

# Women's Experiences of Breast Cancer

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## BACKGROUND

### Why are collections of peoples' lived experiences with of health and illness important?

- Every women's breast cancer diagnosis and treatment pathway is unique. Within this pathway a woman will face several moments where she can make her own health care decisions based on her own personal decision criteria.<sup>1,2</sup>
- Health care decisions, like many other major life decisions, are not solely based on medical information but also on other peoples' experiences.<sup>3</sup>
- Many reliable biomedical resources exist but reliable resources about patients experiences that include a diverse sample are lacking.



Chimamanda Ngozi Adichie (TEDtalk):  
"The single story creates stereotypes, and the problem with stereotypes it is not that they are untrue but they are incomplete."

- Patients' experiences online are rapidly becoming a part of the evidence base that patients seek and learn from; to dismiss them as 'anecdotes' is a serious misunderstanding.

## CONTEXT

- A McGill-St. Mary's research team is developing an evidence-based website featuring peoples' experiences of health and illness in Canada. Breast cancer is the second module (first was family caregiving – launched 2013; others in progress on end of life, perinatal mental health, immigrant mental health).
- This initiative builds upon the [www.healthtalk.org](http://www.healthtalk.org) initiative led by the Health Experiences Research Group at the University of Oxford; and in collaboration with DIPEX International ([www.dipexinternational.org](http://www.dipexinternational.org)) involving 10 countries using the same methods to collect and share patients' stories to support informed decision-making and better communication with healthcare professionals.

## OBJECTIVES

To develop a diverse collection of the experiences of women diagnosed with breast cancer living in Canada (RCN contribution extending sampling in Quebec) to be published on the website [www.healthexperiences.ca](http://www.healthexperiences.ca) so that others can see, hear and read what it is like to live with this disease. Specifically, to:

- Interview 12–18 women with breast cancer in Quebec
- Identify themes important to participants from the full sample (36 women) featuring illustrative video/audio clips from the interviews
- Launch this module on the HERC web site to improve public and professional understanding of women living with breast cancer
- Conduct 2 focus groups with healthcare professional trainees to explore potential value of enhancing exposure to the diversity of patient experiences in the classroom
- Provide research training opportunities for junior researchers and staff.

## METHODS

2-stage qualitative interview (narrative + semi-structured sections) using video/audio recording, conducted at participants' homes or preferred location.

2-step consent for conducting interview and to release copyright to SMRC for use of materials for web, teaching, research, non-commercial purposes; participants review transcripts and remove information not be used for web publication.

Thematic analysis using constant comparison; with NVivo and Transana software; identify illustrative audio/video clips.

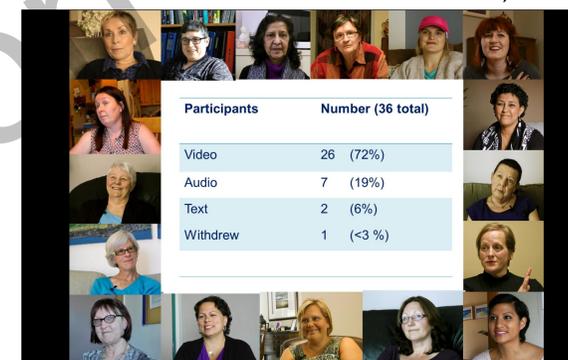
Conduct 2 focus groups (one with medical students and one with nursing students) to elicit their view on the use of patient experiences in the classroom.

[www.healthexperiences.ca](http://www.healthexperiences.ca) / [www.experiencesante.ca](http://www.experiencesante.ca)

For more information contact: [info@healthexperiences.ca](mailto:info@healthexperiences.ca)

## RESULTS

- 36 women have been interviewed (13 in Quebec – as part of the larger pan-Canadian study)
- 28 most important themes to women are summarized with attention to the wide variety of experiences within the sample and illustrated with video and audio clips.
- Medical and nursing students identified positive and negative aspects of developing applications for teaching
- Web module to be launched Fall 2016 in English (translation and launch of French version to follow).



### Focus group with med students (8)

Pros	Limitations or 'downsides'
'helps us pay attention to the little things that matter to patients'	'heard it all before; doesn't help my learning, decisions about their care'
Helps to highlight different responses to the same problem	Experience with a patient presenter who 'got it all wrong' – backfired
Awareness of day to day challenges may help direct patients to particular resources	'seeing the person and not just the disease complicates things' (vs guidelines and streamlined care)
when we have patient experiences, we get to learn about stuff that we can't predict just based on logic	'discomfort with having to listen to certain things that are either critical or just particularly heartbreaking'
Provides a sense of whole person, values, preferences	How to present the unique lived experiences AND a range of experiences vs. individual patient encounters
Hospitals can be pretty impersonal; good to have information about life	

### Access to services and policy



Young women share how their experiences related to fertility during breast cancer treatment were affected by different provincial health policies

References available on request.

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