the trust and engagement that comes through meaningful relationships.

- → **Engaging a cross-sector steering committee.** Engaging key influencers as steering committee members developed champions for the projects across the health and community sectors, as well as supported the ongoing adaptation of project activities. The steering committee supported the developmental approach to the project, where steering committee members at the end reported having gained as much capacity as they contributed. Champions, like those developed through the steering committee, are also critical for influencing change within systems that default to the status quo.

- → **Engaging leadership across settings.** Creating sustainable change takes time and requires the direction and influence of leaders. The team engaged both clinical and

community leaders to build the kind of buy in that would drive the objectives forward. Engaging leadership can be challenging as leaders themselves are balancing multiple priorities and responsibilities. The team responded to this challenge by clarifying the value proposition for leaders across different sectors, including developing sector-specific resources, recognizing that there is no one size-fits all messaging. They also worked to maintain attention and focus on ACP so that it would not get lost or put aside.

→ **Simplifying the message.** In the early days of the program, communication and education attempted to address the complexity of advance care planning and health care consent. Though this approach was appropriate in certain contexts, it did not land well for a broader audience. The team then adjusted its approach to focus communications on identifying SDMs and the core messages. The program was rebranded *Conversations Worth Having* and simple resources were developed, like the wallet card, which were then widely requested and distributed.

→ **Investing in dedicated capacity.** Without the dedicated capacity of the project team (Director, Health System lead and Community lead), ACPEP would not have achieved the simultaneous breadth and depth of its activities. This capacity allowed the team to invest the time to build and steward relationships, engage leaders, and design innovative programming and resources, which paid off through positive change in knowledge and practice.

Overall, ACPEP was successful in its education and capacity building efforts which built the capacity of individuals and organizations with the health and community sectors. From the beginning, it was clear there was readiness for education about ACP and over the course of its implementation, the program consistently exceeded its engagement and education targets. At the same time, the ACPEP encountered entrenched processes and dynamics that presented barriers and challenged assumptions about how best to influence administrative and institutional changes within the health care system. Though program activities established a strong foundation, ACPEP ended before it could fully realize its longer-term outcomes for more systemic chang within the health system (like policy change or a common protocol). However, the ongoing commitment by Hospice Waterloo Region to coordinate a team of volunteer presenters and make available correct education resources is one step towards maintaining positive outcomes.

Appendix A: Education Program Description

The Advance Care Planning Education Program was designed to address the intersection between health care and community. This design recognized that successful negotiation of wishes and values for treatment and health care consent requires the engagement and understanding of both health care providers and residents in the community. As such, the program engaged and supported improved practice among three main target groups:

1. **Health care providers**: this group was the various providers and professionals who are connected to the health care system along the continuum of care including 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 included community leaders and influencers who are in a position to play a role promoting ACP and connecting their clients to ACP resources. It included 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, and funeral directors. 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).

As the project unfolded a second community professional cohort was identified. This cohort included **community support providers** such as social workers, police and other services that bridge the gap between the community and the health care system.

3. **General Public**: this group included community members who do not necessarily hold ACP, end of life or health care consent top of mind; it also included patients and family members, as well as those who may find themselves in the 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.

Strategies and Activities

The Advance Care Planning Education Project was led and coordinated by an internal team at Hospice Waterloo that includes a program lead, community engagement lead, and health sector lead.

In the first year of the ACPEP, initial focus was on outreach, building relationships and engaging key stakeholders from the health sector and the community. This focus was critical in building the trust and influence needed to affect the change within the health system and community. Moving through the second year, relationships and activities deepened as has

learning and the program's theory of change. In the third year, established relationships and nurtured connections served to scale out program activities throughout the community and health care sector. The focus in this year was also on sustainability.

Key strategies for the program include:

Year 1

- Engaging a cross-sector (health and community) Steering Committee to provide program direction, confirm and refine program components, and support the activation of program strategies
- Creating an internalized knowledge base about ACP among health care practitioners and within health care institutions
- Supporting practice and policy change within health care institutions across the WWHLIN to ensure these are consistent with Ontario legislation.
- Establishing partnerships with community groups and key influencers, e.g. financial and insurance industries
- Engaging residents through public education

Year 2

- Establishing the **Conversations Worth Having** campaign as a way to build knowledge and comfort with ACP.
- Education sessions for residents were scaled up in Year 2, being offered through community partnerships. The project developed local resources to include SDM wallet cards, one pagers, and a SDM brochure (Ontario specific)

Year 3

- Continuing the **Conversations Worth Having** campaign as a way to build knowledge and comfort with ACP.
- Continuing to scale education sessions for the general public, disseminating the resources developed in year 2.
- Continuing to engage the health and community care sector in training to build their capacity as educators and ACp ambassadors within the system

Appendix B: Evaluation Approach and Methods

With the aid of Hospice Waterloo Region, we completed the evaluation using mixed qualitative/quantitative methods, guided by the ACPEP's design, implementation, and emerging outcomes. In year, our evaluation questions were outcome focused and included:

1. Did key people and players within the health system and community engage with the project?
2. Did ACPEP foster stronger coordination and consistency with Ontario-legislation?
3. Did ACPEP build capacity within the health system? Is there more consistent and coordinated practice within health and social care organizations.
4. Did ACPEP capacity within the broader community?
5. Did ACP improved end of life and patient/family experiences?

Evaluation Methods

This report draws together findings from Years 1 through 3, which we gathered through the following methods:

Year 1

Environmental scan: The environmental scan in Year 1 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 centers, 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: As part of the baseline assessment in Year 1, 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: As part of the baseline assessment in Year 1, 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, 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.

Judith Wahl Session Feedback Surveys: 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. We collected 324 completed feedback forms.

Year 2

Education Session Feedback: Feedback surveys were collected from ACPEP Education Workshops for both general public and health care providers. The survey period was from May 2016 to the end of Feb 2017. Surveys focused on learning and outcomes associated with the sessions. In total, we received surveys from 1280 general public members and 340 health care providers and community professionals.

Organizational Survey for Health and Social Care Providers and Community Professionals: An online survey of health and social care providers, and community professionals was completed in the fall of 2016. This survey focused on current understanding and practice related to ACP. The survey period was from Oct 7 to Nov 11, 2016. A total of 148 participants completed the survey as follows: 82 from care providers, 31 community support services, and 35 community professionals

1:1 Interviews with Steering Committee Members who were asked about their experience, project impact/learnings as a member and within their sector. Members also identified strengths of approach and suggestions for improvement in process.

Year 3

Conversations Worth Having Steering Committee Focus Group: Hospice Waterloo Region hosted a focus group with the steering committee in October of 2017 to get feedback on their involvement in the project.

Community Survey: 465 members of the general public completed an online survey. The survey period was from October 30, 2017 to December 15, 2017. Similarly structured to the Year 1 Community Survey, participants were asked about their engagement with ACPEP, and their awareness, understanding, attitudes, and barriers and experiences, with ACP. To determine evaluation outcomes, results were compared to Year 1 baseline results. The distribution methods for this survey were the same as in Year 1.

Organizational Survey for Health and Social Care Providers and Community Professionals: As in Year 2, an online survey of health and social care providers, and community professionals was completed in the winter of 2018. Similarly structured to the Year 2 Organizational Survey, we focused on professional's current understanding and practice related to ACP. The survey period was from February 7, 2018 to February 27, 2018. A total of 151 participants completed the survey as follows: 81 from care providers, 29 community support services, and 41 community professionals.

Key Informant Interviews: In February 2018, ACPEP engagement leads conducted 11 key informant interviews. Informants came from the health care, community service, and community professional sectors and were asked about their experience with ACPEP, the

possible impacts the project had in their sector, as well as the barriers ACP champions face. The thematic analysis of these interviews was compared against our evaluation objectives with an eye towards future directives

1:1 interviews with Steering committee members to identify key learnings, project impact as a result of committee participation, observations of impact within own sector as well as recommendations for future engagement/sustainability.

Output Tracking: Over the course of the initiative, Hospice Waterloo Region maintained a database of contacts, activities, participation and resources distributed.

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 identified dominant themes and issues according to topic and by frequency of responses. Quantitative analyses included both descriptives and an analysis of variance where significance was determined at $p<.05$.

Limitations

Though every attempt was made to ensure a diverse range of participants, participation in the evaluation is 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. Results have been aggregated and reported across methods, which draw from varying groups of individuals within each cohort.

The results should thus be considered a snapshot of the experiences, perspectives and trends among those who may have a readiness to learn more about ACP and a willingness to engage in the education program.