

Information, Membership Conditions, Screening Process and Consent

Thank you for your interest in the **Public Interest Group on Cancer Research**.

Please read this document carefully.

If you have any questions, please contact:

Dr. Sevtap Savas,

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Faculty of Medicine,

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Phone: 709-237 4848, email: savas@mun.ca

Our aim:

Our aim is to create an inclusive, province-wide community interest group on cancer research and public engagement.

This group (committee) will advise and talk about the research and public engagement needs of people affected by cancer in our province.

We aim to have 12 community representatives of cancer patients, survivors, and family members from Newfoundland and Labrador.

Why is it important to form this committee?

Partnering with community members and talking with them about their needs and priorities is important to us. This interest group will help us understand the experiences and concerns of patients and families affected by cancer in our province.

Such information is important for researchers and health care providers. For example, opinions and suggestions by the committee members can help guide research and public education & engagement activities in ways most helpful to cancer patients and their families. In the past, such partnerships helped study

how breast cancer patients make decisions about surgery, how patients with colon cancer feel about screening programs, and what might ultimately help improve outcomes for patients and their families in NL.

Who are we?

This interest group is led by the following investigators:

Dr. Sevtap Savas (Faculty of Medicine, Memorial University)

Dr. Farah McCrate (Eastern Health)

Dr. Holly Etchegary (Faculty of Medicine, Memorial University)

Dr. Teri Stuckless (Memorial University; Eastern Health, Cancer Care Program)

Ms. Rebecca Roome, community partner

Mr. Doug Smith, community partner

Who is the funder?

This initiative is funded by the Public Engagement Office of Memorial University.

What is expected from me?

1. If you are selected to be a member of this interest group:

This committee, including the public members and investigators, will meet remotely to conduct meetings (online or teleconference meetings).

We anticipate that the committee will meet regularly, at least once every 3 months. If needed, we will communicate by emails and/or phone between meetings. At our first meeting, the committee will create its own Terms of References to guide our work. We anticipate at least four meetings in 2021.

Each committee member will sign a Confidentiality Agreement; however, protection of committee members' privacy cannot be guaranteed. For example, together with other information, information in the reports and presentations on the committee work may indicate / identify you.

This is a voluntary position that includes a honorarium (\$150) for the 1st year (2021). This honorarium is currently secured for one time only.

We hope to create summaries of the group's discussions and share the main needs and priorities identified widely, with the public, provincial Health Authorities, and researchers. These communications could include media releases, presentations, manuscripts, and reports to the Funder. In communications about this group, we have the option to name group members and thank them for their contributions to the work. We would only use your name like this if you gave us permission to do so.

The summary of information discussed during our meetings and committee communications will be kept for 5 years.

2. Selection process:

We aim to have an inclusive committee with diverse members that are representative of our population.

We hope this interest group will have representatives from different parts of the province, individuals and groups that experience inequity and barriers to equal access, and under-studied cancers.

It is possible that we may get more than 12 individuals interested in sitting on this committee. This means we may have to screen and select the final committee members. That is why we have [Screening Questions](#) for anyone who expresses an interest in this group. To provide your information in screening questions, you will have two options:

1. Phone interviews. Interviews will be done by the staff at Health Research Unit, Faculty of Medicine, Memorial University.
2. Completing an electronic form.

Please see the end of this document about these options.

Your response to the [Screening Questions](#) collected during this screening interview/process will be used only to help select the members of the Public Interest Group on Cancer to make sure we have a diverse group. Information may be shared with the investigators and will only be used for this purpose.

We will keep personal information collected from you during the initial screening interview/process for one year, in case we need additional members for this committee. This information will be kept in a secure network and can only be accessible by password protected computers. Dr. Sevtap Savas and the Health Research Unit at Faculty of Medicine, Memorial University will keep this information secure. While we aim to keep your information confidential, there is a risk of unintentional release of information if there is a security breach in the system that stores your data.

After 1 year, the electronic copies of the personal information you provide during the screening interview/process will be destroyed.

If you are selected for this group, we will contact you soon, and your name and contact information will be provided to the investigators.

If these membership conditions and screening processes are acceptable to you, and you are interested in being a member of The Public Interest Group on Cancer, **please provide your responses to Screening Questions** by:

Completing an electronic form [here](#),

or

Scheduling a phone interview with Dr. Charlene Simmonds at 709 864 6656.

Taking these steps implies that you consent to collection of your information for the purpose described.

For your records, please keep the PDF copy of this document, or ask us to email or mail it to you (please email your request to savas@mun.ca).