



## PARTICIPANT INFORMATION AND CONSENT FORM

### **Title of Study:**

ABLE-Village “Artful Aging: A digital village for older adults to enhance social connectivity”

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**Funding source: Social Sciences and Humanities Research Council (SSHRC) Partnership Development Grant Award Number: 890-2022-0094**

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You are being invited to participate in a research study about connecting virtually to enhance social connectedness. To decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This letter gives detailed information about the research study. Once you understand the study, you will be asked to give consent verbally at an introductory online meeting if you wish to participate. Please take your time to make your decision. Feel free to discuss it with your friends and family, or your family physician.

### **WHY IS THIS RESEARCH BEING DONE?**

We have developed a virtual platform that allows older people to connect, play games, make art, and engage in movement activities with others, including family members in different locations, through computer video at the same time (or “live”). We would like your feedback on the design and the interaction (or “game design”) of this platform and the social, physical, mental, and artistic activities included on the platform.

### **WHAT IS THE PURPOSE OF THIS STUDY?**

The purpose of the study is to show you the virtual platform (ABLE Village: <https://www.ableplatform.ca>) we have developed and get your feedback about what you like, or what you would change, about the platform.

### **WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?**

**If you volunteer to participate in this study, we will ask you to do the following things:**

You would first be asked to complete a brief survey which will ask you some demographic questions and some questions about your leisure preferences, daily activities, and familiarity with digital media. This survey should take 10-20 minutes to complete. You can complete the survey on your own via a link sent to you or a research assistant can assist you by asking you the questions on the survey and filling out the survey on your behalf. The survey is hosted on Microsoft Forms.

After you complete the survey, You would be asked to participate in 5 to 20, one- to two-hour long online focus groups with 1-7 other participants between September 2023 and March 2025 (for a maximum total of 40 hours). During these focus groups, we will show you the platform and ask you for your feedback on the design. You can participate in as many or as few focus groups as you desire, and you will participate in a focus group size of your preference (1-8 participants and 2-6 research team members). You may invite your own friends and family to

participate in the focus group with you or choose to participate with fellow community members. You have the option of observing the platform or testing the platform by using your computer (touch pad or mouse) or tablet. If you wish, we can loan you (free of charge) a tablet and an internet connection, and teach you to use them, so that you can participate in the ABLE Village research. We also can meet with you individually before the research meeting, to help you to use your computer and access the ABLE Village platform.

We will record the audio and video from the online focus group so that we can analyze what was said and done later. The audio and video files will be used for research purposes only, and will not be used for promotion, education, publications, posters, websites, or external media unless you provide your written consent. If you decide you would not like the audio or video of the focus group recorded, you can let the researcher know and we will not record the focus group. The focus group will take place online on Zoom or the ABLE Village platform.

### **Participants Leads:**

At each project site, we will also be recruiting a participant lead who will liaise and serve as an intermediary between participants and academic partners, thus serving as envoys for the larger group of participants. The lead participant at each site will take part in the meeting, answering questions and helping participants to understand the research opportunity. Please let a member of the research team know if you are interested in serving as a lead.

Participant leads will be recruited as follows: If only one participant expresses a desire to serve as lead, then that participant will be lead. If more than one participant expresses a desire to serve as lead, then each prospective lead participant's name will be added to a numeric list and a random number generator will be used to select a random number - the number selected will determine who will be lead participant. If no one expresses a desire to serve as a lead participant, then we will notify the participants that we are looking for a lead participant and ask participants to identify if they would like to serve as a lead. If one or more participants volunteer to serve as lead, then the earlier selection statements will go into effect (i.e., for one participant lead - they will be come lead, for more than one prospective lead - there will be a random draw.). If at that point no one wants to lead, we will ask the community partner or delegate to serve as envoy to participants.

### **ELIGIBILITY**

You are eligible to participate if you are 65 years of age or older and can speak/understand English ([French for Montréal site](#)).

### **WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?**

It is possible that you could experience mild physical, psychological, or social risks when participating in the focus groups.

**Physical Risks:** It is possible that using a computer mouse or keypad in excess could cause pain or discomfort in your hand/wrist. If you feel any pain during the focus group, stop the activity and let a member of the research team know right away. You can still participate in the

study. Also, you have the right to withdraw from the study for any reason, including physical discomfort/pain.

**Psychological Risks:** You will be asked about your experiences related to the ABLE Village platform. For some people, these experiences might be intertwined with negative experiences (such as negative stereotypes about older age and technologies). Therefore, it is possible that this could lead to recalling experiences that were frustrating or stressful. You may also feel uncomfortable providing constructive feedback or recounting negative experiences related to using the platform. To mitigate these risks, the research team will reassure you that we want your constructive feedback, as it will make the platform better. You can also speak to the peer leader or community partner about your concerns. Also, you have the right to withdraw from the study and can skip any questions you desire without any penalty.

**Social Risks:** It is also possible that you may worry that if others hear you speaking about your experiences with the ABLE Village platform. Being that the focus groups are being conducted virtually, you can also choose to participate in a setting that you deem as comfortable and secure. You also have the option to turn your camera off at any point. We will further mitigate these risks by being transparent that you can refuse to answer any questions if you so choose or have the option to withdraw from the study at any point. You can also speak to the peer leader or community partner about your concerns. Moreover, study results will be de-identified and reported in aggregate; therefore, it will be unlikely that others will be able to identify individual participants in any reported results. When we transcribe the audio-recording we will remove all identifying information, so you will not be identified in any reports, presentations, or publications. The online focus group will be password protected to ensure the confidentiality of the information discussed.

This study will use the Zoom platform to collect data, which is an externally hosted cloud-based service (a link to their privacy policy is available here: <https://zoom.us/privacy>), the ABLE platform (see manual here: <https://www.ableplatform.ca/assets/ableusermanual.pdf>) which uses the Jitsi teleconferencing site (a link to their privacy information is available here <https://jitsi.org/security/>), and Microsoft Forms (a link to their privacy policy is available here: <https://privacy.microsoft.com/en-ca/privacystatement>). While the McMaster Research Ethics Board has approved using these platforms to collect data for this study, there is a small risk of a privacy breach for data collected on external servers. If you are concerned about this, we would be happy to make alternative arrangements for you to participate, perhaps via telephone. Please talk to the researcher if you have concerns.

## **HOW MANY PEOPLE WILL BE IN THIS STUDY?**

We are recruiting 6-8 participants and a participant lead (who will liaise and serve an intermediary between participants and academic partners, thus serving as envoys for the larger group of participants) at each project site.

## **WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?**

There are no direct benefits to you from your taking part in this study, although you may have fun enjoying the activities on the ABLE platform, meet new people, and take pride in knowing your feedback shaped the direction of the creation of the ABLE platform. As a result,

your participation may help older people be more socially engaged and active, which may help them to be more mobile and have a greater quality of life.

### **IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES? CAN PARTICIPATION IN THE STUDY END EARLY?**

It is important for you to know that you can choose not to take part in the study as your participation in this study is voluntary. You may withdraw from the study at any time without any consequence to you. You may also refuse to answer any questions you do not want to answer and still remain in the study. If you want to stop being in the focus group you can stay and simply stop talking or you can leave, but it will not be possible for you to pull out your data from the flow of the conversation because of the interconnected nature of this type of group discussion where a person's comments can stimulate the sharing of comments made by others in the group. Similarly, if you decide to withdraw from the study while taking the survey, then do not complete the survey simply exit out of the survey. We will not collect any data from incomplete surveys or surveys that have not been submitted. However, once you have submitted your responses to the survey, your answers will be put into a database and will not be identifiable. This means that once you have submitted your survey, your responses cannot be withdrawn from the study because we will not be able to identify which responses are yours.

If you would like to withdraw, please contact a member of our research team via email at (macpulse@mcmaster.ca) or via phone at 905-525-9140 ext. 27959.

### **WHAT INFORMATION WILL BE KEPT PRIVATE?**

No one but the research team and other focus group participants will know whether you were in the study unless you choose to tell them. Every effort will be made to guarantee your confidentiality and privacy.

This study will use Microsoft Forms to collect survey responses, as well as Zoom and the ABLE Village platform to conduct focus groups. Zoom is an externally hosted cloud-based services. We will record video and audio during the focus groups using the recording feature with Zoom and using the AI-generated transcriptions provided through Zoom. Video and audio recordings and transcripts will be saved to a password protected Zoom cloud account until transcripts of the recordings are cleaned and de-identified by a member of the research team (approximately 2-weeks). Once cleaned, audio and video files from the focus groups will be permanently deleted and only de-identified transcripts will be kept by the research team. In the de-identification process, we will remove any words/phrases (including names) that could potentially identify you. Despite this, it may be possible that you, or someone close to you, might suspect that the quotes belong to you. However, we will be assigning a participant identification number to you. Any quotes will be attributed to pseudonyms. Please note that whilst Zoom is approved for collecting data in this study by the McMaster Research Ethics Board, there is a small risk with any platform such as this that data collected on external servers could fall outside the control of the research team. For more information, a link to their privacy policy is available here (<https://zoom.us/privacy>). If participants have concerns about this, we would be happy to make alternative arrangements for your participation.

All participants will agree that they will not make unauthorized recordings of the content of the focus groups. However, the researchers cannot guarantee that all participants will refrain from recording the session.

Only the research team will have access to the research data. Your information (data) will not be shared with anyone except with your consent or as required by law. De-identified research data will be stored as digital files on university password protected (known as “MacID”) enabled shared drives (McMaster Microsoft Teams & Share Point accounts). Microsoft Teams and Share Point only permits access to authorized users and the Microsoft Teams & Share Point pages where anonymized data will be housed is only open to the research team. All personal information such as your name, email/ mailing address, and phone number will be removed from the data and will be replaced with a number. A list linking the number with your name will be kept in a secure place (in a password protected, locked folder on the Principal Investigator’s personal computer), separate from your file. The data, with identifying information removed will be securely stored in a locked office in the research laboratory. For more information, a link to their privacy policy is available here (<https://privacy.microsoft.com/en-ca/privacystatement>).

We plan on retaining de-identified data for a period of ten years, which is March 2033. This will give the research team time to write up and disseminate results. All data will be permanently deleted, and trash emptied (as data will be electronic), at the end of the retention period.

If the results of the study are published, the data will be reported in aggregate. This means that your name will not be used and no information that discloses your identity will be released or published without your specific consent to the disclosure.

### **WILL I BE PAID TO PARTICIPATE IN THIS STUDY?**

You will receive a \$50 gift card (a \$200 cheque if you are a participant lead) for each year for your participation in this two-year study. You will receive your honorarium for year 1 on April 30, 2024, and on April 30, 2025 for year 2. If you withdraw from the study, you will still be eligible to receive an honorarium; however, the amount you receive will be proportionate to the time in which you participated in the study (e.g., if you withdraw after 6-months of participating in the study, you will receive half of a one-year honorarium, which is \$25).

### **WILL THERE BE ANY COSTS?**

Your participation in this research project will not involve any additional costs to you.

### **INFORMATION ABOUT THE STUDY RESULTS:**

A summary of the results of this study will be posted on the ABLE Village platform and websites affiliated with the study (e.g., The Pulse Lab website). Results can also be emailed to interested participants. You will be able to provide your email address during the survey or interview if you would like to receive a copy of the study’s’ results. Your email address will be kept separately from your survey and/or interview responses. We anticipate that data collection will be completed in/by March 2025 and results will be available thereafter.

### **IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CONTACT?**

**The Pulse Lab:**

If you have any questions about the research now or later, please contact a member of our research team via email at (macpulse@mcmaster.ca) or via phone at 905-525-9140 ext. 27959. or visit our [website](https://pulselab.humanities.mcmaster.ca) (https://pulselab.humanities.mcmaster.ca).]

The Pulse Lab is a transdisciplinary lab in the Faculty of Humanities at McMaster University. We work in collaboration with justice, health-based and equity-seeking groups to co-develop technological solutions, engage social issues, and positively impact people and communities we work alongside. Our art, media and technology research is centered around principles of rigorous co-design with an anti-oppression focus. The goal of our work is to use art, design and play to intervene, experiment, collaborate, negotiate, and create new, innovative digital experiences and tools.

**McMaster University Research Ethics Board:**

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance (MREB #6511). If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Board Secretariat

Telephone: (905) 525-9140 ext. 23142

E-mail: ethicsoffice@mcmaster.ca