

Patient informed consent form



CUMMING SCHOOL OF MEDICINE

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TITLE: Measurement of treatment preferences of people with chronic kidney disease and acute coronary syndrome

SPONSOR: Canadian Institutes of Health Research (CIHR)

INVESTIGATORS: Matthew James, Todd Wilson

This information sheet is only part of the process of informed consent. It should give you the basic idea of what the research study is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information.

BACKGROUND

Heart disease is one of the most common co-existing health problems in people with chronic kidney disease (CKD). Patient-centered care for heart disease requires that care providers understand the preferences of patients facing common treatment decisions in kidney care. Understanding the treatment preferences for heart disease is important when providing decision making support to patients with CKD and their family members.

WHAT IS THE PURPOSE OF THE RESEARCH?

The purpose of the study is to understand treatment preferences of people living with CKD. Specifically, we want to know what is important to people with CKD in the event they have a heart attack and are faced with choosing between treatment options.

WHAT WOULD I HAVE TO DO?

You will be asked to complete a questionnaire by computer. The questionnaire is expected to take 30 minutes to complete and can be completed in the clinic or at home. If you choose to complete the survey at home, you will be asked to provide an email address. Reminders will be sent at one, two and four weeks if you have yet to complete the survey. After that, your contact information will be destroyed.

Ethics ID: REB 17-2333

Study Title Identification of chronic kidney disease patients' and healthcare providers' acute coronary syndrome decision-making needs: CanSOLVE Theme 1.3B

PI: Dr. Mathew James

WHAT ARE THE RISKS?

There are no foreseeable risks from participating in the survey.

WILL I BENEFIT IF I TAKE PART?

If you agree to participate in the study there will not be a direct benefit to you, although by completing the questionnaire it may help you understand your own preferences regarding treatment choices. The information we collect from this study may help us to provide better treatment for patients with chronic kidney disease in the event of a heart attack.

DO I HAVE TO PARTICIPATE?

Your participation is voluntary. Your participation will not influence the actual care you receive and your doctor will not know if you decide to participate or not. You may withdraw at any time, up until you have completed the survey. Once the survey has been completed, all data will be anonymous so it is not possible to withdraw. If you do not participate it will not jeopardize your healthcare or your ability to access healthcare services.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

There are no costs for participating in this survey and you will not be paid for participating.

WILL MY RECORDS BE KEPT PRIVATE?

Yes. All questionnaires will be kept in a secured location. Your individual data will be kept confidential and will be available only to authorized study personnel and the University of Calgary Conjoint Research Ethics Board. Any contact information collected (email address) will be kept for one month in a secured location to send reminders about the study, after which it will be destroyed. Your age and gender will be collected separately from any identifiable information.

This online survey is hosted by a web-survey company located in the USA and as such is subject to U.S. laws. In particular, the US Patriot Act which allows authorities access to the records of internet service providers. This survey or questionnaire does not ask for personal identifiers or any information that may be used to identify you. The web-survey company servers record incoming IP addresses of the computer that you use to access the survey but no connection is made between your data and your computer's IP address. If you choose to participate in the survey, you understand that your responses to the survey questions will be stored and accessed in the USA. The security and privacy policy for the web-survey company can be found at the following link: <http://www.sawtoothsoftware.com/about-us/privacy-policy>".

FURTHER INFORMATION

Submission of this survey indicates you have understood, to your satisfaction, the information regarding your participation in the research project and agree as a participant. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

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PI: Dr. Mathew James

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If you have any questions concerning your rights as a possible participant in this research, or research in general, please contact the Chair of the Conjoint Health Research Ethics Board, University of Calgary at (403) 220-7990

The University of Calgary Conjoint Health Research Ethics Board has approved this research study

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