

## **INFORMATION AND CONSENT FORM PRIOR TO THE ONLINE QUESTIONNAIRE**

For representatives of organizations offering direct services to informal caregivers

We invite you to join a research project. Before accepting, please carefully read this document explaining the process of the project. Do not hesitate to ask any questions you think could be useful to the project coordinator or a member of the research team. By answering the following questionnaire, you consent to participate in this research project. **For your files, you could print and download a complete copy of this form.**

### **Title of the project**

Development of the ARMCAR program: Needs, accessibility and usability assessment

### **Research project managers**

- Mélanie Couture, Lead researcher, Chairholder of the Research Chair on Mistreatment of Older Adults.  
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- Kevin St-Martin, Research project coordinator and coordinator of the Research Chair on Mistreatment of Older Adults.  
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### **Co-researchers, collaborators and partner organizations of the project**

- Sophie Éthier, Co-researcher and full professor at the École de travail social et de criminologie, Université Laval.
- Maryse Soulière, Co-researcher and assistant professor at the École de travail social, Université de Montréal.
- Anna Andrianova, Collaborator and coordinator of the domain of expertise in caregiving, Centre de recherche et d'expertise en gérontologie sociale (CREGÉS).
- Sarita Israel, Collaborator and coordinator of the domain of expertise to counter mistreatment of older adults, CREGÉS.
- Proche aideance Québec, 124 community organizations supporting more than 41 000 informal caregivers throughout the province of Quebec.
- Regroupement des organismes montréalais d'aidants naturels (ROMAN), Organization aimed at regrouping, the support and the accompaniment of organizations supporting informal caregivers of older adults of Montérégie.

### **Funding of the project**

This project is funded by the Public Health Agency of Canada (2023-2026) (2324-HQ-000003). The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

## **Objectives of the project**

The general objective of this project is to offer an online multicomponent intervention program in French and in English for informal caregivers aged 50 years and older, taking care of a person also aged 50 years and older and for the non-profit organizations (NPO), the cooperatives and the domestic help social economy businesses (DHSEB) offering services directly to informal caregivers, whose clientele includes persons aged 50 years and older. This program is about the prevention and management of mistreatment toward persons aged 50 years and older within a caregiving context and it relies on the adaptation and the improvement of two existing tools.

This program entitled *Acknowledging and Responding to Mistreatment in CAREgiving* (ARMCAR) contains: 1) An online educational program for informal caregivers on mistreatment toward persons aged 50 years and older within a caregiving context; 2) An online educational program for organizations offering direct services to informal caregivers on mistreatment toward persons aged 50 years and older within a caregiving context as well as on the management model of mistreatment situations; and 3) An organisational tool to support the development of methods and partnerships for the management of these types of situations.

The project is divided in three steps, 1) Needs assessment of the users, 2) Development of ARMCAR by the adaptation of two existing tools, 3) Pre-test of ARMCAR.

## **Reason and nature of the participation**

We are looking for employees, volunteers or their supervisors within NPO, cooperatives or DHSEB offering services directly to informal caregivers, whose clientele includes persons aged 50 years and older. These persons must be aged 18 years or older, must have at least 6 months of experience working within organizations and must offer a direct service to informal caregivers aged 50 years and older taking care of a person also aged 50 years and older as part of their functions or supervise employees or volunteers offering such services.

The people we are looking for are requested to give their point of view about the training needs of their organization concerning the management of mistreatment toward persons aged 50 years and older within a caregiving context. This data will be used for the development of the ARMCAR program (Step 1).

This will be done with an online questionnaire, filled on Simple Survey, in which their needs on the subject of information and training about mistreatment toward persons aged 50 years and older within a caregiving context will be addressed, as well as the obstacles and the potential facilitators for using the online program. It will take approximately 20 minutes to answer it. At any time, you will be able to save your answers and continue the questionnaire later.

To help us better understand what needs to be in ARMCAR, we would like to conduct with you an individual interview via videoconference (Teams or Zoom) or by phone (depending on your convenience and availability) with an approximate duration of 45 minutes during which we will develop your point of view and your needs. This interview's audio will be recorded. If the interview is done via videoconference and you wish that only the audio portion be recorded, you will have the opportunity to close your camera. Your participation in this individual interview is optional. At the end of the questionnaire, you will be invited to click on a link which will allow you to write down your contact information to be contacted to participate in the interview if you so desire.

Another consent form will be given to you to inform you on the process of the interview. At any time, it will be possible for you to accept or refuse to participate in the individual interview.

### **Advantages, disadvantages and risks of participating**

Your participation in this project will allow you to raise your awareness to the realities of informal caregivers and contribute to the development of an innovative program aimed at preventing and countering mistreatment toward persons aged 50 years and older within a caregiving context. You will also greatly contribute to the advancement of the scientific knowledge on the subject.

Your participation in this project should not cause any significant risks or disadvantages, only giving some of your time. However, if completing the questionnaire triggers moving or unpleasant reflections or memories, do not hesitate to contact your Employee assistance program if you have one. You can also contact the helpline Info-Social at 811 offered 24 hours a day and 365 days a year where a professional can give you advice and offer support. You can also contact The Mistreatment Helpline, 1-800-489-2287. It is a provincial helpline open everyday from 8:00 to 20:00, 365 days a year for any questions linked to mistreatment of older adults. These two phone helplines can also, if needed, refer you to an appropriate resource in the health and social services network or a community resource. Also, if urgent situations happen, the lead researcher or a member of the research team, with your permission, would communicate themselves with a relevant resource to ensure a quick follow-up.

### **Voluntary participation and possibility to withdraw**

Your participation in this research project is voluntary and confidential. Your answers will stay anonymous. Please note that an indirect identification is still possible if the NPO, the cooperative or DHSEB for which you are working is located in a sociosanitary region which has few organizations offering services to informal caregivers. You are free to refuse to participate. You can also withdraw from this project at any time, no matter what step of the data collection is in progress, without giving any reason, by informing the lead researcher or a member of the research team.

### **Consequences on the employment or volunteer relationship**

Your decision not to participate in this research project or to withdraw will have no risk of consequences or reprisals from the organization you are working for, since the latter will have no way to know who is participating in the research. Furthermore, the role of the organization is limited to the transmission of the research teams' communications linked to the project.

In the event of your withdrawal from the research project, the electronic documents about you can be permanently deleted from the secure computer server where they will be saved. If need be, you will be able to ask for it by contacting a member of the research team.

Since the online questionnaire completed via Simple Survey is anonymous and confidential, you will have to provide certain information to the research team, to be able to find it and destroy it, such as the approximate date and time when you completed it.

### **Confidentiality, sharing, surveillance and publications**

During your participation in this research project, the lead researcher, as well as the research team will

collect the answers and other information that you will provide and compile them in a research file. Only the necessary information for the proper conduct of the research project will be collected. It can include the following information: needs on the matter of information and training on the subject of mistreatment within caregiving context, obstacles and facilitators to using the online intervention program, as well as some socio-demographic information (age, gender, etc.) and data on the organization you are working for (mission, etc.). No other personal information will be asked nor collected. Furthermore, nor the IP address nor the email address will be included in the data.

To allow the participants to quit an in-progress questionnaire and come back to complete it later, Simple Survey uses cookies <sup>1</sup>. To benefit from this, you will only need to return to the questionnaire page from your browsing history or by reusing the same access link to the questionnaire from the same device on which you started the questionnaire (computer, tablet, smartphone, etc.). Furthermore, you must not delete your browsing data between each back and forth in the questionnaire. If you do not follow these conditions, you will have to fill in the questionnaire from the start. Once the questionnaire is submitted to Simple Survey, you will be able to delete the cookies from your device by deleting your browsing data in your browser options (Chrome, Edge, Safari, etc.). Note that there are no risks in keeping cookies linked to Simple Survey on your device after the completion of the questionnaire.

The information concerning Simple Survey's security measures can be viewed at the following address: [https://form.simplesurvey.com/oss/external/privacypolicy.aspx?lang=EN&\\_ga=2.33272254.1055855243.1692296767-1329689035.1685562991](https://form.simplesurvey.com/oss/external/privacypolicy.aspx?lang=EN&_ga=2.33272254.1055855243.1692296767-1329689035.1685562991)

For any technical problem encountered during the completion of the online questionnaire, do not hesitate to contact a member of the research team.

All the information collected during the research project will stay strictly confidential in the expected limits by law. To protect your identity and the confidentiality of the information you provide us, you will only be identified by a code number. The document linking the code to your name and your research file will be kept by the lead researcher.

The information collected will be kept under lock and key, as well as on the secure computer server at the Research Center on Aging (RCA) where the Research Chair on mistreatment's office space is located, on the computer server of the Université de Sherbrooke (UdeS), as well as the Simple Survey server for 10 years by the lead researcher exclusively for the purpose of the research project. After 10 years, the lead researcher will manually destroy the electronic data contained on the RCA and the UdeS servers by sending them to the recycle bin of the server and then emptying the latter. The digital data contained in Simple Survey will be manually deleted by the lead researcher by deleting the project from Simple Survey.

The research data will be published or be the subject of scientific discussions, but will not allow your identification. The general results from this research will be viewable on the project's webs page (<https://maltraitancedesaines.com/en/projects/acknowledging-and-responding-to-mistreatment-in-caregiving-armcar/>) some months after the data collection.

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<sup>1</sup> “[...] cookies are text files containing small amounts of information, which are downloaded to your computer or mobile device by websites that you visit. They can improve your experience of using a website, for example, by remembering your preference settings and tracking your use of a website so that it can be improved to meet your needs.” (source: <https://gowlingwlg.com/en/footer/cookies/>). The majority of websites collect cookies.

For surveillance and control purposes, your research file could be consulted by a person mandated by regulatory bodies, representatives of the establishment or the Research Ethics Board. These people and organizations will have access to your personal data, but follow a confidentiality policy.

You have the right to consult your file to verify the collected information and rectify them if need be.

### **Resource person's contact details**

If you have questions or are experiencing problems linked to the research project, you can communicate with Kevin St-Martin, Research project coordinator and coordinator of the Research Chair on Mistreatment of Older Adults, by e-mail: [info@maltraitancedesaines.com](mailto:info@maltraitancedesaines.com) or by phone at: (819) 780-2220 extension 45337.

### **Approval by the research ethics committee**

The Research Ethics Board of the Université de Sherbrooke (CÉR Lettres et sciences humaines) approved this research (file number: 2023-3899) and is responsible for overseeing the study. For any questions about your rights as a participant this research project or if you have comments, you can communicate with this committee at the following phone number: 819-821-8000 extension 62644 (or toll free at 1 800 267-8337) or at the e-mail address [cer\\_lsh@USherbrooke.ca](mailto:cer_lsh@USherbrooke.ca).

### **Continuation of the project**

Note that at the end of the questionnaire, you will be invited to provide your contact information if you wish to be contacted to participate in the following steps of the project, including an individual interview aiming to deepen your point of view and your needs, as well as the pre-test of the ARMCAR program. You will also be invited to indicate if you wish to be contacted to participate in other research projects.

### **Consent**

By clicking the “I accept” button, I:

- Confirm having read and acknowledged the information and consent form;
- Consent voluntarily and freely to participate in this research project;
- Consent voluntarily and freely that a secondary use of the data can be done by the lead researcher, notably as part of student work or thesis.

If you click on the “I refuse” button:

- We invite you to leave the page of the questionnaire since your answers in the next section will not be retained for the project.

- I accept
- I refuse

Thank you!



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Faculté des sciences sociales  
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Centre for Research and Expertise  
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