

A Review and Comparative Analysis of Information Targeted to the General Public on the Websites of Breast Screening Programs in Canada

Revue et analyse comparative de l'information à l'intention du grand public sur les sites Web des programmes de dépistage du cancer du sein au Canada



ANNE J. KEARNEY, PHD, MHSC, BN, RN
*Associate Professor, School of Nursing
Memorial University of Newfoundland
St. John's, NL*

JULIE POLISENA, MSC, PHD
*Manager, Clinical Research
Canadian Agency for Drugs & Technologies in Health
Ottawa, ON*

ANDRA MORRISON, BSC, AHIP
*Program Development Officer
Canadian Agency for Drugs & Technologies in Health
Ottawa, ON*

Abstract

Organized breast screening programs in Canada recommend that women, usually 50–74 years of age, are screened regularly with mammography to reduce their risk of breast cancer death. There is increasing evidence that estimates of mortality reduction are overestimated and harms under-reported. This article will report on a review of the websites of 12 breast screening programs in Canada. The primary goal is to determine what information is provided to enable women to make an informed decision about mammography and whether

choice is emphasized. All publicly available English language information was extracted from the 12 websites by two independent reviewers, using a data extraction sheet. Information extracted included eligible age, screening interval and potential benefits and harms. This review is relevant to policy makers and breast screening program staff so they can determine what additional or alternative information is required on their websites to enable women to make informed decisions.

Résumé

Les programmes de dépistage du cancer du sein au Canada recommandent que les femmes, habituellement de 50 à 74 ans, procèdent régulièrement à une mammographie pour réduire les risques de mortalité liés au cancer du sein. De plus en plus de données font voir une surévaluation des estimations de réduction de la mortalité ainsi qu'une sous-déclaration des effets non désirés. Cet article fait état d'une revue des sites Web de 12 programmes de dépistage du cancer du sein au Canada. L'objectif principal est, d'une part, de déterminer quelle information est fournie aux femmes afin de leur permettre de prendre une décision éclairée au sujet de la mammographie et, d'autre part, de voir si on met l'accent sur la possibilité de faire un choix. Toutes les informations en anglais disponibles au public ont été extraites des 12 sites Web par deux examinateurs indépendants, au moyen d'une feuille d'extraction des données. L'information extraite comprenait l'âge d'admissibilité, l'intervalle entre les dépistages ainsi que les avantages et effets non désirés potentiels. Cette revue est pertinente pour les responsables de politiques et pour le personnel des programmes de dépistage du cancer du sein, afin qu'ils puissent déterminer quelle information supplémentaire ou complémentaire est nécessaire sur les sites Web pour permettre aux femmes de prendre des décisions éclairées.

BREAST CANCER REMAINS A SIGNIFICANT HEALTH RISK FOR WOMEN. IN 2016, THE Canadian Cancer Society estimated that breast cancer will remain the most commonly diagnosed new cancer among women, accounting for 25.8% of all new diagnoses or 25,700 estimated new cases. Breast cancer is the second leading cause of death by cancer among women, at 13.2% (CCSACCS 2016).

Mammography screening is the only early detection method currently recommended to reduce breast cancer morbidity and mortality. The Canadian Task Force on Preventive Health Care (2017) recommends that women aged 50–74 years have mammography screening every two to three years. However, it is a weak recommendation based on the GRADE approach, meaning that clinicians should assist women to make an informed decision about whether or not to have screening, which may be supported by decision aids. It does not recommend that women aged 40–49 be routinely screened with mammography (weak recommendation). These recommendations are currently under reconsideration.

The US Preventive Services Task Force (USPSTF 2017) recommends that women aged 50–74 years have mammography screening every two years. It states that it is an individual decision for women younger than 50 years based on their assessment of benefits and risks. For women of all ages, neither organization recommends clinical breast examination or breast self-examination.

Breast screening programs were first established in Canada in 1988 based on the reports of randomized trials that mammography screening reduces breast cancer mortality up to 35% (Shapiro et al. 1971; Tabar et al. 1985). Recent reports from a Cochrane Collaboration systematic review (Gøtzsche and Jørgensen 2013) and the Canadian National Breast Screening Study (Miller et al. 2014) found no reliable evidence of benefit but did find evidence of harm. The authors of these reports have contributed to the academic debate regarding the future of population-based mammography screening as they recommended that countries offering organized mammography screening reconsider this policy. Changing policy regarding population-based mammography screening – including discontinuation – is a difficult and controversial action for governments to take given decades of targeted promotion to maximize recruitment. Until there is clearer evidence regarding the effectiveness of mammography screening, it is imperative that women receive balanced information regarding potential benefits and harms so they can make an informed decision about participating (Gøtzsche et al. 2009; Gøtzsche and Jørgensen 2011; Gummertsbach et al. 2010; Jørgensen et al. 2009).

Evidence Regarding Harms and Benefits

The evidence suggests several harms associated with population-based mammography screening: diagnostic workup for false positive findings; overdiagnosis; unnecessary treatment; radiation-induced breast cancer and death; and psychological distress. Up to 60% of women will have a false positive finding after 10 mammography screens (Hubbard et al. 2011), which can lead to serious psychological distress – including the belief they are at increased risk for breast cancer – sometimes persisting for three years (Brodersen and Siersma 2013). Overdiagnosis refers to the diagnosis of breast cancers through screening that would not have become clinically detectable or caused harm to the woman in her lifetime, including ductal carcinoma in situ (DCIS). Revised estimates of overdiagnosis from the Canadian breast screening trial are estimated to be 55% and 16% for women 40–49 and 50–59, respectively, 20 years after screening cessation – including both invasive tumours and DCIS (Baines et al. 2016). Overdiagnosed women receive unnecessary cancer treatment including lumpectomy, mastectomy, radiation and hormonal therapy and may believe they are living with a potentially lethal disease. A recent modelling study commissioned by the USPSTF estimated that biannual digital mammography screening – and subsequent diagnostic mammography – of 100,000 average-risk women aged 50–74 years would cause 27 breast cancers and four deaths (Miglioretti et al. 2016). A further harm is the number of false negative results – or missed cancers. The National

Cancer Institute (2017) estimates that up to 46% of women with an invasive breast cancer will have a negative mammogram, giving these women a false sense of security and a delayed diagnosis.

In addition to a lack of evidence of breast cancer mortality reduction or all-cause mortality reduction, there is limited evidence on the effectiveness of population-based mammography screening in reducing the incidence of advanced breast cancer (Autier et al. 2011) or decreasing the rates of mastectomy (Douek and Baum 2003). It is believed that reduced breast cancer mortality observed in many countries is mainly due to improved treatment and awareness of women and not mammography screening (Gøtzsche and Jørgensen 2013).

There are 12 breast screening programs across Canada that offer mammography screening to women 40–75 years of age. It is estimated that 55% of average-risk eligible women in Canada, aged 50–69, have had a screening mammogram (CIHI 2017).

The purpose of this review and comparative analysis is to determine what information is available on the websites of breast screening programs in Canada to enable women to make informed decisions about whether to participate in mammography screening and if choice is emphasized.

Methods

Approach

A review of the website content of provincial and territorial breast screening programs across Canada was performed to document the information directed to the general public. Written English language information presented on all web pages, brochures, fact sheets, letters and direct links to external sources for evidence were eligible for review. Only information pertaining to women at average risk for breast cancer was reviewed. Ethical approval was not required for this document review as no patient information was involved.

Selection criteria

The selection criteria included all provincial and territorial websites in Canada that provided information on their breast screening programs by jurisdiction. Websites that presented on cancer screening in general (e.g., Canadian Cancer Society or Cancerview) were not eligible for inclusion. Information not included in the review was that targeted to women at higher risk for breast cancer, risk factors for breast cancer, lifestyle advice to reduce risk, program performance reports, information directed to healthcare professionals and the Public Health Agency of Canada (PHAC) decision aid for breast cancer screening by mammography (PHAC 2009), which is referenced as a link on some websites.

Data extraction

A data extraction form was designed to document all relevant information from the websites. Two reviewers (J.P. and A.M.) independently conducted the data abstraction for all eligible websites using a pre-specified extraction form. Relevant information extracted were eligibility

age without referral, screening interval and potential benefits (including breast cancer mortality and all-cause mortality relative risk reduction, less aggressive treatment options) and harms (including false positive and false negative rates, overdiagnosis, unnecessary treatment, radiation risk and psychological distress). It was also noted if a link was provided to the PHAC's decision aid on breast screening (PHAC 2009). Any discrepancies were resolved through discussion until consensus was reached. A third reviewer (A.K.) also reviewed the results in the data extraction table and provided feedback, when necessary.

Descriptive analysis

The content on the websites for the breast screening programs were summarized narratively. Subsequently, the results were interpreted and compared to identify the underlying patterns from the information available on the jurisdictional websites.

Results

The information summarized below is based on the web content identified in all jurisdictions across Canada, except for Nunavut (where there is no program). Box 1 provides the web address for each breast screening program at the time of the review. Details related to the information provided on the websites by province and territory are outlined in Appendix 1 (available at: www.longwoods.com/content/25322).

BOX 1. Links to the websites of 12 breast screening programs in Canada

- **Alberta** – <http://screeningforlife.ca/breast-cancer-at-a-glance/>
- **British Columbia** – <http://www.bccancer.bc.ca/screening/breast>
- **Manitoba** – <http://www.getcheckedmanitoba.ca/breastcheck.html>
- **Newfoundland and Labrador** – <http://www.easternhealth.ca/WebInWeb.aspx?d=3&id=1091&p=1078>
- **New Brunswick** – <http://www2.gnb.ca/content/gnb/en/departments/health/NewBrunswickCancerNetwork/content/NewBrunswickBreastCancerScreeningProgram.html>
- **Northwest Territories** – <http://breasthealthnwt.ca/>
- **Nova Scotia** – <https://breastscreening.nshealth.ca/>
- **Ontario** – <https://www.cancercare.on.ca/pcs/screening/breastscreening/OBSP>
- **Prince Edward Island** – <http://www.healthpei.ca/breastscreening>
- **Quebec** – <http://sante.gouv.qc.ca/en/programmes-et-mesures-daide/programme-quebecois-de-depistage-du-cancer-du-sein-pqdc/s/>
- **Saskatchewan** – <http://www.saskcancer.ca/Default.aspx?DN=3f3b564f-a7d1-4bee-bb80-0ec8f2b6b5d4>
- **Yukon** – <https://yukonhospitals.ca/whitehorse-general-hospital/mammographie>

Age of eligibility without referral

The most common eligibility age for mammography screening without a referral is 50–74 years (NWT, AB, ON, NB and NL), while two provinces stop screening at age 69 (SK, QC). Manitoba begins screening at age 50 but does not state the upper age limit. Several jurisdictions begin screening at age 40 (YK, BC, PEI and NS); among these programs, neither Yukon nor Nova Scotia specify the upper age limit.

Screening interval

Most jurisdictions ($n = 8$) recommend a two-year screening interval for mammography (BC, AB, SK, MB, ON, QC, NB and NS) while two recommend every two to three years (YK and

NWT) and one recommends every one to two years (NL). Some jurisdictions recommend annual screening for women 40–49 years of age (YK and NS). Three jurisdictions do not specify a screening interval for women aged 70 and older (NS) or 75 and older (YK and MB).

Relative risk reduction

Most websites state that screening mammography results in reduced breast cancer mortality. The estimates vary including 15%–25% (BC), 20%–30% (MB) and 25%–35% (NWT). The Quebec website cites seven deaths are prevented among 1,000 women who have a mammogram every two years for 20 years and that the goal of their screening program is to reduce breast cancer mortality by 25%. Six websites make a general statement that screening mammography can reduce the risk of death (ON, NB and NL), improve the chance of a cure (NS) or long-term survival (NWT and PEI). Ontario further states that a 42% breast cancer mortality reduction among women 50–74 years of age between 1990 and 2012 is likely due to a combination of mammography screening and improved treatment. No website specifically cites all-cause mortality reduction with mammography screening.

Claims less aggressive treatment

Nine jurisdictions state that screening mammography can result in earlier detection (YK, NWT, BC, AB, ON, QC, NB, PEI and NS) and eight jurisdictions state it can result in less invasive treatment (NWT and MB) including the possibility of no chemotherapy (QC), more effective treatment (YK and AB) and more treatment options (NWT, BC and ON).

False positive rate/recall rate

Cited rates of recall varied including 5% (MB), 7% (AB), 5%–10% (NL) and 10% (NWT and QC). The British Columbia website cites two different recall rates: 7% and 10%. The Yukon site states that digital mammography reduces the rate of “call-back” appointments. Different rates of breast cancer diagnosis are reported among women recalled including 10% (AB and SK) and 5% (NWT and QC). Two provinces give two different cancer diagnosis rates among women recalled: 5% and 10% (BC) and 10% and 20% (MB). Both Ontario and Newfoundland and Labrador websites state that “most” recalled women have a normal result on diagnostic workup. The Quebec site states that almost half of women screened for 20 years will have at least one additional examination.

False negative rate

Eight jurisdictions (NWT, BC, AB, SK, MB, ON, QC and NL) discussed the risk of a false negative result associated with screening mammography. Rates varied from 5% to 10% (NL), 10% (AB), 10% for women aged 50 and older (BC), 10%–20% (NWT), 20% (MB), 25% for women in their 40s (BC) and 27% among 1,000 women screened for 20 years (QC). Two websites generally state that a small number of breast cancers are not seen on mammography (SK) or that screening may miss some breast cancers (ON).

Additionally, the Ontario website states that interval cancers can occur between screens and the Quebec site states breast cancer can occur after a mammogram (i.e., as a missed or interval cancer).

Overdiagnosis

Overdiagnosis is described in various ways by seven websites. Quebec gave the best estimate of occurrence in their program at 13%. Four websites state that breast cancers may be found that may never have become symptomatic, caused harm or affected health (BC, AB, ON and QC). Three websites state that a woman may never have been diagnosed without screening (AB, MB and QC) or that screening could detect a very slow growing or benign tumour (AB and QC). The Manitoba website simply states that overdiagnosis can occur. In addition, the Nova Scotia website states that organized breast screening programs can minimize the unwanted effects of screening but these effects are not described. Five websites state that overtreatment or unnecessary treatment can occur (NWT, AB, MB, ON and QC). The Quebec website is the only one that provides additional information including the potential for frequent medical appointments and the side effects of unnecessary treatment. Also, two websites advise women that their quality of life or lifespan may not increase with mammography screening (AB and MB), two state that breast cancer may not be curable (MB and ON) and two that some women will still die of breast cancer (MB and QC). Quebec states that 17% of 1,000 women screened every two years for 20 years will die of breast cancer even though it was detected by screening. There is no mention of overdiagnosis on five websites (YK, SK, NB, PEI and NL).

Radiation risk

Seven jurisdictions state that women are exposed to a low dose (YK, NWT, SK and ON) or very low dose of radiation from mammography screening (BC, MB and NL). Two more websites state the benefits of mammography screening outweigh the risks associated with radiation (BC and ON). The British Columbia website states it has never been proven that radiation exposure from a mammogram has caused even one case of breast cancer.

Psychological distress

Seven websites discuss anxiety, worry and stress associated with screening – one in relation to waiting for results of the screen (MB), five in relation to being recalled for further tests (NWT, BC, AB, MB and QC) and one in relation to the experience of being overdiagnosed (QC). The Alberta website states that worry can last long after test results are known.

Directed to PHAC decision aid

Five jurisdictions include a link to the PHAC decision aid for breast cancer screening by mammography (PHAC 2009; YK, SK, MB, PEI and NS). Alternatively, the British Columbia website provides a link to the BC Cancer Agency breast screening decision aid (BC Cancer Agency n.d.).

Choice emphasized

Three websites explicitly make a general statement that it is a woman's choice to have mammography screening (NWT, SK and QC); in addition, the Yukon website states it is a choice for women 40–49 years of age. The Quebec website advises women to learn about the advantages, disadvantages and limitations to make an informed choice. Three websites give mixed messages regarding choice. The British Columbia website states that the benefits clearly outweigh the limitations for women 50–69 years of age (but advise women in their 40s to talk to their healthcare provider). The Ontario website states that women should talk to a healthcare provider regarding benefits and harms, and can opt out of the program at any time, while also stating that getting a mammogram is the best way to protect health. The Newfoundland and Labrador website states that women should be informed about benefits and harms and if deciding to participate in screening – to have regular screening mammograms. The choice of eligible women to take part in a provincial or territorial screening program was not explicitly mentioned on five websites (AB, MB, NB, PEI and NS).

Discussion

Breast screening programs in Canada have a legal and ethical duty to inform women of all potential benefits and harms of mammography screening so they can make an informed decision. This is particularly critical for organized programs which recommend mammography screening for all women in their targeted age group. All breast screening program material targeted to women should contain balanced information regarding potential benefits and harms in plain language that can be easily understood. In addition, all program material should emphasize a woman's right to choose whether to be screened and that the choice to not be screened by mammography is a reasonable one.

The purpose of this review was to determine what information is provided on the websites of 12 breast screening programs in Canada to enable women to make an informed decision about mammography screening and whether choice is emphasized. An informed decision regarding mammography screening is enabled if information regarding the potential benefits and harms is accessible to the public. For this to be the case, a breast screening program website would have to provide up-to-date information regarding potential benefits (e.g., reduced mortality, less aggressive treatment) and potential harms (e.g., false positives, false negatives, overdiagnosis and unnecessary treatment, radiation risks and psychological distress). This review of the websites of 12 breast screening programs in Canada determined that none provide comprehensive balanced information to support women to make an informed decision.

This review found that the information available and level of detail provided to the public varied by jurisdiction. As discussed in the results, the websites of six programs did not give specific information regarding breast cancer mortality reduction, and estimates varied among the jurisdictions that did. None of the websites reported on all-cause mortality reduction which the Cochrane Collaboration stated was a better predictor of benefit than breast

cancer mortality reduction. Further, the websites of six programs did not specifically cite their rates of false positives and false negatives. Women should be informed about the most serious risk of mammography screening – overdiagnosis and accompanying unnecessary treatment. Quebec’s website gave an explicit estimate of the risk of overdiagnosis although the websites of Alberta and Manitoba (in addition to Quebec) provided good descriptions of what overdiagnosis is and that it occurs. Radiation associated with mammography screening was generally described as low or very low, when it was described at all. The information on the radiation risks associated with mammography screening, therefore, was limited. The British Columbia website even stated there has never been a confirmed case of breast cancer caused by the radiation exposure of mammography. One website cited the psychological distress associated with screening itself; most described anxiety as normal if a screening result was positive. The Alberta website cited that “worry” may last long after the test results are known, and none of the websites discussed the significant stress associated with overdiagnosis and unnecessary treatment. Six websites directed women to a decision aid but the link to that of the PHAC was broken on several websites during the review phase of our study, and it appears to be archived on the PHAC website. Three websites explicitly stated that it is a woman’s choice to be screened by mammography.

The decision aids to which women are referred on six program websites do not provide balanced information to contribute to their informed consent regarding mammography screening. Information in the PHAC decision aid (PHAC 2009) needs to be updated to reflect increasing evidence that the benefit of mammography screening is lower than once thought and specific information needs to be provided regarding the risks of overdiagnosis and unnecessary treatment, and these factors should be explicitly discussed in the decision aid score card. The decision aid on the British Columbia website (BC Cancer Agency n.d.) collects information from women regarding their age, family history and screening history and provides a personalized estimate that a screening mammogram will find a breast cancer, cause a false positive result and lead to a biopsy for a false positive result. However, it states that mammography reduces breast cancer mortality by 25%, and there is no information regarding overdiagnosis.

The findings of this review are consistent with other reviews of breast screening promotional materials that have been described as emphasizing benefits and minimizing harms (Gøtzsche et al. 2009; Gøtzsche and Jørgensen 2011; Gummertsbach et al. 2010; Jørgensen and Gøtzsche 2006) and being very biased in favour of participation (Jørgensen et al. 2009). The goal of all informational materials should be focused on enabling informed consent, not increasing participation rates. Accessible and balanced information on all breast screening promotional materials will support women’s ethical and legal right to informed consent.

A limitation of this study is that the websites of breast screening programs in Canada are updated regularly, so it is not possible to confirm the results of this particular review. This risk was mitigated by having three reviewers involved in this review, and they agreed on the findings. The findings reported here are from a review conducted April 12–19, 2017.

A future direction for research is a review of invitations, recall letters and consent forms to determine what information is provided to women to enable informed consent. Moreover, it would be very useful to assess the understanding of women who engage in mammography screening regarding the potential benefits and harms.

In summary, breast screening programs have a legal and ethical responsibility to provide accessible information to eligible women regarding the potential benefits and harms of mammography screening in all program and promotional materials, including on their websites and in their consent forms. Women should be informed – in plain language – of the increasing evidence that organized breast screening is less effective than once thought. Screening personnel administering the consent forms should confirm women’s comprehension of the information presented before securing consent. It is critical that women are able to make an informed decision about participating in mammography screening.

Correspondence may be directed to: Anne J. Kearney, Associate Professor, School of Nursing, Memorial University of Newfoundland, St. John’s, NL A1B 3V6; e-mail: akearney@mun.ca.

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