

## Consent Form

### The information needs and information-seeking behaviour of young women with breast cancer in relation to the Internet

August 30, 2004

ACTION for Health

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## Consent Form

The information needs and information-seeking behaviour of young women with breast cancer in relation to the Internet

### **Principal Investigator:**

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This study is part of a larger project, "The role of technology in the production, consumption and use of health information in varied settings: Implications for policy and practice". This larger project is led by Dr. Ellen Balka and is being funded by the Social Sciences and Humanities Research Council of Canada.

### **Purpose:**

The purpose of the study is to 1) understand what young women with breast cancer have viewed as "all the information they needed" once being diagnosed, and 2) understand their experience seeking information, especially in relation to using the internet. The findings from this study will be added to the findings from other studies that are also part of the larger project, and be used to make recommendations for government policy and health care practice.

### **Study procedures:**

**If you agree to participate in this research study you will be contacted by email and asked to write about your experience, in the form of a story, of seeking information following your diagnosis of breast cancer. We want to understand what information you have been seeking since your diagnosis, and what things you've done to find information.**

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There will be a number of questions given which you can use to help write your story, such as:

- **What kind of information did you feel you needed in the weeks after being diagnosed with cancer? During treatment? After treatment?**
- From whom and where did you get information?
- What things did you want to know right away? What things did you need to know later on?
- Do you use the Internet to get information? Which types of information? Which people helped you use the internet to find information?

You will also be asked to complete a questionnaire that asks some background information. Participation in this part of the study will take between 1 and 2 hours, depending on how much you decide to write. Your story may be short or long.

Once we have collected many stories we will summarize them into descriptive "themes". A portion of participants will be emailed an invitation to take part in on-line focus groups to discuss the themes. An on-line focus group brings together 6-8 women and a facilitator who have an email "discussion". If you participate in a focus group, you will be asked to give feedback on the themes and to discuss related issues and questions with each other. Participation in this part of the study will take about 1.5 hours.

By signing this consent form you are simply agreeing to be invited into a focus group. You may refuse the invitation and just write your story if you wish.

## **Confidentiality:**

Your rights to privacy are protected by the Freedom of Information and Protection of Privacy Act of British Columbia. This act lays down rules for the collection, protection, and retention of your personal information by public bodies, such as the University of British Columbia and its affiliated teaching hospitals and Simon Fraser University and its affiliated institutions.

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Your name and all matters relating to you and your treatment will be kept completely confidential at all phases of the study. You will be given a code name immediately after we receive this consent form and only the code name will be used during data analysis. Your personal information from the questionnaire will be kept in a locked filing cabinet. Your story and focus group discussion will be stored electronically in the UBC Faculty of Medicine research server where privacy is protected. If you take part in a focus group, you will be given a login and password; your name and email address will be kept confidential. If you join a focus group, specific information from your personal story will not be disclosed unless you choose to do so.

Information in a summarized form – the descriptive themes and background information about the study participants as group -- may be reported in a scientific paper. The descriptive themes will be posted on the web site of The Young and the Breastless for anyone to read.

## **Benefits:**

Many people find benefit from sharing their experience and hearing about the experiences of other people like them. Many people find benefit from being able to help improve things for others like them. Your participation in this research will allow for a better understanding of the ways young women with breast cancer seek and obtain information with the eventual goal of providing feedback for government and health care agencies to implement programs.

## **Risks:**

Your participation in this study poses no medical harm or risk, and there will be no effect to the medical treatment you are receiving or you will eventually receive.

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## Contact for Information about the Study:

If you have any questions with regard to the study you may contact the Dr. Joanne Stephen, at 604-877-6000 local 2187.

## Contact for concerns about the rights of research subjects:

If you have any concerns about your treatment or rights as a research subject, you may telephone the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

## Consent:

Your participation in the study described here is completely voluntary and you are free at anytime to withdraw from the study without jeopardy.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

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Signature of Participant

date

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Printed Name of Participant signing above

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