



**SCI Step Together: Improving Physical Activity Participation Among Individuals With  
SCI Who Ambulate**

Consent form



## Consent to participate in physical activity intervention

### “Assessing the acceptability and feasibility of an mHealth app to increase the quantity and quality of physical activity experiences among individuals with spinal cord injury who ambulate”

#### Identification of Investigator

You are invited to participate in a research study, titled “Assessing the acceptability and feasibility of an mHealth app to increase the quantity and quality of physical activity experiences among individuals with spinal cord injury who ambulate”. This study is conducted by student investigator Sarah Lawrason of the University of British Columbia, for partial fulfillment of the Degree Doctor of Philosophy. She may be reached at (613)-539-3447 and/or [svcl11@mail.ubc.ca](mailto:svcl11@mail.ubc.ca). Dr. Kathleen Martin Ginis is the Principal Investigator of this study. She can be reached at 250-807-9768 and/or [Kathleen\\_martin\\_ginis@ubc.ca](mailto:Kathleen_martin_ginis@ubc.ca). Sarah Lawrason is a PhD Candidate in the School of Health and Exercise Sciences and has a BScH in Kinesiology and a MSc in Sport Psychology. Dr. Kathleen Martin Ginis is a Professor in the Faculty of Medicine and School of Health and Exercise Sciences. This study will be conducted in partnership with Curatio, Inc. Lysa Campeau is the External Project Manager for Curatio, Inc. for this study.

#### Background and Purpose of Study

Individuals living with spinal cord injury (SCI) who walk participate in less physical activity than individuals with SCI who use wheelchairs. Lower levels of physical activity may be due to barriers such as increased pain and fatigue, lack of time, and lack of knowledge. Additionally, quality of physical activity experiences also play an important role in participation. However, there are no physical activity interventions available targeted specifically for individuals with SCI who walk.

Curatio’s private social network platform provides curated content about specific health conditions, offers digital tools to help manage those conditions, and a secure way to connect with others who are “just like you.” Privacy and regulatory compliant, it works like a social plug-in, also giving health providers a tool to remotely connect their patients to evidence-based programs and peer support groups. Users download the app to their smartphone and the company works behind the scenes to power the platform.

Your participation and feedback will help guide the design and delivery of an app to virtually provide users with the support they need to stay healthy at home during the COVID-19 pandemic and beyond. As a key participant in this project, you will have the chance to share your voice and recommendations so that we can design a patient support tool that works best for people like you!

**Purpose:** Therefore, this study will develop and assess the acceptability and feasibility of a mobile app called Stronger Together to increase the quantity and quality of physical activity among ambulators with SCI according to evidence.

#### Your participation is voluntary.

Your participation is voluntary. You have the right to refuse to participate in this study. If you decide to participate, you may still choose to withdraw from the study at any time without any negative consequences to the medical care, education, or other services to which you are entitled or are presently receiving.



Please review the consent document carefully when deciding whether or not you wish to be part of the research. Sign this consent form only if you accept being a research participant.

### **Who can participate in this study?**

You may be able to participate in this study if:

- You can read and write in English
- You own a smartphone or tablet compatible with the Stronger Together app (e.g., iOS, Android)
- You are 19 years of age or older
- You are a Canadian or United States resident
- You have sustained a spinal cord injury
- You are greater than 1 year post spinal cord injury
- You walk for your daily mode of mobility (do not use a wheelchair for daily mode of mobility)

### **What does this study involve?**

If you decide to join this study, you will be randomized into either a wait-list control or intervention group. If you are randomized into the **wait-list control** group, we expect you to:

- **Maintain current health habits:** Please maintain current health habits. We would prefer that you do not engage in any new physical activity program from the next 8-weeks.
- **Remove Stronger Together program:** If you are currently enrolled in the Stronger Together program, please remove the app from your devices and stop participation for the next 8-weeks.
- **Online surveys:** You will be asked to take part in online surveys over the 8-week study. The first survey will happen when you consent to the study. Follow-up surveys take place at 4 weeks and 8-weeks after your initial surveys. Each survey is expected to take approximately 45 minutes. You will complete an additional 5-minute survey on demographic information at the beginning of the study (only once).

If you are randomized into the **intervention** group, we expect you to:

- **Participate in daily programming:** Over the span of 8-weeks, you will be asked to participate daily in the Stronger Together program via your mobile device. You may participate in the daily programming for as long or as little as you please. We ask that you engage with the program **at least once per week**.
- **Online surveys:** You will be asked to take part in online surveys over the 8-week study. The first survey will happen when you consent to the study. Follow-up surveys take place at 4 weeks and 8-weeks after your initial surveys. Each survey is expected to take approximately 45 minutes. You will complete an additional 5-minute survey on demographic information at the beginning of the study (only once).
- **Optional interview:** After the 8-week Stronger Together program is complete, you will have the option to participate in an exit interview where you can talk about your



experience in the program. The interviews are expected to take about 45-60 minutes. Interviews will occur over UBC licensed Zoom and the servers for these are located in Canada.

### **What are the possible harms and discomforts?**

There are no known major risks for this study. You do not have to answer any questions that you are uncomfortable answering. Information provided by the health coach (i.e., community manager, Sarah Lawrason) should not be prioritized over advice given by your health professionals, and if you have such concerns, this should be raised with the health coach, and if not resolved, then with the project coordinator.

### **What are the potential benefits of participating?**

There may not be direct benefit to you from taking part in this study. We hope that the information learned from this study can be used to help you engage in more physical activity and help to improve your overall health and wellness and be used in the future to help benefit other persons living with a physical disability.

The researchers involved in this project may benefit from increased awareness, sharing and use of their original knowledge. Curatio may benefit from this project through an increased program portfolio. In turn this could lead to increased funding opportunities and/or financial rewards later for Curatio.

### **Participation or Withdrawal**

You may withdraw from this study at any time without giving reasons. If you choose to enter the study and then decide to withdraw later, you have the right to request the withdrawal of your information collected during the study. This request will be respected to the best extent possible. Please note however that there may be exceptions where the data will not be able to be withdrawn. For example, where the data is no longer identifiable (meaning it cannot be linked in any way back to your identity) or where the data has been merged with other data. If you would like to request the withdrawal of your data, please let the student investigator know.

### **Confidentiality of Data**

Your confidentiality will be respected. However, research records and health or other source records identifying you may be inspected in the presence of the Investigator or designate and by representatives of UBC's Behavioural Research Ethics Board for the purpose of monitoring the research. No information or records that disclose your identity will be published without your consent, nor will any information or records that disclose your identity be removed or released without your consent unless required by law.

You will be assigned a unique study number as a participant in this study. This number will not include any personal information that could identify you (e.g., it will not include your Personal Health Number, SIN, or your initials, etc.). Only this number will be used on any research-related information collected about you during this study, so that your identity will be kept confidential. Information that contains your identity will remain only with the Principal Investigator and/or designate. The list that matches your name to the unique study



number that is used on your research-related information will not be removed or released without your consent unless required by law.

All data will be accessible via Curatio and Qualtrics (i.e., survey tool). This data will be provided by you (e.g., email address, name - if chosen to provide in app). This data will not be identifiable unless you choose to disclose/share your personal information. For example, you can sign up with your email address and choose a display name that is not connected to you (pseudonym) if you prefer and choose not to provide any more personal information about yourself. Data from questionnaire responses will be tied to your profile in the app to connect any changes in your responses to your in-app activity. However, data from the questionnaires and the in-app activity data will be stored using a participant ID that is not connected to any of their personal information shared in app.

Within the Stronger Together app, your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected. You also have the legal right of access to the information about you and if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request to the study team. Curatio uses service providers located in Canada and countries other than Canada, including the United States, to deliver Stronger Together. These other countries may have different privacy laws than Canada and your personal information may not be as well protected as it is under Canadian privacy law. For more information on Curatio's privacy policy please refer to the following: <https://legal.curatio.me/privacy-stronger-together>

Sarah Lawrason and Dr. Kathleen Martin Ginis are the only investigators that will have access to the raw data. Furthermore, Sarah Lawrason will be participating in the app as the health coach (i.e., community manager). Curatio partner Lysa Campeau will not have access to the raw data, but rather a final report. Lysa will also have access to participants' emails for those who enrol and download the Stronger Together program. Currently, no one else is involved, but other potential people that may have access to the raw data are any temporary student assistants who may join and assist with the project in the future (when new research staff/collaborators are identified we will submit an amendment to bring them onto the ethics application).

Please note we strongly encourage all participants to refrain from disclosing the contents of the discussion outside of the group. However, we cannot control what other participants do with the information discussed.

### **What happens if something goes wrong?**

By signing this form, you do not give up any of your legal rights and you do not release the principal investigator, participating institutions, or anyone else from their legal and professional duties. If you become ill or physically injured as a result of participation in this study, medical treatment will be provided at no additional cost to you. The costs of your medical treatment will be paid by your provincial medical plan.

### **Compensation for Participation**



You will receive complementary access to the Curatio app and all of the content and supports that are included in the app and their respective Stronger Together health self-management programs.

You will be compensated for your time! You can receive up to **\$100** for partaking in this study if you complete all questionnaires and the interview. You will be compensated for completing questionnaires at each time point: **\$20 at time 1 (baseline)**, an additional **\$30 at time 2 (week 4)**, and an additional **\$40 at time 3 (week 8)**. In total, if you complete all questionnaires at all time points, you will receive **\$90**. If you are randomized into the intervention group and you partake in the interview, you will receive an **additional \$10**.

### **Who do I speak to if I have questions about the study during my participation?**

You can contact Sarah Lawrason (the student investigator) at 613-539-3447 or [svcl11@mail.ubc.ca](mailto:svcl11@mail.ubc.ca)

### **Who do I contact if I have any questions or concerns about my rights as a participant?**

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca) or by phone at 604-822-8598 (Toll Free: 1-877-822-8598.) Please reference the study number H21-01279 when calling so the Complaint Line staff can better assist you.

### **Who is funding the study?**

- Social Sciences and Humanities Research Council (SSHRC): Partnership Grant [grant number 895-2013-1021] for the Canadian Disability Participation Project ([www.cdpp.ca](http://www.cdpp.ca)).
- SSHRC Doctoral Fellowship (Sarah Lawrason)
- WorkSafe BC Doctoral Research Training Award (Sarah Lawrason)

### **Participant Consent**

Clicking YES on this consent form means:

- I have read and understood the information in this consent form.
- I have been able to ask questions and have had satisfactory responses to my questions.
- I understand that my participation in this study is voluntary.
- I understand that I am completely free at any time to refuse to participate or to withdraw from this study at any time.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me.

By clicking YES below, I accept the conditions of this study and provide my consent. I will keep a copy of this webpage for my own records.

Do you consent to participate in this study?



YES (please provide your name)

▪ Name \_\_\_\_\_

NO

Please provide your contact information.

First Name: \_\_\_\_\_

Last Name: \_\_\_\_\_

Email: \_\_\_\_\_

Phone Number: \_\_\_\_\_

### **Study Results**

Are you interested in learning about the study results in the future?

Yes  No