PARTICIPANT INFORMATION AND CONSENT FORM

Research Title

Equitable people-centred health measurement (EPHM)

Principal Investigator

Richard Sawatzky, Professor, School of Nursing, Trinity Western University
Email: rick.sawatzky@twu.ca, Phone: 604-513-2121 ext. 3274

Co-Principal Investigators

Kara Schick-Makaroff, Professor, Faculty of Nursing, University of Alberta
Email: kara.schickmakaroff@ualberta.ca, Phone: 780-248-1096

Maria Jose Santana, Associate Professor, Cumming School of Medicine, University of Calgary
Email: mjsantan@ucalgary.ca

Lisa Lix, Professor, Department of Community and Health Services, University of Manitoba
Email: Lisa.Lix@umanitoba.ca

This project is funded by:

1) The Canadian Institutes for Health Research
2) The BC Office of Patient-Centred Measurement

Cambian Business Services, a Canadian technology partner, is providing in-kind support. You can learn more about Cambian at www.cambian.com.
The researchers are receiving funds to cover the costs of doing this project. You are entitled to request any details concerning this funding from the (Co-)Principal Investigator(s).

Why am I being asked to take part in this project?

We are interested in learning how your pain experience and emotional wellbeing change over time. We are inviting you to take part and answer different surveys. You are eligible if you are:

- an adult (≥ 18 years)
- residing in Canada
- able to complete questionnaires online or by phone
- able to read and speak English

This form entails information about the project. You are free to ask questions. You will be able to download a copy of this form for your records.

What is the reason for doing this project?

Health surveys often use a “one-size-fits-all” approach by asking everyone the same set of questions about their health. This works well for some people but not for everyone, because people from diverse cultures, traditions, and life experiences may understand and interpret questions differently. We aim to change this by tailoring questionnaires to each person.

The purpose of the project is to develop shorter, more accurate, and tailored health surveys that reflect each person's unique experiences and background. The work will inform future use of an online tool with a wide range of health outcomes in diverse populations. The project will ensure that patients' diverse health experiences are described in a way that is truly equitable.

What will I be asked to do?

You will be asked to complete a series of surveys over a period of 6 months. You can decide to complete the survey online or by phone.

Online survey participants

1. Using a web-enabled device (such as cell phone, tablet, or computer), you will be asked to follow step-by-step instructions to register an account on a website called Cambian Navigator (https://cambiannavigator.com/). You will need an email address and a password of your choice. Cambian Navigator is where you will fill out the surveys.
2. You will be asked to complete the following online surveys over 6 months:
   - **First survey**: After setting up your Cambian Navigator account, you will receive an invitation via email to complete a survey about your demographics, social circumstances, diagnoses and health information, and your views of your health and quality of life. This first survey will take between 25-30 minutes to complete.
   - **Repeated surveys (every 2 weeks)**: Within two weeks, and every second week thereafter, you will receive an invitation email or phone call to answer questions about your pain experiences and your emotional wellbeing. This second survey will take 10-15 minutes.
   - **Last survey**: 6 months after the first survey, you will be asked to complete a final survey about any changes in your circumstances, your diagnoses and health information, and your perceived health quality of life. This final survey will take 20-30 minutes.

Phone survey participants

1. You will consent for a research team member to register a Cambian Navigator on your behalf.
2. You will be asked to complete surveys by phone over 6 months (see #2 above).

Projects, such as ours, involving human participants now routinely collect information on race and ethnic origin, as well as other characteristics because they may influence how people respond to different medications/treatments. Providing information on your race or ethnic origin is voluntary.

How long will I be in this project?

You will be asked to complete the surveys over a period of 6 months.

What are the risks or discomforts?

There are no known risks involved with taking part in this project. Whether you choose to participate in the project or not will not affect the care services you receive. Some questions may cause emotional discomfort. The project team will provide information on resources available to you.

What are the benefits to me?

There may or may not be direct benefits for you from taking part in this project. You will be able to see and track your survey results over time. You may be able to reflect upon your needs and to share this information with your healthcare providers.

Do I have to take part in this project?
Taking part in the project is voluntary. If you decide to join, you can change your mind and leave the project at any time without providing an explanation or reason. You do not have to answer any question you do not wish to answer while filling out the survey online or on the phone.

Will I be paid to be in the research?
No, you will not be paid. You will receive a $10 e-gift card after completing the first survey and the first repeated survey. You will receive another $10 e-gift card after completing the last survey.

Can I save the information and return later?
Yes, Cambian Navigator provides you with an option to save your responses and return later to continue the survey(s).

Will my information be kept private?
Your rights to privacy are protected by federal and provincial laws. This is done to ensure that your privacy is respected. It gives you the right to access the information about you that has been collected. It also gives you an opportunity to correct any errors in this information. Consenting to participate in the project does not mean you are forfeiting your right to legal action in the event of research-related harm.

You will answer questions online on a secure platform, called Cambian Navigator, a Canadian company, or a research team member will read the questions to you on the phone. Your responses will be saved on your Cambian account that is controlled by you and managed by Cambian. Your participation in the project means agreeing with Cambian's terms of use and privacy statement when you are registered on their site. Any information that can identify you will be kept in Cambian's secure database. After the project is completed, your information will remain in Cambian until you choose to delete your account.

Cambian offers high security standards plus individual choice: You own the provided data, and you are in control of sharing it with the research team by connecting to the project within navigator and submitting your responses at the end of a survey. Cambian does not collect any 'hidden data' using cookies or other means (e.g. saving your IP address).

At the beginning of the project, Cambian will assign you an identification (ID) number. No data relating to this project that includes your name will be released or published by the research team. We will do everything we can to make sure that this data is kept private. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.
The research team will keep your contact information for five years and then it will be destroyed.

Can you withdraw data?
You can withdraw from the ongoing project at any time. This will not impact any care that you may be

receiving. Your project data that was recorded before you withdrew will continue to be used but no information will be collected after you withdraw your permission.

How will the data be stored?

Your answers will be stored on two secure servers:

1) During data collection, the survey data are stored on Cambian's (= the survey vendor) servers in Canada.
2) The **de-identified survey data** will be transferred based on best-practice data security protocols and stored on a secure server of the project lead at the School of Nursing, Trinity Western University. Only trained research team members will have access to the data.

What do we mean by '**de-identified data files**'? In the transferred data files, your name will be replaced by the ID number and other personal information will be removed.

How will my information be used?

We plan to share results with the healthcare community. This might include conferences, written papers, and classroom presentations. Your de-identified data will be available online to the public for the purposes of publishing papers. That is, we will provide public, free, and unrestricted online access to our findings which will include your de-identified data. Your identity (i.e. your name or any other information that could identify you) as a participant in this project will be kept confidential. There will be no risk to you of being re-identified when we make the data public.

Will I receive the project results?

Yes, we will email you the overall results once the project is complete. If you prefer not to receive the project results, please let us know.

What if I have questions?

If you have any questions about the research project, please contact the research coordinator Charlotte Berendonk at 1-800-882-3188 or charlotte.berendonk@twu.ca. The contact information for project investigators is provided above.

If you have any questions about your rights as a research participant or complaints about your rights as a research participant and/or your experiences while participating in this project, you may contact one of the following ethics boards:

If you live in BC:	• Ethics Compliance Officer in the Office of Research, Trinity Western University at 604-513-2167 or HREB@twu.ca, • or the UBC Office of Research Ethics at 604-822-8598 or e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598,
If you live in Alberta:	• the University of Alberta, Health Research Ethics Board at 780-492-2615 • or Conjoint Health Research Ethic Board (CHREB) at 403-210-6421 or email chreb@ucalgary.ca
If you live in another province or territory:	• Ethics Compliance Officer in the Office of Research, Trinity Western University at 604-513-2167 or HREB@twu.ca,

These offices have no affiliation with the project team.