



Participant Consent Form – (Patients with Chronic Back Pain)

You are invited to participate in a research study entitled: *Living with Chronic Back Pain: A patient-led investigation of health care access challenges for back pain care across the rural-urban continuum in Saskatchewan*

Students:

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Researcher(s):

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Purpose and Objective of the Research:

The purpose of this study is to learn about the experiences of people with chronic low back pain across Saskatchewan. We will also study the experiences of the healthcare providers. The purpose is to learn about some of the strengths and weaknesses to accessing health care in Saskatchewan.

Procedures:

- Taking part in this study will include an interview with one of our researcher team members. You will be asked about your experience living with low back pain. You will also be asked to complete a survey about you, your back pain, and your general health.
- You have 3 options for completing the survey: 1) you can answer the survey online by clicking on a secure personal link that will be e-mailed to you using REDcap software. For more information on the security and privacy of REDcap, please visit the following link: <https://projectredcap.org/software/> 2) You can complete the survey on a paper copy that is mailed to you (we will include postage for you to mail it back). 3) We can set up a time for you to answer the survey questions over the phone or over video conference.
- The interviewer will ask for your consent for audio recording the interview. The recording helps us keep an accurate record of what you said. We will not use the recording for any other purpose. You may ask to have the recording device turned off at any time, without giving a reason. The consent for audio recording is at the bottom of this form.
- Interviews will take place in person, or over the phone or video conference, depending on your preference and any public health guidelines in place. In person interviews will take

place at the University of Saskatchewan or the researcher can travel to you when a secure location for the interview can be arranged. We will reimburse you for any parking costs if you choose to travel to meet us.

- The interviews will take about 30 minutes to one hour.
- Interviews will take place using Zoom Pro version. The privacy policy for Zoom can be found here: <https://zoom.us/privacy>
- If you require a translator, a translator will be provided at no cost to you. The translator will sign a confidentiality agreement.
- After your interview, you will be given the chance to review the typed copy (transcript) of your interview. You can add, change, or remove information from the transcript as you see fit. You will be given one week to provide changes to the transcript, otherwise it will be used in the form that it was sent to you. A transcript release form will be provided.
- Audio recordings will be sent to the Social Sciences Research Laboratory (SSRL) at the University of Saskatchewan for transcription and analysis. Recordings will only be identified by first name and an ID number to maintain confidentiality.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

Funded by:

- This study has been funded by the Saskatchewan Center for Patient Oriented Research, the College of Medicine, and the Canadian Institutes of Health Research. The research team has no conflicts of interest to be declared.

Potential Risks:

- There is a chance that you might experience mental or emotional discomfort as we ask you to talk about your back pain experiences.
- If you feel that support is needed, please feel free to let the research team know so that we can assist you to find appropriate support. You may also follow up with your family physician or counsellor, if appropriate and available. Additional sources of support include:
 - Professional Health Advice and Mental Health Support (8-1-1)
 - Crisis Services Canada – Suicide Prevention and Support (1-833-456-4566)
 - Prince Albert Mobile Crisis Unit (306-764-1011)
 - Regina Mobile Crisis Services (306-525-5333)
 - Saskatoon Mobile Crisis (306-933-6200)

Potential Benefits:

- There will be no direct personal benefits for taking part in the study. However, as we share the findings of the research, we expect impacts on future access to care for people with chronic back pain.

Compensation :

- Participants will be offered a \$50 honorarium for their participation. Traditional Indigenous Healers, Indigenous Elders or Traditional Knowledge Keepers will receive a \$100 honorarium and gifts of tobacco or cloth as appropriate. Withdrawing from the study will not affect the payment of honorarium.

Confidentiality:

- The information we collect in this study will be shared through presentations, conferences, and journal publications.
- In all publications or presentations, your identity will be kept confidential. Data will be presented in a summarized form, with information from all participants combined. Direct quotations may be reported from the interview, but your name will never be used. All identifying information will be removed from the report.
- Patient advisors are important members of our research team and will be involved in the analysis and interpretation of the combined and summarized data.
- By signing this consent form, you are giving your permission to have the interview be audio recorded.

Storage of Data:

- Paper copies of surveys and consent forms will be stored in a locked cabinet, in a locked office at the University of Saskatchewan. Electronic information will be stored on a password-protected computer during data collection, and immediately transferred to a secure online storage site at the University of Saskatchewan.
- Data will be stored for the minimum required storage period of five years post-publication. The master-list that connects your name to your participant identification code will be kept for a 6-month period. This list will be stored separate from all other data in a secure electronic folder. It will be permanently deleted after a 6-month period.
- Once the data is no longer required and following the required storage period, the data will be destroyed beyond recovery.
- Identifying information, (e.g., Consent Forms, master list) will be stored separately from the data collected.

Right to Withdraw:

- Your participation is voluntary, and you can choose to answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without a reason or penalty of any sort.
- Should you wish to withdraw, please contact our research team using the contact information provided, and your data will be deleted from the research project and destroyed.
- Your information/data will not be shared with your treating health care practitioners; therefore, any current or future health care provided will not be affected by participating in this research.

- Your right to withdraw data from the study will apply until one month following your interview. After this, it is possible that some form of sharing the research findings will have already occurred and it may not be possible to withdraw your data.

Follow up:

- We will share findings from the study with all participants through e-mail or mail.
- Research findings will also be posted on the CCHSA website: <https://cchsa-ccssma.usask.ca/research.php>

Questions or Concerns:

- Contact the researcher(s) using the information at the top of page 1.
- This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office: ethics.office@usask.ca; 306-966-2975; out of town participants may call toll free 1-888-966-2975.

Preferred method of receiving documents (research findings, copy of signed consent form):

E-mail: Please provide your e-mail address : _____

OR

Mail: Please provide your mailing address : _____

Preferred method of providing consent :

- Signed Consent**
- Oral Consent**

Signed Consent:

Your signature below indicates that you have read and understand the description provided. I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project, including being audio recorded. A copy of this consent form has been given to me for my records.

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
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<i>Researcher's Signature</i>	<i>Date</i>
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A copy of this consent will be left with you or sent to you via email or mail (as you have indicated your preference above), and a copy will be taken by the researcher.

To be completed by the researcher(s):

Oral Consent:

- For participants who are taking part remotely (ie – via telephone or videoconference) or who do not feel comfortable providing a signature, consent will be obtained orally, and the following section will be completed by our researcher.

I read and explained this consent form to the participant before receiving the participant's consent, and the participant had knowledge of its contents and appeared to understand it.

<i>Name of Participant</i>	<i>Researcher's Signature</i>	<i>Date</i>
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