



Breast Health and Young Women:

INFORMATION NEEDS AND PREFERENCES

MAY 2009



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EXECUTIVE SUMMARY

Women of all ages may have breast health information needs. This project addresses one particular gap in educational resources. Currently, there are few resources available that have been designed for women in their twenties and thirties. We explored the breast health educational needs of young Yukon women: what they want and need to know about breast health, and how they wish to receive this information.

The goal of this project was to provide guidance to the Health Promotion Unit in the Yukon Government Department of Health and Social Services, so they may develop educational materials and/or activities to meet the breast health education needs of young Yukon women.

The project was completed in three phases, between January and April, 2009. We began with an internet-based environmental scan of breast health information geared to the target audience. The objective was to identify educational resources that are readily available to women, breast health educators and health professionals. Next, we interviewed expert key informants on women's health and breast cancer to learn what types of information they thought young women should have, and what available educational resources and gaps in resources they were aware of. In the final phase of the project, we conducted focus groups with young Yukon women in Whitehorse and two rural communities. The focus groups were designed to help us get a better understanding of what women see as their breast health information priorities and knowledge gaps, as well as their preferred sources of health information.

In this project we confirmed that (a) there is a dearth of age-appropriate breast health education materials available for women in their twenties and thirties, at least that which is comprehensive, accessible, and compiled in a format that appeals to Yukon women; and, (b) there is an appetite for breast health education programming that goes beyond basic cancer awareness messaging.

Broadly, the topic areas recommended by the key informants and the focus groups, is as follows:

- Breast cancer screening,
- Breast cancer risk factors,
- Breast cancer treatment,
- Breast health promotion,
- Bra fitting,
- Body image,
- Diverse images of breasts.

Of these topics, only breast cancer treatment is likely outside the scope of a health promotion breast health education strategy. It is specialized knowledge which may be unnecessary unless women develop breast cancer. Also, given some women's fears around cancer screening, it might be more beneficial to promote screening tools such as breast self-examination as holistic wellness tools, enabling women to recognise natural changes in their breasts in a positive context.

We asked the focus groups: in a breast health education campaign for young Yukon women, where should the information be made available? The groups gave us numerous suggestions, such as a workshop or event, a sex education program for school-aged children, a website, an advertising campaign, and other resources such as a booklet, swag (such as key chains or t-shirts), and health care staff that specialize in women's health or breast health. Most women seemed to think a combination of these approaches would be best, such as an ad campaign pointing to an interactive website, or an event or contest in which women are challenged to create educational materials.

From the discussion, it was apparent that key life-events heightened the women's breast health information needs, bringing the topic to the forefront. These life-events included (1) puberty, (2) pregnancy/lactation, (3) the occurrence of breast tissue abnormalities such as lumps, cancer, mastitis, and (4) breast augmentation or reduction surgery. Breast health information would best be delivered within the broader context of women's life-course, rather than focusing exclusively on adverse events such as breast cancer.

An effective educational campaign will capitalize on these life events when breast health is on women's minds. In addition, it will attract the attention of women for whom breast health is not currently a top priority. It is widely accessible and addresses the information needs of women in Whitehorse, as well as those living in smaller Yukon communities. It is delivered in a fashion that appeals to both aboriginal and non-aboriginal women; those in their twenties and those in their thirties; those with children and those without. There is likely no single product that will meet all these needs. Rather, a multi-faceted approach is required: one that utilizes web-based and hands-on teaching materials; one that is widely advertised and accessible throughout the territory; one that addresses the diverse information needs of women across the life-course.

Some women said they would like to be able to access information privately, either through a website or a nurse or doctor. Others said they preferred workshops or events that they could attend with other women, or with a group of their friends. The latter concept was particularly popular among First Nations women. Some women are highly health-literate, while others have more difficulty interpreting health information and navigating the confusing and often contradictory information that is found in the internet. An effective education campaign will meet the diverse needs of all these women.

Taken together, these results support that breast health education be comprehensive and multi-faceted, capitalizing on existing resources such as community health centres and the 811 Yukon HealthLine, while introducing new web-based and hands-on teaching materials.

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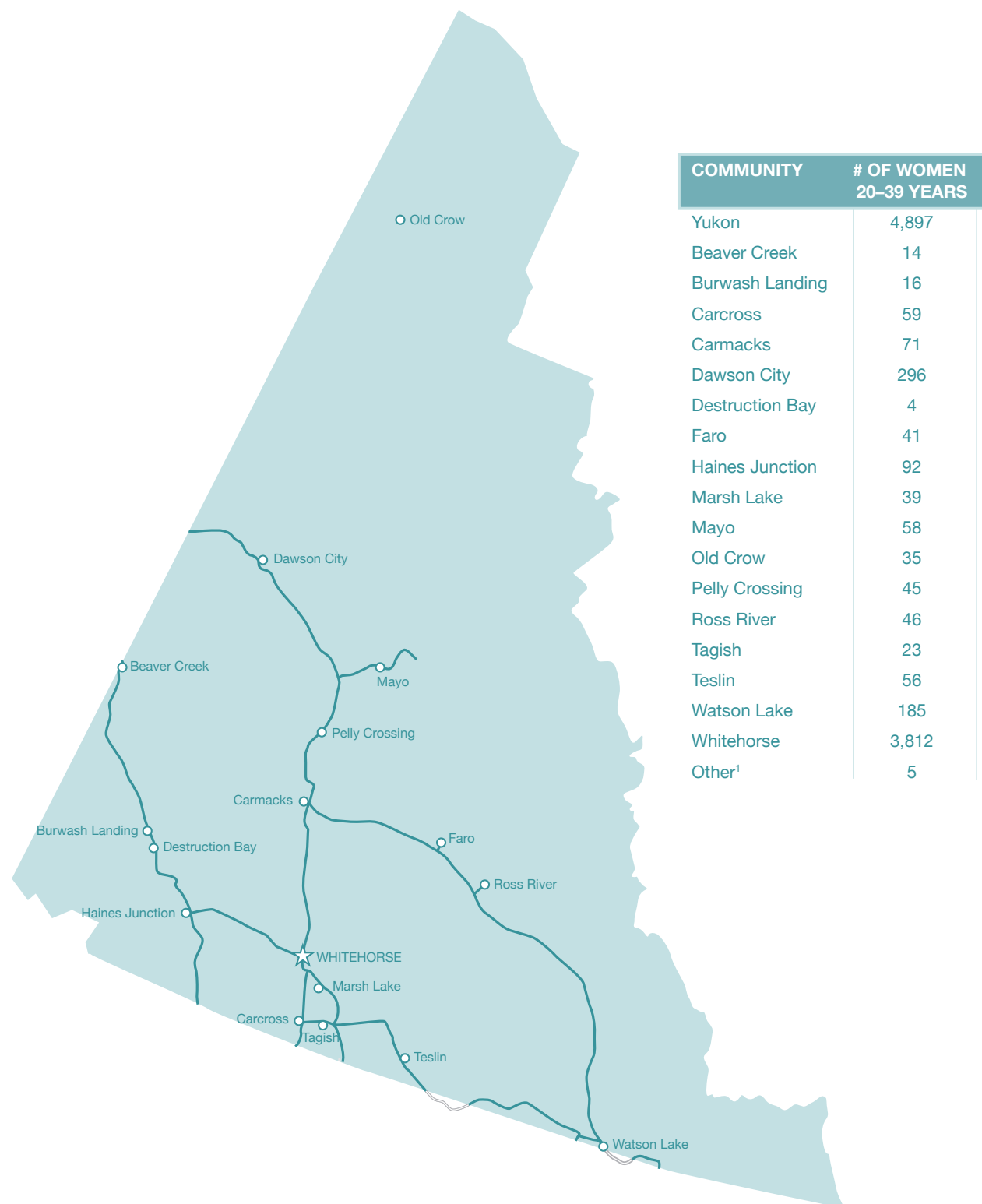
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Yukon Women (20 – 39) Living in the Yukon



Source: Government of Yukon, Department of Health and Social Services and Yukon Bureau of Statistics. These population estimates are statistically based on the Yukon Health Care Registration file. The figures are sorted by community codes and postal codes. Community population estimates include not only the legally defined city limits, but also the population that lives in the immediately surrounding area. ¹Includes communities such as Champagne, Johnson's Crossing, Keno City, Stewart Crossing, Swift River and Elsa.

2. ENVIRONMENTAL SCAN

The first phase of this project was an internet environmental scan of breast health educational materials and programs. The objective was to identify educational resources that are readily available to women, breast health educators and health professionals.

We catalogued (1) web-based educational resources, and (2) other educational resources, such as booklets, pamphlets, and videos, that could be found on the internet and ordered or downloaded. The compiled lists and the internet search terms are included as Appendix I-III.

We placed most of our emphasis on non-profit sources of information, including government and non-government organizations (such as non-profit societies and hospitals). We did not include educational resources that had been produced by for-profit organizations with a clear bias, such as breast augmentation/reduction information provided by cosmetic surgery clinics. We looked for materials that were designed for a general audience of adult women, as well as materials that were designed for a specific sub-population such as younger women, aboriginal women, or women who have had breast cancer.

The second phase of the project, the key informant interviews, will help us to identify what resources health professionals and breast health educators are recommending for women aged 20-39. In some cases, the key informants may identify resources that we did not find in the environmental scan. These will not be added to the environmental scan catalogue, as they were not readily found in our internet search, and therefore are likely not readily available to the public by means of a similar search.

2.1 WHAT WE FOUND

Of the resources we catalogued, a great many were on the subject of breast cancer prevention, treatment and awareness. The internet appears to be a great place to learn the signs and symptoms of breast disease. There were also a number of resources to help women become breast self-aware. There are quite a few places online where a woman can learn how to perform breast self-examination, for instance, and there are also videos, handouts, calendars, and even a shower card on this topic.

A smaller number of resources focused on holistic self-care: keeping your breasts healthy through a healthy diet and lifestyle, and avoiding pesticides and plastics, for instance. Still fewer non-commercial resources were available on the topic of breast alterations, such as nipple piercing, breast augmentation, and breast reduction. Those which we found were catalogued.

The vast majority of resources which we found to be relevant to our local population were from Canadian, Australian, UK and US organizations. For instance, the following Canadian organizations had produced a variety of breast health education materials that could be viewed or ordered online:

- NWT Breast Health/ Breast Cancer Action Group- pamphlets, booklets and displays, mostly on the subject of breast self-examination;
- First Nation Breast Cancer Society (BC)- an instructional video and booklet teaching breast self-examination to First Nation women;
- Canadian Breast Cancer Network- online information resources as well as DVDs on topics such as breast cancer and sexuality;
- Canadian Cancer Society- a breast cancer information kit distributed free to breast cancer patients in BC/ Yukon;
- Vancouver Island Health Authority Breast Health Centre- patient information sheets on various breast diseases and treatment protocols;
- Health Canada- a information sheet on issues to consider before having breast implant surgery.

Here are a few of the organizations from countries outside of Canada that offer noteworthy breast health education materials:

- Breast Cancer Care (UK)- a variety of posters, booklets, pamphlets, videos and so on, including a series on breast cancer issues faced by younger women such as its impact on pregnancy and breastfeeding;
- Young Survival Coalition (US)- a variety of educational resources for young women who have had breast cancer;
- Susan G. Komen for the Cure (US)- an extensive web resource on breast health and breast cancer, including information designed specifically for younger women;
- Cancer Council Victoria (Australia)- booklets, brochures, videos and so forth on various issues relating to breast cancer, including a brochure/poster set targeting young women;
- Alaska Native Medical Center (US)- a video and booklet on breast self-examination and breast health for native women.

While this environmental scan did not include a review of the academic literature, a general theme emerged from academic articles that turned up as a part of the internet search. Generally speaking, breast health education materials should be developed with a specific audience in mind, and should be culturally relevant for that audience. Accordingly, while information and ideas could be taken from existing resources, it would be most beneficial to develop new, locally-relevant resources in order to reach the target audience effectively. This approach is consistent with other Yukon health promotion programs which have been developed through focus group research, and/or have made use of images of local people, contexts, and ‘inside’ humour in order to draw the audience in.

2.2 SUMMARY

The first phase of this project was an internet environmental scan of breast health educational materials and programs. The objective was to identify educational resources that are readily available to women, breast health educators and health professionals.

Of the resources we catalogued, a great many were on the subject of breast cancer prevention, treatment and awareness. Most of these materials were intended for a general audience. Very few resources were specific to young women, except those targeting young women who have experienced breast cancer. Also, very few materials addressed breast health broadly, outside the context of cancer.

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3. KEY INFORMANT INTERVIEWS

In the second phase of the research, we interviewed a series of key informants with expertise in breast health and/or health communications.

3.1 WHO WE INTERVIEWED

An initial list of key informants was identified by the project steering committee. This list was augmented by the environmental scan component of this project. In building this list, our aim was to reach a diverse group of people from a variety of occupational backgrounds including breast cancer care, breast health education, breastfeeding support, conventional clinical practice and alternative medicine. We placed the greatest emphasis on reaching key informants who were local, or who provided services to Yukon women. Additionally, we interviewed some Canadian and international key players in the field of breast health and breast cancer education.

Some of the people on our initial contact list could be reached for an interview, while others were unavailable, had retired, or suggested that we contact another individual from their organization. Our list was later expanded to include some additional contacts who were identified by key informants in the first round of interviews. In total, we conducted twenty-three interviews.

Eleven of our informants are in a clinical role, such as nursing, medicine or naturopathy. Most of them work specifically in the area of breast cancer, breast health or lactation support, while one works in the area of nursing education and two are general health practitioners.

The remaining twelve key informants are in a public education role. Specifically, they provide information and support to women on the topic of breast cancer. Though some of these informants are medical doctors or nurses, their current role is not clinical.

A full list of our key informants and their organizational affiliations is included in Appendix IV.

3.2 HOW WE INTERVIEWED THEM

We conducted the key informant interviews by telephone, using a structured questionnaire. Each interview took 20-30 minutes to complete. During the interviews, the interviewer typed the informants' responses to the interview questions into an electronic copy of the questionnaire. Once the interviews were completed, we compiled the data and thematically analyzed the qualitative data-rich questions.

The questionnaire included questions on the following topics:

- background information about the key informant's work, how it relates to breast health, and whether they worked with a specific demographic target audience, such as young women, aboriginal women, or women with breast cancer;

- in the informant's opinion, some key things women in their twenties and thirties need to know about breast health;
- any recommended breast health education materials for this age cohort;
- and any informational needs young women have that aren't currently being met.

3.3 WHAT WE LEARNED

3.3.1 Key things women need to know about breast health

The informants were asked to identify some key things they thought women should know about breast health. Their responses were thematically analyzed and coded into four broad categories and forty-six sub-categories. The four broad categories included: risk factors, health promotion, breast cancer screening, and breast cancer treatment. While none of the informants covered all four categories in their responses, the majority bridged two or three of the categories.

While the informants tended to emphasise the area in which they worked (for instance, a person working in a cancer treatment program was likely to raise issues regarding cancer treatment), there was clear pattern between the themes covered by the informants and their lines of work.

Of the four themes, *breast cancer screening* was mentioned most often. Nineteen of the key informants addressed cancer screening in their response to this question. Their responses included, in order of frequency from most to least:

- knowing one's breasts and body, so you can recognise what's normal and notice changes,
- breast self-examination (either to teach it, or to move away from it in line with current clinical guidelines),
- knowing to have an annual clinical exam including a breast examination,
- knowing when it's appropriate to have mammography screening,
- knowing the warning signs of breast cancer and see your physician if any of them appear,
- knowing how your breasts change with your menstrual cycle,
- knowing what services are locally available,
- advocating for appropriate care,
- have someone else assess your breasts,
- and knowing about thermography as a screening option.

The second most often-raised theme was *breast cancer risk factors*, which was addressed by thirteen respondents. Their responses included, in order of frequency from most to least:

- risk factors in general,
- awareness of genetic predisposition and family history of breast cancer,
- weight and obesity,
- age, with cancer spreading more quickly in younger women, but occurring more frequently in older women,
- smoking, alcohol, and hormonal birth control,
- other hormonal exposure,

- environmental factors such as exposure to toxic chemicals,
- and diabetes.

Close in frequency to risk factors, and in some cases overlapping, was the theme of *health promotion*, which was also addressed by thirteen respondents. Their responses included, in order of frequency from most to least:

- exercise,
- diet and nutrition, with an emphasis on eating fruits and vegetables and avoiding meat and dairy products,
- taking steps to prevent cancer, in general,
- using appropriate supplements such as flax seeds and omega fatty acids,
- breastfeeding, which is protective against breast cancer,
- being aware of how breast alterations such as augmentation, reduction and nipple piercing can have an impact on breast health,
- and an assortment of specific self-care techniques such as removing one's bra in the evening, daily breast massage, detoxifying saunas, alternating hot and cold water in the shower, promoting lymph circulation, stress management, and focusing on physical, mental and spiritual well-being.

Finally, three informants raised issues that were specific to *breast cancer treatment*. They talked about the impact of breast cancer treatment on:

- fertility,
- sexual relationships,
- caring for the family,
- career interruption,
- financial pressures,
- and the fact that women need not disclose their diagnosis in the workplace.

3.3.2 Unmet breast health education needs of young women

We asked the key informants whether they thought women in their twenties and thirties had any specific information needs that aren't currently being met. Their responses were thematically analysed and coded into the same four broad analytical categories that were used to analyze the "what women need to know" data: cancer screening, risk factors, health promotion, and cancer treatment.

Not all of the key informants were aware of any unmet informational needs for this age group. Two respondents said they thought there wasn't much information out there for women in their twenties and thirties, and a third respondent pointed out that the informational needs of young aboriginal women are not well understood.

Those who identified specific unmet informational needs divided their responses fairly evenly between cancer screening, knowledge of risk factors, and health promotion, while several respondents raised the issues women face when undergoing breast cancer treatment.

In terms of *cancer screening*, unmet informational needs fell into the following areas:

- knowing the new guidelines regarding breast self-examination and frequency of clinical exams,
- knowing mammography screening protocols, as well as the risks associated with mammography,
- becoming familiar with one's breasts and whole body,
- and the need to advocate for appropriate care, including annual clinical breast exams.

With regards to *risk factors*, it was stated that women have unmet informational needs in the following areas:

- knowing what the risk factors for breast cancer are, and the extent to which one is at risk, being a younger woman,
- knowing that family history is important, but also that family history is only relevant to approximately 10% of all breast cancer cases,
- knowing that the age of first menses and the age at which a woman first experiences pregnancy both impact her breast cancer risk,
- and knowing the importance of environmental factors such as exposure to toxic chemicals.

Regarding *health promotion* and self-care, the following unmet informational needs were identified:

- general breast health care,
- the steps one can take to prevent breast cancer,
- the importance of exercise,
- and how to eliminate toxins from the body.

In terms of *cancer treatment*, these unmet informational needs were named:

- the impact of breast cancer treatment on sexual identity, physical appearance (such as hair loss), sexual relationships, and fertility,
- how breast cancer impacts the care of the family, in terms of child care as well as long-term planning,
- issues around career interruption, financial pressures and work-life balance,
- and how to get involved in fund raising, awareness raising and breast cancer activism.

We asked a follow-up question about why women's needs aren't being met. In response to this question, we heard about a variety of problems associated with either (a) the lack of existing, relevant informational resources, or (b) barriers to women's accessing existing resources. Responses were coded into twenty sub-categories within these two broad themes.

Access to information was the largest thematic category, both in the frequency of responses, and in the number of sub-categories. Regarding access to information, the following issues were raised, beginning with the issue that was raised most often:

- fear and denial keeps women from seeking out or taking in information about breast cancer,
- the topic is not a priority for this age group,
- most funding and resources are channelled into cancer screening and treatment, while prevention and public education programs lack the funding to produce and distribute educational resources,
- women don't know how to access existing resources,
- women don't know what resources are available, and particularly what is locally available,
- information overload,

- lack of critical reading skills to decipher contradictory messaging and scientific research papers,
- people are busy with other things,
- breasts are a taboo subject,
- young women's focus is often on caring for others, not self-care,
- there is no captive audience for this age group (such as a classroom),
- and there are cultural or language barriers in some communities.

The other broad thematic category was that appropriate *informational resources do not exist*. This encompassed the following issues, beginning with the issue that was raised most frequently:

- doctors may be unaware of available educational resources, and the information is not made available in doctor's offices,
- available information focuses on detection and treatment, not preventative measures,
- breast health is either not discussed in the media, or is not accurately portrayed,
- the available information is incomplete, doesn't cover the current screening guidelines, or is lacking altogether,
- this age group hasn't been targeted in the existing educational resources,
- and breast health has been omitted from general health messaging.

These responses pointed towards a need for a two-pronged approach which (a) gets young women talking about breast health, while giving them access to age and culture-appropriate information, and (b) ensures that health practitioners are aware of current guidelines, know where to access relevant and timely patient information, and take a leading role in providing women with the information they need to promote breast health.

3.3.3 Different informational needs of sub-populations of women

We recognized that women in their twenties and thirties are not a homogenous group, and that sub-groups of women may have specific informational needs. We asked the key informants to tell us about any specific issues that might relate to younger or older women in this age group, as well as other subsets of women, such as rural or aboriginal women.

Most of our key informants did not raise any differing informational needs for women in their twenties compared to those in their thirties. All of these women are younger than the age at which regular mammography is recommended. One informant raised the point that women in their thirties are more likely than younger women to have been taught to perform breast self-examination, which is no longer considered to be an effective cancer screening tool. She thought women should not be discouraged from performing self-examinations, but they need to be taught that the guidelines have changed and an annual clinical exam is now recommended. In comparison, women in their twenties are more likely to have been exposed to the new guidelines, and are somewhat less likely to have been taught to rely on breast self-examination.

One respondent noted that women in their twenties often live within a different social context from women in their thirties, and the issues they face may be somewhat different. She talked about how the faster metabolism of younger women can lead to more rapid spread of breast cancer to the lymph nodes. She thought it important that younger women are aware of the impact that breast cancer and cancer treatment would have on them, as well as the incidence rate of breast cancer among women in their twenties. Another of our informants mentioned that younger women tend to drink more alcohol and smoke more than older women, so it may be worthwhile to emphasise those risk factors when addressing women in their twenties.

One respondent stated that age is irrelevant, when it comes to breast health promotion; we all need to be aware of what we can do to improve our health and prevent cancer, at any age.

The key informants raised a number of specific considerations regarding the breast health education needs of other sub-populations of women such as aboriginal, ethnic minority or rural women. The following issues were raised, beginning with the most frequently raised issue. Please note, these are general statements based on the opinions and experiences of the key informants, and may not all apply to the Yukon context.

- Access to clinical and preventative care is often more difficult in rural and remote areas. A number of barriers exist, such as the need to travel to access services.
- Cancer incidence rates differ between women with different genetic and socio-economic backgrounds. While breast cancer has typically been more common among Caucasian women of higher socio-economic status, they have also typically had the best access to care, and as a result of earlier detection of cancers, they have a higher survival rate than other women.
- In some cultures, there is a taboo towards touching or talking about breasts. This can be a barrier to promoting breast self-awareness and regular clinical exams.
- There is a need for programs and services to be delivered in a culturally sensitive fashion. In some cases, it may be more appropriate for someone from the community to deliver educational programs, rather than having the information come from an 'outsider.'
- Aboriginal women may be shy to come forward with concerns about breast health. Participation in screening and educational activities can be enhanced by making it a social activity involving the whole community of women.
- Rural communities often face challenges accessing information.
- Literacy rates vary between women, so it's important to make educational resources accessible to an audience with a range of literacy skills.
- In some communities, secrecy and stigma surround cancer, so there can be a reluctance for people to come forward with their concerns.
- In some communities, there is a cultural belief that what happens is 'meant to be' or 'God's will.' This can impact the uptake of health promotion and self-care messaging.
- In some rural and remote communities, people may not have mirrors or regular access to bath or shower facilities; also, they may keep their bodies covered due to cold weather. These factors need to be taken into consideration regarding breast self-awareness campaigns.
- A traditional northern diet can include a high level of toxins from fish and seal fat; this may increase cancer risk.
- There are high smoking rates in many northern communities; smoking is a risk factor for breast cancer.
- Language barriers must be considered.

3.3.4 Recommended breast health education materials

We asked the respondents if there were any existing breast health education materials that they would recommend for women in their twenties and thirties, what they like about those materials, and whether there are any shortcomings we should be aware of. This set of questions drew our attention to a variety of existing materials, including some which we had not encountered in the environmental scan. This information is compiled in Appendix V.

Generally speaking, our informants directed us towards materials that had been written for a general audience, or in a couple of cases, materials that had been developed specifically for teenagers. Very few of the recommended educational materials were geared towards young women. This was consistent with the findings of our environmental scan, which also uncovered few educational materials that were specifically for young women.

3.3.5 SUMMARY OF OUR FINDINGS

The key informant interviews shed light on a number of critical issues regarding the breast health education needs of women in their twenties and thirties. Our respondents identified informational needs in four areas. The first area, breast cancer screening, included issues such as breast and body awareness and self-examination, knowing the clinical screening guidelines such as when to have a physical exam, knowing the warning signs of breast cancer, and knowing what services are locally available. The second area, breast cancer risk factors, included factors such as genetic predisposition, weight, age, and exposure to tobacco smoke and other toxins. The third area, health promotion, included a variety of strategies that women can use to reduce their risk of breast cancer, such as exercise, eating low on the food chain, and breastfeeding. The fourth area covered some issues that women face when they undergo breast cancer treatment.

Of these informational needs, the key informants named a variety of needs that aren't currently being met by existing, accessible breast health education materials. They said these needs aren't being met either because there is a dearth of existing, relevant informational resources for this age group, or there are barriers to women's accessing existing resources.

In addition, our informants raised a number of specific considerations regarding the breast health education needs of other sub-populations of women such as aboriginal, ethnic minority or rural women. These included concerns such as barriers to accessing information and clinical services in some rural and remote areas, differing risk factors between sub-populations, and cultural barriers to accessing appropriate, timely care.

When we asked the respondents if there were any existing education materials that they would recommend for women in their twenties and thirties, they suggested some materials, including books, websites and other resource materials, but very few of these materials had been developed specifically for young women. This was consistent with the results of our environmental scan.



4. BREAST HEALTH FOCUS GROUPS

In the third and final phase of the project, we invited women between the ages of 20 and 39 to take part in focus groups to discuss their breast health education needs and experiences.

4.1 FOCUS GROUP METHOD

The focus groups were advertised by means of a poster hung at a number of prominent locations around Whitehorse and in two community health centres, a newspaper ad in the Whitehorse Star and the Yukon News, in an ad on the internal Yukon government website, in a short article in the community health newsletter Tracks, and by word-of-mouth. Of these methods, word-of-mouth proved to be the most effective recruitment method, followed by the posters, the Yukon government intranet ad, the newspaper ads, and Tracks.

We held nine focus groups in total: seven in Whitehorse (six downtown and one at the Kwanlin Dun First Nation health centre), one at the health centre in Carmacks, and one at the Haines Junction health centre. Each focus group had a lead facilitator who directed the discussion, as well as a co-facilitator who took notes and asked occasional probes. The same focus group team facilitated all nine groups, and we sometimes switched roles. As the sessions were held at lunch or dinner time, we provided food and beverages to the participants, and we offered the participants a \$25 honorarium as a thank you for their participation.

4.1.1 Focus group participants

In total, 56 women took part in the focus groups. Of these women, 20 were under 30 years of age (6 were under 25), while 36 were in their thirties (18 were under 34, and 18 were 35 and older).

Thirty-six of the participants were non-aboriginal, and 20 self-identified as First Nations (19) or Inuit (1).

4.1.2 Focus group content

Each focus group was approximately 55 minutes in length. We began by setting the stage for the discussion. We explained the purpose of the project, then we did a round of first-name introductions and shared some tips for how to get the most out of the focus group experience.

The discussion was shaped by a set of general questions, designed to help us get an understanding of what breast health means to women, what they have learned about breast health and from what sources, what they wanted to learn, where they looked for health information, and how they suggested a breast health education campaign could be designed to meet their needs.

The focus groups were digitally recorded and transcribed. We edited the transcriptions for accuracy, then we coded the data, question by question, into themes that emerged from the data. The results of this thematic analysis are presented below.

4.2 WHAT BREAST HEALTH MEANS TO YOUNG WOMEN

Following the introductions and orientation to the focus group, we began each session with this question: When I say “breast health”, what comes to mind for you? An overview of their responses is given in the table below.

Table 1. What does breast health mean to the participants?

TOPIC	# OF TIMES MENTIONED
<i>Medical topics</i>	
Breast self-examination	51
Breast cancer	26
Clinical breast exam	25
Mammograms	15
Breast cancer prevention	7
<i>Non-medical topics</i>	
Breastfeeding	26
Body image	18
Bra fitting	10
Breast care	3
Normal breasts	1

4.2.1 Medical Topics

The responses we got were mostly oriented around illness and cancer screening, rather than health. The most often-mentioned topic, breast self-examination, was always discussed in the context of cancer screening, not as a tool for self-knowledge or monitoring normal changes in breast tissue. Breast self-examination and breast cancer came up in all nine groups, while six groups mentioned clinical breast exams and four groups talked about mammograms. They talked about these things in the context of their personal experiences, and also in terms of their learning needs. As one woman put it:

For me, breast health is just learning about it and knowing and trying to see what things you can do to prevent (problems). So breast health is learning more, that's actually why I'm here too.
(GROUP 4)

Another woman talked about the intimate nature of the topic, which for some, appeared to have been a barrier to their accessing the breast care information they felt they needed.

Breast health for me is something like personal, intimate, that you need to take care of and nobody teaches you how, in a way. You have to figure out by yourself how to take care.
(GROUP 6)

Cancer prevention, cancer awareness and fundraising events such as Run for Mom came up only occasionally.

4.2.2 Non-medical Topics

On topics other than cancer, eight of the nine groups mentioned breastfeeding. Five groups mentioned bras (and how to choose one that fits properly), while four groups talked about body image. As one woman put it, breast health meant, to her:

Loving your breasts; accepting them.
(GROUP 4)

These non-medical issues came up repeatedly throughout some of the discussions, and they will be described in more detail further on in this report. Meanwhile, two groups brought up breast care in general.

I think taking care of ourselves and understanding the many lives of breasts, many stages in life. Different functions, different care.
(GROUP 6)

Just one group raised the concept of a normal, healthy breast as an image of “breast health”.

4.2.3 Information Gaps

In response to Question 1, several groups talked about the lack of information about breast health (2 groups), as well as the observation that the available information is sometimes confusing or contradictory (2 groups). For example:

Confusing information, because at first you were supposed to do this self exam, now they say it's only supposed to be done by a doctor and then...you know. You go to your doctor and you're still encouraged to self-exams, and it's a bit confusing.

(GROUP 3)

We explored these information gaps in greater depth in subsequent questions.

Also, two groups raised the point that youth have unmet educational needs in the area of breast health. These information-related themes were raised at later points in many of the group discussions.

I just thought about the stuff I would have liked to know when I was younger. This discussion would have been a good thing to have when I was 17, 18, 25.

(GROUP 2)

A recurring theme throughout the discussions was how breast health is rarely a specific focus or priority for women, especially young women, unless something goes wrong. We talked later on in the discussions about how to raise awareness among younger women, making breast health a priority.

It's easy to ignore them. Like your legs and your arms; you don't think about it.

(GROUP 9)

These themes also came up again in response to subsequent questions.

4.2.4 Crucial Life Events

Many of the women were comfortable sharing their personal stories, which greatly enriched the discussion. Crucial life-events heightened their information needs, bringing breast health to the forefront. From the stories we heard, at the following key times, their information needs were most apparent: (1) puberty, (2) pregnancy/lactation, (3) the occurrence of breast tissue abnormalities such as lumps, cancer, mastitis, and (4) breast augmentation or reduction surgery. Puberty was discussed as a time when girls need to understand what breasts are for, beyond their role in attracting male sexual partners. Issues such as healthy sexuality and breast sensation were not raised, though these are likely an important missing part of a comprehensive breast health education. At all of these critical times, there appeared to be unmet information needs. Some women expressed frustration towards educators and health care professionals who they felt had not provided them with adequate information at these critical times. One woman talked about her experience with breastfeeding as a teenage mom:

If you feed your baby too much, especially if you're a teen and you're not really sure how to do it in the first place and you keep your baby on one side and then you don't realize, you try the other side and they won't eat no more and, you know, one big boob, one little boob... So information and stuff like that would have been helpful.

(GROUP 8)

Another woman talked at length about her experience with breast cancer, returning to it several times during the discussion to express her frustration about the lack of information available to her on the subject.

And then they didn't even have a bunch of information on that kind of breast cancer then... the one that comes out more liquid rather than a tumor, they didn't have hardly any information then at all. And I bet that there isn't a lot of information out there yet. Did you know that? You see? Nobody knows, there isn't any information unless you go looking for it. There isn't even a pamphlet on it.

(GROUP 9)

As these crucial life events bring breast health to the forefront, the challenge may be to meet the informational needs of women who are at one of these life stages, while simultaneously drawing the attention of other women for whom breast health is not currently a pressing concern.

4.2.5 SUMMARY OF QUESTION 1

To summarize, when we asked the groups what breast health means to them, the responses we got were mostly oriented around illness and cancer screening, rather than health. Other key topics were breastfeeding, bras, and body image. From the discussion, it was apparent that crucial life-events heightened their information needs, bringing breast health to the forefront. From the stories we heard, at the following key times, their information needs were most apparent: (1) puberty, (2) pregnancy/lactation, (3) the occurrence of breast tissue abnormalities such as lumps, cancer, mastitis, and (4) breast augmentation or reduction surgery.

4.3 THE MOST IMPORTANT THINGS THESE WOMEN EVER LEARNED ABOUT THEIR BREASTS

In our second question, we asked the women, “What are the most important things you have ever learned about your breasts, and where did you learn them?” Here, we examine the two parts of this question in turn.

4.3.1 The most important things they have learned about their breasts

What are the most important things women learn about their breasts? When we asked the groups about this, we did not prompt for specific issues, though we did sometimes ask women to expand on the issues they raised. They talked about the following broad issues, from the most to the least-often mentioned: breast self-examinations, breastfeeding, cancer and cancer prevention, and bra fitting.

Table 2. What the participants have learned about their breasts

TOPIC	# OF TIMES MENTIONED
Breast self-examination	28
Breastfeeding	16
Breast cancer	10
Breast cancer prevention	3
Bra fitting	2

Breast self-examinations

Breast self-examinations were mentioned and discussed in all nine groups, and it came up 28 times in total. Nearly all the women knew something about breast self-examination, though many said they had not learned how to do it, or they lacked confidence in their ability to do it properly.

I think that something I wish I'd learned, or would like to learn better is how to do a self-exam; that seems important. Just to have the confidence to do it.

You know, the doctor tells you how, or maybe you have read about it, but having some help.

(GROUP 4)

I've never actually learned how to do it either, because my doctor does it for me every year. She's never asked me, "Do you want me to teach you how to do it?" She just does it herself.

(GROUP 6)

Those who said they felt confident doing a self-exam had typically received personal instruction from a doctor or nurse, instruction that was often repeated.

I had a doctor in university and she wouldn't do a Pap test without a breast exam, and she did the education for it every time. She would do it with you to make sure you had the technique. Like she would find like a different sort of lump and would say, "That's OK, that's normal," or "You want to watch for this." She would do it until you knew.

That was helpful; it forced me to do it.

(GROUP 1)

Some said they had received information on breast self-examination from a pamphlet or shower card, but most didn't find it sufficient on its own (without hands-on teaching).

Even those who had received hands-on teaching weren't necessarily comfortable performing a self-exam. Many said they weren't sure how to check their breasts properly, or how often to do the exam, or what exactly they were looking for. Several women raised the question of how to tell a problematic breast lump from normal lumpy or fibrous tissue.

It's funny how they show you, and then you try do you it yourself and then there's lumps all over the place.

(GROUP 2)

It was rare for anyone in the focus groups to question whether breast self-examination is a good thing to be doing. Those who said they avoided self-examination on principle said they didn't want to make themselves fearful, or they had more confidence in their doctors' abilities than their own.

*I'm hesitant to try it, because I'm worried, yeah, I wouldn't know how to do it.
I like when my doctor does it, because I trust her more than myself.
Not that I like her doing it, but you know what I mean. It feels more accurate.*

(GROUP 1)

Others felt they lacked the knowledge, but would like to have it.

That would be great, you know. If we were trained that would empower us.

(GROUP 6)

Those who had experienced breast cancer or other breast health challenges were strong advocates of self-examination:

*I had a hanging shower breast self-exam thing, I had it. But was it in my shower? No, it was sitting on the shelf.
I think everybody should have them in their shower. You take the extra couple of minutes and you just check.
Because it's a scary thing, you know. And, to go through chemo and radiation, and it makes you sick, very sick.
And, if somebody could understand that, then maybe they would check their breasts every day.*

(GROUP 9)

Breastfeeding

At the beginning of this project, we had thought the information needs of the participants might differ by age (for instance, those in their twenties versus compared with those in their thirties). However, we found that it was childbearing experience- not age cohort- that differentiated the women clearly into two groups. Those with children typically raised breastfeeding information as one of the most important breast health topics they had learned about, and it was identified as such in 8 of the 9 groups. The women raised not only the importance of breastfeeding, but also its mechanics, relevant breast care information, problems that they encountered such as mastitis and engorgement, and the impact of previous breast surgeries on their ability to breastfeed.

One woman talked about breastfeeding as a pivotal experience around which she learned about breast anatomy and physiology:

I don't think I've ever really learned much about breasts at all. Like, even having a friend that went through breast cancer and died, even then I didn't learn much about the disease or about breasts. Only when I started breastfeeding, that I started reading about breastfeeding and looking up what is the anatomy of the breasts and what actually happens in the breast that I learned what they do, what they look like on the inside.

(GROUP 2)

Many others expressed similar points of view.

I'm learning about breastfeeding right now, and I've never realized before that there could be monster books on breastfeeding, like I thought it was a no-brainer. For me, at this stage of my life, right now, that's the most important thing that I've learned about breasts so far.

(GROUP 3)

Breastfeeding also presented observational learning opportunities for some.

Watching my sister breastfeed I learned a lot. I watched her struggle to learn to breastfeed and having problems and stuff, I learned a lot about breastfeeding and breasts and what is normal and why she was having difficulties and stuff.

(GROUP 6)

In groups where most of the women were mothers, their breastfeeding experiences dominated the discussion, and at times, we had to put special effort into ensuring those who were not mothers had an opportunity to speak and raise other issues. In hindsight, it may have been beneficial to sort the participants into groups based on whether or not they had children.

Cancer and cancer prevention

Some of the women said they had received anecdotal information on breast cancer from women in their families and communities. This information included self-care tips for cancer prevention and screening advice. They thought this information was not necessarily reliable, as it was sometimes incomplete or inaccurate. In one group, everyone had an urban legend to bring to the table:

*Falseness and truth. Sometimes we hear things, like urban legends, stuff like that, about breasts...
Implants gone wrong...Implants exploding on planes...Getting implants will give you breast cancer...
Wired bras...Sleeping in bras.*

(GROUP 6)

So long as they steered clear of obvious urban legends, women who had experienced breast cancer appeared to play a role in peer education and awareness-raising. For example:

*My aunty had cancer and she had her breast removed, so now she's telling us a whole bunch of things.
Like, the wire in your bra can cause breast cancer. Just like birth control and smoking.*

(GROUP 8)

The media also came up as a common source for breast cancer information. Several women mentioned their confusion around this information. Recommendations and self-care guidelines frequently change or contradict one another. While the women said it was important to them to know more about how to prevent breast cancer, they seemed unsure of where to find reliable information on this subject. One woman described it like this:

Where it gets really muddy is the information around what contributes to breast cancer. You have the news reports: "Don't drink coffee because it can increase your risk of breast cancer." The next study comes out: "Oh, it's OK, drink a lot of coffee." So, there's a lot of conflicting information out there and it's really hard today. Who do you believe? What information is right with regards to prevention, and life changes and stuff like that? I found that I haven't been able to get a lot of information from my doctor or a nurse, because there's no real guidelines out there that can help them out to give the proper information, so that's definitely a big gap.

(GROUP 3)

Bra fitting

A few groups talked about the importance of learning how to get a properly fitted bra. In these groups, only a few women said their mothers had helped them to get well-fitting bras when they were younger. Most had figured it out on their own, or with friends, and they didn't feel well-informed about it. While a number of women said they had great learning experiences with a Whitehorse bra saleswoman, they also mentioned the high cost of a well-fitting bra, a cost that is prohibitive to many.

4.3.2 Where the participants gained their breast health knowledge

In the second part of the question, we asked the women where they had learned the things about breast health they considered to be most important. They said their knowledge had come from a variety of sources, some of which were formal (such as health care providers), while others were informal (such as friends or family). The table below outlines which information sources were mentioned, and how many times. Interestingly, while learning about breast health from a doctor came up 17 times, a number of women talked about things they had not learned from a doctor (and would have liked to).

Table 3. Where the participants gained breast health knowledge

SOURCE OF INFORMATION	# OF TIMES MENTIONED
Learned from doctor	17
Didn't learn from doctor	6
Learned from self-examination instructional card	12
Learned from having surgery	8
Learned from nurse	7
Learned from family	6
Learned from media	6
Learned from event	4
Learned from friends	4
Learned from post-secondary education	3
Learned from books	3
Learned from internet	2
Learned from bra store	2
Learned from pamphlet	2
Learned from prenatal classes	1
Learned from Thing-A-Ma-Boob keychain	1
Learned from model breast	1

Again, a number of women raised concerns about confusing or lacking information. Though they had gained breast health knowledge from a variety of sources, nobody seemed to consider their knowledge base adequate. We addressed this issue more directly in the next question.

4.3.3 SUMMARY OF QUESTION 2

When we asked the women to tell us about the most important things they had learned about their breasts, they identified the following broad issues, from the most to the least-often mentioned: breast self-examinations, breastfeeding, cancer and cancer prevention, and bra fitting. They said they had learned these things from a variety of sources, some of which were formal (such as health care providers), while others were informal (such as friends or family).

4.4 THINGS YOU HAVE WONDERED ABOUT BREAST HEALTH

In our third question, we asked the women whether there was anything they had wondered about breast health, or felt in the dark about. We heard about a variety of topics the women had wanted to learn more about at some time in their lives. Many of the topics overlapped with the previous question, though this discussion emphasized lack of knowledge rather than knowledge gained.

Table 4. Breast health topics the participants have wondered about

TOPIC	# OF TIMES MENTIONED
Breast cancer	17
Breast self-examination	14
Breastfeeding	11
Bra fitting	4
Cancer prevention	4
Mammograms	4
Breast lumps and lumpy breasts	4
Breast enlargement or reduction surgery	2
Changes in breast appearance	2
Clinical exam guidelines	1

4.4.1 Lack of information

In response to this question, many women raised the point that they felt quite ill-informed about breast health in general. Overall, among the nine groups, the dearth of breast health information was raised 26 times in response to question 3 alone. For instance:

I don't hear a lot of talk about breast health. I hear a lot about breasts, not health.
(GROUP 1)

I actually don't know anything about breast health. I could think about three different spots in my life when I got breast education as a small snippet. It's not talked about, it's not advertised.
(GROUP 2)

It's not like you see a lot of other women's nipples around there, there's no opportunity for that, so you don't know if there's something not right about yours.
(GROUP 3)

My mom didn't have any kind of information like that, you know. She didn't know either, she couldn't teach me about how to do exams.
(GROUP 9)

I think it's interesting that we tend to teach young women about menstruation and that kind of thing, but we never address the issue of breasts...It's kind of an embarrassing thing, you know. And that's why you see all these teenage girls with a hunch.
(GROUP 9)

The lack of information was such that some women said they had volunteered for the focus groups because they were hoping to learn something by participating. Others told us that they learned some things they hadn't known from the discussion. The format of the groups—a small circle of women having open dialogue—seemed very conducive to learning and sharing.

4.4.2 Cancer

The topic mentioned most often as a learning need was breast cancer. What are the risk factors? What are the real risks, and what are urban myths? How does the genetic link work? How do you watch out for breast cancer, and what are the warning signs, aside from breast lumps?

What are the associated symptoms if you do have breast cancer? Would you feel more run down, would you have fever and chills, would there be other indications? What should you be looking for, what should you do, and what are the procedures?
(GROUP 3)

There are the urban myths you hear: if you eat from plastic...My grandma said she got her cancer because she was drinking a lot of Pepsi from tin cans, so it came from the can.
(GROUP 6)

Some women also wanted to understand the cancer screening protocols better, as well as the reasoning behind them.

One of the things I wonder about is why they don't start testing you until you're in your 40s (I mean, I could be wrong, but I think it's in your 40s). Some of the people I know were in their early 30 when they got breast cancer, so, I think that if they started the testing earlier, or maybe if they had done their examination earlier, that they could have caught it earlier. That's one of the things I'm in the dark about: Why they don't start it until you're older?

(GROUP 5)

Though cancer came up very often as a topic, cancer prevention only came up occasionally.

I'm all for having something that gives information about prevention, about changing your life style, to get through the jungle of information that's out there. Sometimes it's really hard to know what is the right information, because it changes weekly. Don't smoke. I think it's probably the most established fact right now, but there is other stuff out there, you know, different information.

(GROUP 3)

I also think of microwave ovens, how it's mostly women in the kitchen and they are all around breast level height. I haven't heard about any real conclusive evidence if it's safe to be around microwaves.

(GROUP 3)

I think there's lots of things. Birth control is another thing that I've been trying to figure out, whether the birth control pill is contributing to the cancer rates. There's no definitive answer on that, and that's frustrating.

(GROUP 3)

Breast cancer prevention. I don't know if there is, is there? Is there a way to prevent breast cancer?

(GROUP 8)

Cancer prevention seemed to be a black box, with very few of the women knowing any of what lay inside.

4.4.3 Breast self-examination

Another key topic for discussion, related to cancer, was breast self-examination. The frequency with which it came up throughout the focus groups suggests that social marketing campaigns promoting self-examination as a cancer detection tool have been highly successful with this age cohort. It came up in the discussions far more often than any cancer prevention strategy. Women talked about wanting to learn how to do the exam properly, and also, wanting to remember to do it regularly. For example:

I think that something I wish I'd learned, or would like to learn better is how to do a self-exam, that seems important. Just to have the confidence to do it.

(GROUP 4)

In addition, several women talked about breast lumps, and their difficulty in telling a “problem” lump from healthy, lumpy breast tissue when they examine their breasts.

What type of lump am I supposed to be checking for, and if I find one, then what? Because if you have lumpy breasts, which I do, it's like: “Oh, here's a lump, here's another one,” you know. So, what type am I supposed to be looking for exactly?

(GROUP 3)

4.4.4 Mammograms and clinical exams

A few women said they felt in the dark about mammograms—when best to have them, and whether there are risks involved. Some clarity was needed on why mammograms are not typically recommended for younger women, even though younger women can get breast cancer.

Is it a good thing or a bad thing? It is radiation. And then there's conflicting information out there around when you are younger but you have your mammograms done, how effective are they, as a diagnostic tool?

(GROUP 4)

Because you don't get mammograms till you're 40 or 50, obviously nothing can happen till then. You know, which is obviously not true. But that's what I always figured, obviously things just don't happen till then.

(GROUP 6)

Similarly, the clinical exam guidelines were a source of confusion for one woman.

I do find it odd that on all promotional material it talks about getting your yearly clinical breast exam, but yet I found that some people would say that their doctor never offers this to them, or I've actually heard people say that their doctors say that they don't do that. So, that seems to me kind of strange.

(GROUP 5)

This pointed to a need to ensure that public messaging is well-aligned with clinical practice.

4.4.5 Breastfeeding

Breastfeeding came up often, and the questions women had about it were quite diverse. They included questions about the impact of breast implants and breast reduction on breastfeeding, breastfeeding after breast cancer treatment, how breasts change physically during pregnancy and lactation, and things like inverted nipples, engorgement, and social support that can impact breastfeeding success.

I felt in the dark around breastfeeding and I had difficulties with it. When I first started breastfeeding, I remember having lots of difficulties and getting infections and I really had to seek that information out. I had difficulty accessing some of that information.

(GROUP 5)

For young mothers, especially in the smaller communities, breastfeeding support was a crucial, yet lacking, element. As with other breast health topics, the women talked about the importance of normalizing the experience, so they can discuss it openly and find the information they need.

Probably I needed to know that I needed to be on a schedule. I was so young, just didn't even know what I was doing half of the time. I didn't even like doing it, I was so ashamed to breastfeed, actually, I would just hide in my room and do it. Like, three weeks of that and that was enough. But I wish I had some information about it, so I wouldn't have been embarrassed about it. Because I was feeding my baby, I shouldn't have. But, I don't know, that's how I felt. Probably more information, I should have asked someone.

(GROUP 8)

They also emphasized the need for judgement-free support, so that they could find the information they needed, without feeling inadequate if they had difficulties breastfeeding.

I think breastfeeding was an important issue for me. It should be a no-brainer. It's not, it's really hard. Where I had my children, they had really combative breastfeeding nurses: "No, we're not going to lose you as a breast feeder. You're going to be a breast feeder." It was really hard work for me, not even possible for my first child and they were really against you going to the formula, and said: "No, that's so bad." And I felt like a failure, I felt like "I'm a terrible mother because I can't breastfeed my child and my nipples are all wrong."

(GROUP 3)

Others who had positive breastfeeding experiences agreed that adequate, non-judgemental support and timely information were essential.

4.4.6 Bras

Some women talked about how they had wanted to learn how to fit a bra properly, and to better understand the connection between bras and breast health.

I always struggled to find the right bra size. Because that, wearing the right bra, affects the health of your breasts. It would have been nice to have that information when I was younger.

(GROUP 2)

Actually, that's one more thing I thought about. Just in terms of bras, like what a proper fitting bra is. In the last few years I've been learning, and thanks to [the bra store], they've been really good. A large percentage of women walk around with bras that don't actually fit them.

(GROUP 3)

At night mostly, after wearing a bra for the whole day, I start aching here so bad that sometimes I can't even touch it, like the bottom of my bra or the top of my rib cage and it hurts and it's so painful and I'm thinking: "Is this normal, is my bra too small, or is it because of wires, or what?" I have no idea if it's my bra that's doing that or if it's something wrong with my chest area.

(GROUP 3)

Those who had learned how to get a well-fitting bra thought it was important to pass the information along to other women. They encouraged the other women in the focus groups to get a well-fitting bra, and some mentioned giving similar advice to younger friends and relatives.

I always tell my niece – she’s 13 and she’s pretty developed, too – and she wears these skimpy little tops, “Do you ever get support?” Like, “You need to have good support to pull those puppies up or else they’re going to be way down here when you’re 30.” And she’s like, “Oh, my God, is that true?” And I’m, “Yes, so make sure you shop for your bra, don’t just buy whatever is on sale.” And she’s, “Down to here!?” “It could be, they keep growing!”

(GROUP 9)

4.4.7 Breast aesthetics

Though not given high priority in any of the groups, several women brought up information needs around breast aesthetics, including natural changes in the appearance of their breasts, as well as breast enlargement and reduction surgery. The topic relates closely to body image, as it ties in with how women expect their breasts to appear.

One woman was amazed by how much her breasts changed after she had children.

I wasn’t quite prepared to what happens to your breasts when you have kids. I was quite shocked. It was great when I was pregnant, “Woohoo, look at me!” Right? But then, you know, afterwards, when you’re done breastfeeding, the composition has completely changed so now I’m like, “Ok, so how do I get these things back up?” And that’s not something that I even fathomed before I got pregnant.

(GROUP 2)

A few others discussed their desire for information on breast enlargement or reduction, and how these surgeries could potentially impact breast health and breastfeeding.

4.4.8 SUMMARY OF QUESTION 3

In our third question, we asked the women whether there was anything they had wondered about breast health. Some women responded by saying they felt in the dark about breast health in general. Others described some specific gaps in their knowledge. They also raised specific medical topics, including breast cancer and cancer prevention, breast self-examination and clinical exam guidelines, mammography, breast lumps. They also raised some non-medical topics, including breastfeeding, breast appearance changes, breast enlargement and reduction, and bra fitting.

4.5 SOURCES OF HEALTH INFORMATION

We asked the groups to tell us where they go to find answers to questions they have about their health. Repeatedly, we heard that the women had a preferred sequence of information sources. Some said they start by looking on the internet, then talking to friends or family, then seeing the doctor or nurse if they decided they had a health problem that needed to be looked at. Others might talk to a family member, then call 811, then see a doctor if they were advised by the 811 nurse to do so. As one woman put it:

It would probably be a series of my friends, internet, and then if there was something I need to talk to my doctor about, that would be step 3.

(GROUP 5)

It was surprising to see the internet ranked so highly here, because it did not come up as a significant source of information in question 2, which examined where the women had gained their existing breast health knowledge. Also, we observed that the internet and friends came up frequently as key information sources for non-aboriginal Whitehorse residents, but were not ranked as highly by the groups of First Nations or rural women.

Table 5. The participants’ preferred sources of health information

INFORMATION SOURCE	# OF TIMES MENTIONED
Internet	25
Not the internet	1
Doctor	21
Not the doctor	6
Nurse or health centre	11
Friends	11
811 Yukon HealthLine	10
Family	4
Books	3
Not books	1
Naturopath	1
Health Resource Centre (Francophone Association)	1
La Leche League	1

4.5.1 Internet

The internet came up repeatedly as a primary source of health information, especially for non-aboriginal Whitehorse residents. Many women said they appreciated the privacy and immediate accessibility of the internet, even though it often meant sifting through vast amounts of information to determine what is credible and what is not.

*You've got to pick a good site...I'd go to Health Canada or something.
Like a government site, normally it's pretty trustworthy.
I would go to the government and get a referral from them.*
(GROUP 1)

*When I book a doctor's appointment it's going to be two weeks before I get in, anyway, or a week.
It depends how great your relationship with your doctor's nurse if you have a regular doctor and if you don't,
then God only knows. So the Internet is the most quickly available form of information.*
(GROUP 2)

*If you go to the Internet, whether the information is accurate or not, at least you can have a bunch of questions,
or an article, or things to talk to your doctor and so you're more likely to get your answers.
Or, when you have freedom to go on the Internet, you can follow the path of every possibility,
and then you can decide whether you actually need to go to the doctor or not.*
(GROUP 2)

*I find that the doctors and nurses are so pressed for time and just very limited in their capacity,
that everything is always rushed and they're not fully there when I am visiting, so it's like:
"Oh, never mind, I'll just look it up on the Internet."*
(GROUP 3)

*When I have any kind of health issue, I look it up on the Internet.
I surf on several different web sites, and I have an idea of what kind of questions
I should ask before I go to the doctor...I'd Google it.*
(GROUP 5)

Though the vast majority of the women said they used the internet to look up health information, a few women said they did not find the internet especially useful as a health research tool.

You get 20 times more information than you want and half of it is not reliable.
(GROUP 6)

Internet serves for other things.
(GROUP 8)

4.5.2 Doctor

Many women said they see their doctor for health information, or they look at information pamphlets in the doctor's office to see what applies to them. The doctor was rarely the first stop for information, usually because of the wait to get in to see a doctor, and the limited amount of time doctors can spend with each patient. A number of women also said they don't rely on a doctor for health information.

*Doctors are so stretched thin these days too. "I've had my 15 minutes." ...
Yeah, and I've had numerous times when I walked out with some
prescription and I just basically shredded it and threw it in the garbage.
Like: I have 15 minutes, what can I do? Well, I can prescribe something.*
(GROUP 1)

One group identified the historical and current treatment of First Nations people in the health care system as a barrier to accessing appropriate, timely care.

*There's a huge number of persons that won't go out to seek medical treatment, because of past history or how they've
been treated, due to the doctor shortage or whatever. They have a hard time getting people go in and getting properly
assessed because of history and how they've been treated before. ...Or maybe it's fear, that you find that there is
something wrong and you don't want to. And when they finally do see a doctor it's too late, so they might be spreading
more fear into other family members, so that might lead to not trusting the doctor and that might go back to being
neglected as First Nations people, thinking that they're just being send somewhere just because it's paid for and they're
not really looked after.*
(GROUP 7)

This issue did not come up in the communities, where care is available through a community health centre instead of through family physicians, walk-in clinics and the emergency room at the hospital.

4.5.3 Nurse/ Health centre

Some women said they relied on public health nurses or a community health centre as a source of health information. The types of concerns women had about physician care did not appear to apply to the community nurses.

I think I would call the public health nurses. Or use the resources that they have, because I happen to trust them and the information that they gave me.
(GROUP 3)

I did find the nurses at the health centre quite helpful with breastfeeding questions.
(GROUP 5)

Maybe every once in a while I would go to my friends, on certain things, but if they are too private, I would probably phone the health centre.
(GROUP 8)

4.5.4 Friends

Some women said they talk to friends who have common experiences when they need health information.

Friends too. When I was nursing, it was like: Hey, I'm done feeding my kid, but apparently I'm not. Is that what happened to you?
(GROUP 2)

Other women, not for specific medical advice, but, you know: "Have you had this experience" or "I don't know what to do" or "Oh, my God, I'm so worried" or whatever.
(GROUP 4)

I would go to a friend who has already been through something similar.
(GROUP 6)

We noticed that those who said they'd turn to friends for information were all of European ancestry. Instead, many First Nations women said they would want to attend information sessions with a group of friends, but none said they turn to their friends for health information.

4.5.5 Yukon HealthLine (811)

Some women mentioned the 811 Yukon HealthLine as a source of health information. Everyone seemed to know about it, as a result of advertising. However, it appears to have some limitations.

I'd call 811 if I had a health-related issue, but sometimes, if someone is telling you over the phone, it's hard to understand than if you're looking at a diagram or being shown in person.
(GROUP 6)

811. But they're only good for information and then they tell you to go to the hospital, they keep you on the phone for half an hour and then they tell you to go to the hospital.
(GROUP 7)

Lately, since 811 started up, I've been phoning there, but it just takes forever. You go through all this information and then they're looking it up and I was like: "I thought it was faster. I might just as well go to my computer."
(GROUP 8)

You're telling them everything that happened to you, and what your best friend's name was in grade 6 and it's really, it can be very useful. But they ask you too many questions.
(GROUP 9)

4.5.6 Other sources of information

Other sources of information that were mentioned by a few respondents were family members (a mother, sister or aunt), books such as the Yukon health guide (mentioned once) and Our Bodies, Ourselves (mentioned twice), a naturopath, the Francophone health resource centre, and La Leche League (for breastfeeding information).

4.5.7 SUMMARY OF QUESTION 4

We asked the groups to tell us where they go to find answers to questions they have about their health. Many women said they liked to triangulate, looking for information from a series of several familiar sources. The internet often came up as a primary information source, ahead of doctors and nurses. This was curious, because the internet was not ranked highly as a place where women had gained their existing breast health knowledge (Question 2).

Also, though many women had said they gained existing knowledge from a doctor (Question 2), in Question 4, many said doctors are too busy and are not readily available as an information source. They tended to look for information elsewhere, then use that information to help them decide whether or not to see a doctor.

4.6 DESIGNING A BREAST HEALTH EDUCATION PROGRAM TO MEET YOUNG WOMEN'S NEEDS

In this question, we asked the groups to give us suggestions for how best to design a breast health education program for women in their 20s and 30s. We asked them where the information should be made available, and what types of information should be included. As this was a two-part question, each part is discussed here in turn: where, then what.

4.6.1 Where should the information be made available?

In the ideal breast health education campaign for young Yukon women, where should the information be made available? The groups gave us numerous suggestions, such as a workshop or event, a sex education program for school-aged children, a website, an advertising campaign (typically linked to a website), and other resources such as a booklet, swag (such as key chains or t-shirts), and specialized staff such as a women's health nurse.

Table 6. Where should breast health information be made available?

LOCATION OR FORMAT	# OF TIMES MENTIONED
Workshop or event	17
At home or school, for children and youth	13
Website, chatroom or forum	12
Advertising campaign	9
Booklet or pamphlet	6
Info line	2
Swag	2
Bilingual print materials	2
Women's health nurse	1
Breast model	1

Workshop or event

In earlier questions, very few women said they had gained breast health information from a workshop or event. However, those who had attended such a workshop talked about how effective it had been as a learning tool. Also, even groups with no workshop experience among their members said they would like to have a women's health event which included a focus on breast health. This would include things such as bra fitting, breast self-examination, clinical exams, and breast care and cancer prevention education.

I'd like a whole "women by women for women" health event, not just breast health, but everything.
(GROUP 4)

I think it would be nice to have a breast health seminar, where you could learn. I think that would be fantastic. Somewhere where you could go and be around a whole bunch of women, and have a doctor come in, and the model boob, and do some demonstrating and answer some questions.
(GROUP 6)

I think there should be something that is friendly, but, at the same time, intelligent, I mean we talked about research. In a group situation, where there's a whole bunch of women and everybody is giggling.
(GROUP 6)

Or what about something like what they did when they had the flu shots. You know, you could do it once or twice a year, have a thing where you have people who were trained in breast self-exams and set it up somewhere in a couple of rooms and people could come in like they would for a flu shot. Come in and have a breast exam, maybe have someone show you how to do a self breast exam. I think that would be hugely popular.

(GROUP 6)

Attendance was a concern in the communities. Something of general interest would have to be included as a draw for attendees, such as bra fitting.

I haven't seen a lot of health programs, like after hours stuff and workshops, in the communities, because frequently they are pretty poorly attended. So, stuff tends to run out of steam really quickly. You get really excited about something and then you get one person there or no people show up.

I wonder if you could include the bra lady coming up. ...

Have breasts exams, and have something interactive for fun, that would be good.

(GROUP 9)

Women in Carmacks and Haines Junction told us about successful health fairs that take place in some of the communities; perhaps there is an opportunity to add a breast health component to those fairs.

At home or school

Many women raised the importance of addressing the breast health education needs of girls, at home or in school. Though it is outside the scope of this project, it came up often enough that we have included it in this report.

If it's open you're more prone to talk about it when you're older too. I mean, even if you were to develop something, not necessarily only for the 20 and the 30 year-olds, for 12, 13, 14, because that's when they start to develop breasts, even earlier. ...It's not only when you start to develop, but that's also when you're most interested too.

(GROUP 2)

As a 30-40 year old woman, I wouldn't seek that information out. I would argue that there should be a mandatory health education in school.

(GROUP 3)

I think of awareness at an earlier age, or education at an earlier age, so we're not taught to be leery about asking questions or empowering women, like early adolescence or pre-adolescence.

(GROUP 5)

In sex-ed they should be talking about bra-fitting.

(GROUP 6)

Website

A number of women said they'd like to see a government-hosted website, chatroom or discussion forum online addressing the need for breast health information. This was not surprising, since so many of women said they used the internet as a health research tool.

I think a website, especially for the younger generation.

I think they're totally in tune with technology.

Seriously, it's also available 24 hours. And it's private.

You have your privacy at home, when the parents are in bed.

(GROUP 2)

If you had a website, at least then people would know that that's legit, because that's my problem with going on the Internet is you don't know if it's garbage or not.

(GROUP 4)

A lot of people choose forums to gather information, if you have all the information and still have questions, you could ask your questions and they suggest answers.

(GROUP 4)

I always go to the internet, so a really easy internet website address that you can look at on a poster or ad.

(GROUP 5)

If you had a chatroom with nurses or doctors, I could quit using 811.

'Cause that would be a more private than the 811.

(GROUP 8)

Overall, the women recommended a government-hosted website with an easily remembered address, advertised in conspicuous places and spots women frequent. They wanted it to be interactive, concise, and informative.

Advertising campaign

Some women suggested an advertising campaign promoting breast health. They thought this would be a good way to promote a website. Suggestions included ads in public spaces, on the buses, on Facebook, and on the radio. They liked the ad campaigns that used images of people they knew, like the Smoke Free posters.

I was thinking public spaces, like bus panels or something, something like that, where it's in the public arena, that kind of normalizes it too. ... You know, like the quit smoking thing, it's always in your face, you always see it, why don't you put something like breast health all over the place?

(GROUP 3)

I like the idea of more in-depth information on the website and then a simple kind of poster that catches your eye and has an easy web address, one you can remember, not have to write down.

Posters in women's washrooms.

(GROUP 5)

More visual, I mean that's the key, an image. It's a quiet thing, it's a private part of your body, but the cancer rates are so high that it needs to be in your face.

(GROUP 7)

While some thought posters should be in very public spaces, others thought they would best be placed in spots women frequent, such as change rooms, gyms, and recreation centres.

Booklet or pamphlet

A few people said they would like to have an informative booklet or pamphlet on breast health. They suggested it could be distributed widely, in the doctor's office, hospital or wherever baskets of condoms are currently placed. Francophone women said they would like this print material to be available in French as well as English.

Other formats

A couple of women suggested a breast health information line, something more readily accessible than 811. One suggested having a women's health nurse with expertise in women's health issues. Others liked the idea of swag such as water bottles or bags with health messaging on them. One woman said she would like to learn from a model breast, which can be used to teach women what a breast lump feels like. Another woman said she'd like to learn breast self-examination from her doctor.

4.6.2 What information should be included in a breast health education campaign?

When we asked the groups what types of information should be included in a breast health education campaign, their suggestions were quite diverse. They ranged from breast self-examination to body image; from breastfeeding to bra fitting. The full list of topics is included as a table, below.

Table 7. What information should be included in a breast health education campaign?

TOPIC	# OF TIMES MENTIONED
Breast self-examination	10
Body image	9
Medical information	5
Breastfeeding	5
Bra fitting	5
Breast enlargement, reduction, and nipple piercing	4
Breast health promotion	3
Cancer risk factors	3
Photos of a variety of breasts	1

While breast self-examination was mentioned most often, body image came up next. A healthy body image would encourage women to take good care of their breasts, avoid damaging behaviours (like smoking, which some young women take up to try and be thin), and avoid potentially damaging cosmetic surgeries.

I think they can be a big source of shame. I know we're talking about physical health, but mental health, or the emotional side of it is really playing a part in breast health. I think it's not just breast health, but a healthy relationship with your breasts, appreciating them, knowing that there are really all kinds and sizes.

(GROUP 1)

People in their 20s today are exposed to much more imagery of naked breasts and naked bodies than when we were growing up, and it's just this one kind of media-approved body they see over and over. I think it's really important when you're young to be aware that the variety is normal, like how different people's bodies are one from another. You don't normally see live human bodies naked, you just see these people in the media or on the internet or whatever.

(GROUP 5)

It has to do with the general tone of sex-ed and like in high-school. It could be so much more sort of sex-positive, and body-positive, there are so many opportunities. I don't know how it looks like now, I was there like ten years ago. To have that sort of perspective where it's more like a positive experience and you're going away understanding that the media has an interest in you not liking your body, I think it would go towards removing some of the stigma around both touching yourself and the general idea of breasts.

(GROUP 1)

In addition to the key topics of breast-self examination and body image, some women said they would like an educational campaign to include medical information such as the warning signs of breast cancer, and other things that can go wrong with breast health.

I've never heard any talk about anything other than breast cancer, so I'm not going to watch for things that I don't even know. But, if I was aware that other conditions and risks exist, that changes the tone and the priority on paying attention to that stuff. So, education is huge.

(GROUP 1)

Others said they would like to see breastfeeding information included, and some wanted something on bra fitting. Others said they would like to see health information on breast enlargement, reduction and nipple piercing, to enable women to make informed decisions. A few women said they would like to see information on breast health promotion (such as what dietary and lifestyle things to avoid to reduce breast cancer risk), and others asked about cancer risk factors. One woman said she'd like to see photos of a variety of breasts, demonstrating the range of "normal."

Other themes: make it relevant and positive

In addition to the topics mentioned above, two generic themes emerged from the discussions. Some women emphasized the importance of providing women with relevant information that would catch their attention; this came up five times. Secondly, the issue of positive messaging was raised four times.

What kinds of relevant information did the women want to see? They wanted it to be concise, timely and current. They wanted it to catch their attention. Also, they wanted it to be clearly aimed at their age demographic.

It's got brevity to begin with. Like, you've literally got probably 20 seconds of my time. And that's just generous. I'm busy, and if I'm not really interested, you have to get me right away. I mean, we are bombarded with health information all the time. So why is breast health more important than the foot care pamphlet that's sitting right beside it? That's why – sad as it is – it's got to be attractive to the eye. I think people would stop and look at stuff that pops out to them rather than Oh, another thing about breast health or whatever.

(GROUP 1)

It would need to say the age group, "This is for you", so whenever you're scanning, "Oh, this is information for me." Because maybe if you see "breast health" you might think it is for someone older.

(GROUP 5)

As for positive messaging, some women thought it important for this age demographic to focus on getting to know one's body in a positive, empowering way, rather than using scare tactics to promote cancer screening.

Instead of marketing from a perspective of what can go wrong with your breasts, focus on what are healthy breasts and what are the healthy things you can do, like having the proper bra, things like that. I mean, from a more positive goal instead of scaring.

(GROUP 3)

You're probably not going to develop cancer in your early 20s, but it's about getting to know your breasts, and an ethos of empowerment, getting to know your body.

(GROUP 5)

*I think it is about empowering yourself, to not have the fear factor there but rather to say,
“Hey, know about your own body because that’s a powerful thing.”
...Because everywhere we look it’s like cancer, cancer.*

(GROUP 1)

4.6.3 SUMMARY OF QUESTION 5

In the ideal breast health education campaign for young Yukon women, where should the information be made available? The groups gave us numerous suggestions, such as a workshop or event, a sex education program for school-aged children, a website, an advertising campaign, and other resources such as a booklet, swag (such as water bottles, key chains or t-shirts), and specialized staff. Most women seemed to think a combination of these approaches would be best, such as an ad campaign pointing to an interactive website, or an event or contest in which women are challenged to create educational materials.

When we asked the groups what types of information should be included in a breast health education campaign, their suggestions were quite diverse. They included, in order of the frequency with which they were mentioned, breast self-examination, body image, medical information about breast health, breastfeeding, bra fitting, breast alteration, breast health promotion, cancer risk factors, and photos of a variety of breasts to illustrate the full range of “normal.” Some women also recommended that we strive to make the campaign relevant to young women, and to use positive messaging rather than promoting fear.

4.7 FOCUS GROUP SUMMARY

In the third and final phase of the research, we invited women between the ages of 20 and 39 to take part in focus groups to discuss their breast health education needs and experiences.

The women considered some medical and non-medical breast health issues important. When we asked the women to tell us about the most important things they had learned about their breasts, they identified the following broad issues, from the most to the least-often mentioned: breast self-examinations, breastfeeding, cancer and cancer prevention, and bra fitting. Cancer prevention seemed to be a black box, with very few of the women knowing any of what lay inside.

We also asked the women whether there was anything they had wondered about breast health. Some women responded by saying they felt in the dark about breast health in general. Others described some specific gaps in their knowledge. These included specific medical topics, such as breast cancer, screening and prevention, as well as non-medical topics like breastfeeding, breast appearance changes, breast enlargement and reduction, and bra fitting.

The women said they had learned what they knew about breast health from a variety of sources, some of which were formal (such as health care providers), while others were informal (such as friends or family).

To find answers to their health-related questions, many women said they liked to triangulate, looking for information from a series of several familiar sources. Many said that doctors are too busy and are not readily available as an information source. They tended to look for information elsewhere, then use that information to help them decide whether or not to see a doctor. The internet often came up as a primary information source, ahead of doctors and nurses. This was curious, because the internet was not ranked highly as a place where women had gained their existing breast health knowledge.

In the ideal breast health education campaign for young Yukon women, where should the information be made available? The groups gave us numerous suggestions, such as a workshop or event, a sex education program for school-aged children, a website, an advertising campaign, and other resources such as a booklet, swag (such as water bottles or t-shirts), and specialized staff. Most women seemed to think a combination of these approaches would be best, such as an ad campaign pointing to an interactive website, or an event or contest in which women are challenged to create educational materials.

When we asked the groups what types of information should be included in a breast health education campaign, their suggestions were quite diverse. They included, in order of the frequency with which they were mentioned, breast self-examination, body image, medical information about breast health, breastfeeding, bra fitting, breast alteration, breast health promotion, cancer risk factors, and photos of a variety of breasts to illustrate the full range of “normal.”

At the beginning of this project, we had thought the information needs of the participants might differ by age (for instance, those in their twenties versus compared with those in their thirties). However, we found that it was childbearing experience- not age cohort- that differentiated the women clearly into two groups. Those with children typically raised breastfeeding information as one of the most important breast health topics they had learned about.

In addition to age, we had anticipated that there could be differences between breast health information needs and information-seeking strategies of aboriginal and non-aboriginal women. By and large, we found no notable differences between the information needs of these two groups of women. However, there were some noteworthy differences in their information-seeking behaviour. We noticed that those who said they’d turn to friends for information were all of European ancestry. Instead, many First Nations women said they would want to attend information sessions with a group of friends, but none said they turn to their friends for health information. Also, First Nations women were somewhat less likely than non-aboriginal Whitehorse residents to say they used the internet as a key information source. There were some exceptions to this, most notably aboriginal women working in a health-related field.

Some women said they would like to be able to access information privately, either through a website or a nurse or doctor. Others said they preferred workshops or events that they could attend with other women, or with a group of their friends. The latter concept was particularly popular among First Nations women.

Some women are highly health-literate, while others have more difficulty interpreting health information and navigating the confusing and often contradictory information that is found in the internet.

Crucial life-events appeared to heighten their information needs of women from all age and ethnic groups, bringing breast health to the forefront. From the stories we heard, at the following key times, their information needs were most apparent: (1) puberty, (2) pregnancy/lactation, (3) the occurrence of breast tissue abnormalities such as lumps, cancer, mastitis, and (4) breast augmentation or reduction surgery. The challenge may be to design a breast health education strategy that meets the information needs of women at these key times, while also attracting the attention of women for whom breast health is not currently a top priority.

5. DISCUSSION AND RECOMMENDATIONS

Women of all ages may have breast health information needs. This project addresses one particular gap in educational resources: currently, there are few resources available that have been designed for women in their twenties and thirties. We explored the breast health educational needs of young Yukon women: what they want and need to know about breast health, and how they wish to receive this information.

In this project we confirmed that (a) there is a dearth of age-appropriate breast health education materials available for women in their twenties and thirties, at least that which is comprehensive, accessible, and compiled in a format that appeals to Yukon women; and, (b) there is an appetite for breast health education programming that goes beyond basic cancer awareness messaging.

Our environmental scan confirmed that there are some breast health education resources available, but few were developed with young women in mind, particularly young women who have not experienced breast cancer. Also, very few materials addressed breast health broadly, outside the context of cancer. This was confirmed through our key informant interviews.

5.1 BREAST HEALTH EDUCATION TOPICS

Our key informants identified young women's informational needs in four areas. The first area, breast cancer screening, included issues such as breast and body awareness and self-examination, knowing the clinical screening guidelines such as when to have a physical exam, knowing the warning signs of breast cancer, and knowing what services are locally available. The second area, breast cancer risk factors, included factors such as genetic predisposition, weight, age, and exposure to tobacco smoke and other toxins. The third area, health promotion, included a variety of strategies that women can use to reduce their risk of breast cancer, such as exercise, eating low on the food chain, and breastfeeding. The fourth area covered some issues that women face when they undergo breast cancer treatment.

The topics identified in the key informant interviews had considerable overlap with the informational needs women said they had in our focus groups. However, there were also some notable differences. When we asked women to tell us about the most important things they had learned about their breasts, they identified the following broad issues, from the most to the least-often mentioned: breast self-examinations, breastfeeding, cancer and cancer prevention, and bra fitting. Similarly, when we asked them to tell us if there was anything they had ever wondered about breast health, they described a series of medical and non-medical subjects, such as breast cancer, screening and prevention, as well as breastfeeding, breast appearance changes, cosmetic breast surgery, and bra fitting. Though both the key informants and the focus group participants saw breast cancer and cancer prevention as important components of breast health, the focus group participants seemed to define breast health more broadly than the experts in the field.

Many of the focus group participants said they preferred to go to a series of sources for health information. Similarly, they suggested that a breast health education program would ideally use multiple delivery methods, such as an attention-grabbing poster which directs women to an informative website with a memorable address. One popular suggestion was to hold a workshop or event for young women, where they could learn everything from breast self-examination to bra fitting.

The women suggested a range of topics for a breast health education program, including, in order of the frequency with which they were mentioned: breast self-examination, body image, non-cancer breast health issues, breastfeeding, bra fitting, breast alteration, breast health promotion, cancer risk factors, and photos of a variety of breasts to illustrate the full range of “normal.” The list encompasses three of the four topics the key informants said they thought women should know about: breast cancer screening, risk factors and health promotion. Only cancer treatment was mentioned by some key informants, but wasn’t given high priority in the focus groups. A blend of the two lists may be most effective, as it would encompass the information that experts in the field want women to know, while also including the subjects that women want to learn more about.

Table 8. Breast health education topics recommended by focus groups and key informants

TOPIC	FOCUS GROUPS	KEY INFORMANTS
cancer screening	√	√
cancer risk factors	√	√
cancer treatment		√
non-cancer breast health issues	√	√
breast health promotion	√	√
breastfeeding	√	√
breast alteration	√	√
bra fitting	√	
body image	√	
diverse images of breasts	√	

A comprehensive list of broad topic areas, including those recommended by the key informants as well as those suggested by the focus groups, is as follows:

- Breast cancer screening,
- Breast cancer risk factors,
- Breast cancer treatment,
- Breast health promotion,
- Bra fitting,
- Body image,
- Diverse images of breasts.

Of these topics, only breast cancer treatment is likely outside the scope of a health promotion breast health education strategy. It is specialized knowledge which may be unnecessary unless women develop breast cancer. Also, given some women’s fears around cancer screening, it might be more beneficial to promote screening tools such as breast self-examination as holistic wellness tools, enabling women to recognise natural changes in their breasts in a positive context.

5.2 BREAST HEALTH EDUCATION CAMPAIGN STRATEGIES

Our key informants identified access to information as a significant barrier young women face when it comes to breast health. Similarly, some participants in the focus groups said they struggled with the sheer volume of health information that is available to them on the internet and through the media, much of which is contradictory or unreliable. They also said physicians were not readily available to answer their questions, so they tended to look elsewhere for answers before deciding whether it was necessary to go see a doctor.

We asked the focus groups, in a breast health education campaign for young Yukon women, where should the information be made available? The groups gave us numerous suggestions, such as a workshop or event, a sex education program for school-aged children, a website, an advertising campaign, and other resources such as a booklet, swag (such as water bottles or t-shirts), and specialized staff. Most women seemed to think a combination of these approaches would be best, such as an ad campaign pointing to an interactive website, or an event or contest in which women are challenged to create educational materials.

From the discussion, it was apparent that key life-events heightened the women’s breast health information needs, bringing the topic to the forefront. These life-events included (1) puberty, (2) pregnancy/lactation, (3) the occurrence of breast tissue abnormalities such as lumps, cancer, mastitis, and (4) breast augmentation or reduction surgery. Breast health information would best be delivered within the broader context of women’s life-course, rather than focusing exclusively on adverse events such as breast cancer.

An effective educational campaign will capitalize on these life events when breast health is on women’s minds. In addition, it will attract the attention of women for whom breast health is not currently a top priority. It is widely accessible and addresses the information needs of women in Whitehorse, as well as those living in smaller Yukon communities. It is delivered in a fashion that appeals to both aboriginal and non-aboriginal women; those in their twenties and those in their thirties; those with children and those without. There is likely no single product that will meet all these needs. Rather, a multi-faceted approach is required: one that utilizes web-based and hands-on teaching materials; one that is widely advertised and accessible throughout the territory; one that addresses the diverse information needs of women across the life-course.

Some women said they would like to be able to access information privately, either through a website or a nurse or doctor. Others said they preferred workshops or events that they could attend with other women, or with a group of their friends. The latter concept was particularly popular among First Nations women. Some women are highly health-literate, while others have more difficulty interpreting health information and navigating the confusing and often contradictory information that is found in the internet. An effective education campaign will meet the diverse needs of all these women.

5.3 NEXT STEPS

Taken together, these results support that breast health education be comprehensive and multi-faceted, capitalizing on existing resources such as community health centres and the 811 Yukon HealthLine, while introducing new web-based and hands-on teaching materials.

6. APPENDICES

APPENDIX I – ENVIRONMENTAL SCAN: WEB RESOURCES

Appendix I. Organization	Topic	General Public	Comments	URL
Better Health Channel (Australia govt)	Breast cancer and other disease prevention, treatment, awareness	General public	Breast screening fact sheet (webpage; concise descriptive information)	http://www.betterhealth.vic.gov.au/ bhcv2/bhcarticles.nsf/pages/Breast_ screening?OpenDocument
Better Health Channel (Australia govt)	Breast cancer and other disease prevention, treatment, awareness	General public	Fact sheet about having mammograms when you have breast implants	http://www.betterhealth.vic. gov.au/bhcv2/bhcarticles.nsf/ pages/Breast_implants_and_ mamograms?OpenDocument
Canadian Breast Cancer Foundation	Breast cancer and other disease prevention, treatment, awareness	General public		http://www.cbcf.org
Canadian Breast Cancer Network.	Breast cancer and other disease prevention, treatment, awareness	General public	Breast cancer information, resource list	http://www.cbcn.ca/en/?section=3
Huntingdon Breast Cancer Action Coalition: Prevention is the Cure	Breast cancer and other disease prevention, treatment, awareness	General public	collaborative educational campaign focusing on environmental causes of disease	http://preventionisthecure.org

Appendix I. Organization	Topic	General Public	Comments	URL
Maurer Foundation	Breast cancer and other disease prevention, treatment, awareness	General public	breast health education	http://www.maurer-foundation.org
National Breast and Ovarian Cancer Centre (Australia)	Breast cancer and other disease prevention, treatment, awareness	General public	Awareness, screening, treatment information (online resource)	http://www.breasthealth.com.au/
National Cancer Institute	Breast cancer and other disease prevention, treatment, awareness	General public	breast cancer prevention-patient information	http://www.healthlinkbc.ca/kbase/nci/ncicdr000257994.htm
Naturopathic approach Canmore, AB	Breast cancer and other disease prevention, treatment, awareness	General public	Web info on natural health and breast care, including “ten ways to prevent breast cancer”; healthy breasts email series (each emailed newsletter includes action steps)	http://pinkandgreenribbon.com
Rethink breast cancer	Breast cancer and other disease prevention, treatment, awareness	General public	(ontario- breast cancer and prevention)	http://www.rethinkbreastcancer.com
Susan G. Komen for the Cure	Breast cancer and other disease prevention, treatment, awareness	General public	Various breast health / cancer information pages designed for the general public	http://ww5.komen.org/
Native American Programs	Breast cancer and other disease prevention, treatment, awareness	General public- aboriginal	List of breast health resources and articles pertinent to native women	http://www.nativeamericanprograms.org/breast.html

Appendix I. Organization

Organization	Topic	General Public	Comments	URL
Breast Services (Australia)	Breast cancer and other disease prevention, treatment, awareness	General public- with breast cancer	Breast Services Loddon Mallee has designed this website primarily for the woman with breast cancer, her family and loved ones. We follow her journey from healthy breast through diagnosis & treatment, also exploring the available range of resources & support.	http://www.breastservices.lmha.com.au/index.htm
Canadian Breast Cancer Network website	Breast cancer and other disease prevention, treatment, awareness	General public; these links are specific to Rural/minority/FN	resources includes cancer prevention publications aimed at FN/ Inuit audiences. And ethnic minorities	http://www.cbcn.ca/en/?section=3&category=296&regionid= http://www.cbcn.ca/en/?section=3&category=294&regionid=
Imaginis.com	Breast cancer and other disease prevention, treatment, awareness	Young women	Webpage: what young women should know about breast cancer/ breast health	http://www.imaginis.com/breasthealth101/breasthealth.html
Breast cancer now what?	Breast cancer and other disease prevention, treatment, awareness	Young women- with breast cancer	Uniting young women with breast cancer (info website)	http://www.breastcancerowwhat.ca/?q=home
Breast Cancer Resource Directory of North Carolina	Breast cancer care and self-care	General public- aboriginal with breast cancer	3-page report on breast cancer and aboriginal women, including a list of books, organization and other resources	http://bcresourcedirectory.org/assets/files/directory/chapter_5/BCRD_C5_S3_Native_American.pdf

Appendix I. Organization	Topic	General Public	Comments	URL
The breast care site	Breast cancer care and self-care	General public with breast cancer	Website- includes topics such as sexuality after breast cancer	http://www.thebreastcaresite.com/tbcs
National Breast and Ovarian Cancer Centre (Australia)	Breast cancer care and self-care	Young women with breast cancer	Australian webpage addressing issues young women face with breast cancer	http://www.breasthealth.com.au/treatment/youngerwomen.html
Willow Breast Cancer Support Canada	Breast cancer care and self-care	Young women with breast cancer	The best ever list- information and support resources for young women with breast cancer. Created by women with breast cancer. Short list of books, websites, support groups	http://www.willow.org/pdfs/BESTEVERLISTforYou84.pdf
Native American Cancer Research	breast cancer- risk factors	General public- aboriginal	webpage- risk factors for breast cancer (minimal information)	http://natamcancer.org/
Canadian Women's Health Network	Breast health	General public	Keeping your breasts healthy (plain language article)	http://www.cwhn.ca/resources/faq/breastCare.html
Canadian Women's Health Network	Breast health	General public	Keeping your breasts healthy- Breastfeeding (plain language article)	http://www.cwhn.ca/resources/faq/breastFeeding.html
Canadian Women's Health Network	Breast health	General public	Breast Health (FAQs)	http://www.cwhn.ca/hir/faq-breast.html

Appendix I. Organization

Organization	Topic	General Public	Comments	URL
Dr. Christine Horner	Breast health	General public	extensive website with 25 breast health tips (nutrition etc.)	http://www.drchristinehorner.com/25tips.html
MCG Health iHealth for women	Breast health	General public	Women's health general information- variety of topics including breast health, broken up by age group	http://www.mcghhealth.org/ihealth_women/index.htm
The breast site	Breast health	General public	consumer information website based in Ontario. Breast health, cancer, surgery, breastfeeding, bras.	http://www.thebreastsite.com/
University of Rochester Medical Center	Breast health	General public	Breast care information (physician exams, mammography, breastfeeding, prevention etc.)	http://www.stronghealth.com/services/womenshealth/breastcare/index.cfm
Health Canada	Breast implant surgery	General public	info sheet- issues to consider before implant surgery	http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/med/questions-eng.php
BC (Yukon) health guide/ Healthlink BC	Breast self-awareness and self-exams	General public	breast problems info	http://www.healthlinkbc.ca
Better Health Channel (Australia govt)	Breast self-awareness and self-exams	General public	Breast awareness fact sheet (webpage; concise descriptive information)	http://www.betterhealth.vic.gov.au/bhcv2/bharticles.nsf/pages/Breast_awareness?OpenDocument

Appendix I. Organization	Topic	General Public	Comments	URL
Breast of Canada	Breast self-awareness and self-exams	General public	How to do a BSE	http://www.breastofcanada.com/bse.html
Breast Self Exam website	Breast self-awareness and self-exams	General public	How to do a BSE	http://breastselfexam.ca/index.html
Canadian Cancer Society	Breast self-awareness and self-exams	General public	Know your breasts (webpage)	http://www.cancer.ca/Canada-wide/About%20cancer/Types%20of%20cancer/Know%20your%20breasts.aspx?sc_lang=en
lorainccc.edu	Breast self-awareness and self-exams	General public	power-point presentation for women- recognising breast cancer, BSE	http://www.lorainccc.edu/NR/rdonlyres/C91C9FC9-1557-4D68-A06B-49725A05F19F/3956/PromotingBreastHealth.pdf
Maurer Foundation breast health education	Breast self-awareness and self-exams	General public	How to do a BSE	http://www.maurer-foundation.org/self_exam.html
Susan G. Komen for the Cure	Breast self-awareness and self-exams	General public	How to do a BSE	http://www5.komen.org/BreastCancer/InteractiveTools.html

Appendix I. Organization

Organization	Topic	General Public	Comments	URL
Rethink Breast Cancer	Breast self-awareness and self-exams	Young women	charity awareness campaign; the booby wall (web-based interactive breast photo project); TLC campaign (touch look check); Canadian	http://www.rethinkbreastcancer.com
10 fun facts about breasts	Breasts- miscellaneous	General public	webpage	http://www.womens-health-issues.us/breast-facts.php
Natural breast care- young and firm	Breasts- miscellaneous	General public	webpage-- get breast enhancement naturally	http://www.green-beauty.info/ENGLISH/Tips/breast-enhancement.htm
Better Health Channel	Nipple piercing	General public	webpage- information about nipple piercing- procedure, complications, avoiding infection	http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Nipple_piercing?OpenDocument
La Leche League International	Nipple piercing	General public	webpage- article on breastfeeding and nipple piercing	http://www.llli.org/llleaderweb/LV/LVJunJul99p64.html
Nipple Piercing	Nipple piercing	General public	webpage- article on breastfeeding and nipple piercing	http://www.nipple-piercing.info/facts-about-surgery-nipple-piercing-and-breast-feeding.html

APPENDIX II – ENVIRONMENTAL SCAN: EDUCATIONAL MATERIALS

Appendix II. Organization	Product	Description	URL
Aboriginal Women's Breast Health Care Project	Breast health care teaching modules (\$95 per module).	Four modules, by age group: teens, young adults/ parents (19-35), middle aged (35-55), seniors (55+). Targets aboriginal women	http://www.anishnawbe-mushkiki.org/breast_health.htm
Alaska Native Medical Center	Movie: Weaving Breast Health Into our Lives and accompanying booklet	Breast health education resource for aboriginal women (Alaska)	http://www.medicalnewstoday.com/articles/55608.php
Avon Foundation	Breast Health Resource Guide "Early Detection Saves Lives"	information about breast cancer screening; booklet; available in PDF	http://www.avoncompany.com/women/avoncrusade/resource_guide.html
Beyond Boobs	A Calendar to Live By	Breast cancer awareness info calendar for young women (15-54)	http://www.beyondboobsinc.org
BreaCan	Young Women Talking DVD	personal stories of 4 women who had breast cancer in their early 30s	http://www.theyoungones.asn.au/articles_of_interest
Breakthrough	Breast cancer information booklets and fact sheets	Mostly aimed at women; one booklet is aimed at health professionals. Most address risk factors.	http://www.breakthrough.org.uk/what_we_do/breakthrough_publications/index.html
Breast Cancer Action Ottawa	Young women's breast health program	presentation slides	http://www.bcaott.ca/bca-programs/ywbhp.cfm
Appendix II. Organization	Product	Description	URL
Breast Cancer Care (UK)	Breast health promotion talks, training courses on breast awareness and breast health	educational workshops;uk	http://www.breastcancercare.org.uk/content.php?page_id=3461
Breast Cancer Care (UK)	Breast changes during and after pregnancy; breast cancer risk: what it means to you (booklets); breast aware (poster)	downloadable booklets and posters ; high quality; women are the targeted end user	http://www.breastcancercare.org.uk
Breast Cancer Care (UK)	Breast health information resources	videos, CDs, posters, booklets for download or order	http://www.breastcancercare.org.uk/content.php?page_id=5253
Breast Cancer Care (UK)	Breast health information resources for younger women	posters, booklets on breast cancer issues for young women (including bc with pregnancy, fertility issues, and standards of care)	http://www.breastcancercare.org.uk/content.php?page_id=5256
Canadian Breast Cancer Initiative	Questions and answers on breast cancer: a guide for women and their physicians	Based on the Canadian clinical practice guidelines for care and treatment of breast cancer; published in CMAJ; Health Canada and CMA stamped; 47pp.	http://www.cancercare.mb.ca/resource/File/Hope/questionsandanswers.pdf
Canadian Breast Cancer Network	Grrr.... Femininity	Book and DVD about impact of breast cancer on relationships and sexuality; how to deal with	http://www.breastofcanada.ca/CBCNmessage.html
Canadian Breast Cancer Network	Empowerment DVD series: "the faces of breast cancer", including "not too young... stories of" and "aboriginal breast cancer journey"	DVD series (breast cancer)	http://www.breastofcanada.ca/CBCNmessage.html

Appendix II. Organization

	Product	Description	URL
Canadian Cancer Society (found on VIHA website)	breast cancer information kit	provided free to breast cancer patients in BC and Yukon. Includes a book, map, guide, nutritional guide, abrest in the west newsletter.	http://www.viha.ca/breast_health_services/breast_cancer_treatments/default.htm
Cancer Council Victoria (Australia)	Resources available to order (free within Victoria region)	Booklets, brochures, dvds, flyers etc. on various cancer issues. Booklets, brochures include breast issues. One 'breast aware' poster is for aboriginal women. Your breast health: a guide for young women (brochure and poster).	http://www.cancervic.org.au/resources/default.asp
CDC	Understanding Breast Health	Fact sheet for women (available online)	http://www.cdc.gov/cancer/breast/fact_breast_health.htm
CDC	Mammograms & breast health: an information guide for women	24 pp. booklet; available online	http://www.cdc.gov/CANCER/breast/pdf/cdc_mammogram_brochure.pdf
CURE Foundation	Self breast examination card; guide to breast health care (free booklet)	Can be ordered online from the foundation	http://www.curefoundation.com/curefoundation/cure_en/default.asp?disp=item_promo
DAWN (Disabled Women's Network Ontario)	Breast Self-Examination: A Handbook for Women with disabilities	online handbook; general overview	http://dawn.thot.net/BSE_Handbook.html
Fertile Hope	Breast cancer and fertility booklet (downloadable)	Organization produces materials for women and health care providers regarding reproduction after cancer treatment	http://www.fertilehope.org/learn-more/publications/print-materials.cfm

Appendix II. Organization

	Product	Description	URL
First Nation Breast Cancer Society (BC)	Instructional video: first nations breast self examination. Awareness video: echoes of the sisters: first nations women and breast cancer	Available for purchase; seems to be dated around 1999; described as a "do or die" approach	http://www.fnbreastcancer.bc.ca/awareness_video/awareness_video.htm
First Nation Breast Cancer Society (BC)	Breast self-examination guide (booklet)	content available online	http://www.fnbreastcancer.bc.ca/early_detection/early_detection.htm
Health Promotions Now	commercial breast cancer awareness products	includes a "health fair kit" for \$200, with a self-exam shower card, pocket calendar/health guide, etc.	http://www.healthpromotionsnow.com/SubCategory.aspx?id=269
Huntingdon Breast Cancer Action Coalition	Art & Facts breast health kits	"a beautiful craft, artfully presented compilation of up to date breast health information. Designed as a gift box, it provides vital knowledge and helpful insights."	http://hbcac.org/involvement.html
Lange Productions	Patient education videos: bse, mammography, BSE for young women, breast facts, guide to breast health	for purchase; each video is 7-9 minutes long	http://www.langeproductions.com/pem.html
McGrath Foundation	breast awareness card	"to give women the tools they need to conduct regular breast checks" - distributed at Foundation events	www.mcgrathfoundation.com.au

Appendix II. Organization	Product	Description	URL
McKinley Health Center, University of Illinois at Urbana-Champaign	Breast health handout (available online)	Student info sheet describing normal, benign diseased, and malignant diseased breasts, including Fibrocystic Breast Condition(FBC). Includes BSE instructions.	http://www.mckinley.uiuc.edu/handouts.breast_health/breast_health.html
Melbourne IVF and the Royal Woman's Hospital	Can I still have children? Fertility options for young women having chemotherapy and radiotherapy	booklet (downloadable)	http://www.mivf.com.au/downloads/FPSbooklet.pdf
National Cancer Institute (via Healthlink BC)	Patient information handout on breast cancer prevention	breast cancer prevention-patient information. Summary information; not gliitsy at all.	http://www.healthlinkbc.ca/kbase/nci/ncicdr0000257994.htm
NWT Breast Health/ Breast Cancer Action Group	Pamphlet: "You are worth it: Breast self-examination"	illustrated pamphlet	http://www.breasthealthnwt.ca/resources.html
NWT Breast Health/ Breast Cancer Action Group	Booklet: "Breast Health: caring for yourself"	plain language booklet explaining BSE	http://www.breasthealthnwt.ca/resources.html
NWT Breast Health/ Breast Cancer Action Group	Toolkit	Display, handouts, tactile displays, video; tabletop display explaining BSE, CBE and mammography	http://www.breasthealthnwt.ca/resources.html
NWT Breast Health/ Breast Cancer Action Group	Patient care kit	Set of booklets/ books addressing women's information needs following breast cancer diagnosis	http://www.breasthealthnwt.ca/resources.html

Appendix II. Organization

Organization	Product	Description	URL
NWT Breast Health/ Breast Cancer Action Group	In Your Hands video	2001 video demonstrating BSE, explaining importance of CBE and mammography; distributed to all NWT health centers/ mammography clinics	http://www.breasthealthnwt.ca/resources.html
NWT Breast Health/ Breast Cancer Action Group	"you are worth it" brochure	BSE reminder pamphlet for women who've been taught how to do BSE.	http://www.breasthealthnwt.ca/resources.html
NWT Breast Health/ Breast Cancer Action Group	Breast surgery booklet	Booklet for NWT breast cancer patients	http://www.breasthealthnwt.ca/resources.html
Prevent Cancer Foundation	Breast health education for young women	Video; facilitator's guide; designed for young women especially minorities in the US. Breast cancer; how to do a BSE	http://www.preventcancer.org/education2c.aspx?id=968&ekmsenl=15074e5e_34_40_968_5
Prevention is the Cure Huntingdon Breast Cancer Action Coalition)	Toxic triggers handout	Descriptions of environmental causes of cancer/disease, and alternatives to toxic products	http://preventionisthecure.org/ToxicTriggers1.pdf
Susan G. Komen for the Cure	Breast Health Basics Flyer	2-sided flyer; breast cancer facts; targets young women	http://www3.komen.org/promiseshop/ProductInfo.aspx?productid=806-302A
The royal women's hospital, Victoria, Australia	Fact sheets for women- breast health issues; available in a number of languages	content available online	http://www.thewomens.org.au/BreastChecks
Vancouver Island Health Authority Breast Health Centre	general patient information sheets on a variety of breast disorders	info sheets for patients	http://www.viha.ca/breast_health_services/common_concerns/

Appendix II. Organization	Product	Description	URL
Wyoming Institute for Disabilities	Women First: Breast Health for Women with Developmental Disabilities (guide).	Developed to help women with developmental disabilities learn basic breast health information	http://wind.uwyo.edu/breasthealth/handbook.htm
Wyoming Institute for Disabilities	Program development, training and support materials list	List of breast health education materials designed for women with disabilities. Includes guides, videos etc.	http://www.uwyo.edu/wind/breasthealth/bibliography.htm
Young Action on Breast Cancer- care package	YABC Care package	Care package for women under 40 receiving treatment for breast cancer at Western Health Hospital (Australia). Put together by young women; home help and pamper items.	http://www.theyoungones.asn.au/articles_of_interest
Young Survival Coalition	ResourceLink Guidebook; Brochures; DVDs; book; fact sheets for young women regarding breast cancer	Primarily supports young women who have breast cancer; US	http://www.youngsurvival.org/en/merchandise/programming/
Youth Information- Breast Cancer webpage (UK)	Breast Cancer Basics	online video	http://www.youthinformation.com/Templates/Internal.asp?NodeID=90473

APPENDIX III – ENVIRONMENTAL SCAN: SEARCH TERMS USED (GOOGLE)

- breast health
- breast health awareness aboriginal Australia
- breast health awareness Australia
- breast health campaign
- breast health educational materials programs Canada
- breast health campaign young women UK
- breast health campaign young women Europe
- breast health education young women
- breast health educational materials programs
- breast health targets young women
- breast health young women Europe
- breast health in the west
- bse
- the body beautiful
- you tube
- breast health education perceptions qualitative research young women
- breast health young women podcast
- breast health education health care provider
- breast festival
- Young Women’s Breast Health Program
- breast case
- oncologist breast specialist
- oncologist breast specialist Canada
- oncologist breast specialist women’s health collective
- a breast in the west
- bc women’s hospital
- BC Yukon Cancer Agency
- breast care young women
- breast health 20-40 year old women what they want and need
- breast health augmentations
- breast health body image
- breast health educational materials programs Canada
- breast health nipple piercing
- breast health podcast
- breast health standards education young women Denmark
- breast health standards education young women Sweden
- breast health young women
- breast health young women campaign
- breast health young women podcast
- breast health young women Europe
- Canadian association of oncologists

- Canadian breast cancer network
- Canadian breast oncologist
- Canadian women's health network
- Excellence women's health program
- EPA Division of California Family Health Council breast health young women
- inspire health
- National mammography group Canada
- oncologist breast specialist
- oncologist breast specialist women's health collective
- oncologist breast specialist Canada
- rural and remote women's health
- san diego state university
- the body beautiful
- the breast health program bc women's hospital and health center
- the young and the breastless
- thecorefoundation.org
- victoria breast health centre
- women health organization
- women health organization Canada
- women's health organizations
- wilo breast cancer support Canada
- Young Women's Breast Health Program
- you tube
- Young Women's Breast Health Program Scripps Polster Breast Care Center
- "Health promotion" government "breast health"
- "breast health promotion"
- "health promotion" canada breast
- "health promotion" breast education
- "nipple piercing" health information
- "breast reduction" health information
- "breast augmentation" health information
- "native american" breast health

APPENDIX IV – KEY INFORMANTS

Name	Organization	Position	City	Province/ State	Country
Linda Tkachuk	Comprehensive Breast Care Program	Nurse Navigator	Edmonton	Alberta	Canada
Shelley Cloutier	Comprehensive Breast Care Program	Nurse Navigator	Edmonton	Alberta	Canada
Monika Herwig	pinkandgreenribbon.com	Doctor, Naturopath	Canmore	Alberta	Canada
Deborah Rusch	BC Cancer Agency	Director, Breast Tumour Group Secretariat	Vancouver	BC	Canada
Avril Douglas	BC Women's Hospital and Health Centre Foundation	Clinical Nurse	Vancouver	BC	Canada
Julie McMillan	Canadian Breast Cancer Foundation BC/Yukon Region	Director, Health Promotion	Vancouver	BC	Canada
Shawna Bond	Victoria General Hospital – Breast Health Center	Registered Nurse	Victoria	BC	Canada
Wendy Cyr	The Breast Health Program, Women's Health	Nurse Case Manager	Saint John	New Brunswick	Canada
Debbie Polakaoff	NWT Breast Health/ Cancer Action Group	Group Coordinator	Yellowknife	NWT	Canada
Nancy Cymbalisky	NWT Breast Health/ Cancer Action Group	Patient Navigator / Board Director	Yellowknife	NWT	Canada
Jackie Manthorne	Canadian Breast Cancer Network	Executive Director	Ottawa	Ontario	Canada

Name	Organization	Position	City	Province/ State	Country
St Dharam Kaur	Healthy Breast Program	Doctor, Naturopath	Owen Sound	Ontario	Canada
Liz Cole	Willow Breast Cancer Support Canada	Director, Support Services	Toronto	Ontario	Canada
Carol Sectar	Breast Cancer Action Montreal	Board Member	Montreal	Quebec	Canada
Joanne Braun	The CURE Foundation	Director / Event Coordinator	Ville Mont-Royal	Quebec	Canada
Ngozi Ikeggi	Aurora Clinic at Whitehorse General Hospital	Physician	Whitehorse	Yukon	Canada
Sue Lightford	YG, H&SS Community Nursing	Manager	Whitehorse	Yukon	Canada
Colleen Hemsley	YG, H&SS Community Nursing	Quality Improvement & Training Coordinator	Whitehorse	Yukon	Canada
Brenda Dedon	YG, H&SS Whitehorse Health Centre	Community Health Nurse / Lactation Consultant	Whitehorse	Yukon	Canada
Dixie Mills	Dr Susan Love Research Foundation	Medical Director	Santa Monica	California	USA
Christine Horner	Christine Horner MD	Doctor	Arroyo Seco	New Mexico	USA
Jean Sachs	Living Beyond Breast Cancer	Chief Executive Officer	Haverford	Pennsylvania	USA
Susan Brown	Susan G. Komen for the Cure	Director, Health Education	Dallas	Texas	USA

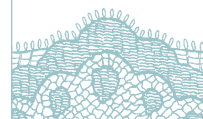
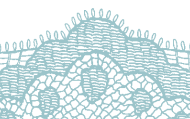
APPENDIX V – RECOMMENDED BREAST HEALTH EDUCATION MATERIALS, STRENGTHS AND SHORTCOMINGS IDENTIFIED BY OUR KEY INFORMANTS

Name	Type	Strengths	Shortcomings
The complete natural medicine guide to breast cancer: a practical manual for understanding, prevention and care by Sat Dharam Kaur	Book	(1) Comprehensive; well referenced. (2) Comprehensive breast health bible; well laid out; can read it in pieces or cover-to-cover.	(1) none known. (2) People are overwhelmed by the volume of material in it; it is not a beginner book; it meets the needs of educated people but not a younger or less literate audience.
Dr. Susan Love's Breast Book	Book	A down-to-earth guide in basic language; clear, using lay terms.	It doesn't have a strong focus on diet and exercise.
Intimacy After Cancer: A Woman's Guide by Sally Kydd and Dana Rowett	Book	Very practical book; written after 10 focus groups	none known
Taking Care of your Girls by Marisa Weiss	Book	Lots of illustrations, explaining how your breasts grow, what a normal breast looks like. Easy to understand, plain language.	American (may not be fully relevant to our local context); targets girls and teens
Total Breast Health by Robin Keuneke	Book	Offers positive ideas, not fear. Focus on food.	none stated
Waking the Warrior Goddess by Christine Horner	Book	Empowerment-based, not fear-based; all researched and documented. Addresses risk factors for cancer that tend to get overlooked, such as food and lifestyle choices.	none stated

Name	Type	Strengths	Shortcomings
Breast health curriculum developed by BC Cancer Society	Public education materials	Includes a DVD called E3 (eat right, exercise, and examine). Messaging is around the idea of getting to know your body; not specific to breast cancer. It includes the voices of young people and their ideas about what health is.	Geared towards high schools. Needs a sponsor to cover publication costs.
TLC campaign (touch, look, check) from Rethink Breast Cancer	Public education materials	Geared towards young adults; TLC is a catchy approach to BSE. While the eat right, exercise messages are widespread, the message of knowing your body is not adequately addressed; this type of product fills the gap.	Not well distributed in this region (BC/ Yukon).
NWT Breast Health/ Cancer Action Group pamphlets	Public education materials	Informative, available in different languages, easy to understand, accessible. Fills a gap for locally relevant materials.	none known
Hook Up to Cancer Prevention poster	Public education materials	targets younger women	Anything produced by the breast cancer community faces the problem of limited money and resources for production and distribution.
Breast Cancer Action Montreal pamphlets	Public education materials	Clear, accessible, practical	none known
Cancer Smart 3.0 Consumer Guide by Labour Environment Alliance Society	Public education materials	Clear, accessible, practical	none known

Name	Type	Strengths	Shortcomings
Thing-a-ma-boob	Public education materials	Visual concept of what could be happening in your breast; locally available	Could be slightly alarming
Honoring our Breasts CD; music and voice instruction on how to do a BSE; by Dixie Mills	Public education materials	Offers positive ideas, not fear.	It's not clear now whether BSE should be recommended. There is no need to do BSE monthly, but women need to have a baseline for what is normal for them.
Willow reference list (www.willow.org/pdfs/YoungWomen.pdf)	Reference list	The organization has an on-staff librarian; the list is highly selective.	From the vantage point of the patient, there is no perfect answer in any written document.
Promise shop	Website	Accurate information directed to younger women; focus tested for this age range	none known
Rethink Breast Cancer	Website	none stated	none stated
Susan Komen	Website	none stated	none stated
Be Pink (www.bepink.com)	Website	Related to breast cancer; targets high school students, but would benefit young women as well	Websites are only useful if people are aware of them
Breast Self Exam (www.breastselfexam.ca)	Website	Teaching tool related to breast cancer detection	Websites are only useful if people are aware of them
Young Adults Cancer (youngadultscancer.ca)	Website	none stated	none stated
Young Women's Health (yongwomenshealth.org)	Website	none stated	none stated

Name	Type	Strengths	Shortcomings
Intimacy workshops for young women with breast cancer (Canadian Breast Cancer Network)	Workshop	targets younger women	Anything produced by the breast cancer community faces the problem of limited money and resources for production and distribution.





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