Parent/Guardian Consent and Youth Assent Form

You are invited to participate in a research study entitled: Assessing the need for pediatric gait analysis in Saskatchewan: A mixed methods needs assessment

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Research Team:

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PART 1: Information for the Parent or Guardian

Please read this section carefully. It contains detailed information you need to decide if you want to allow your child to participate in this study.

Purpose and Objective of the Research:

Currently, Saskatchewan does not have a local program for specialized walking assessments (gait analysis) to guide rehabilitation for children and youth. Families must travel out of province for this care. This project aims to build a sustainable, fair, and accessible walking assessment program right here in Saskatchewan.

Through this interactive virtual workshop, we aim to:

- **Engage participants across Saskatchewan** by securing broad geographic representation from families and clinicians in rural, remote, and urban communities alike.
- **Remove participation barriers** (such as travel, time, and cost) by providing a highly accessible, flexible digital platform.
- **Validate and build upon findings** by collaboratively sharing and refining the key priorities, barriers, and solutions identified during our initial in-person sessions.

- **Co-develop next steps** to help design a local service pathway, a project website, and educational resources tailored to the needs of Saskatchewan families and healthcare providers.

Ultimately, your child's virtual participation will help shape the future of local pediatric healthcare and improve walking outcomes for children in our province.

Who can participate?

Eligible participants are residents of Saskatchewan, and meet at least one of the following criteria:

Healthcare provider criteria:

- Allied health professionals who practice in Saskatchewan and assess and treat pediatric patients with disabilities/injuries/diagnoses that directly impact their walking ability
- Physicians who practice in Saskatchewan, in a pediatric specialty, and assess and treat patients with disabilities/injuries/diagnoses that directly impact their walking ability

Patient/Caregiver criteria:

- Families or support persons of children who live with a disability/injury/diagnosis that causes a gait impairment (may be permanent or temporary)
- A person with lived experience as having trouble walking as a child
- The minimum age requirement for youth participants is 10 years old, corresponding to grade 6

Community and other relevant groups:

- Government representation
- SHA Administration
- Non-profit organizations
- Licensing and Regulatory bodies
- Other relevant organizations focused on pediatric care delivery

Participants who do not live or practice in Saskatchewan, or who are not involved in the access, provision, administration, or policy development of pediatric gait-related services, are ineligible to participate in the World Cafe discussions.

Your child's participation will have no impact on access to care, your child's relationship with anyone on the research team or your work within the SHA or with the University of Saskatoon. Participation will not impact access to care or services, employment, relationships with the research team or other organizations.

Procedures:

If your child chooses to participate, you will join a 1.5 hour online World Café discussion session on Zoom. The session will include:

- A brief review of findings to date
- Small group breakout discussions focused on walking care and access to care
- Sharing ideas, reflections, and recommendations with other stakeholders

A trained research team member will facilitate each breakout room and will take notes on key points, ideas, and suggestions shared during the discussion.

Respectful Engagement:

While our team is fully committed to implementing robust measures to protect all the information you share, maintaining a secure environment is a collective responsibility. To ensure everyone feels comfortable contributing openly, we kindly ask that all participants refrain from recording, photographing, or taking screenshots of any conversations or presentations during the session.

Please also be aware that despite our best efforts to enact data protection protocols, virtual events have inherent technical limitations. While we take every precaution to prevent unauthorized captures, we cannot provide an absolute guarantee against participants who may choose to record information secretly. We appreciate your cooperation in helping us foster a space built on mutual trust and privacy.

Information shared:

During the discussion, facilitators will take digital written notes, and ideas added to notes will be saved to a secure password-protected repository in an anonymized format. This consent form is intended to provide detailed information about the event, and what will be recorded, and for what purpose. With your child's registration, you will be consenting to this process, including audio recording and note taking. When the event starts, you will join a main Zoom room session as well as be put into smaller breakout rooms, and both the main Zoom room and the small breakout room sessions will be video recorded.

This discussion will be recorded to help us gather your child's thoughts and different recommendations that evolve during this dialogue. Your child's ideas will play an important role in shaping recommendations for future actions and policy planning. Please note that Zoom's recording feature captures both audio and video. However, should your child prefer to keep their camera off, or turn it off any time, they can do so.

Immediately following the event, we will download the recording to our secure password-protected repository and permanently delete the file from the Zoom cloud. The recording will not be shared and will only be used for generating a post-event report. We will only retain the audio portion for transcription purposes; the video recording will only be retained till point of transcription, and the audio recordings will be retained for the full five-year post-publication retention period.

Funded by:

This project is funded by the College of Medicine Research Awards at the University of Saskatchewan & the Saskatchewan Health Research Foundation Mobilize Grant. The researchers have no conflicts of interest, and the funding agency does not influence the discussions or outcomes of the World Café event.

Potential Risks:

We do not anticipate any risk associated with participating in this discussion. However, some of the questions in the table discussion may ask you to reflect on barriers to access healthcare services, which may cause psychological or emotion distress or discomfort. Your child has the right to withdraw from the study at any time or skip any question(s) without penalty. Should they require mental health assistance during the study, please call 811 or go to https://www.counsellingconnectsask.ca/ to connect with a healthcare professional.

Participation will not impact your child's access to care, services, or relationships with the research team.

Potential Benefits and Compensation:

Five gift cards of $50 each will be available for virtual participants. Participants can enter the draw by providing their email address in registration. Your child will be entered to win the gift cards even if you withdraw during the session. Any personal information collected as a record of compensation will be stored separately from the data by the PI and may be kept for 7 years in case the University of Saskatchewan is audited by the Canada Revenue Agency.

This initiative will determine the need for a walking assessment program in Saskatchewan. It may help children receive the right care at the right time, improve therapy outcomes, and empower families with clearer paths forward.

Confidentiality and Data Protection:

We will take all reasonable steps to protect your information. Notes will be stored in a secure, password protected University of Saskatchewan digital repository accessible only to authorized research team members. Your child can keep their camera on or turn off their camera or microphone at any point without giving a reason. The interviewer will conduct the meeting from a private location, to which only research team members will have access during the meeting. We recommend that your child do likewise.

For your child's privacy, this table discussion will be conducted via Zoom's secure platform, which utilizes end-to-end encryption to ensure our conversation remains confidential. You can review Zoom's specific privacy and security measures here. While these safeguards are in place, please be advised that confidentiality of data transmitted electronically cannot be fully guaranteed.

Due to the group nature of the event, complete confidentiality of your child's identity cannot be guaranteed. By signing this consent form, your child agrees to respect the privacy of all participants and keep all personal information and discussions shared during the event strictly confidential. No identifying information will appear in reports, summaries, or publications. The findings will be disseminated through academic channels: such as peer-reviewed journal articles, conference presentations, as well as shared in summary reports with community

stakeholders. All data will be presented in aggregate form or using de-identified information to protect participant confidentiality.

It is possible that authorized USask representatives like members of the Research Ethics Board and Responsible Conduct of Research may look at your child's data, if required as part of an investigation into the conduct of the study.

Storage of Data:

Your child's ideas from this discussion will be written down by the facilitators and stored securely in the University of Saskatchewan's protected digital system, where only the research team can access them. The audio recording of the session will be captured and stored in OneDrive (under secured university credentials and password-protected files). This will strictly be limited to the research team via multi-factor authentication (MFA) to ensure data integrity. Temporary data storage will be kept on the Principal Investigator's USask OneDrive account, and long-term data storage will be kept by the Principal Investigator, digital will be kept on their Datastore account and paper data will be kept in a locked cabinet in a locked office. The consent forms and master lists will be stored separately from the data. The data will be stored for five years post-publication.

After the event, we will organize the main points into a summary that will be shared with you and your child. This summary will also help us create final reports, policy briefs, a presentation to the working group, community stakeholder events, community presentations, webinars, and other materials to share what we learned in a useful and respectful way.

Right to Withdraw:

Your child's participation is entirely voluntary. You or your child may withdraw them from the project at any point during the virtual event by simply exiting the Zoom meeting space. Because this is a collaborative group discussion, individual spoken contributions cannot be isolated or deleted once they have been integrated into group notes. However, no names will ever be attached to these notes.

Follow up:

If you would like to know the results of this study, please contact Dr. Valerie Caron at valerie.caron@usask.ca. Results will be available in the Summer of 2027 at which time they will be shared with participants of the study.

Questions or Concerns:
You can contact Dr. Valerie Caron using the contact information on the first page of this document, please feel free to ask any questions regarding the procedures and goals of the study or your child's role.

This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board (#6616). 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.

PART 2: Information for the Youth Participant (Assent)

This section is written for you. Please read this (or have a parent read it to you) before deciding if you want to join our online discussion.

What is this project about?

We want to make it easier for kids and youth in Saskatchewan who have trouble walking to get special check-ups (called "gait assessments") close to home. Right now, many families must travel to other provinces for this help. We want to build a local program in Saskatchewan, and we need your help to design it.

What will I do?

We would like you to join a 1.5-hour online group video chat on Zoom.

- You will be in a small group with other youth, parents, and healthcare helpers.
- You will be able to talk about your experiences with walking care and how hard or easy it is to get help.
- You can share your ideas on what an ideal walking assessment program should look like.

Will anyone know what I said?

- We will record the audio of the meeting so we don't forget your ideas, but we will never use your name in our final reports.
- If you don't want your face on screen, you can keep your camera turned off.
- We ask everyone in the group to respect each other's privacy and not take screenshots or recordings of the chat.

Do I have to join?

No, it is completely up to you. Even if your parent or guardian says yes, you can still say no if you don't want to do it. No one will be mad at you, and it won't affect your healthcare or therapy.

If you join the Zoom meeting and decide you want to leave, you can just click "Leave Meeting" at any time. If you leave, we won't be able to delete the ideas you already shared in the group notes, but your name will never be attached to them.

PART 3: Consent and Assent Signatures

Please note: For a youth under the age of 18 to participate, **both** the youth and the parent/guardian must sign their respective sections below. A copy of this consent will be left with you, and a copy will be taken by the researcher.

1. Youth Participant Assent (Aged Under 18)

- I have read this form (or had it read to me), and I understand what I am being asked to do.
- I have had my questions answered, and I know I can ask more questions later.
- I know that I can change my mind and stop participating at any time.
- I agree to join this virtual World Café.

Youth Participant Name (Printed): _____

Youth Participant Signature: _____

Date: _____

2. Parent or Guardian Informed Consent

- I have read and understood the detailed participant information sheet (Part 1) regarding the pediatric gait analysis needs assessment.
- I understand the virtual procedures, potential risks, and data limitations regarding my child's right to withdraw.
- I give my full, informed consent for my child to participate in this virtual study.

Parent/Guardian Name (Printed): _____

Relationship to Child: _____

Parent/Guardian Signature: _____

Date: _____