

Information Publicly Available on the Websites of Organized Breast Screening Programs in Canada: A Review and Comparative Analysis

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Breast Cancer in Canada

Most commonly diagnosed new cancer among women

- 25.8% of all new cancer cases
- 25,700 estimated new cases

Second leading cause of death by cancer among women

- 13.2%

Current Screening Recommendations

Mammography (mammo) is the only early detection method currently recommended by CTFPHC and USPSTF

CTFPHC

- Women 50-74 every 2-3 years
- Does not recommend 40-49
- Does not recommend clinical breast examination or breast self examination
- Recommendations currently under review

USPSTF

- Women 50-74 every 2 years
- Individual decision for women < 50 based on their assessment of benefits and risks
- Does not recommend clinical breast examination or breast self examination

Breast Screening Evidence

Reports from randomized trials that mammo could reduce breast cancer mortality by up to 35%

- Led to the establishment of breast screening programs in Canada, starting in 1988

Recent evidence from Cochrane Cochrane and Canadian National Breast Screening Study

- No reliable evidence of mortality reduction with population-based mammo screening
- Evidence of harm
- Recommended that countries offering population-based mammo screening reconsider this policy

Evidence

Benefits

- Reduced breast cancer mortality
- Less aggressive treatment

Harms

- False positive findings: 60% after 10 screens
- Overdiagnosis: Up to 55% including invasive and DCIS
- Overtreatment for overdiagnosis: Including surgery, chemotherapy, radiotherapy, hormonal therapy
- Radiation-induced breast cancer and death: modeling study estimated 27 and 4/100,000 women 50-74 screened biennially
- Psychological distress – can be significant; can last for 3 years
- False negatives – up to 46% of women with breast cancer

Additional findings in the literature

Population-based mammo screening

- Does not reduce the incidence of advanced breast cancer
- Does not result in less mastectomy

It is now believed that reduced breast cancer mortality seen in many countries is because of improved treatment and awareness of women and not mammo screening

Breast Screening in Canada

There are now 12 breast screening programs in Canada

- All provinces and territories except Nunavut
- Usually 50-74
- Usually every 2-3 years

CIHI estimates 55% of eligible Canadian women have had a screening mammo

Breast screening programs have a legal and ethical obligation to inform women about the potential harms and benefits of mammo screening

- Balanced information
- Plain language
- To enable informed consent

Purpose of this study

To determine what information is available on the websites of breast screening programs in Canada to enable women to make informed decisions about participating in mammography screening and if choice is emphasized

Method

All provincial and territorial websites in Canada were reviewed

Looked at English-language info regarding women at average risk directed to the general public including

- Web pages, brochures, fact sheets, letters, and direct links to external sources for evidence

Two independent reviewers (JP and AM) using a data extraction form

Third reviewer reviewed their findings (AK)

Consensus was reached on all findings

info not included in the review

- Directed to women at higher risk
- Directed to health professionals
- Risk factors for breast cancer
- Lifestyle advice to reduce breast cancer risk
- Program performance reports

Results – Information re Benefits

Breast Cancer Relative Risk Reduction

- Most websites state reduced breast cancer mortality but estimates varied
 - 15-25% (BC)
 - 20-30% (MB)
 - 25-35% (NWT)
- QC states 7 deaths prevented among 1000 women screened 20 years and their goal is to reduce breast cancer mortality by 25%
- ON states that a 42% breast cancer mortality reduction among women 50-74 between 1990 and 2012 is likely due to mammo screening and improved treatment
- 6 websites generally state that:
 - Screening mammo can reduce risk of death (ON, NB, NL)
 - Improve the chance of a cure (NS)
 - Improve long-term survival (NWT, PEI)

No websites cite all-cause mortality reduction

Results – Information re Benefits

Less aggressive treatment

- 9 websites state that screening mammo can result in earlier detection (YK, NWT, BC, AB, ON, QC, NB, PEI, NS)
- 8 that it can result in:
 - Less invasive treatment (NWT, MB)
 - More effective treatment (YK, AB)
 - More treatment options (NWT, BC, ON)
 - Or that chemotherapy may not be needed (QC)

Results – Information re Harms

False Positive Rate / Recall Rate

- 5% (MB)
- 5-10% (NL)
- 10% (NWT, QC)

- BC gives two different estimates: 7% and 10%,
- QC states that almost half of women screened for 20 years will have at least one additional examination
- NWT states that digital mammo reduces 'call-back appointments'

- Cancer detection rate among women recalled
 - 5% (NWT; QC)
 - 10% (AB, SK)
 - Two different rates given in BC (5% and 10%) and MB (10% and 20%)
 - Both ON and NL state that 'most' women will have a normal result after diagnostic workup

Results – Information re Harms

False Negative Rate

- 8 websites mention the possibility of false negatives (NWT, BC, AB, SK, MB, ON, QC, NL)
 - 5-10% (NL)
 - 10% (AB) and for women 50+ (BC)
 - 10-20% (NWT)
 - 20% (MB)
 - 25% from women in their 40s (BC)
 - 27% among 1000 women screened for 20 years (QC); they also state that breast cancer can occur after a mammogram
- SK states that a small number of cancers are not seen on mammo
- ON states that screening may miss some cancers and that interval cancers occur

Results – Information re Harms

Overdiagnosis

- QC gave best estimate at 13%;
- 4 websites state breast cancers may be found that would never have become symptomatic, caused harm, or affected health (BC, AB, ON, QC)
- 3 state that a women may never have been diagnosed without screening (AB, MB, QC) or that screening could detect a very slow growing or benign tumour (AB, QC)
- MB states simply that overdiagnosis can occur
- 5 have no mention of overdiagnosis (YK, SK, NB, PEI, NL)

Unnecessary treatment

- 5 websites state that overtreatment or unnecessary treatment may occur (NWT, AB, MB, ON, QC)
- QC states that there is a potential for frequent appointments and side effects of treatment
- 2 state that quality of life or lifespan man not increase (AB, MB)
- 2 state that breast cancer may not be curable (MB, ON)
- 2 state that some women will still die of breast cancer (MB, QC)
- QC states that 17% of 1000 women screened every 2 years for 20 years will die of breast cancer even though it was found by mammo screening

Results – Information re Harms

Radiation risks

- 4 websites state that women are exposed to a low dose (YK, NWT, SK, ON)
- 3 to a very low dose (BC, MB, NL)
- 2 websites claim the benefits of mammo screening outweigh the risks associated with radiation (BC, ON)
- BC states it has never been proven that radiation exposure during a mammo caused even 1 breast cancer

Results – Information re Harms

Psychological Distress

- 5 websites state that anxiety, worry or stress can occur with screening
 - 1 while waiting for the results
 - 5 for being recalled for further tests (NWT, BC, AB, MB, QC)
 - 1 because of overdiagnosis (QC)
 - Only AB states that worry can last long after the test results are known

Results

Directed to a decision aid for mammo screening

- 5 websites included a link to the PHAC decision aid (YK, SK, MB, PEI, NS)
- BC directed women to the BC Cancer Agency decision aid

Choice emphasized

- 3 websites explicitly stated that it is a woman's choice to be screened (NWT, SK, QC)
- YK stated it was a choice for women 40-49
- QC advises women to learn about advantages, disadvantages and limitations to make an informed choice
- 3 websites give a mixed message (BC, ON, NL)
- Choice was not explicitly mentioned on five websites (AB, MB, NB, PEI, NS).

Discussion

Breast screening programs have a legal and ethical duty to inform women of all potential benefits and harms of mammo screening

- Particularly critical for organized programs that recommend that all women of their eligible age be screening regularly

Balanced info should be provided to women, in plain language

All program materials should emphasize the right to choose and that the choice to not have screening is a reasonable one

Discussion

In order for women to make an informed decision about mammo screening, info re potential harms and benefits must be provided

NONE of the websites of the 12 breast screening programs in Canada
provided comprehensive balanced info

Discussion

The PHAC and BC Cancer Agency Decision AIDS do not provide balanced information to enable informed consent

PHAC decision aid

- Needs to be updated to reflect increasing evidence that the benefits of mammo screening are much lower than once thought
- Does not include risk of overdiagnosis and unnecessary treatment

BC Cancer Agency decision aid

- States that mammo screening reduces breast cancer mortality by 25%
- Does not include risk of overdiagnosis and overtreatment

Discussion

Findings of this review are consistent with other reviews of breast screening promotional materials

- Several reviews have stated that materials emphasize benefits and minimize harms
 - (Gotzsche et al. 2009; Gotzsche and Jorgensen 2011; Gummersbach et al. 2010; Jørgensen and Gøtzsche 2006)

And are very biased in favour of participation

- (Jørgensen et al. 2009)

Breast screening programs must meet their ethical and legal requirement to provide accessible balanced information in all promotional and informational materials to enable informed consent

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