

**Research Project Title:** taskIt: Evaluative Study

**Funding:** CIHR, JPI - MYBL

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**Student Researcher:** Sheida Marashi, University of Waterloo ([smarashi@uwaterloo.ca](mailto:smarashi@uwaterloo.ca)).

You are being invited to take part in a research project, therefore it is important for you to understand why the research is being done and what it will involve. Please take time to carefully read the following information and to decide whether you wish to take part. If anything is unclear or if you would like more information, please contact **Sheida Marashi**, Ph.D. student investigator, at [smarashi@uwaterloo.ca](mailto:smarashi@uwaterloo.ca).

### **What is the purpose of the research study?**

We are inviting you to participate in trying out and giving us feedback about a new mobile application called *taskIt*. *taskIt* has been designed by a team of researchers and people living with mild cognitive impairment (MCI) and dementia and is intended to support problem-solving, communicating, and strategy-building tasks. Our goal is to make *taskIt* usable by and accessible to as many people as possible, including people living with MCI/dementia.

### **Why am I being asked to participate?**

You are being invited to voluntarily participate in this study because you could be a potential user of this digital application. For this study, we are hoping to recruit approximately 12-20 individuals who are regular users of smart, touchscreen devices. Between 6 to 10 of the participants will be people who have or suspect they have early-stage MCI or dementia.

### **Do I have to participate?**

It is completely up to you to decide whether you wish to take part in this research study. If you do decide to take part, you will be asked to verbally express your consent. Even if you do consent, you can withdraw from the study at any time without any consequences.

### **What do I have to do to participate?**

- a. After agreeing to participate in this research, you will be sent a screening questionnaire. We will use your answers to the screening questionnaire to determine whether you are eligible to participate in this study. Examples of questions on this questionnaire include your birth year, and if you can operate an app with or without help from a support person. If the research team decides that you are not eligible to participate in this study, all your data will be deleted from this study. However, if you agree to participate in future research, we will keep your contact information for that purpose.
- b. You will be asked to complete a demographic questionnaire. Examples of questions on this questionnaire include gender identity, birth year, highest level of education, and whether you are diagnosed or suspect to be a person with mild cognitive impairment or dementia.

If you do not wish to answer any of the questions, you may choose to leave them blank. It will take approximately 20 minutes to complete the demographics questionnaire.

- c. You will be scheduled to participate in an evaluative study with the study investigator. This study will take place over the duration of 5-7 weeks depending on your availability. You are expected to spend about 4 hours per week.

During each week, the researcher will ask you to document a cheat sheet for at least 3 work-related tasks of your choice. The tools you will try will be one of the following: (i) taskIt; (ii) a commercial mobile application for task management or note taking; and (iii) your own strategies for note-taking, cheat-sheet making, and task-planning.

You will be given three forms per week to record observations on your reactions/interactions to the app. Each form includes 6-7 questions about your experiences and any challenges you may have had with the tool you used that week.

During the study period, the study investigator will be in contact with you to collect your filled forms and answer any questions you may have.

After you finish trying each of the suggested tools for 1-3 weeks, the investigator will send you a Usability Questionnaire with 10 questions that ask you to rank the tool you used. And finally, with all the tools tested, the investigator will schedule a one-hour interview session with you to ask you to express your overall experience with each tool. With your permission, the final interview session will be audio and/or video recorded.

### **What are the possible disadvantages or risks of taking part?**

The probability of you experiencing any disadvantages or risks by taking part in this research is low. You may find it challenging to share your experiences while performing the tasks while using taskIt and/or you may find some questions uncomfortable to answer. In addition, the need to use the suggested tools in the workplace may disrupt your work schedule.

With your permission, researchers may use short clips of the video-recordings or photos in academic presentations for educational or illustrative purposes. While your face will be blurred out and your voice be distorted to protect your privacy, this could put you at risk of being identified. At the end of this document, we ask for your permission to share pictures or video-clips outside of the immediate research team; you may agree or disagree without affecting your study participation.

### **What are the possible benefits of taking part?**

We do not anticipate any direct benefits to yourself for participating. Your participation in this research may benefit others in the future, including better and more user-friendly technology design for people with MCI or dementia, especially those with employment responsibilities.

### **Will I be remunerated for taking part?**

You will be offered \$60 CAD per week for up to 7 weeks in the form of cheque or direct deposit for taking part in this study. If you withdraw from the study, remuneration will be given based on the number of weeks completed in the study. The remuneration will be transferred to you after your termination of the study, which will be by the end of the study period or by the date of your withdrawal from the study, whichever comes first.

For a total remuneration of \$300 or above, the amount received will be taxable. You will be asked to sign a release of personal information form that includes details such as Social Insurance Number (SIN), Date of Birth, etc., for the purposes of remuneration and issuing a tax slip. The University of Waterloo's Human Resources will be responsible for providing you with the payment and the related tax documents.

**Will I be reimbursed for any expenses that I incur?**

There will be no expenses to participate in the study. In the case of in-person participation for the final interview session, the parking costs will be reimbursed.

**What if I want to withdraw from the study?**

Your wellbeing is our top priority and your participation in this study is voluntary. You may decide not to participate in this study, or to leave the study at any time - please let the researcher know at any time if you no longer wish to participate. There are no consequences for doing so. Should you decide to withdraw, if your data has been aggregated with others during the data analysis process and/or has been submitted for presentation or publication (whichever comes first- approximately about 45 days from the date of your interview) we will not be able to remove it. *If you have any questions, or wish to withdraw from the study, please contact: Sheida Marashi (Investigator) at [smarashi@uwaterloo.ca](mailto:smarashi@uwaterloo.ca).*

**Will my participation in this project be kept confidential?**

Your participation in this study will be kept confidential. Data from this study, such as demographic information, parts of video recordings, taskIt screen shots (if you provide us with any), and quotations from interviews and follow-up phone calls may be used in any thesis or publication that comes from this research. This data will be anonymized to protect your privacy. We will ask for your explicit permission to use your de-identified quotations from interviews in publications.

**Will I be recorded and how will the recorded media be used?**

You will be audio and/or video recorded during your participation in the final interview session, so that the research team can review and analyze the recordings after the session. The recordings are an important part of the research as they allow the research team to understand how you interact with taskIt, which may include demonstrations. At the same time, if you do not wish to be viewed on camera, you may turn off your camera, but you will need to remain within a reasonable audible range and share video of your screen so that we can hear you and see what you are doing as you explore the application. All study recordings will be transcribed. All identifying information will be removed from the transcripts and stored separately.

The application prototype itself is an offline app and will only save your information on your personal device. It will not send us any of the information you save on it. Moreover, you will not be asked to share any of the information you save on the app with the research team.

**Who will have access to the data and where will it be held?**

This research is part of an international research consortium with the University of Waterloo in Canada, Toronto Rehabilitation Institute in Canada, the Karolinska Institute in Sweden, and the University of Eastern Finland, Finland. All research data will be held securely at the University of Waterloo under the supervision of Drs. Jennifer Boger and Shi Cao. De-identified copies of your data and themes arising from your data may be shared with the international research team. All

data will be stored for at least seven years after the completion of the project. Measures will be set in place to protect the safety and confidentiality of all participants involved in the study.

The data collected for issuing the tax slip for remuneration will be for accounting purposes only and will be stored by the University of Waterloo's Human Resources, separately from the research data.

### **What will happen to the results of the research project?**

When we are finished collecting data for this study, we will analyse the collected data to understand what about taskIt worked well and identify areas of improvement in the design that would make it more effective, usable, and inclusive to people with MCI/dementia. Results will be published as journal and conference publications and presentations as well as a Ph.D. thesis. This means your name will not be included in any publication without your expressed permission.

Since the present research is specific to the design of taskIt and its context of use, the likelihood of using the collected data in future research will be very low. However, should we decide to utilize your data in future research with your permission, we will only use de-identified data from interview transcriptions, or the usability forms you completed during the study. Similar to the present research, the purpose of any future research that utilizes your de-identified data will be to advance interaction design for people with dementia and/or mild cognitive impairment. Additionally, we do not anticipate any risks to the participants regarding the use of their data in future research.

Before collecting any data in this research, we will ask for your explicit verbal permission to use your anonymized data in future research. This permission will not affect your participation in this study, and it will be entirely voluntary. In the event that you wish to withdraw this permission, you can contact the research team in the future.

### **Who may I contact if I have questions about the study?**

If you have any questions or concerns, or would like to speak to the research team for any reason, please contact: **Sheida Marashi**, Ph.D. student investigator, at [smarashi@uwaterloo.ca](mailto:smarashi@uwaterloo.ca), **Dr. Jennifer Boger**, Principal Investigator, at [jboger@uwaterloo.ca](mailto:jboger@uwaterloo.ca), or **Dr. Shi Cao**, Faculty Supervisor at [s34cao@uwaterloo.ca](mailto:s34cao@uwaterloo.ca).

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #45544). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4440, or [reb@uwaterloo.ca](mailto:reb@uwaterloo.ca).