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## Study information posted on website Invitation to share your story of information seeking with researchers and influence policy and practice

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## Study information posted on website

## Invitation to share your story of information seeking with researchers and influence policy and practice

We are researchers wanting to understand what information young women with breast cancer are seeking, and what their experiences have been seeking information through the Internet and other means. If you are a young woman with breast cancer (under 45 years old) or a young breast cancer survivor (diagnosed with breast cancer before 45 years old) and have used the internet as one of the ways to find information, we are interested in hearing from you!

This study, "The information needs and information-seeking behaviours of young women with breast cancer in relation to the Internet", is part of a larger study funded by the Social Sciences and Humanities Research Council of Canada (SSHRC), a federal agency that promotes and supports university-based research and training. It is being conducted jointly by the British Columbia Cancer Agency and Simon Fraser University in Burnaby, British Columbia.

We want to learn about *what* information you've been looking for as well as **how** you've gone about looking for it. For instance, we are interested in hearing about your successes and frustrations in information-seeking; your thoughts and feelings about the information you have found or not found; who and what was helpful; where you ran into obstacles. Anything you share with us could potentially be useful and we are therefore interested in *hearing your own story in whatever manner you choose to tell it.* We will be asking for your participation in the form of 'email stories', email correspondence and possibly online focus groups. We expect this will take 1 to 2 hours depending on how much you want to say. Later on we may request another hour and a half of your time during a focus group.

We will analyze the stories everyone sends into descriptive 'themes', which will then be posted on this web site for other young women with breast cancer to read. Everyone will have an opportunity to respond to the themes. Your participation will result in policy recommendations that will be made to federal agencies in an effort to improve services and shape future programs.

We hope that you will consider participating in this project. Whether you do so is entirely voluntary and you may withdraw at any time for any reason. We hope that you will share your personal expertise with the hope of helping others who may be in your situation.

If you are interested in participating in this study or you have questions, please contact Bev Holmes. Thank you for considering our invitation!

Joanne Stephen, PhD, BC Cancer Agency, Vancouver, British Columbia

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