

# Examining breast cancer information from racially marginalized perspectives: a community-based analysis<sup>1</sup>

*Project report  
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## **Project summary:**

In 2005 - 2006, researchers from the Ontario Breast Cancer Community Research Initiative gathered immigrant women from different communities together to give their opinions on breast cancer information. Thirty eight breast cancer survivors from the Toronto area participated in focus group discussions or interviews. The women studied several samples of breast cancer information. They were guided in a discussion about its content, quality, tone and appearance.

The women were asked to comment on what was helpful about the information and what was missing, as well as what they would have liked to see and read when they were diagnosed. The information studied was commonly-available to breast cancer patients, written in English, and intended for a general audience.

This report summarizes the project's objectives, approaches, methods, and results. It should be noted that the report is not meant to be an in-depth analysis of all the data; it is intended to present the main themes and conclusions from the perspectives of the women who took part in the study.



## **OBJECTIVES AND METHODS**

### **Rationale:**

Healthcare professionals and breast cancer groups are aware that many differences exist in the prevention, screening, diagnosis, treatment and quality of life aspects of breast cancer for different ethnic and racial groups. (For further reading about these aspects, see the references at the end of this report).

Still, we know little about the breast cancer education needs of different communities. Several studies have addressed this gap. A project by *Willow Breast Cancer Support and Resource Services* explored the needs of different racial groups in the Toronto area (Willow, 1999). This study found that women were dissatisfied with current information about breast health and screening, and the ways it was presented.

Two reports on cancer care in the Nova Scotian black community showed that people receive little information and find it difficult to navigate the health system (Canadian Cancer Society, 1999; Benton & Loppie, 2001). Another Toronto study by *Women's Health in Women's Hands Community Health Centre* found that immigrant and refugee women receive little information, and report their primary sources of learning as television, magazines and pamphlets from clinics (Women's Health in Women's Hands, 2003).

So far, we know little about the content of the information that women do see and read, and little about what might be "wrong" or missing it in. We also have little research from Canada. This study set out to contribute to these aspects of information needs for racially marginalized and immigrant women who have had a breast cancer diagnosis.

While some aspects of an illness like breast cancer are common to all patients, it is important to consider that information needs differ according to a group or individual's background, history, and experiences in society. Women of colour may experience many things – for instance, family life, work, poverty or violence - differently than white, mainstream women do (hooks, 1990, 1992; Fellows & Razack, 1998).

Likewise, women of colour can experience bodily changes and illness specific ways. They often live in and rely on community networks that differ from those of white women. Many find it difficult to seek support and information due to community-wide and personal experiences of racism (Essed, 1991; Higginbotham, 1992). Many also live with financial problems, and many immigrants face an unfamiliar healthcare system. These factors make it important to consider women's information needs within their social contexts.



## **Methods:**

In this project, we asked women from immigrant groups in the Toronto area to read and analyze some common breast cancer information materials, in small focus groups. Although the conversation did not focus only on the information materials, they provided good “starting points” to discuss related issues and experiences. Guided by a facilitator, the women talked about their views on the information and gave many concrete suggestions about how to improve these written materials.

The study used qualitative, participatory methods. Qualitative research is useful when very little is known about a problem or issue, and when the goal is to gain an in-depth understanding of people's experiences or views. It tends to involve small numbers of participants, which allows researchers to go into great detail, and it often uses focus groups or interviews to learn about the topic.

**Qualitative** research is concerned more with “why” questions, than with simply “what is happening”. **Quantitative** research gathers numbers or statistics, so that we learn how many people hold a certain belief or act in a certain way. Qualitative methods ask people to speak in more depth about why they feel that way, or why they do what they do. (Some sources about this research method are included in the references section.)

In this case, the women were asked to talk in depth about what they liked and disliked about the information sources they read. They were invited to talk about their own experiences if they wanted to, to help us understand why they liked or didn't like aspects of the information, and what they needed that was missing.

**Participatory** research is research that is done in a way that includes people who are affected by the issue or problem being studied. Often, members from the groups affected help to develop the research study and are invited to give feedback about its results and how the study information should be used.

Participatory work is also concerned with making the research results available to the groups and individuals affected by the issues, and to those who can do something to improve the situation - for instance, policy makers, healthcare workers, social workers, support group leaders, and others who provide information.

In keeping with the participatory approach, we formed a project team with an advisory committee made up of members from community and healthcare groups, breast cancer survivors, and two facilitators who lead the focus groups and interviews during the study. The project team offered advice about the recruitment of participants, the research questions, and the discussion of the results. Advisory groups help to ensure that the project stays relevant and accountable to the researched populations.

Thirty-five women attended focus groups, and three were interviewed individually (at their request). In one group, only one participant showed up, so it became more like an interview even though she had been willing to participate in a group. At two other groups, only 2 people arrived. Overall, eight focus groups were held; they ranged in size from 2 to 7 women. It was very difficult to find times when everyone could make it to a group, therefore, we often went ahead even when there was only a small number, so we did not lose the chance to speak with the women.

The focus group discussions took place over four to five hours during one day each. Women were brought in for the day, provided with lunch and refreshments, and were paid for their time. Childcare and travel costs were also covered when needed.

Each focus group viewed as many samples of information as the time allowed. For instance, they would read a short magazine article, look at three or four information pamphlets, and spend some time talking about the photos and drawings in the material. The facilitator introduced each session with some basic guidelines, stressing the importance of privacy and respect for all participants. These guidelines were also distributed to all participants (see Appendix A).

The facilitator guided the discussion by asking questions about the information's content, quality, communication style, appearance, target audience, and effectiveness (see the focus group question guide in Appendix B).

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### **Materials studied:**

As the goal was to study commonly-available, "mainstream" resources, we asked support groups, hospitals, fundraising groups and resource centres in the Toronto area to supply samples of the education materials that they most often give to breast cancer patients. From these materials, we chose eight that covered a broad spectrum of themes or topic areas; we tried to avoid duplication of similar information (see Appendix C for a list of the materials used).

Topics covered included: nutrition, exercise, treatment decision-making, emotional issues, diagnosis, financial problems, and "general overviews" of breast cancer. We also included magazine excerpts of women's personal stories of breast cancer, and we collected breast cancer

booklet and magazine covers so that the women could discuss the images. In many cases, the brochures were too long for women to read the whole thing, so we chose excerpts of a few pages or a main section for them to read and discuss.

All groups were able to cover about six of the materials in the time allotted, sometimes discussing the others briefly. In the case of the three individual interviews, the women were sent four materials to look at ahead of time, because the time allotted was shorter. Normally, informal discussion continued over the lunch break, and we often used this time to talk about the pictures in the materials. (Appendix C notes how many groups reviewed each item.)

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**Recruiting participants:**

We wanted to be sure to speak with women from the most common immigrant groups in the Toronto area. These communities include, from largest to smallest, South Asian, Chinese, Black, Filipino and Arab/West Asian (Statistics Canada, 2001). Most of the participants were from these communities, but the study was not limited to them; the criteria were only that women had experienced a breast cancer diagnosis and that they came from a racial minority and/or immigrant community.

All participants were immigrants to Canada; most had lived here for at least ten years, many for more than twenty. An overview of the participants is provided below. (n/a means that the question was not answered in the questionnaire given to participants before their focus group or interview. See Appendix D for this questionnaire.)

**Participant Profile (n = 38)**

**By race/ethnicity (self-identified)**

Black Caribbean (Jamaican, Guyanese, Barbadian) n = 9  
 East Asian (Chinese, Filipino, Korean, Malaysian) n = 10  
 South Asian (Pakistani, Indian) n = 11  
 African born (South Asian or Black African) n = 3  
 Mixed race, n = 1  
 West Asian, n = 1  
 Latin American (Chilean, Native) n = 3.

**By age**

**Time living in Canada (in years)**

30-39	n = 2	3-9	n = 4
40-49	n = 8	10-19	n = 7
50-59	n = 23	20-29	n = 10
60-75	n = 4	30+	n = 14
n/a	n = 1	n/a	n = 3

### **By time of diagnosis**

1990-1994	n = 6
1995-1999	n = 9
2000-	n = 21
n/a	n = 2

We contacted women through hospitals, social service groups, community health centres, the project advisory committee, and word-of-mouth. Overall, recruitment was the most difficult phase of the project and took longer than expected. Focus groups and interviews were held from July, 2005 to January, 2006, as participants became available.

There are many different communities, races, cultures, religions, and individuals represented. It was never the intent of the project to suggest that all women of colour are similar, or that different groups necessarily have a lot in common. Nor are we suggesting that women of colour are fundamentally different from all women from the dominant group. What we wanted to learn about is *how* the information addresses a specific kind of patient – usually one who is Canadian-born, white, middle-aged, and with a particular level of education, income, and familiarity with the health system. We wanted to hear from many different perspectives how the material and the system could be changed to meet everyone’s needs.



### **Focus groups:**

All of the participants appeared to enjoy the focus groups. In several cases, the women all exchanged phone numbers afterward so they could keep in touch. Several commented that just the act of getting together to talk about their breast cancer with other women had been helpful and enjoyable.

The tone of all the discussions was respectful and positive. Even when they offered criticism and spoke about difficult times, the participants were not cynical. The discussions occurred in a spirit of “hope” about making things better for other women from immigrant communities.

*[I’ve been] through everything ... surgery, double mastectomy, reconstruction, everything. And radiation. So I have been through the whole works. But what I want to mention, particularly in here, is that at no time did I find it intimidating, or did I find that, oh God, I can’t handle it anymore. It is not that formidable as ... you know, some people would think. There is a lot of hope in all the treatments... we have excellent staff and excellent health care here which is very supportive.*



## FINDINGS

For this report, the findings have been categorized by general theme, as follows. We have included several direct quotations from the participants as examples within each category. After the findings, we discuss the recommendations offered by the participants.

### Reasons for participating:

The majority of the women felt it was important to reach other women of colour, as they had felt isolated during their cancer treatment. Another common reason for participating was to contribute to a knowledge base needed to develop new materials for different communities.

Many women stated that they had not been given much information when they were diagnosed, yet some felt that too much written information was available, so that it was overwhelming or confusing. Some stated that they wished they had had the materials from our focus groups when they were diagnosed, noting that they would have been very helpful. One participant said that she had received no information to read until after her surgery to have her breast removed. Others who had been diagnosed some years ago also mentioned that there had been little information available at that time.

*...when I see the (flyer ) for marginalized breast cancer survivor, I was (really eager to come,) it was because like maybe at this point, in the future, if someone ... for example, some Chinese woman who is suffering from the same illness, they don't have no one to talk to ... if they're not ... (versed) in English or don't speak much English ... then I can come forward and share my own experience and give them some support.*

*...it was like 7 or 8 years ago that I was diagnosed with breast cancer, and it was also at that time that I was pregnant. So I had to undergo ... (very traumatic) treatment. And I guess... we don't have too much material which is culturally sensitive. I really would like to contribute some of my effort so that people who are suffering (the same thing) can get some support.*



### Diet and nutrition:

Women were very concerned with what to eat and not to eat. Under this subject, the participants read one of two different versions of a booklet about nutrition. (We originally received an older version of the booklet from the Canadian Cancer Society, and partway through the study, were sent an updated version. The content of this new version is basically the same but it has a different cover.)

Generally, the women all agreed that nutrition was very important when coping with cancer, and nearly all of them had something to say about the lack of racial and cultural diversity in the diets represented in the booklets.

From a participant who runs breast cancer support groups:

*We try to get somebody to come in and talk about different topics that would interest the women. And I find that the response to nutrition ... the percentage is a lot higher than all the other topics. Everybody wants to know about nutrition.*

While people came from different cultural backgrounds, virtually all agreed that the information they read about diet was addressed to a white, mainstream Canadian audience; they had seen no information about other culturally-specific diets. Pamphlets and articles made no reference to the foods they were used to eating from their countries of origin. They wondered if the food they normally ate was safe, or if they needed to change their diets until their cancer was gone.

*I don't see my normal diet here - do I ignore this altogether and assume that my regular diet is fine, or do I ignore my diet and switch to whatever it says here?*

*This is a white person's food. So it doesn't really attract my attention.*

*It's like, you know... because you've become ill, so you have to have western food ...*

*...my breakfast is probably going to be green bananas, and salt fish... So... is it OK for me to eat my stuff? - because it really isn't in here, and it's not telling me anything about the diet that I would normally eat.*

*Somebody... who's living a very modest life and especially is short of cash ... [and] new in Canada, has no idea about the system, and no idea about the western food, would just say, oh, this is so (privileged).*

*people from Somalia ... I mean they don't eat grapefruit and they don't eat peanut butter, and they don't have split pea soup, and apple sauce. [laughter] None of this is relevant.*

*...when I got diagnosed with breast cancer, talking about the diet, I never heard of tofu in my entire life. [laughter] And there was nowhere for anybody to tell me, what in the world is tofu?*

Some women also discussed dietary advice that they had received from other sources, like friends or alternative practitioners. Often, they had been advised to give up meat. In some cases, they found this difficult as they were used to having meat in their diets and had to cook for families who were used to eating meat.

*A friend [who is a dietician] told me that, you know... you might [want to avoid] genetically modified foods and canned stuff, because of the chemical changes [in them ...] you don't want to take that (risk). And I'm not taking them even now.*

Many women felt that buying organic food and shopping at health food stores was important. Often, they had read this, or heard it from other survivors or healthcare practitioners, although some had also been told that it wasn't necessary. Most of them commented that organic foods are

very expensive. The brochures they read for the focus group neither advocated nor opposed buying organic foods, but mentioned them as an option.

*Even now, I think twice before going to places like [a large health food store], (they are) expensive, they are really expensive. So ... just mentioning as if this is the normal way of life is really not fair. Like, not everyone can afford paying double the money for organic...*

*Health food stores are extra trips. If you don't have the motivation like [another participant] did to really search them out, you have to rely on what you can get from the grocery.*

*But if you're... on a budget, that means another (public transit token)...*

*Or 2.*

*I asked my oncologist... should I start eating organic food. And he was deadly against it. He said you don't know [if it is really safer]... just eat normal food. So I'm really confused about organic food. How organic is it? [laughs] And as well, it is expensive. But (if it's) good for health, (and) if you can afford it, I don't see any reason why [not]. But there's ... once again, this controversy about that... how organic is it? There's nothing pure, even the rain that comes down is not just plain water.*



### **Exercise:**

Most women liked the brochure about exercise following breast cancer treatment. Some had had it when they were diagnosed and many commented that they found it useful. A few commented that the brochure did not make clear how long one has to keep doing the exercises, or how soon after surgery to begin. Some also suggested that, like with the diet information, different forms of activity from different traditions, such as yoga and tai chi, could be included.

A few women mentioned that one exercise – “hair brushing” for lymphedema – was not relevant because many cancer patients lose their hair. One was not certain if it meant “actual” hair brushing or just the particular arm movement.

*I think this brochure is OK, but I mean a lot of alternate ... forms of exercise should be included ... and there should be ... some addresses where ... a person can go for a follow-up to see if they're doing it right or if there's something else that needs to be changed.*

*What I like about it is that ... it represents an active lifestyle, so that's good. It gives hope, because if a person is healthy, they can exercise and they can go biking... it sort of represents something that a cancer patient aspires to be... I am able to do all this, so that's good enough.*



## Images in the literature:

We asked participants to comment on the cover pictures and images in all the information they read. In the focus groups, they also looked at a series of covers (about 12) of a breast cancer magazine called *InStride*, and were asked what they thought of the cover images. Most noted that there were very few women of colour pictured in the information overall, and that when they did appear, they tended to be light skinned, representing few different cultures or ethnicities. Some commented that the materials never pictured women in different traditional forms of dress such as *hijab*.

Nearly all the women commented on the class backgrounds of the women represented, noting ways in which they looked affluent (using cell phones, working at offices, riding bicycles, wearing nice jewelry). They often noted that those from working class or poor backgrounds were absent. One woman said that the people pictured all appear to be “corporate” and “middle aged”. One said that she had thrown out a brochure that did not appear to reflect her life.

On the other hand, some women liked the same pictures because the women looked happy and healthy, which made them feel more hopeful about getting well.

about images overall:

*I was really happy to see a black person's face [laughs]...at least one woman is a colored woman. The rest belong to a section of the society ... that [laughs] I don't belong to.*

*Not only black, but ... these don't reflect ... women of color on the whole*

*I mean they make an effort to show women of color, but it's also... I work with low-income communities. And it's [not] even middle-class women, OK - with jobs, with cells, with bicycles [laughter] ... And I'm not saying that, you know, you have to portray misery. [But] the reality is that a lot of women are (not) going to identify with that ... with this picture.*

about an InStride Magazine cover:

*She looks like she retired on a pension! (group laughter)*

about the booklet “A Nutrition Guide for Women with Breast Cancer”:

*the people are ... I mean just look at it, it's so like ... one of those 1940[s] comic strip pictures ... is this an attempt to depict people of color (and) East Asian women... Latin American women, and where's a black woman in this? I mean, is that woman in the blue supposed to be the black woman and the South Asian woman and the ... you know, Latin American woman and ... all in one? Or maybe it's a combination... I don't know. [laughs]*

Some women discussed a nude image of Venus on the cover of one information booklet. There were different responses to this: one woman simply wondered what it was doing there and didn't see its relevance to breast cancer; one stated that she did not mind nudity. Another agreed, and said that the picture reminded her to think of the body as a whole, and not just focus on breasts.

Some women noted that this image would dissuade them from picking up the booklet; one stated that she would prefer to see clothed bodies; one said “she’s awfully blond”. Another commented, “People seem to be making money off women’s bodies”. A few women simply said “I don’t like it”, while one said that it made her think of religious imagery, which didn’t appeal to her.

A number of women criticized a booklet entitled “living and learning” for its cover image. This cover pictured a collage of various objects – a flower, a leaf, an old stamp, some parchment-style paper and a photograph, all tied with a straw ribbon. Some women found its meaning and content unclear. One noted that it was depressing:

*You know, they might have written “dying and funeral” on top of this brochure instead of “living and learning”! ... Why? Because ... you see the way the picture, [laughs] the cover is so horrible... it’s a dried and worn-out ribbon... you know when somebody / probably like your grandmother [dies]... you would collect her memorabilia or whatever, you know... the things that belonged to her, and you put it in a box that has her letters ... that kind of thing... And look (at the) paper... it’s a parchment ... it’s almost (50) years old ... It looks like a dead person’s ... you know, something that belongs to a dead person. So if they really want it to be read by people who are ill and who hope to live ... they should change the picture immediately, this is really unfair, actually. You know, when somebody’s ill, even little tiny things mean so much.*

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### **Accessibility and language:**

Many women found that the information presented was too complex and medical – if not for them personally, for many women in their communities. The majority of them talked about how language barriers and lower literacy would prevent some women from understanding the material. They also felt that the medical terms used would not be familiar to many women, and were not explained well enough.

Some women spoke of their concern about older women who were recent immigrants and were not familiar with Western health systems and terms. They felt this material would be especially unclear for those women. Many older women depend on their children to translate the language and explain the meaning of information.

*I think in terms of the English language, it’s very overwhelming. It’s just too much.*

*...my husband translate by my language, (all, ) everything ... every night he explained to me. Because he just want [me to be] comfortable dealing with breast cancer. (So) every day, he translate, all the books from hospital...he doesn’t know about the breast cancer neither, but explain, explain, explain, it took ... more than a couple of weeks.*

*...the first generations who’ve been here... they tend to depend on the second generation, which are their children, who speak English and have gone through the English system here, to provide that information, but it becomes threatening for a child to translate it to the mother, because it’s not ... the child doesn’t have it, it’s their mother who has it, right?*

*your mind is battling with the emotions of having been diagnosed with something you don't know whether you're going to survive or not. And on top of that... all these documents (are thrust) under your nose which are very good for you, but you need a very calm mind, so I guess ... what somebody has to do is, make the language more accessible, more readable.*

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### **Body image:**

Women were concerned with the effect of cancer treatment on their appearances and bodies, for example, through hair loss, loss of a breast(s) and other effects of being ill and tired. Some noted that appearance concerns were not as important as other health issues, but most of them did find these aspects difficult to deal with. They were critical of programs that claimed to help with their cosmetic concerns, but only supplied make-up products and wigs for white skin and hair.

Several women said that prosthetic breasts did not match their skin tone. They were supportive of one another and traded tips and information about things like prostheses, foods and vitamins, often with humour.

*I went to [a pharmacy at hospital 3], and asked to get a prosthesis... And they've given me a white breast because they didn't have a brown breast.*

*Well, you guys want to hear something funny? I remember when I had my mastectomy and I went to get a prosthesis, they didn't have nothing for women of color. Nothing!*

*I think you should match it to the color of your bra, because if you're a black woman and... you've got a dark-brown breast and it's sitting on your floor in the middle of the morning and you've got to get dressed, you ain't going to find it! So you need something pink! [laughter] ...that's my whole analysis, it's got to be pink! [laughter]... [My friend] likes things to match her skin-tone just in case [her shirt] comes up... [voices agreeing] So we were able to find the exact same brown that matches her. But usually you can't.*

Several discussed hair loss as an important factor, and said that many people are not warned about it when they begin chemotherapy. One woman noted that her fingernails and toenails also fell off, and that she wished her healthcare providers had warned her about this. In general, many women felt they were ill-prepared for the possible side effects of treatment.

*[Participant 1]: I finished my treatment 3 years [ago]... my hair don't grow back.*

...

*[someone else]: Mine grew back, but (a) complete different texture.*

*[Facilitator]: So would you like a special brochure that focused on hair?*

*(Yes...) Hair! [different voices agreeing]*

*[various voices] Hair is very important ... very important ... [to] women of color [laughter]*

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### **Finances:**

Several focus groups read a chapter of the brochure “living and learning” that dealt with financial concerns. We asked about their views on this section and about financial concerns in general.

Most women in the study were well educated and employed; they tended to come from families with other sources of income (husbands, partners, adult children). Some, however, did experience financial hardship, and some who did not have financial problems themselves mentioned that it was still a big concern for many in their communities. They also noted that finances were a barrier to taking part in clinical trials, due to the added travel and other costs.

*You know, people in low-income communities can't afford to go to those places where the clinical trials are being held... you've got to fly to this place.*

*I remember, I just told the social worker at that time, can you just tell me how to keep the shelter and food on my table ... because I just knew, I had to stay in that apartment, I couldn't be homeless, and I had to feed my daughter and myself. And ... that's all, and I had no idea how to go about it. It's a big problem, the financial concerns are huge.*

Financial concerns were often linked to the other themes, because it was costly to make some of the lifestyle changes that were recommended or perceived to be helpful. As mentioned above, buying organic food and shopping at expensive health food stores were common examples.

*I went to [a support organization] and they kept on telling me things that I couldn't afford... [They] kept on mentioning things like, oh, you went through chemotherapy, you must take ... those energy drinks and all. And ... she kept on insisting that I should take them, and really, I couldn't afford to take them at that time... Those people have no idea, they're just a bunch of privileged people who made it good, you know, even if they are ... from an ethnic group, they have made it good in Canada, and they have... no idea how people (abide out there.)*

A common problem the women mentioned was that patients were unaware of financial support services that do exist.

*But the key point is really the presence of Trillium, the drug plan ... I heard about Trillium only from word of mouth. But I simply don't know how it works.*

*The drug plan, it doesn't give any information (about the) drug plan! And that's another big concern, you know... you're supposed to take medicine, how are you going to buy them if you don't even have money to buy groceries?*

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### **Other practical support:**

Many women noted that, as with financial resources, they did not know how to find out about support that was available. Sometimes they had found out about such services later on, once their treatments were over. They mentioned lack of information about: transportation to appointments, home care, social work services, where to find information, and peer support.

*Luckily, I got the transportation from the homecare people. But this is not a common thing (and) it was just by chance I got it. And I really thanked them so much after that ...because I didn't know the bus system, I was too new to understand that... if I didn't have that transportation assistance, I would have been lost about how to get to the treatment, because you're really ill and (you've) just had a chemotherapy shot, (you) really need to go to the bathroom ... (like,) in a public transport ... it's like, [laughs] how can I reach home? ... you know, there's all sorts of things happening to you... So ... maybe some information could be there to guide people how to deal with this...*

*...you know, it's a very weird thing ... [the cancer organization] does a lot of wonderful things. But on the other hand, they're not very clear. And ... if you don't ask about the rides to treatment ... [a transportation program], then you don't know about it. Where do you expect to get this information from?*

*It would have been nice to have known if there was any help I could get to get to the next oncologist's visit.*



### **Emotional and spiritual support:**

Several women noted that the information seemed to assume that everyone has good support structures in place during their illness. One felt that the information made an assumption that people have a good relationship with their doctors and can simply call on them to answer questions or explain things, while this is not always the case.

The article that some groups read about emotional issues was generally appreciated, because there were few resources about this aspect of coping with the disease. Some women liked how it explained the sadness and fear about breast cancer.

However, some were also critical because the article told the story of a woman with a “perfect” life, which was suddenly disrupted by breast cancer. They felt this was not realistic and did not reflect their own lives. Some felt sorry for the woman in the story because her “perfect life” may have given her an “illusion of control” over life, so that she was not prepared to cope with a crisis.

*I have nothing so I didn't have that sense of control.*

*For us, it's more [like] “this on top of everything else!”*

One woman felt that the article adopted Buddhism and concepts like “mindfulness” in a simplistic way, which was insulting to those who come from those traditions. This was interesting, since the article appeared in a magazine that most women felt was geared toward affluent white women.

At a few points during the discussions, women noted that much of the literature seems to assume that patients will have support from spouses, family, and friends, or that these relationships are stable and helpful, which may not be the case.

*And you have this fantasy that, oh, when it does happen, everyone'll be around you, and it'll be like a happy thing and you'll reconcile and all... It did not happen!... (laughs). [That] just went out the door - I'm thinking, what could be worse than this! And I remember going to my mother's... deliberately, I took the scarf off, and was just [sitting there] bald. And ... the family members were there and they just kind of ... it was like a... total glaze, and I remember the last thing ... one of them had said to me was, why don't you get a job. [laughs]*

A very common point was that there were few resources for families or children. Participants also noted that there was little attention to different home situations, for instance, women who live alone. One group in particular discussed the need to make support options clearer and to offer support in formats that are appropriate and open to different women.

*People typically think of ... and please excuse me, I'm going to be very blunt about it... “support” – [the] word is associated with some club where white women meet and talk about cancer... And ... people are really intimidated, people of our background are really intimidated.*

*you know, I went to the [emotional support program] at [a hospital]. And you know, I absolutely loved the program, even though [leader's name] puts me to sleep. But ... again, the whole thing is in English. But ... we've been reading *The Power of Now* and other spiritual stuff, and I find more and more as I'm trying to grow spiritually that that sort of is (kind of) helping, but you have to have a really good knowledge of the English language to (really) get to that.*

## §

### **Alternative treatment:**

Alternative or non-Western forms of healthcare were important topics in most focus groups and there were a variety of views about this issue. A number of women expressed interest in new research and information on alternative cancer treatment. Some women spoke of being offended when healthcare workers were insensitive toward cultural beliefs and health practices.

Several participants expressed suspicion of Western medicine, and some viewed healthcare staff who were critical of alternative treatments as less trustworthy. Others were very cautious about alternative medicine and its possible interactions with cancer treatments.

*It seems judgmental - "These have not been shown effective by scientific methods." - It depends what research reports you're doing. [One cancer agency's] scientific evidence has shown that it is an effective method of reducing nausea, of reducing the effects of chemotherapy. Not treating the cancer. But dealing with the symptoms.*

*...we're talking about cultural beliefs. Some folks hold that very dear.*

*I also went to a naturopath. (And) I went to a Chinese doctor (who) only knew Chinese, and through interpretation (through his son) we followed what he advised.*

*...myself, I don't go for the Chinese medicine. But I'm saying like, at this stage, when people are very vulnerable, maybe the older generation will recommend alternate healing methods...*

*[It's important] just to have knowledge about it, not that you believe [all of it]... It's more of (really) what are available. And then of course you've got to read it and ... find out whether it's valid. There are so many things, especially with the Internet availability. There are so many things that you've read and then they talk about these ... other alternatives, even going to Mexico [laughs], or all those things. I think the bottom line is really making it available, and... I would put it more cautiously. More cautiously. But make it available. Cautious in a sense that they might negate already the proven ... way of handling cancer...*

Overall, it seems true to say that there is a need for more education and discussion about research on this topic.

## §

### **Relationships with health professionals:**

Many women were very happy with the treatment they had received, and felt that their doctors were helpful and sensitive. They especially liked it when doctors took the time to answer questions. Some noted that their doctors did not have good "people skills", or gave examples of other problems they had encountered.

*I've changed my oncologist. She would not make eye contact, she would not answer my questions. Later I find out, she was very good, but she was in the statistics area, a researcher. She had no personal human skills, you know, people skills.*

*Male doctors tend to ... especially if it's a female patient they're dealing with, tend to downplay ... they don't recognize the fears that women go through when they're being talked to about their disease...*

*They were very very kind. You know, I like my surgeon more than my oncologist... With the surgeon, he is (a) very, very good doctor, maybe because he was talking to me very friendly, and my oncologist doctor, very, very nice, very, very good, but ... I'm not comfortable with her.*

*Yeah, my surgeon was very good, he came up to me (that) morning, I was prepared, and then he told me exactly what was going on. A day before the surgery I went (in) his office, and he said...*

*we think it's cancer... He explained [it] to me... he looked very ... he looked genuine, and ... before the surgery he gave me his personal cell number. He said... I'll see you after the surgery, give me a ring if you have any concerns.*

*Q: ...so you went to your GP to tell him about your fibromyalgia that's developed...?*

*A: [Yes...] He didn't believe me... He said (it's) in my head, there's nothing wrong with me... I don't know how to explain to him. Now the worst part is that somebody said, change your doctor, but I said, if I get somebody worse than him, then I'm in a worse position. So I'm stuck with him, but sometimes I'm very, very depressed with his behavior.*

*I think that ... my surgery (is) excellent. He provide a lot of information... I have a lot of psychological preparation before.*

*He did not like to be challenged about his medical decisions, but in terms of... the emotional support, he has really good people skills, and he said things like, after I got the septic infection, he came in, and he apologized, he said, you never should have gotten a secondary infection, it was probably surgeon error ... and I really want to say I'm really sorry about that.*

Many women talked about health system “overload”, which meant doctors and nurses were often too busy to take time and answer questions. Because of the lack of time, they were afraid that taking up too much time to ask questions might annoy the staff, meaning they might not get the best service.

They were also concerned that newer immigrants who were unfamiliar with the health system would not be comfortable asking questions. A few pointed out that older generations and some cultures do not encourage anyone to question medical knowledge.

*Especially somebody new in Canada, [voices agreeing] they would still be ... [trying to understand] the system, and find it too difficult to question the doctor*

*...maybe the doctor thinks I'm asking too many questions and maybe I won't get treated properly.*

One group discussed clinical trials in some detail, noting that the information provided by health professionals about trials is not always clear, and that they didn't know how to find out more about them or how to make decisions about participating.

*Participant 1: ... I remember my doctor saying to me, they're going to have a trial... Well, I like to be a guinea pig as usual, but it so happened that ... I don't know what happened, he didn't tell me why I didn't take part [in] it, I don't know if it's my colour or whatever ... he didn't choose me, he chose somebody else.*

*Facilitator: But were you given information to make your own decision?*

*Participant 1: No, he just asked me if I wanted to and I said, yes, I would be gladly part of it, you know. But he didn't choose me.*

*Participant 2: [I'm] trying to ... sort of recruit minorities to clinical trials ... there's not enough education done on it, there's not enough outreach on it...I mean how reflective is that research if you're not incorporating these people in your studies? So ... how legitimate is that?*

*Participant 3: And the way it's written it's mixed messages... Why don't [they] explain what a treatment clinical trial is and then say, you know, you don't have to do it, you know, you have a choice, its up to you.*

Some women talked about the difficulty of navigating the healthcare system, coordinating different aspects of care and communicating their needs to various providers who may have inconsistent information about them.

*I always think (that) there can be like better coordination ... in the system, I'm sure like everyone wants to do a nice job. But then, like ... realistically, they all have constraints, and they are doing one part. And now, I think it's important that they're putting it all together, like giving the patient a feeling that the journey is... continued, and that no matter which department they go to, they stay connected...*



### **Expert advice and trust:**

Women often talked about needing to trust the source of the information they were reading. They felt uncertain when forced to rely on an unfamiliar system. They were sometimes confused about the “weight” they should place on the advice and information, wondering if it was meant as a basic guide or as things that one “had to do”.

*you're here in this country and all of a sudden, you've got all this information from the source who knows best for you ... I mean, my thing is, first, I need to trust you to even think about it.*

*my question is... where's it coming from, do I trust these people?*

*I'm in their country, so I have to accept what they have, right?*



### **Survivor stories:**

Some groups read a series of breast cancer survivors' stories in a *Chatelaine* magazine article. There were pictures of each woman, and a paragraph with her advice or tips about how she had coped with breast cancer. Most women enjoyed hearing about other women's stories of survival, but they didn't always relate to their lives.

*You know... if I imagine that I am right now very ill and I am jobless, and I'm like lost ... totally lost... [I'd think] “these women are so privileged ... maybe they survived because they're privileged, and because if I'm not privileged... I can't do all these things.” That kind of thing... puts a person in a very low self-esteem kind of ... frame of mind. Doesn't help. Because a*

*person who can identify themselves with these women would say, “oh yeah, great, you know, they did it, I can do it also”. But not everybody can identify...*

*For this magazine, I think it's quite ... it's the middle-class, at least high educated, professional person...*

*I think [the stories] give other people encouragement... she shared, and she survived, you know, I can come out and share about my grief or my fear... So I think it's very, very important... I like the age group, the variety... and [there are] interesting things they advise... it's nice... because everybody said something different. And all useful... very beneficial.*

Another woman, who enjoyed this article, said that she would have liked more detail about the women's advice, rather than the large pictures that the article showed, with only a little space for text.

## §

### **Racism in healthcare:**

While few women gave explicit examples of discrimination on an interpersonal level, they sometimes talked about incidents in which they felt healthcare providers treated them differently because of race, culture, or social class position. Sometimes they were not certain how to judge a particular incident – recall the woman who wasn't sure why she was not included in a clinical trial: “*I don't know if it's my colour or whatever*” – it just felt like something was wrong.

*If you're kind of middle class, or you're somebody who kind of has a lot of family support, I think you get treated a lot better by doctors.*

*My doctor is really good, she's a really qualified surgeon, but I don't know why, the first time I met her, she looked at me and she said, “how long have you been in Canada?”. I said, 5½ years. And ... I don't know what she meant, but the words that came out of her mouth were, “who let you in? [laughs] who let you come to Canada?” ... [I said] my immigration points were so high that they said, please come to Canada. So it's not that I had to struggle to come to Canada, I almost got an invitation... So it's just by chance that I got ill - I didn't plan on this... I had no other problems with her. But I don't know why... Maybe she was thinking that, you know ... maybe there (are other) people who misuse the system. They get ill and then they come to Canada, they use the medical system over here. But it wasn't like that for me...*

In one group, a number of Muslim women discussed how health professionals and office staff tended to “talk down” to them when they wore headscarves (*hijab*). Despite their annoyance, they found this quite amusing, and told stories amid much laughter about how people would speak very slowly and loudly to them, assuming they would not understand.

Another woman felt there was a general racist environment in healthcare, and added that she had also felt discrimination from her own ethnic community:

*I'll tell you something, Canada has a fantastic medical system. We're so lucky over here that cancer treatment is paid for, basic cancer treatment... It is a big privilege, because I know of other countries that it's really expensive. A single chemotherapy [treatment is]... more than 100,000 (rupees.) So that way... the system, it is (working). But the people in the medical system, I don't know why, but everywhere I've gone I've found a racist environment. And [discrimination] is not only coming from white Canadians. I found it coming from ... even people from my community.*

This participant went on to describe how, as a single mother, she was looked upon suspiciously by some people from her South Asian community, who, she said, seemed to feel that her move to Canada on her own with a child might mean she had a “dark, shady background”. This is one example of how different forms of marginalization can occur together. It is not simply racism, but also cultural (Canadian and other) ideals about the nuclear family or the “proper” place of women, that make it difficult to obtain respectful treatment and support.

Often, people do not express discrimination explicitly; it may be unconscious, and others may experience it more at a systemic level than an interpersonal level. In essence, though, the data collected here are all about discrimination, because the ways in which information is developed and conveyed tend to exclude women who are already marginalized, or do not meet the profile of the “dominant” patient.

## §

### **Overall:**

Most participants did find the materials useful. Even when they were critical, they often noted that it was good to have any information at all, and they were used to adapting the information to suit their own needs. Many were very pleased and surprised to find new materials, such as *InStride* Magazine, which they hadn't heard of before; they wondered how to subscribe to it.

Considering the overall lack of relevance in the material to many of their cultures, backgrounds, lifestyle factors and needs, they were appreciative of what was available. Some also noted that in crisis situations like a breast cancer diagnosis, they just wanted information and were more concerned with the topic and content than, for instance, the cover images.

However, since we also heard that some women would not even pick up a book that didn't reflect their lives or cultures, we know that presentation and appearance are important – they can affect whether women get information or not. More than one participant noted that when materials only reflect white, middle class women, it can seem as if only those women get cancer.

*The information that was out there seemed to always focus on white women, to the extent that you would almost think that breast cancer is a white disease...*

*I think it's not that they are excluding anyone, but they just think that it's just the same for everyone.*



## RECOMMENDATIONS

Overall, the most common themes that arose concerned:

- socioeconomic or class position
- information and images that were mostly of and for white middle class women
- lack of information on specific ethnic and cultural foods and lifestyle factors
- difficulty due to language
- not understanding the terms used

Most suggestions the women made for improvements to the information reflect these themes.

### Images:

Things they liked and wished to see continued:

- Attempts to show racial diversity
- Pictures of women of all ages
- Bright and attractive colours in general
- Pictures of people as opposed to just drawings

Recommendations:

- more pictures of people who look like them, including darker-skinned women
- more diversity in traditional dress, i.e. *hijab*, *sari*
- attention to class, economic and lifestyle differences in the images, for example, not showing only middle class or affluent women and signs of privilege, i.e. office jobs, expensive-looking clothes or jewelry, cell phones.
- Diversity in activities that are represented, i.e. show someone doing tai chi or yoga, someone in a wheel chair
- Sensitivity to the body-image issues around breast cancer for women of colour, i.e. some might not be comfortable with bathing suits; some did not like pictures of naked women, especially “beauty ideals”, as in the image of Venus.

*Well I like the fact that they put, you know, faces as opposed to some abstract picture there... “the face of cancer”... but I think they could do with a lot more colour... it wouldn’t hurt.*



### Appearance and readability

Suggestions:

- Use large fonts
- Keep paragraphs short, with spaces in between
- Use columns
- Use graphics and illustrations to break up the text

- Provide pictures to illustrate medical terms where possible, e.g. lymph nodes
- Use bullet points where possible
- Make clear from the cover and title what the information is about

*I wouldn't even know that this is associated with breast cancer ... "living and learning" ...  
Yeah, "living and learning"... maybe it's a ... craft thing...?  
[It has a] stamp on it...  
Yeah, and then the way they do the ribbon and then the flower and all...  
Maybe it's a dried flower kind of...craft book.*



### **Content:**

Things they liked:

- Just about any information in general is helpful
- Any tips about what to do to stay healthy and to aid recovery: information about what to eat, general nutrition, vitamins, supplements, how to exercise, and other lifestyle factors

Recommendations:

Over and over again, we heard words like: simple, clear, direct, support, and resources...

*[written information] should be very simple and direct. I mean, like I think I'm using the words simple and direct for every single brochure, but it has to be really simple, straightforward, and just giving the information... Because a person who's ill really isn't thinking too much... they just want somebody to help them. They just want answers at that time.*

- clearer explanations, in simple language, of some statements or terms (i.e. TMN system, lymph nodes)
- more information that explains what clinical trials are and how to make choices about taking part
- different food choices in the menus, with options from different cultural diets; alternative foods of equal nutritional value
- Some reassurance and clarity about the degree of "control" one has over cancer and its causes

*I was scared, because I thought, oh my God, what did I do, I got cancer. I think I did something wrong...*

*...that was one basic question we were looking for in terms of nutrition: What was wrong that maybe created part of our breast cancer...?*

- more information for families, friends and children

*I find that normally when people are diagnosed with cancer, people [say] “oh, I’m really sorry to hear, and call me when you need me”. So maybe some guidance for caregiver(s)... don’t wait for (a) patient who is going through a chemotherapy to come and call you. You go and make an effort to go and see them. [voices agreeing] So I think I find that (is) really lacking. The majority of the people who say, “oh call me when you need me” - are you going to call? No. [laughter]*

*There should be more brochures... for children with a sick parent. Because there’s lots of ... a lot of people who get diagnosed with breast cancer are single mothers. So ... it’s really traumatic for children who have a sick parent.*

- Better explanations, with attention to different levels of understanding: i.e. what does it mean to “participate in your treatment”? What does it mean to say “the disease behaves...”? What does “too early” mean, in guidelines about when to start exercising?
- Be more specific about general terms: What is meant by “support”? What is a “successful outcome”? What is “aggressive” cancer?

*In my case, I don't know what my cancer was ... I don't know if it was severe or not. The only thing I know, the doctor said it's very aggressive. Aggressive in what way, I don't know.*

- more clarity around what the treatment choices are and how to decide, without putting all the onus on the patient.

*Q: What if you could create your own brochure?*

*A: My brochure would clearly tell the person ... what to do about finances, but in a very straightforward way. If you’re employed, this is what you need to ask your employer. If you’re not employed, these are the 800 numbers you can go and get help, and they can guide you how to get assistance... Um ... my brochure would definitely have information about ... sorting-out of the mind, you know... the way they’ve been dealing with their problems... they can’t put everything in one brochure, but they can guide people, you know. For meditation instruction, they should go to these places... numbers and information about... services, like [first cancer support organization] and [second cancer support organization] and ... all other support services must be available (more) clearly to people, because a lot of people don’t even know that such organizations exist.*

## §

### **Unclear information:**

Women often expressed frustration about specific topics for which the information was confusing. They knew that research was often inconclusive, or that doctors simply don’t know enough about certain things yet, but it left them wondering whether to use certain products, or whose advice to trust. They talked a bit about how they thought such topics should be handled.

*they make a statement, like ... they recommend something, and then just in the next line or in the next paragraph they say, you know, maybe it's not, like, it's good, but maybe it's not. This whole brochure is like that.*

*...if I were to read this, after first few lines, I would just throw it away... I don't understand what's going on here ... what should I take, what should I not take. It has to be more clear, and it has to be more specific, geared to informing you, not confusing you.*

*[I]f they are uncertain, then they shouldn't even mention it ...*

*...if [the cancer organization] is really scared about making... suggestions... recommending flax seed and yet not really wanting to recommend flax seed, recommending... soy products and not really actually wanting to do that also ... they should avoid information if they're not really sure that they want to give it out.*

- Information on alternative treatments was confusing

*[The brochure] says, "contrary to what you have heard, evening primrose oil does not contain estrogen" ... [But] my doctor specifically bashed me for [taking] it (and she said) [exasperated voice] "you should not even go near it!" So that's one controversy right there. [laughs] Who should I believe, this brochure, or my oncologist? ...she's a very well known oncologist also, (like I know) she's qualified. So I would be really confused. In the end I would leave it because I would believe the doctor... when I said controversy... it was things like this...*

- Discussion of "hormone therapy" in the literature was sometimes confused with hormone replacement therapy (HRT) for menopause

*Some research says that hormone therapy... increase(s) the chance of breast cancer. That's why I don't understand why they still put the hormone therapy on that page... people will [be] quite confused.*

- Delays in treatment seem to conflict with advice or information in the literature

*what you are supposed to do and what the brochures are telling me are all different. Like the treatment plan they say should be done within 3 months and then they tell you, oh, we don't have any slots [for appointments] in 3 months.*

- Flax seed
- Tofu and soy products

*I have always stayed away from [soy] because I have read articles on soya which scared me, [laughs] frankly, so I don't take soya at all. But ... All it said was, women who have had breast cancer should not take concentrated soy components. And that to me is a little misleading,*

*because what do you mean by concentrated? ...[and] some women have been misled to believe that you should be drinking soya milk every day.*

*[My doctor] told me ... buy flax seed, and have it, and it's going to help you. And as soon as I got (out of) the hospital, I bought, and I eat it... and it was helpful. But I read in [a study by a professor] ... women that [take] Tamoxifen, they cannot have flax seed... I (thought) you know ... he is professor. And that lady is oncologist, radiation. And which one has to be [right]?*

- The terms phytochemicals and phytoestrogen were sometimes confusing or alarming, especially because estrogen is known to be potentially harmful.
- One woman suggested that medical information from new clinical trials should not be made public until they are in a late stage, when it appears that the results are promising. She felt that mentioning new trials that were only in stage 1 or 2 could give people false hope about new treatments.



### **Tone:**

#### Recommendations:

- Information that offers a positive message and says what one can do to improve health and healing
- Information that is respectful of different cultural beliefs, i.e. alternative health practices, even if these are not effective treatments for cancer itself

*I think what happens is, when you go to a typical cancer-related website, it doesn't open with a message of hope. It just kind of puts the information, bang, in front of you.*



### **Communication with health professionals:**

#### Recommendations:

- more discussion with and patience from some health professionals when answering questions and discussing options
- more suggestions in the information samples about how to get the most from medical appointments, i.e. bringing a friend, writing down questions, taking notes during the consultation

*In some places, some books, they'll encourage you to take notes, or to take someone else with you who will take notes. And I think that's a very important tool. But you know, it's not really stressed in much of the literature.*

*I told [my] friend ... she just got diagnosed with breast cancer... I said, you can take somebody with you. She said, are you sure? I said, of course you ... it's your treatment, and you have to be*

*vocal about it... I said, your husband will not remember anything... because they're too busy with emotions. Take a friend who will be separated from your issues, and they can write down things for you, and ask questions. So, we sat down prior to going, we wrote down questions.*

- Encouragement to ask questions; assurance that asking for more information will not compromise their treatment
- More attention to communication training for health professionals

*[I have heard] women saying ... do you think that they would treat me differently if I ask too many questions. Sometimes they don't want to get a second opinion, because the original doctor might think, well, you don't trust me, so you have to go and get somebody else's opinion. So ... sometimes I think a lot of the times it's just fear of what the repercussions may be if they seem to be asking too many questions.*

*Somebody has to be really kind and give a lot of time to guide a person. You know, even a person who might be able to / like even somebody who's been here, like a Canadian-born person ... your mind is blank, you really don't know.*

*(I was reading) an article... [An oncologist] was talking about the lack of communications skills within the medical profession, [voices agreeing] how little they know how to interact with people. ( they're) so busy prescribing, they forget how to describe... he was just saying that...when they're going through a medical... specialty or whatever, they should be taught these communication skills... [voices agreeing]*



### **Translation:**

Almost all participants stressed the importance of translating information into different languages. Although the content of the message is important too, just being able to read something or communicate with a healthcare worker would go a long way to improving women's understanding of their disease. While some hospitals do provide translators, others still do not.

*But if they can be printed in their own languages, and (we) know ... what languages are predominant in Toronto. And by 2017 [laughs] these languages are going to be very, very ... you know, a dominant factor in the society.*

*If somebody doesn't know English, they just do whatever they give to her. They just accept it... they don't have any choice.*



## Preferred formats:

The formats in which women wanted to receive information varied widely: some wished they could talk face-to-face with their doctor at first and then have information to read later; some preferred only written materials; some found that too much written material was offered, so that it was difficult to “take it all in”. Some wanted a longer discussion with a health professional than they had received, especially about their treatment options. Many women wanted, first and foremost, just to be told “what to do”.

*What I needed was somebody to talk to, that's what I needed. I needed somebody that would sit across the table from me and say, you know what, [her name], this is what has just happened, these are your options, this is what you can do, you know, this would work better for you, and at least listen.*

*[I don't] think that I would read all of this [laughs] when I came home after diagnosis. Somebody would have to read this for me.*

*I just want to know what to do. Straight to the point, tell me what to do, rather than reading all this long information.*

*I'd like a video, because (if) I'm in denial, (then) maybe at least I would watch a video ...*

*I don't know, you just collect all of them, you know. But I think for me, what I needed the most was information like this in a human context, like face-to-face.*

*For me, I like the written material because I like to read (and I) can take it anywhere. I can take it to the bathroom, I can take it to bed ... I'm not confined to like in front of the TV, or ... whatever. For me, written material is best.*

## §

## Where and how to provide information:

### Recommendations:

- Place information brochures in different languages in places that women often go, i.e. beauty salons in different communities, ethnic grocery stores, places of worship and community centres
- Give more contact numbers in booklets and brochures, for instance, for dieticians in the nutrition booklet, more support organizations, how to contact transportation services and find out about financial support
- Create public service messages in different languages on culturally-specific television stations, such as the Asian Television Network, to raise awareness
- People who produce information could learn more about writing for low literacy audiences, through a resource like the Clear Language and Design tool (CLAD) <http://www.eastendliteracy.on.ca/clearlanguageanddesign/start.htm>. This web site offers a

guide to assess whether a piece of writing will be clear enough for the grade level of your audience. The organization also offers consulting to assess new materials.

- One group discussed the need for different literacy levels in information. They favoured simpler language overall, but with references or web links that defined the terms used, and gave more in-depth or scientific explanations for those who wanted to read more:

*...if there is a word that a layperson would ignore, but someone like [laughs] us... you know, all of us are into information-gathering, we would like to click on that link and go further, right? So there should be links provided on difficult words, or very medical-type terms ... so if there is someone from a medical background who can understand, go ahead, navigate further, get more information, right? But if you're a layperson, you could just ignore it.*



## CONCLUSION

The findings and recommendations here point to the need to think about diversity and power relations on many levels. While we set out to explore immigrant women's views about what was wrong with cancer information, we found a wide variety of views and needs, and, naturally, women did not always agree on the necessary changes. Even though the participants were from relatively marginalized groups in Canadian society, we were constantly reminded of differences among them as well - in interests, education, financial resources, family dynamics, community and personal preferences.

At the same time, on many topics, considerable commonalities were expressed, as can be seen in the various recurrent themes. What was perhaps the most common overarching lesson from this study was the need to de-centre the notion of a "model" patient who is not representative of so many women's lives and needs.

As a final note, it is clear that no study is capable of addressing all the relevant and important issues, and every form of project design has both limitations and benefits. The following are some challenges that are important to keep in mind; we plan to continue addressing these gaps and further questions in future work. We then close with some key strategies for sharing this study, many of which are already underway.

### **Some research limitations:**

*Participants were generally well-educated:* Because we were looking at mainstream resources in English, it was necessary to have literate women who were relatively fluent in English. Most were quite well educated. They often pointed out that newer immigrants would have a harder time than they did, and that language and comprehension would be greater barriers for other women in their communities than for them. This is important to know but it does mean that such information was "second-hand".

*Many were active in the breast cancer community:* Women who came out were often those who were already active in cancer organizations or support groups; it was difficult to reach more

isolated women, so a particular segment of the survivor population was represented. The study also used English materials; it did not evaluate the (relatively few) materials that are being offered in different languages.

*Most women had lived in Canada for long periods of time:* The data does not give us a full picture of the cancer care experience for recent immigrants who are not familiar with the healthcare system.

*Not reading whole materials due to lack of time:* We attempted to mitigate this problem by showing participants the whole brochure or publication at the beginning of discussions and making it available for them to look at during breaks. When questions or criticisms arose that were answered elsewhere in the same publication, the facilitator pointed this out, or, sometimes, another participant would mention that it might be answered elsewhere, so the criticism would be qualified. Still, it is likely that reading the full materials would help to facilitate greater understanding. It was not possible to do this in a short period of time and still cover a range of different topics.

## §

### **Distributing the study results:**

So far, the researchers have presented the results of this study at several healthcare conferences, where they reach medical and supportive care audiences. These conferences have included the Qualitative Health Research conference, the International Psychosocial Oncology Society conference and the meeting of the Canadian Association of Nurses in Oncology.

Further steps:

- This report is being posted on women's health and breast cancer web sites.
- An introduction and the weblink to the report are being sent to breast cancer groups and support agencies, including those that produce breast cancer information materials.
- Some hard copies have been mailed out where email addresses were not available. Hard copies can be made available if requested by contacting the Ontario Breast Cancer Community Research Initiative (OBCCRI).
- OBCCRI is currently involved in an intensive program of knowledge exchange, in which the results of our research will be used to strategize for change in cancer organizations and hospitals, and with policy-makers. This study will contribute to this knowledge-sharing venture.
- This study has contributed to another project that is looking at education requirements for cancer care support staff who work with patients across cultural and racial differences.

*I see this [study] as very important. It's a piece of the bigger picture. And I think it's crucial for community agencies out there and government bodies ... did I leave out anybody? ... to understand these issues ... relating to immigrant women and refugee women and marginalized women.*

## ACKNOWLEDGMENTS



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**Many thanks to the advisory and research team members. Your commitment and advice has been invaluable.**

*Advisory Committee:*

Sheryl Nestel, *Department of Sociology and Equity Studies, OISE/UT*

Sharmini Fernando, *Diversity Consultant, Canadian Cancer Society*

Linda Cornwell, *Women's Health in Women's Hands Community Health Centre*

Karen Chan, *Toronto Public Health*

Erica Lawson, *HIV/Social, Behavioural and Epidemiological Studies Unit, UT*

*Team members:*

Leslie Norville, *Research Assistant*

Teresa Macias, *Research Assistant*

Nilofar Ellahi, *focus group facilitator*

Amoaba Gooden, *focus group facilitator*

Tara Zarrin, *volunteer focus group assistant*



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Women's Health in Women's Hands Community Health Centre (2003). *Breast Health Awareness for Immigrant Refugee Women: Improving Access to Breast Health Initiatives* Toronto, Ontario.



### Further Reading:

#### *Racial disparities in screening:*

O'Malley, M. S., Earp, J.-A., Haley, S. T., Schell, M. J., Mathews, H. F., & Mitchell, J. (2001). The association of race/ethnicity, socioeconomic status, and physician recommendation for mammography: Who gets the message about breast cancer screening? *American Journal of Public Health*, 91(1), 49-54.

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***Breast cancer incidence and survival rates among racial groups (US):***

Yood, M. U., Johnson, C.C., Blount, A., Abrams, J., Wolman, E., McCarthy, B.D., Raju, U., Nathanson, M., Worsham, M., & Wolman, S. R. (1999). Race and differences in breast cancer survival in a managed care population. *Journal of the National Cancer Institute Monographs*, 91(17), 1487-1491.

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***Qualitative research on the breast cancer experiences of racially marginalized women:***

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#### ***Impact of racism on minority healthcare:***

King, W. D. (2003). Examining African Americans' mistrust of the health care system: Expanding the research question: Commentary on "race and trust in the health care system". *Public Health Reports*, 118(4), 366-367.

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***General health of immigrants and racial minority groups in Canada:***

Mulvihill, M. A., Mailloux, L., & Atkin, W. (2001). *Advancing policy and research responses to immigrant and refugee women's health in Canada*. Winnipeg: Canadian Women's Health Network.

Mackinnon, M., & Howard, L. L. (2000). *Affirming immigrant women's health: Building inclusive health policy*. Halifax: IWK Grace Health Centre.



***Financial issues in cancer care:***

Gould, J. (2004). Lower-Income Women with Breast Cancer: Interacting with cancer treatments and income security systems. *Canadian Women Studies*, 24 (1), 31-36.

Longo, C. (2005) *Characteristics of cancer patients' out-of-pocket costs in Ontario* (University of Toronto, unpublished doctoral dissertation)



***Participatory research methods:***

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Reviews in Public Health*, 19, 173-202.

Wallerstein, N., & Duran, B. (2003). The conceptual, historical and practice roots of community based participatory research and related participatory traditions. In M. Minkler & N. Wallerstein (Eds.), *Community based participatory research for health*: Jossey-Bass.



***Qualitative research methods:***

Denzin, N.K. & Lincoln Y.S. (2005) *The SAGE handbook of qualitative research*. Thousand Oaks: Sage Publications.

Denzin, N.K. (2003) *Collecting and interpreting qualitative materials*. Thousand Oaks: Sage Publications.

Ulin, P.R. (2005) *Qualitative methods in public health : a field guide for applied research*. San Francisco: Jossey-Bass.

## APPENDIX A: GUIDELINES FOR FOCUS GROUP DISCUSSION:

- We value everyone's participation and we want to know how you feel about the materials and issues being discussed – whatever your views might be. We ask that everyone work together to create a comfortable and respectful setting in the room.
- Please respect everyone's right to speak – try not to interrupt others, and listen carefully even if you do not agree with another person's view.
- If you feel you're not getting a chance to jump into the conversation, raise your hand and make eye contact with the facilitator – she will ensure that you get a chance to speak.
- Remember that we are discussing *opinions* about the materials and issues here today – there are no “right” or “wrong” views; it is perfectly fine if everyone does not agree; *respectful* disagreement is the key.
- We encourage you to speak up even if you're not certain how you feel about a particular issue.
- Remember that no one is under obligation to answer any question or give their view on specific issues if they aren't comfortable. Feel free to “pass” or say, “I don't feel I can comment on that right now”.
- Respect others' rights to avoid certain questions or topics too.
- Remember that no one is expected to talk about personal issues or experiences, but you are welcome to do so if you like.
- We request that you keep the group discussion confidential – this means not using anyone else's name if you talk about the group discussion outside of the group.
- If any issue comes up that is too difficult emotionally, you are welcome to be excused, to take a break, or talk with one of the other facilitators outside the room. You will not be pressured to return to the discussion unless you wish to do so.
- In case of physical illness, please let the facilitator know you're not feeling well so we can help you.
- If there is anything you'd like to share that you didn't feel comfortable talking about in the group, you are welcome to stay after sessions or at the end of the day and talk to one of the facilitators in private.

## APPENDIX B: FOCUS GROUP QUESTION GUIDE

### Facilitator's Questions/Guide for Discussion:

1. What was your overall impression of this material (i.e. article, pamphlet, pictures)?
2. As we discuss specific questions, you are encouraged to tell us what you like or dislike in each area of discussion. Also feel free to share anything that you are uncertain about.

If it helps, think of your own experience when you first received your diagnosis. Would these materials have been useful at that time? How might the materials have been helpful to you? In what ways might they have been unhelpful or inappropriate?

- a) Quality of the information conveyed: Did you find it convincing? Was it understandable? Do you think it is appropriate for a non-medical audience, specifically for non-medical members of your own community?
  - b) "Tone" of the material: Does the way things are stated make sense? Is the language and writing style appropriate? Did anything about it bother you?
  - c) Appearance: What do you think of the pictures, images, graphics or symbols used (where applicable)? What do you think of the overall appearance, presentation and layout/design of the material? Would you pick up this material in a store or library or community centre?
  - d) Audience: Who do you think is the intended audience for this material? Who does it seem to be speaking to? Does this material apply to your life, your culture, your experience with breast cancer? If not, how would it need to be different to address you?
  - e) Medium: What do you think of this *form* of communication (i.e. print, visual, audio)? Would this be an effective way to reach you and other women in your community?
3. What do you think health professionals need to keep in mind when they are speaking to a woman about her breast cancer diagnosis and treatment?
  4. Can you think of things that health professionals did or said, or ways in which they behaved, that were helpful to you?
  5. Can you think of things that health professionals might have done differently?
  6. (Brainstorm:) If you could design information that would have helped you when you were diagnosed, what would it look like? What would it say?

## APPENDIX C: MATERIALS USED

*A Nutrition Guide for Women with Breast Cancer.* Canadian Cancer Society, 1997. pp. 12 – 16.  
(reviewed by 4 groups)

*Nutrition and Breast Cancer: What you need to know.* Canadian Cancer Society, 2002.  
(reviewed by 5 groups and 3 individuals)

*Breast Cancer and You, 2<sup>nd</sup> Edition.* Amgen Canada. pp. 5 – 6, “Participating in your Treatment”  
(reviewed by 4 groups)

*Exercise After Breast Surgery: What You Need to Know.* Canadian Cancer Society. 2002. pp. 1 – 8.  
(reviewed by 4 groups)

*Living and learning.* AstraZeneca, 1999. pp. 22 – 27, “Financial Concerns”  
(reviewed by 5 groups and 3 individuals)

*Breast Cancer: What You Need to Know.* Canadian Cancer Society. 2001. pp. 5 – 7.  
(reviewed by all)

*Coping: Get off the emotional roller coaster.* In Stride Magazine. Fall 2004. pp. 10 – 11.  
(reviewed by 4 groups)

*In Stride Magazine Covers (Fall 2001 – Summer 2005)*  
(reviewed by all focus groups, not in individual interviews)

*Survival Guides.* Chatelaine. October 2003. pp. 68 – 76.  
(reviewed by 5 groups and 3 individuals)

## APPENDIX D: SCREENING QUESTIONNAIRE

Name: \_\_\_\_\_

1. How did you hear about our focus group?

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2. Are you between the ages of:

- 20 – 29
- 30 – 39
- 40 – 49
- 50 – 59
- 60 – 75
- Other \_\_\_\_\_

3. When were you diagnosed with breast cancer? \_\_\_\_\_

4. How do you identify?

- African
  - Somali
  - Ethiopian
  - Other \_\_\_\_\_
- Caribbean
  - Jamaican
  - Grenadian
  - Indo-Caribbean
  - Other \_\_\_\_\_
- East Asian
  - Korean
  - Laotian
  - Vietnamese
  - Other \_\_\_\_\_
- South Asian
  - Punjabi
  - Other \_\_\_\_\_
- European
  - Portuguese
  - Greek
  - Other \_\_\_\_\_
- West Asian

5. Are you a woman with a disability? Yes  No

If yes, and if you're comfortable, please let us know what is your disability?

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6. Were you born in Canada? Yes  No

If no, how long have you lived here?

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7. Do you know anyone else participating in this focus group? Yes  No

*Throughout the focus group session you will need to assess and comment on breast cancer literature and educational resources, which will require you to do some reading:*

8. How comfortable are you reading English?

Somewhat comfortable

Very comfortable

Fluent

9. How comfortable are you writing English?

Somewhat comfortable

Very comfortable

Fluent

10. How comfortable are you speaking/understanding English?

Somewhat comfortable

Very comfortable

Fluent

11. Will there be an issue for you sitting in on a focus group with women of different ages, ethnic groups and/or religions?

12. What dates are you available? (dates to change accordingly)

Saturday, June 18 from 10:30 am – 2:30 pm

Saturday, June 25 from 10:30 am – 2:30 pm

Saturday, July 16 from 10:30 am – 2:30 pm

Saturday, June 25 from 10:30 am – 2:30 pm

13. Do you have access to email?

Address: \_\_\_\_\_

## APPENDIX E: CONSENT FORM

**Principal Investigator:** Dr. Jennifer Nelson

**Sponsor:** Canadian Breast Cancer Research Alliance

**Study Title:** Examining breast cancer information from racially marginalized perspectives: a community-based analysis

### **Background:**

Very little research has addressed the informational needs of women of colour and those from diverse communities, who experience a breast cancer diagnosis. Many women find that mainstream resources do not address their questions and are not relevant to their lives and cultural backgrounds. However, the specific problems relating to breast cancer information for some women have not been analyzed and documented.

This research study will call upon immigrant women and women of colour who have had a breast cancer diagnosis to analyze several breast cancer educational and informational materials, through a group discussion. Effort will be made to include representatives from racial minority groups in the Toronto area. No special skills are required to participate. The researchers are interested in the views and opinions of women about these materials, whether positive or negative. The material might include flyers, magazine articles, news clippings or excerpts from videos. The participants will be divided into focus groups, where they will have a group discussion about their responses to the materials.

The goal of this study is to better understand how mainstream breast cancer information does or does not address the needs of immigrant women and women of colour. The information will be made available to healthcare practitioners, service providers and other women with breast cancer.

### **Length of Study**

The workshop will take approximately four hours during one day. Each participant will attend only one workshop.

### **Purpose and Design of Study**

I understand that the purpose of this study is to better understand the informational needs of immigrant women and/or women of colour who have received a breast cancer diagnosis.

I have been asked to take part in a focus group. Approximately 5 to 7 women will be involved in this focus group, along with a facilitator.

I will be asked to view or read a few different sources of breast cancer information in the small group setting. After each source has been presented, the group participants will talk about our responses to the material. The facilitator will ask questions and help to guide the discussion.

**Possible Side Effects and Risks**

I understand that it may be difficult to talk about some of the issues related to my experience with cancer. In this case, the researchers can offer a referral to an appropriate support service or counsellor if I wish.

**Possible Benefits**

The goal of this study is to learn how breast cancer information does or does not address the needs of women of colour. I understand it is unlikely that I will benefit directly from participating in this study; rather, the information I provide will contribute to developing educational and supportive programs.

**Voluntary Participation**

I understand that I am under no obligation to participate in this study. I can withdraw at any time or refuse to answer any question, with no consequences.

**Confidentiality**

I understand that this focus group discussion will be taped. The tape will be typed out to create a transcript. A copy of this transcript will be sent to me.

I understand that a researcher will observe the session and take notes, but will not participate in the discussion.

The transcript of the focus group discussion will not be distributed to anyone outside the research study. My name will not be recorded on the transcripts. I understand that some of what I say may be quoted in presentations or papers, but my name will not be used.

**Further Questions**

I have been given a copy of this consent form.

If I have any questions, I understand that I may contact Leslie Norville at 416-351-3800 X 2128, or Dr. Jennifer Nelson at 416-351-3807. If I have any concerns about my rights in this research project, I may contact Research Administration, Sunnybrook & Women’s College Health Sciences Centre, at 416-480-4276.

My signature on this consent form means that I agree to take part in this study.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Principal Investigator

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Date