

Message from the Project Leads

Welcome to the first edition of our newsletter!

The project is off to a great start. We had our first Research Team meeting on February 5th, 2018 in Toronto, with 45 team members participating in a one-day session. Each project team provided an overview of their work and planned activities.

We're also pleased to introduce our new website: <http://icanacp.ca>. The website will provide updates on our activities, highlight related news and events, and link to important resources and research. The Member Login link on the website is a portal to a secure site for research teams to share files and communicate on progress.

The iCAN-ACP project is bringing together a team of 32 investigators from 16 universities, 5 international collaborators and 42 partner organizations – and we believe that a strong communications network will help us all succeed together. We hope you enjoy this newsletter, and invite you to send us feedback and suggestions for making it a relevant and interesting read for you and your team.

John You & Michelle Howard
Project Co-Leads, iCAN-ACP Study

The iCAN-ACP Study

Advance care planning (ACP) is a process that supports people in understanding and sharing their personal values, life goals and preferences related to future medical care. The goal of ACP is to prepare people, and their substitute decision maker(s) for future "in-the-moment" treatment decisions so that people get medical care that is consistent with their values, goals and preferences during serious illness. ACP can:

- improve the patient experience
- align treatment with patient preferences
- avoid unwanted and costly invasive treatments near end of life
- improve psychological outcomes for family members during bereavement

A national, multi-year study involving seriously ill, older Canadians revealed that even though 28% of the participants stated a preference for "comfort care" (no curative treatments), this was documented in only 4% of charts.

The iCAN-ACP Study (continued)

The iCAN-ACP study, funded by the Canadian Frailty Network, is being conducted in long-term care homes, family doctor's offices and hospitals across Canada. Team members will be working with elderly Canadians living with frailty and their families to evaluate and tailor ACP tools in all of these settings, while paying particular attention to the needs of marginalized groups in this demographic.

Read Project Lead Dr. John You's article about iCAN-ACP at theconversation.com.



Project Updates

The **Primary Care Team** is busy with training on the Serious Illness Conversation Guide ([Ariadne Labs](#)).

The team is working with family practices as study sites in Alberta, British Columbia, Ontario and Nova Scotia to implement ACP conversations using tools to prepare both patients and clinicians. Training sessions involving physicians, nurses and other health professionals on the Serious Illness Conversation Guide have been completed and enrolment of patients for the evaluation stage is starting. The primary care team has noted a desire in family practices for: an interprofessional approach to ACP where possible, the importance of a structured approach typically over more than one visit, and including substitute decision-makers in conversations. In a pilot, patients found the process very valuable. The primary care team has been engaging with a number of partners including Canadian Hospice Palliative Care Association, McMaster University Department of Family Medicine, Sunridge Family Medicine Teaching Clinic (Calgary), the B.C. Centre for Palliative Care, and New Westminster Family Practice (B.C.).



The **Long-Term Care Team** has been actively collecting baseline surveys, and conducting a pilot of chart audit data collection. They've also organized staff education sessions and champion team meetings, and have worked on adapting the [Conversation Starter Kit](#) tool.

The team is currently working at four long-term care sites, including two in Toronto and two in Hamilton. They've held 13 staff focus groups, 4 resident focus groups and 3 family focus groups, along with a number of resident, family and clinician interviews. Partner engagement includes Extendicare Canada, Shalom Village, Canadian Hospice Palliative Care Association, Alzheimer Society, Canadian Virtual Hospice and Hospice Palliative Care Ontario.

The Long-Term Care team has noted that many staff in long-term care homes do not have a good understanding of advance care planning, and many also feel that they do not have permission to have these types of discussions. They've also found that many residents feel that, when having these discussions, the personal relationship with staff matters more than their specific discipline. One resident noted: "I think it wouldn't matter who it was, it could be a nurse or a doctor. Somebody you're close to, somebody you feel comfortable with. So it could be anyone, it could be my PSW [Personal Support Worker], it could be my med nurse."

Project Updates (continued)

The Hospital Team has been focused on the local adaptation and implementation of the [Serious Illness Care Program](#) on hospital medical wards in Hamilton, Calgary and Montreal, aimed at promoting more, better, and earlier person-centred conversations about goals of care with hospitalized patients who have serious illness. The Hamilton program celebrated its one-year anniversary in March -- 29 clinicians have received training and 94 Serious Illness conversations with patients have taken place over the past year. The Calgary program successfully launched in early March, and the Montreal program launched in May.



In Ottawa, the Hospital Team is leveraging additional local funding and international expertise in decision science to support a randomized controlled trial of a decision support intervention aimed at increasing the quality of hospitalized patients' decisions about cardiopulmonary resuscitation, with patient recruitment well underway.

The Hospital Team has been engaging with a number of partners, including the Canadian Hospice Palliative Care Association, Hamilton General Hospital and Hamilton Health Sciences Centre, the Foothills Medical Centre in Calgary and the Montreal General Hospital.

At a recent departmental meeting, a Chief of Medicine at one of the hospital sites stood up and called the Serious Illness Conversation Guide a "transformational experience", describing how the Guide "fundamentally changes the nature of our conversations with patients and takes us from paying lip service to 'patient and family centered care' to actually doing it."

Partner Profile: Canadian Hospice Palliative Care Association

Even though the iCAN-ACP study is taking place in hospitals, long-term care homes and doctor's offices across Canada, it can be challenging to communicate the project's work, especially given the sheer number of individuals and organizations participating in this important project. As a knowledge translation partner in the study, the Canadian Hospice Palliative Care Association (CHPCA) is helping to provide that critical outreach, while contributing to the development of ACP tools for elderly Canadians living with frailty.

A national voice for hospice palliative care in Canada since 1991, the CHPCA collaborates with a wide array of professional and non-profit organizations to support excellence in palliative care in Canada.

For the past six years, the CHPCA has facilitated the Advance Care Planning (ACP) in Canada project, an initiative that has brought together a network of partners, including researchers, health care professionals, governments, institutions, non-profit organizations and relevant stakeholders, such as legal and financial associations.

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"Our stakeholders across Canada have expressed the importance of engaging frail, elderly Canadians in advance care planning, in order that their wishes are effectively communicated and followed. It's critical to have specific tools adapted to this population, and so we are very pleased to support and be engaged in the iCAN-ACP project."

- Sharon Baxter,
Executive Director, CHPCA

Partner Profile: Canadian Hospice Palliative Care Association

The project includes the national Speak Up campaign, with downloadable tools and resources that individuals and organizations can use to facilitate advance care planning discussions.

Two of the campaign's resources – the national versions of the Speak Up ACP Workbook and the online interactive workbook (www.myspeakupplan.ca) – are being evaluated as part of the project.

The CHPCA will act as a KT partner on the iCAN-ACP project, helping to raise awareness of the study through its networks. Some of their major connections include a national Community of Practice of over 100 ACP educators across Canada, and the 37-member Quality End-of-Life Care Coalition of Canada, composed of professional associations, patient and caregiver advocacy organizations, and disease-specific societies.



Resources

Recent articles/publications:

- [Poor communication is compromising care for the dying](#)
- [Family Perspectives: death and dying in Canada](#) (Vanier Institute)
- [Frailty can be grievous and irremediable](#)
- [Barriers to and enablers of advance care planning with patients in primary care](#)



Event Calendar

- [CMA Health Summit](#), Winnipeg, MB, August 20-21
- [International Congress on Palliative Care](#) Montreal, QC, October 2-5
- [Canadian Association of Gerontology Conference](#), Vancouver, BC, October 18-20
- [Canadian Society of Internal Medicine Conference](#), Banff, AB, October 10-13
- [Canadian Frailty Network Meeting](#), Toronto, ON, September 20-21



Canadian
Frailty
Network

Réseau canadien
des soins aux
personnes fragilisées

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