

Risk-Stratified Screening: Advocating for Breast Cancer Screening Guidelines Based on Risk

The Canadian national guidelines for breast cancer screening are for people at average risk of developing the disease, and most people are considered average risk. However, this means that if your risk is higher than average, there are currently no national standards that you can use to be aware of the most appropriate screening for you as an individual. This includes not understanding the most appropriate screening and detection method (for example mammography versus ultrasound, or both) as well as the most appropriate time interval for screening (for example once a year versus once every two years). Providing screening guidelines at the national level that are based on an individual person's risk level is important for prevention and early detection.

This advocacy guide reviews the different risk levels of developing breast cancer, Canada's current approach to screening for different risk levels, and how to bring equity into this approach.

# **Understanding Risk Levels**

According to the Canadian Cancer Society, 1 in 8 women (12.5%) will develop breast cancer in their lifetime. This means that if we had a group of 100 women who were 90 years old, 1 in 8 had, or currently has a diagnosis of breast cancer. This is consistent with the fact that although breast cancer can occur at any age, the risk increases with age. This demonstrates that breast cancer is common, but it does not reflect how individual risk impacts the chances of developing the disease. A person's risk for developing breast cancer is based on a combination of modifiable and non-modifiable risk factors. This means that you can change some risk factors, but you cannot change others. Additionally, some risk factors will have a bigger impact on your chances of developing breast cancer than others.

Your overall risk of developing breast cancer is determined by combining all modifiable and non-modifiable risk factors. Based on your overall risk, you would be considered as being at average, elevated, or high risk of developing breast cancer in your lifetime.

According to the Canadian Partnership Against Cancer (CPAC)'s definition, people at elevated risk are "those who are considered to have a greater than average risk for developing breast cancer, but less than the highest risk group". On the other hand, CPAC defines people at high risk as those who "have a greater lifetime risk of developing breast cancer or developing more aggressive breast cancers at an earlier age".

## Canada's Current Approach

Research by CPAC shows that Canada's approach to screening for people at elevated risk (such as persons with dense breasts) and high risk (such as those with a hereditary risk) varies greatly across the country. Canada has not created national guidelines around how to manage elevated or high-risk conditions. Instead, provinces and territories have regional guidelines.

Nine provincial and territorial breast screening programs have standards for people at elevated risk, but only three provinces or territories have standards for people at high risk. This means that some people have better access to enhanced screening than others solely depending on where they live. Where you live also impacts how elevated and high-risk are defined. For example, the conditions included or excluded in the definitions of high and elevated risk vary by province and territory.

#### Addressing the Issue with Canada's Current Approach

When someone is at elevated or high risk of developing breast cancer, their chances of developing the disease are higher than average. It may also impact the age when the cancer may develop. For example, an inherited BRCA1/2 mutation can increase someone's lifetime risk of developing breast cancer up to 85%. A BRCA1/2 mutation can also increase the likelihood of developing breast cancer at a younger age.

It is important to fully understand your individual risk. For example, hereditary risks only impact a minority of people but may be from either side of the family. It is important that people have proper information and tools that can assess their risk level and have access to screening guidelines that support them in making appropriate healthcare decisions.

When screening programs are tailored to all risk levels, not just average risk, it is called a risk-stratified approach. Canada should adopt a risk-stratified approach to breast cancer screening to ensure screening matches each person's risk. When a person knows their risk level, they can also take preventive measures, such as reducing their modifiable risks or in less common situations, getting preventive surgery.

Before a risk-stratified approach can be established, elevated and high risk needs to be defined. This includes how conditions contribute to risk level. These definitions must be used across Canada to ensure people have the same access to screening, regardless of where they live. As well, these guidelines must be clear and accessible to health care providers.

Once a definition is agreed on, then research can investigate the most appropriate screening and detection method for each risk level. Existing guidelines for average-risk breast cancer are based on decades of research. Without similar dedicated study, appropriate screening practices for people at elevated or at high risk of developing breast cancer remain unclear.

# Self-Advocacy for pan-Canadian Guidelines and Definitions

Developing screening guidelines for people at elevated and high risk of developing breast cancer is urgent. Only then can Canadians feel confident that they will have screening guidelines that match their needs, regardless of their risk level. Here are some steps you can take to advocate for elevated and high-risk screening guidelines so that Canada uses a national and risk-stratified approach to breast cancer screening.

#### Learn about your risk

It can be challenging to understand individual risk. But knowing puts you in a better position to detect cancer early and make appropriate health decisions. The first thing to do is speak to your healthcare provider and learn about your risk. You can also use an online assessment tool to learn more about your risk level. We recommend the NCI Breast Cancer Risk Assessment Tool, the Tyrer-Cuzick Risk Assessment Calculator, or the Ontario Health Breast Cancer risk assessment tool.

#### Ask for more research

Before Canada can have national guidelines, we need evidence about the best screening approaches for those at elevated or high risk. We also need to agree on the conditions that contribute to risk, and how much they contribute. For example, more research needs to be done on the appropriate screening guidelines for people with dense breasts, a condition that puts individuals at elevated risk of developing breast cancer.

The best way to get strong evidence about elevated and high-risk guidelines is to use relevant data. It is crucial that we use Canadian data to inform Canadian healthcare policies and decisions. Write a letter, or share one of ours asking your premier, provincial Minister of Health, or federal Deputy Minister of Health to collect demographic health data, such as race and ethnicity. Researchers have found that race and ethnicity contribute to a person's risk of getting some subtypes of breast cancer. Let our decision makers know that demographic health information is essential to inform national screening guidelines for those at elevated and high risk of developing breast cancer.

### Contact the Public Health Agency of Canada

The Public Health Agency of Canada (PHAC) is responsible for developing national guidance on this issue, and they want to hear from you. Let them know you want evidence-informed national standards for breast cancer screening. You can contact PHAC through their online web portal.

#### Talk to the federal Minister of Health

Contact our federal Minister of Health and ask them to support national risk-stratified breast cancer screening. Let them know how important it is for everyone to have breast cancer screening guidelines that match their risk level. You can email the federal Minister of Health at hcminister.ministresc@hc-sc.gc.ca.