



TITLE: Information Use and Sharing through an Online Patient Health Portal: A Survey of Albertans' Views on Access to their Health Information

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This consent form is only part of the process of informed consent. It should give you the basic idea of what the research 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 the information. You will receive a copy of this form for your records.

BACKGROUND

Having secure and comprehensive health information sharing between care team members such as physicians, specialists, and patients is key for high quality health care. There is currently no system in Alberta that communicates health information between patients and their care team. While Alberta has an electronic health record that stores data from a variety of hospital and outpatient services (such as laboratory services) this system does not capture information from primary care or other community-based health care providers. Furthermore, patients do not have access to this electronic health record, which may limit their ability to be an active member of their own health care team.

The development of an integrated electronic health record has the potential to enhance the way patients and health care providers experience and use the health care system. As such, researchers at the University of Calgary are conducting this study to understand Albertans' views

regarding the use of an online patient health portal to access, manage, and share health information.

WHAT IS THE PURPOSE OF THE STUDY?

We would like to understand your views regarding the use of an online patient health portal. We would like to know the following:

- What information and features you would find useful for an online patient health portal
- How, or if, you would like your health information shared through an online patient health portal
- What you think may be beneficial or concerning regarding the use of an online patient health portal.

WHAT WOULD I HAVE TO DO?

If you choose to participate, you will be asked to complete a 10-15 minute online survey. You will be asked to answer questions on the following topics:

- Who should have access to their own health information through an online patient health portal
- What health information and functions you would like to use in an online patient health portal
- How you would like to interact with members of your healthcare team through the online patient health portal
- What health information you would like to have shared with healthcare providers
- What you think may be benefits to using an online patient health portal
- What concerns you may have in using an online patient health portal.

If you would prefer to complete the survey by telephone or on paper, please contact Jenny Kelly, W21C Research Associate (1-800-587-9580; w21c@ucalgary.ca).

WHAT ARE THE RISKS?

There are no risks to taking part in this study. All responses will be confidential and anonymous. All data will be presented in aggregate form so no individual participants can be identified.

WILL I BENEFIT IF I TAKE PART?

There will be no direct benefit to participating in this study. However, the information gathered in this study will highlight Albertans' views regarding an online patient health portal. In the future, this information may assist in the development of an online patient health portal.

DO I HAVE TO PARTICIPATE?

Participation in this study is voluntary. Your access to care or services will not be affected by your choice to participate in this survey. Should you choose to participate, your responses will be kept confidential and will be analyzed and reported without specific reference to you.

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

You will not be compensated for the survey. You are not expected to incur any costs.

WILL MY RECORDS BE KEPT PRIVATE?

All information collected in this survey will be kept private. Only members of the research team or Conjoint Health Research Ethics Board will have access to the information. You will not be asked to enter any identifying information such as your name, and the research team will not know your identity or be able to identify your individual responses. All data will be stored in a secure online database and/or password protected computer in a secure office accessible only to the research team. Data may be used for future academic presentations and publications, but it will be presented in aggregate form so you will not be identifiable. Any quotes we present will be screened to ensure individual participants are not identifiable.

AGREEMENT TO PARTICIPATE

Your decision to continue with this survey will be interpreted as agreement to participate. 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 or to refuse to answer specific questions. Any responses you enter can be used in our analysis. You will not be able to withdraw your responses since the research team will not be able to identify your individual data.

If you have further questions concerning matters related to this research, please contact:

Jenny Kelly, W21C Research Associate: 403-210-9264
jekelly@ucalgary.ca

Or

Dr. Doreen Rabi: 403-220-8867
doreen.rabi@albertahealthservices.ca

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

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

Ethics ID: REB17-1417

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