



**Centre hospitalier de St. Mary**

**St. Mary's Hospital Center**

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Centre de recherche de St. Mary / St. Mary's Research Centre

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## PARTICIPANT INFORMATION BOOKLET

### **TAKING PART IN RESEARCH - Experiences of Breast Cancer in Women**

Hello,

My name is Ilja Ormel. I am a researcher working with the St. Mary's Research Centre. I would like to talk to you about my research, why it is being done, and what you can expect if you agree to participate. Please read this information booklet carefully before you decide whether you would like to take part in our study. Talk about it with friends, relatives or your family doctor if you wish. You can contact me if you have any other questions. Please take as much time as you like to decide.

Thanks you for your consideration.

## What is the purpose of the study?

The aim of our research program is to improve understanding of people's experiences of health and illness, and provide resources to support people living with a wide variety of health conditions as well as to their families, friends and the health professionals involved in their care. We collect video, audio and the written transcripts of interviews, which may be used in several ways:

- to find out what is important to people faced with different health issues
- to contribute to the Canadian version of the [www.healthtalkonline.org](http://www.healthtalkonline.org) website ([www.healthexperiences.ca](http://www.healthexperiences.ca))
- to develop other support and information resources for people
- to train health and social care professionals
- to write research papers

[www.healthtalkonline.org](http://www.healthtalkonline.org) is a website that has:

- people's stories of health and illness
- information about tests and treatments
- details about support groups & other resources (e.g. self-help books),
- a teaching and learning area for health and social care professionals and staff

This project will contribute to the development of a Canadian version of this website ([www.healthexperiences.ca](http://www.healthexperiences.ca)).

The idea is that [healthexperiences](http://www.healthexperiences.ca) will help people to:

- share their experiences and lessons
- understand & cope with health problems and issues
- know what really matters to people when they are ill or are facing health issues
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- answer common questions and provide information about their situation

People who are faced with difficult choices (e.g. which tests or treatments to choose) will be able to go to the Healthexperiences website to find out how others have made their decisions. Health professionals who want to understand what it is like for people to have an illness or face health choices can also visit the website.

Anyone who has access to the Internet would be able to use the Healthexperiences website. The interviews we collect contribute to the information presented on the site, and extracts from many of them will be used to show what it is like for people facing illness or health issues. The interviews will not be used for profit or commercial gain.

We may also use interviews to help create other information and support resources, such as DVDs or short films. These may for example be shown to people by health professionals as part of their care or they may appear on other websites approved by the St. Mary's Research Centre.

Interviews can be used to develop training materials for health and social care professionals, so they can learn from people's experiences and improve the care they provide. Again, these training materials may be presented on the teaching and learning area of [www.healthexperiences.ca](http://www.healthexperiences.ca) website, on other approved websites, and on DVDs.

All the interviews we collect are included in our analysis for preparing research articles and papers.

### **Why have I been chosen?**

You have either been contacted by your healthcare provider, you may have contacted us, or you have picked up an information package in a public place. I am looking for people who have been diagnosed with breast cancer or who have survived breast cancer diagnoses. This study does not include breast cancer in men, women younger than 18 years old and women diagnosed with

DCIS. I will be interviewing a range of women about their experiences with breast cancer. Your name has not been given to us at the St. Mary's research centre by any other means, so I will only be able to contact you if you fill in the 'reply slip' (in this information pack) and post it to us in the prepaid envelop.

### **Do I have to take part?**

No. It is entirely up to you to decide whether or not you want to take part. If you decide to take part, you will be given this information booklet to keep. You will also be asked to sign a 'consent form'. You are still free to stop at any time without giving a reason. No questions will be asked if you stop. Deciding whether or not to take part in the study will not affect the standard of medical care you receive.

### **What will happen if I take part?**

If you complete and send back the enclosed 'reply slip', I will contact you by telephone to arrange an interview. Most interviews are conducted in participants' homes; if you would prefer to conduct this interview somewhere else in your community, then costs of your travel will be reimbursed. The interview will be conducted by either me or another researcher on our team.

Before the interview I will show you the healthexperiences website on a portable computer. You can see how clips from other people's interviews look in video, audio and written formats. I will try to answer any questions you may have about the interview or the Healthexperiences project.

### **What would the interview be like?**

I will ask you if you are willing to have the interview video or audio tape recorded. You will be given the 'consent form'. You only sign this form if you

agree to take part in the interview. You will be given a copy of the consent form to keep.

The interview will be a little like a conversation, in which I will ask you to talk about yourself in your own words. I will ask you to share your story since you first suspected something was wrong. I will ask questions about what happened to you, what your thoughts and feelings have been at different stages, how you obtained information, what you have done, and what have been the good and bad parts of the experience.

### **How long would the interview take?**

The time it takes for an interview varies, depending on how much you have to say, but most interviews last about an hour. If you would prefer, I can interview you on two different occasions. Remember, if you want to stop the interview at any time, you can do so without giving any reason at all.

### **What if I decide to withdraw after the interview has taken place?**

You are free to withdraw from the study at any time. If you decide to withdraw after an interview has taken place, all video, tapes, transcripts and typing of your interview would be destroyed. If you decide to withdraw after the website or other audiovisual resources have been finished, we would remove your contribution from all later versions, but we would not be able to destroy existing material, which other people could already have seen or copied.

### **What would happen after the interview?**

I will label the interview tape with a code number and give it to a typist who will type out everything you said in the interview. The typist has signed an agreement to keep everything you say in the interview confidential. The tape and the typed up record (transcript), identified only by the code number, would be kept in a locked cabinet at the St. Mary's Research

Centre. All electronic information will be kept on Susan Law's and Ilja Ormel's password-protected computer in their office at St Mary Research Centre.

I will send you a copy of the interview transcript to help you decide whether you want your interview to be made available to use for our research, including on the Healthexperiences site and other audiovisual resources. A copy of the interview tape can also be provided if requested. You would be asked to read or listen to the interview and consider if there was anything you would like to change or remove, to keep anything confidential or hide your identity, or to delete or change some of your interview. We can remove any sections that you do not want us to use. You can take as long as you need to do this. You can also choose how your interview will appear in any resources we produce (see below).

### **How would the researcher use the interview tape and transcript?**

You will be asked to sign a form entitled '**Further use of my interview**'. If you sign this form, you give copyright of the interview to the St. Mary's Hospital centre. It is very important that you take time to think about and discuss the copyright form before you sign it. You will be given a copy of this form to keep.

If you do decide to allow your interview to be used for the study, it would be used along with interviews from between 30 and 50 other women who have been diagnosed with breast cancer. A summary of these interviews would be prepared for the Healthexperiences website. People who use the site would be able to see the summaries of the interviews as well as read extracts from the interviews and view the video clips of people who agree to this kind of use of their interviews. Data will be used strictly in compliance with the laws of Canada and Quebec. The study data may be looked at by individuals from the Research Centre of St. Mary's Hospital, for the purpose of audit and monitoring.

### **Can I choose how my interview will appear?**

You will have a choice about whether a video, audio and/or written version of your interview is included. If you want to be anonymous, you will be invited to use an alias for yourself and others and you can keep out of the interview anything which might identify you.

### **Are there any risks involved in participating in this research?**

During the interview all questions will be about your experience. Some people find it helpful to tell their story to researchers, others may feel sad, emotional or overwhelmed when talking about their experiences with breast cancer. This research is not the same thing as counselling. However, I will prepare a list of useful contacts which can be used to get more help as needed.

When you choose to have your video published on the internet you may be recognized by other people. If you are recognized on a website or a DVD, this would be a little like appearing on TV.

**You may wish to discuss this with members of your family, since they might possibly be connected to your appearance on screen.** The material on the website is protected by copyright and people are not allowed to copy or record what they find there but it is possible that they could. If you have any doubts about how you want the interview to be included (as a video, as text only or with an alias), talk to me, or I could find an independent adviser for you to talk to if you prefer.

### **Who has reviewed the study?**

This study was approved by the St. Mary's Research Ethics Committee.

### **Who is organising and funding the research?**

The Research Group is based at the St. Mary's Hospital. The project "Experiences of Breast Cancer in Women" is being funded by The St.

Mary's Hospital Foundation. Healthexperiences.ca will be run by KnowledgeOne, an independent organisation with expertise in website management.

### **Contact for further information**

I hope that this information booklet about experiences of women living with breast cancer has told you what you need to know before deciding whether or not to take part. The investigator, the sponsor, the St. Mary's Hospital Research Ethics Board (REB) do not routinely offer compensation, but you are not giving up your legal rights with regards to indemnification in signing this consent form. You are not waving your legal rights nor are the sponsor, research ethic board and investigator waived of any professional responsibility.

If you have any queries at all about the project or wish to discuss anything, please telephone Ilja Ormel at 1 855 531 2775, or Susan Law of the Research team at 514 345-3511 #5797.

If you want to talk to someone not connected with the study about your rights as a study participant, or if you have any complaints about the research, you can call the St. Mary's Ombudsperson at (514) 345-3511 #3301.

### **Notes:**

- I am a professional researcher and am paid for my work.
- The study has been approved by **St. Mary's Research Ethics Committee for health research**

**Many thanks for reading this information booklet.**

**Ilja Ormel**