

2024 DRAFT BREAST SCREENING GUIDELINES

SUBMISSION TO THE HOUSE OF COMMONS

STANDING COMMITTEE ON HEALTH

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Diagnosed and living with de novo stage 4 breast cancer since March 2019

THE QUESTION

How have breast screening guidelines impacted me and how will the 2024 draft guidelines impact women like me?

BACKGROUND

NATALIE KWADRANS

I always had a healthy lifestyle and ate well. I was a university-level volleyball player. I competed for Team Canada as a snowboard racer from 1995-1998. I lived in British Columbia when I found a lump in my breast. My GP sent me for imaging. Upon getting the results, I was told I had "lumpy" (doctor's word) breasts and should get screened every 2 years, which I did until I moved to Alberta in 2007. In 2008, I found a GP near my home in Calgary's suburbs. I asked my GP for a mammogram but was told screening started at 50. I explained I was "lumpy" and should be followed but it was denied. I tried again several years later and was denied a second time, again being told screening did start until 50.

Despite having concerns that I was unable to get a mastectomy in AB yet was being followed bi-annually in BC because I was "lumpy", I went about my life. I'm not a doctor and relied on their expertise to guide my decisions. Five days after my 46th birthday, I found a tiny split pea sized lump in my right breast. I went back to my GP and he sent me for screening, although told me that it was a precautionary scan since breast cancer is very rare in women my age. I felt reassured.

A week later, I got my mammogram and ultrasound. The Ultrasound Technician left the room and came back with the Radiologist. He told me he didn't like what he saw and insisted I book a biopsy before even leaving the clinic. He sent my imaging results to my GP and referred me to the Calgary Breast Health Clinic. On March 18, 2019, just under a month of finding the lump in my breast. I was diagnosed with de novo, stage 4, aggressive, triple-positive breast cancer.

DRAFT 2024 GUIDELINES

INTERPRETATION OF GUIDELINES BY PHYSICIANS

Based on my lived experience, guidelines need to have precise and unambiguous wording, and remove the ability for subjectivity. The previous guidelines were unclear and the proposed 2024 guidelines are even more confusing.

According to the guidelines for women in the 40-49 age group, there are three areas within this age group that are confusing. The wording of the three confusing sections are listed below¹:

1. "Because individual values and preferences may differ, women 40-49 who want to be screened after being informed of the benefits and harms should be offered screening every 2 to 3 years. (conditional recommendation, very low certainty)"
2. "If interested in screening, women with moderately increased risk due to a family history of breast cancer or dense breasts should refer to the recommendation that corresponds to their age group."
3. "If a woman aged 40 to 74 is considering screening, provide information in absolute numbers, about the possible benefits and harms. When possible, this should be done through a process of shared decision-making to arrive at a decision that aligns with the woman's values and preferences."

The wording in these bullets above are unclear for the following reasons:

- Bullet #1: the word "should" is ambiguous because it could be interpreted as a recommendation instead of a directive.
- Bullet #2: this blatantly states that known high-risk factors are being disregarded and simply refers the women back to the guidelines for women at average risk.
- Bullet #3: absolute numbers don't tell the full story. The Task Force should include relative numbers so the size of the issue is obvious. Another concerning element of this sections is the fact that the guidelines suggest that shared decision making be used "if possible". This creates a loophole for physicians.

EXCLUSION OF KEY RISK FACTORS

The guidelines do not include proper guidance on key risk factors such as breast density, race/ ethnicity and genetic predisposition. The sections in question are identified below.

4. For race/ ethnicity: "But there is a lack of data on the benefits and harms and on values and preferences from racial and ethnically diverse populations."
5. For density: "For women with moderately increased risk due to high breast density (Category C and D), we did not find any evidence on the benefits of supplemental screening for outcomes important to patients (e.g., stage at diagnosis, death)."

¹ Draft 2024 Canadian Breast Cancer Screening Guidelines. Accessed June 9, 2024.
<https://canadiantaskforce.ca/guidelines/published-guidelines/breast-cancer-update-2024>

6. For genetic predisposition: "They [the guidelines] do not apply to those with a personal or extensive family history of breast cancer, genetic mutations that would increase breast cancer risk, or symptoms suggestive of breast cancer."

By excluding these key risk factors, it creates the following issues:

- Bullet #4: Data regarding race/ ethnicity exists, however the Canadian Task force, through its arbitrary and heavy weighting of "preferences" and "values". The criteria the Task Force creates to include or exclude research creates an near impossible threshold which research must meet to be included. For example, the Task Force criteria only allows for research that compares include screened v. unscreened patients to be included. If data relating to race/ ethnicity, which is currently excluded because of the criteria, was to be included, it would change the outcome of the guidelines.

The United States and many Canadian jurisdictions have found and used data relating to race and ethnicity. As an example, one can simply review the US Task Force's bibliography which shows the availability of that data.

According to Statistics Canada, 26.8%² of women are part of a racialized group. This is a significant portion of the population that is excluded from the guidelines, and this creates further systemic racism.

- Bullet #5: Similar to the comments of the race/ ethnicity data discussed above, research also exists for breast density. The data exists and several studies are referenced in the US Task Force's bibliography.

Approximately 40% of women have dense breasts. This means that almost half of the Canadian women population are excluded from these guidelines because of the criteria set by the Canadian Task Force.

- Bullet #6: The guidelines simply state that women with genetic predispositions are excluded, with no rationale for their exclusion. There are no guidelines for a woman considered high-risk.

² Statistics Canada "The rich diversity of women in Canada. (2021). Accessed June 9, 2024. <https://www.statcan.gc.ca/o1/en/plus/4652-rich-diversity-women-canada>

EXCLUSION OF BENEFITS, EXCLUDING DEATHS AVOIDED

The guidelines and their associated tools are very heavily weighted to highlight the harms. In fact, the only benefit that is discussed is the metric of “deaths avoided”. There is no information about significant benefits of screening women in their 40s, such as:

- early detection, which results in less aggressive treatments and better outcomes;
- less damaging side effects experienced with more aggressive treatments;
- quicker recovery and ability to return to work.

None of the documents refer to the harms “under-diagnosis”, meaning a harm resulting from women not being screened in their 40s:

- risk of a later-stage diagnosis, requiring more aggressive treatment and a less favorable outcome;
- ongoing screening and monitoring associated with a later stage diagnosis, such as more frequent screening over a longer period, such as CT scans to monitor for cancer progression. The increased radiation from these scans put women at risk for a secondary cancer.
- Death that could have been prevented with earlier screening.

LACK OF GUIDANCE FOR HIGH-RISK WOMEN

By not having any guidelines for women who considered high-risk, physicians are at liberty to recommend what they want to the patient. This creates a disparity in basic health care needs for all women that fall in this category, regardless of their age.

SHARED-DECISION MAKING

The concept of shared decision making in healthcare is simple. The healthcare provider presents unbiased information to their patient. This must provide a balanced view of the benefits and harms of the decision being considered. The patient shares their preferences and based on that discussion, the patient and doctor agree on the most appropriate next steps for the patient.

For shared decision making to work, the clinician must follow general ethical principles, even if the healthcare provider does not agree with the patient’s decision. There cannot be a shift in power, such as:

- questioning the patient’s decision;
- trying to convince the patient to come to a different conclusion; or
- undermining the decision by withholding the requisition.

The 2024 draft guidelines are ambiguous and silent on crucial information that informs a woman’s decision.

- the wording in the guidelines is subject to interpretation;
- the information focuses heavily on the harms and fails to include any benefits of screening women in their 40s and the harms of not screening;
- the guidelines incorrectly suggest that data isn't available for about key risk factors relating to breast density and race/ ethnicity;
- the guidelines are silent for high-risk women, regardless of their age.

These guidelines provide physicians with ambiguous and incomplete information. As a result, physicians can interpret the guidelines as they want. What is worse it that it also creates screening inequities across municipalities, provinces and the country.

THE QUESTION ANSWERED

I was hoping the 2024 would be updated to reflect new research that resulted in the United States, and in ten of our thirteen Canadian jurisdictions lowering their breast cancer screening age. The 2024 draft guidelines aren't better than the previous guidelines. In fact, I think they are more ambiguous than before.

Their lack of clarity means decisions are in the physician's hands, not the woman's. I was denied screening because the previous guidelines lacked clarity. If I was to return to a physician's office under these guidelines, there is a strong probability I'd be denied screening. The guidelines put the onus on women to build their case for screening. Not all women can advocate for themselves. Women should not have to opt in to a basic life-saving screening tool. Instead, it should set up for them to opt out if they chose to. This would also allow women that do not have access to a family physician to receive the same services as women with a family doctor do.

I worry the guidelines are purposefully silent in areas which impact the largest populations of Canadian women: those with dense breasts or those part of a racialized group. I am one of the 40% of women with dense breasts. Women like me were not considered in previous guidelines, and once again, they are excluded from these guidelines, despite the availability of research suggesting they receive incremental screening in addition to basic screening. To not reflect critical data because the Task Force weighs research against arbitrary criteria set by the Canadian Task Force is dangerous for Canadian women. Similarly, to be silent on guidance for high-risk women is unacceptable.

I was discouraged, disappointed and upset when the draft 2024 guidelines were released. Women in situations like I was in a few years ago could still find themselves, like I am, dying a preventable death and leaving behind a young family.

RECOMMENDATIONS

To prevent women like me from being diagnosed too late going forward, I would recommend the following steps be taken.

1. Review all data included in the Canadian guidelines. Compare these sources against those used in the US or by Canadian jurisdictions who have updated their guidelines.
 - a. Review the methodology that excluded data due to artificial criteria that results in the exclusion of critical research relating to higher-risk factors.
 - b. Review the guidelines to factor in previously excluded research.
2. Be inclusive of the diversity of Canadian women.
 - a. Include research relating to breast density.
 - b. Include research relating to race/ ethnicity.
3. Give all women 40-49 the ability to be screened and opt out if they choose
4. Create guidelines for high-risk populations.
5. Eliminate ambiguity in how the guidelines are written.
6. Create tools that are balanced for all harms and benefits.