

Canadian Post Mastectomy Breast Reconstruction Priority Setting Partnership

Why are we doing this?

This study is meant to improve the lives of women who are thinking about undergoing breast reconstruction after mastectomy. We want to identify questions about reconstruction that are important to patients and have not been answered by research. We want to know what questions you have about breast reconstruction. The results of this study will help ensure that their work focuses on the needs of women requiring breast reconstruction.

Who should take part in this study?

- Women who have undergone or are currently waiting for a mastectomy (for treatment or prevention of breast cancer)
- Friends and family of women who have had or will undergo mastectomy
- Health and social care providers (including doctors, nurses, social workers and others who care for patients with mastectomy)
- People who are interested in this topic

What's involved if I take part in this study?

Participating in the study is voluntary. It involves completing a questionnaire, but you do not have to answer any question that you do not want to answer. By completing the questionnaire you have consented to participate in the study. At the end, you will be asked if you would like to participate in the second phase of the study by helping to decide which of the research topics identified from this questionnaire are most important. If you agree, you will be asked for your name and contact information. We will only contact you if you provide this information. If you do not provide this information, your participation will be anonymous and we will not contact you again.

Will my answers be kept confidential?

All of your answers are completely confidential and anonymous. Any personal information we collect will remain confidential and when we release the results of this study, we will never identify any individual who took part in this questionnaire. Data will be kept at the University Health Network in Toronto and only the study team will have access to it.

Who is supporting this study?

This study is being funded by the [Canadian Institutes of Health Research](#) (CIHR) and follows the rigorous scientific methods of the [James Lind Alliance](#).

What will happen to the results?

The final results will be made public on the [University Health Network Breast reconstruction program site](#) and we will work to promote the results with other researchers and organizations that fund research.

Who can I contact for more information?

If you would like more information, please go to www.myreconstruction.ca/nrc.html or contact:

Muna Hassan

Clinical Research Coordinator-*National Research Consortium*

Toronto General Hospital, University Health Network
Dept. of Plastic & Reconstructive Surgery
200 Elizabeth St. 8NU Toronto, ON M5G 2C4

Email: muna.hassan@uhnresearch.ca

Telephone: (416-340-4800 ext. 5799)

or Dr. Toni Zhong

Director, UHN Breast Reconstruction Program

Email: toni.zhong@uhn.ca

Telephone: (416-340-3858)

If you would like more information about your rights as a participant, please contact University Health Network Research Ethics Board at (416-581-7849).

INSTRUCTIONS FOR COMPLETING THIS QUESTIONNAIRE

STEP 1: Your questions about breast reconstruction

We are asking for your questions about breast reconstruction. When you answer, please:

- Think about your own personal and/or professional experience with breast reconstruction. Your experience is what makes you the expert.
- Provide the question(s) about breast reconstruction that are important to you.
- Research can cover a wide variety of topics including physical, mental, emotional and societal factors.
- Don't worry about what box to write your question(s) in. Some of the questions might seem similar or overlap so please write your responses in any box you feel is appropriate.
- Write any question you feel is important regardless of if you think that someone else might ask them or that they may have already been answered.

STEP 2: Your information

We ask for some information about you so that we can understand who has responded to our questionnaire and make sure we hear from all groups.

STEP 3: Your contact information

The next phase of the study involves putting the research topics identified from this questionnaire into order of importance.

If you are interested in participating in this next phase of the study, you can provide your name and contact information.

STEP 1: Your questions about breast reconstruction

1. What questions or comments do you have about breast reconstruction information that would help you (or someone you know) make a decision about having breast reconstruction?

2. What comments or questions do you have about improving your (the) experience prior to meeting a plastic surgeon to discuss breast reconstruction (e.g. referral process, wait times etc.)

3. What questions or comments do you have about breast reconstruction surgery (e.g. techniques, which type to choose, when to do it etc.)?

4. What questions or comments do you have about your (the) experiences after breast reconstruction surgery (e.g. recovery, long term results etc.?)

STEP 2: Your information

This will help us keep track of who is completing the questionnaire and make sure we hear from all groups.

1. Which of the following best describes you?

- Person with breast reconstruction
- Partner/relative/friend of a person with breast reconstruction
- Person with breast cancer
- Partner/relative/friend of a person with breast cancer
- Person with mastectomy
- Partner/relative/friend of a person with mastectomy
- Caregiver/former caregiver of a person with breast cancer
- Health and/or social care provider, current profession:
 - Nurse
 - Occupational therapist
 - Pharmacist
 - Physician
 - Medical Oncology
 - Radiation Oncologist
 - General Surgeon
 - Plastic Surgeon
 - Surgeon
 - Physiotherapist
 - Personal support worker, care aide or community health worker
 - Social worker
 - Other, please specify: _____
- Part of an organisation representing people with breast cancer
- No direct experience with breast reconstruction, but interested in it
- Other (please specify _____)

2. Which part of Canada do you live in?

- | | |
|--|---|
| <input type="checkbox"/> Alberta | <input type="checkbox"/> Nunavut |
| <input type="checkbox"/> British Columbia | <input type="checkbox"/> Ontario |
| <input type="checkbox"/> Manitoba | <input type="checkbox"/> Prince Edward Island |
| <input type="checkbox"/> New Brunswick | <input type="checkbox"/> Quebec |
| <input type="checkbox"/> Newfoundland and Labrador | <input type="checkbox"/> Saskatchewan |
| <input type="checkbox"/> Northwest Territories | <input type="checkbox"/> Yukon |
| <input type="checkbox"/> Nova Scotia | |

3. What were the ethnic or cultural origins of your ancestors?

- | | |
|--|--|
| <input type="checkbox"/> North American Aboriginal | <input type="checkbox"/> Caribbean |
| <input type="checkbox"/> Other North American (e.g., Canadian or American) | <input type="checkbox"/> Prefer not to say |
| <input type="checkbox"/> European | |

Latin, Central or South American

African

Oceania (e.g., Australian)

Asian (e.g., Middle Eastern, South, East and Southeast Asian)

4. How do you identify?

Male

Female

Other

Prefer not to say

5. What is your current age?

15-24

25-34

35-44

45-54

55-64

65+

Prefer not to say

STEP 3: Your contact information

Thank you for completing this questionnaire!

The next phase of the study involves putting the research topics identified from this questionnaire into order of importance. If you would like to go through the list of research topics and tell us which ones you think are most important, please provide your contact information either on line <http://myreconstruction.ca/nrc.html> or by contacting the study office by telephone, email or in writing:

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University Health Network

Dept. of Plastic & Reconstructive Surgery

8NU-818, 200 Elizabeth Street

Toronto, ON M5G 2C4

Email: muna.hassan@uhnresearch.ca

Telephone: (416-340-4800 ext. 5799)

To maintain your confidentiality, please do **not** provide your contact information when returning the questionnaire.