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FAMILY MEDICINE

Study Information Sheet

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

Principal Investigator: Dr. Michelle Howard mhoward@mcmaster.ca

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

Sponsors: Funded by Tech Value Net and the Ontario Ministry of Health and Long Term Care

You are being invited to participate in a short survey on Advance Care Planning. We are looking for patients to complete a survey about their opinions on making plans for their future health care if they became seriously ill.

To decide if you want to be a part of this study, you should understand what is involved and the benefits and risks. This form provides detailed information about the study. Please take time to make sure you have understood all the information. After you have had a chance to read the study information sheet and ask questions, you will be given a copy to keep for your records.

PURPOSE OF THE RESEARCH

There are many people with chronic illness or advancing disease because of the aging population. This puts strain on the health care system. Often near the end of life, patients are treated aggressively in the hospital because they have not thought about or decided what care they would prefer near the end of life. Most people prefer comfort care at some point, but many are over-treated because of lack of planning. Having an advance care plan can help with this situation. It would be best for people to consider and document their plan before an acute illness and hospital admission, however this is not happening often enough. One way to have the conversation earlier might be for the family doctor to bring it up and help patients understand and document their decisions. As a starting point to increase advance care planning, the purpose of this research is to measure how much family practice patients have thought about or done an advance care plan.

WHO IS DOING THIS STUDY?

Dr. Michelle Howard from the Department of Family Medicine will lead this study.

DO I HAVE TO TAKE PART?

No. Participating in this study is voluntary. If you choose not to participate, it will not affect your medical care.

IF I DECIDE TO TAKE PART, WHAT DO I HAVE TO DO?

If you volunteer to take part, we will ask you to complete the survey in your family doctor's office. It will take about 10 minutes to complete. The survey will ask about your thoughts and opinions and also a few questions about you. The research assistant will also look at some sections of your medical chart to record your health conditions and if there is information about advance care plans.

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CAN I CHANGE MY MIND ABOUT BEING IN THE STUDY?

You can stop participating in the study at any time if you wish by not completing the survey.

WHAT ARE THE BENEFITS OF THE STUDY?

Although there may be no direct benefit to you through participation in this study, the information from this survey will help with research to improve the way health care is provided.

WHAT ARE THE RISKS TO ME?

It is not likely that there will be any harms, risks or discomfort associated with your participation in this study. However, if there are questions that you do not feel comfortable answering, you do not have to answer them.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

There will be 30 to 50 people enrolled at each family practice clinic in the study.

WHAT ABOUT CONFIDENTIALITY?

All information gathered in this study will be kept strictly confidential; all of your answers will be confidential. The research assitant will ask your name to look up your chart but will not put **your name on your survey or other information for the study.** The information from the study results will not be identifiable.

The surveys will be stored in a locked McMaster research office. 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?

If you have any questions about participating in this study you may contact:

Dr. Michelle Howard, PhD.

P: 905-525-9140 ext. 28502

E: mhoward@mcmaster.ca

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.