



## DECIDE Study Information Sheet

**Title of Study:** Improving General Practice Advance Care Planning (iGAP) Study

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**Co-investigators:** Dr. Daren Heyland; Dr. Doug Klein; Dr. Doris Barwich; Dr. Amy Tan; Louise Harvey; Dr. Carrie Bernard; Dr. Marissa Slaven; Dr. Konrad Fassbender; Dr. Lee Green; Dr. Jessica Simon; Dr. Rebecca Sudore

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### ADVANCE CARE PLANNING IN PRIMARY CARE

Evidence strongly supports Advance Care Planning ACP for improving quality of patient care. With the increasing number of patients experiencing chronic illness and living longer with declining health, conversations about planning can avoid poor quality of care at the end of life, invasive unwanted medical care and wasted resources in the health care system. When asked, patients and providers alike want this communication to happen however it is not clear how often it is happening in community primary care settings. Ideally ACP would happen in the family practice setting with the doctor and health care team who are the primary medical home for the patient, and would transport to the acute care and other sectors when needed.

### ABOUT THE RESEARCH

In Canada we do not have much research about ACP in primary care. This study aims to understand the barriers to achieving high quality advanced care planning (ACP) in primary care and to develop practices and tools for patients and health care providers in family practice.

Research conducted by investigators in CARENET ([www.thecarenet.ca](http://www.thecarenet.ca)) has looked at barriers to ACP in the acute care setting. Each year, hospitals in Canada can audit their activities relating to doing ACP with patients by collecting data and sending it to a central site for analysis and a feedback report.

This method has been expanded to primary care. You are invited to join this initiative by collecting data in your practice that will help us understand the activities of Canadian family practices regarding ACP.

**DESCRIPTION OF THE RESEARCH** The study will survey physicians, nurses (RN/RPN, NP, APN, CNS etc.) and other allied health professionals using an online survey tool. All health care providers in primary practices will be invited to participate. The survey consists of three sections that address different aspects of advance care planning and will take approximately 10-15 minutes to complete.

### HOW MANY PRACTICES WILL BE INVOLVED?

We aim to recruit between 50 and 100 family practices across Canada.

**POTENTIAL HARMS:** There is no expected harm from participating in this study. There is a very low risk of potential breach of confidentiality.

**POTENTIAL BENEFITS:** There may be no direct benefit to you if you choose to participate. The information that you provide may help to better understand barriers to advance care planning in primary care practices and add to a limited body of knowledge in this area.

**CONFIDENTIALITY AND PRIVACY:** All information gathered in this study will be kept strictly confidential; all of your answers will be confidential. Your name will be on a list for addressing the survey and tracking responses but your survey answers will be kept separate from your name. The information from the study results will not be identifiable.

Secure computers will be used to input the answers. The data for this research study will be kept for 10 years then destroyed.

Data will be stored behind locked doors and made available only to qualified study personnel who are coordinating the study, and the Research Ethics Board that oversees the ethical conduct of this study. Names and personal information will not be made available to anyone who is not involved in this study unless disclosure is required by law.

### **WHO DO I CALL IF I HAVE QUESTIONS OR PROBLEMS WITH THE STUDY?**

Dr. Michelle Howard from the Department of Family Medicine will lead this study. Primary care practices in Ontario, Alberta and British Columbia will be participating. If you have any questions about participating in this study you may contact:

Dr. Michelle Howard, PhD. 905-525-9140 ext. 28502 [mhoward@mcmaster.ca](mailto:mhoward@mcmaster.ca)

### **RESEARCH ETHICS**

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

