

Failing Canadian Women

The impacts of outdated and inconsistent breast screening practices



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Executive Summary

Each year in Canada, 27,100 women are diagnosed with breast cancer and 5,100 die. Early detection can drastically improve outcomes and save lives. A recent survey of 2,530 Canadian women, by Dense Breasts Canada, shows there are significant gaps in knowledge and best practices for the early detection of breast cancer in Canada.

Key Findings

Women and health care providers lack important information about breast screening

- 42% of women surveyed did not know the age they were eligible for mammography screening in their province.
- Many women are either not getting advice about the benefits of screening (32%) from their health care providers or do not remember having a discussion (27%).
- One-third (34%) of all respondents and 40% of women aged 40-49 did not feel that discussions with their health care providers about breast screening were adequate for their needs.

- Six in ten women are not aware that 75% of women diagnosed with breast cancer do not have a family history or risk factors.
- Women above age 75 reported feeling dismissed once their eligibility for screening in the program ended.
- Women younger than age 40 reported feeling dismissed when presenting with symptoms of possible breast cancer.

2 Lack of access and confusion around screening at age 40

- Over half (58%) of women in their 40s did not know that the decision whether to have a mammogram in their 40s is a woman's decision. Half of respondents of all ages did not know this.
- 11% of respondents, aged 40-49, indicated that they were denied a requisition for a mammogram by their health care provider, based on the breast screening guidelines from the Canadian Task Force on Preventive Health Care.
- Nearly all respondents (97%) felt that women in their 40s should be allowed to self-refer for a mammogram.

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Limited awareness on breast density risks and screening options

- Overall, almost one third of women who had a mammogram were not informed of their breast density (30%) and 10% did not recall.
- 44% of respondents were not aware of the two risks associated with dense breasts: increased risk of developing breast cancer and reduced ability to detect it.
- 1033 of the 2530 respondents completed the open-ended question about their breast screening experience. Of those respondents, 17% stated that they had difficulty accessing supplemental screening for dense breasts.



Calls to Action

10 key actions government must take to stop failing women

Based on the survey findings and research on best practices, we call upon the provincial and federal governments to remove barriers to optimal breast cancer screening and revise screening policies to address the need for clarity, equity, and professional education. To stop failing our women we need to:

> Increase women's general understanding of when they are eligible for screening. All provincial/territory screening programs should send invitation letters to women at the eligible age. Currently, only six do so.

Implement culturally adapted awareness campaigns across all screening programs to address knowledge gaps amongst minority women. Present the benefits and
limitations of screening to health
care providers based on current
evidence. Outdated research
currently provided by the Canadian
Task Force on Preventive Health
Care understates the benefits of
screening and ignores the other
important benefit of early detection
– less aggressive therapy (1).

Allow self-referral for mammograms across provinces and territories starting at age 40. Only BC, NS, PEI, and YT permit selfreferral at 40. In ON, QC, SK, MB, NB, and NL a requisition is needed for women in their 40s. In AB and NWT, women require a doctor's requisition for their first screen in their 40s but can self-refer thereafter. Early detection of cancer should not depend on one's postal code or access to a family doctor.



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Offer annual screening to women in their 40s in all provinces. This is only offered in PEI, NS, and YT. Women screened annually have smaller cancers, are less likely to have positive lymph nodes or other metastases, have fewer interval cancers, and have less aggressive therapy than women screened every two years or less often (2).

Track breast cancer incidence by ethnicity across all screening programs and act to eliminate screening gaps in minority women. Women from some minority groups are more likely to have cancer earlier than age 50, resulting in poorer outcomes (3).

All provinces/territories should directly inform all women having a screening mammogram of their breast density and the associated risks of dense breasts in the mammogram results letter mailed to them. Currently, only six do so. Women who learn they have dense breasts can be more proactive about their breast health. Offer supplemental screening in addition to mammograms to all women with dense breasts
(Category C and D).
Ultrasound is a validated modality to detect cancer missed in mammograms in women with dense breasts (4).

All women who are in good health should be able to continue to selfrefer for a mammogram, at least until age 80. Eligibility in a screening program should not end at 74 (age 69 in Quebec).

Address gaps in health care provider education relating to dense breasts, screening at age 40 and optimal screening for all women with CME's and professional discussion.

DENSE BREASTS CANADA IS CALLING FOR ACTION ACROSS CANADA. BREAST SCREENING IS NOT EQUITABLE FOR WOMEN IN CANADA AND IS AFFECTING THE LIVES OF THOUSANDS EACH YEAR.

The Voices of Canadian Women

"If I had had a screening before 45 and been told I had a risk factor of dense breasts, I would have not been diagnosed with late-stage cancer (stage 3b) at 47."

"I find this very frustrating in Saskatchewan. I have asked my doctor several times and he doesn't seem to think I'm old enough for a mammogram yet. I'm 44."

"The cancer I had was extremely aggressive but hadn't started that way. If I had been able to have a mammogram at 40 a less invasive tumour would have been found according to my breast surgeon." "I asked at 40 for a mammogram and was told I didn't need one, if I didn't have symptoms and that Ontario didn't do them until 50. I am now 44 and have just been diagnosed with metastatic breast cancer. If I had access to one earlier, the cancer may have been found sooner!"

"I wish I knew I had dense breasts and the risk factors associated with it before I was diagnosed with breast cancer. I feel ultrasound should be an option for those with dense breasts."

"Women of colour should have further breast screening, since they are at a higher risk for early detection."

"I have been repeatedly refused a screening ultrasound despite having "D" density breasts."

All quotes are from a 2021 survey of 2,530 women in Canada.

"Take women seriously. If there is an undiagnosed anomaly, do the tests necessary to diagnose. Don't allow the mammogram to be definitive if there is other evidence of concern. In my case a palpable lump evident on ultrasound but mammogram "clear". Women should not have to fight to get the tests necessary for a diagnosis."

Introduction

A breast cancer diagnosis can be devastating. Each year in Canada, 27,100 women are diagnosed with breast cancer and 5,100 will die (5). Nearly 40% of breast cancer cases are expected to be diagnosed in females aged 30 to 59 (6). Early detection can drastically improve outcomes and save lives.

Practices of screening programs vary considerably across the country, differing in the age screening begins, the ability to selfrefer in the 40s, how often screening is performed, if women are told their breast density, if additional screening for women with dense breasts is offered, and the age screening ends.

There is unequal access and disparate standards of care across the country. Finding breast cancer early should not depend on a woman's postal code.

In addition to geographical disparities, there are racial disparities impacting early detection of breast cancer in minority women, some of whom have a higher incidence of advanced disease and mortality before age 50. Furthermore, breast screening experts have highlighted disparities between outdated Canadian Task Force on Preventive Health Care breast screening guidelines and experts' recommendations based on current research.

As an advocacy organization dedicated to seeing optimal breast cancer screening for all women, Dense Breasts Canada wanted to hear women's voices to understand their awareness and experiences related to their breast screening and to uncover the impacts these inequities have on women's lives. We launched a national, anonymous, online survey for one month in the summer of 2021. There were 2,530 respondents, over the age of 20, proportionally distributed across Canada, except for Quebec, which had a smaller number of respondents.

This report amplifies the voices of the women who generously shared their awareness and experiences of breast screening in Canada, and outlines gaps and opportunities to drive equity in women's breast screening.



Women's responses revealed three major themes:

Women and health care providers lack important info about breast screening

Lack of access and confusion around screening at age 40

3

Limited awareness about breast density risks and screening options

In the pages that follow, this report explores key findings associated with each of the three major themes.

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Women and health care providers lack important information about breast screening

42% of respondents were unaware of the age they are eligible for breast screening.

With almost half of respondents unaware of the eligible age, it is clear that there is a significant gap in information regarding the importance of breast cancer screening and early detection. That provinces have different ages of eligibility increases the confusion and inequity. Even in British Columbia and Nova Scotia, where women may self-refer starting at age 40, 20% of women aged 40–49 were unaware when screening begins.

- Lack of knowledge that breast cancer occurs in significant numbers in women in their 40s.
- A gap in communication between health care providers and women.
- Not all provinces send mailed invitations to women at the eligible age.
- Provincial variations in screening.
- Many women do not have a family doctor.

32% of respondents reported that their health care provider did not discuss the benefits and limitations of mammograms with them. 27% could not recall if they had this discussion.

The current breast cancer screening guidelines are based on the premise that there will be shared decision-making between patients and health care providers. According to the Canadian Task Force on Preventive Health Care, following a discussion of benefits and limitations, the decision as to whether or not to be screened is based on what a woman prioritizes in terms of benefits and harms of mammograms (7). If discussions are not taking place, then shared decision-making is not either.

"I was told screening at age 40 wasn't recommended, due to lack of risk factors, and then I was diagnosed with triple negative breast cancer metastasized to lymph nodes at age 42. I wish I had pushed for a mammogram at age 40." Of those respondents who discussed the benefits and limitations with their health care providers, 34% felt that the discussions did not help them make an informed decision on breast screening. 32% of respondents reported that the discussions were not tailored to their ethnicity or family history.

Shared decision-making requires that both parties have access to accurate and up-to-date information about the benefits and limitations of mammograms. The Canadian Task Force on Preventive Health Care's Knowledge Transfer materials are based on data from randomized trials done 30-50 years ago, this is forcing doctors to base their recommendations on outdated information (8).

The Task Force's emphasis on the anxiety women may experience from a call back for further tests is patronizing to women. Discussions should also consider ethnicity and family history. Black, Asian, and Hispanic women are at an increased risk for breast cancer at a younger age than white women (9).

Women with a family history are almost two times more likely to develop breast cancer.

59% of all respondents did not know that the vast majority (75%) of breast cancers occur in women with no risk factors. 65% of women aged 40-49 were not aware.

Many women believe that they are not at risk and do not need to be screened if they do not have a family history. Better education of both health care providers and women is needed to ensure both are aware that all women are at risk and that risk increases as women get older.

> "I was diagnosed with Stage 3 breast cancer at the age of 43 because I found a lump in my breast. I think the earlier the screening, the better."

> "I just moved to N.S. from NB recently. I asked about a mammogram in NB and was told usually don't have it there until 50. Seemed strange to me as friends in N.S. start at 40. I would have selfreferred in NB if that was an option."



of all respondents did not know that most breast cancers occur in women with no risk factors.

Women over age 74 felt that their lives were devalued because they weren't included in the screening mammography program.

All screening programs no longer invite women after age 74 and Quebec stops at age 69. In some provinces, women, if they are aware, can continue to self-refer. However, women in other some provinces, who have been self-referring for 25-35 years, are frustrated that they now require a requisition from their health care provider, which might be denied.

Experts recommend that women continue as long as they are in good health, with a life expectancy of 10 years (10). According to Statistics Canada, for women at age 80, the average life expectancy is 10 years (11). Women under 40 presenting with breast cancer symptoms are being dismissed due to their age.

Young women presenting with breast cancer symptoms remarked they were dismissed as being too young for breast cancer, 4% of breast cancer in Canada is identified in women under 40 (12). Women from minority backgrounds, including Black, Asian, and Hispanic, are at greater risk of breast cancer under 40 (13). Recent studies show that younger and younger women are getting breast cancer (14).



"Since I turn 75 in April, I was sent a notice that I will not be eligible for a mammogram unless my doctor orders it. Guess when you get old, you're not worth the expense of a mammogram."

> Women are not too young to have cancer. They are too young to die from cancer.

FAILING CANADIAN WOMEN

Calls to Action

Decision makers need to improve awareness and education about breast screening

Send invitations to women when they are eligible for screening to increase participation rates and understanding of screening programs.

Deliver educational campaigns, as part of screening programs, to women and health care providers to address knowledge gaps and enhance shared decision-making discussions. Education should be culturally adapted for younger women and those at higher risk, including minority women, to make them aware of when they will be eligible for screening and the importance of breast screening. Revise the composition and procedures of the Canadian Task Force on Preventive Health Care to align with current and accurate evidence.

Allow women over age 75, who are in good health, to be able to self-refer for a mammogram and be part of the screening program, if they choose to continue screening. Education campaigns should be directed to older women as well.

Begin risk assessment for younger women between the ages of 25-30.

FAILING CANADIAN WOMEN



Breast screening is a postal code lottery

Screening in the 40s can be lifesaving, but only 4 provinces allow women to self-refer for screening mammography starting at age 40: BC, PEI, YT, NS. In AB and NWT, a requisition is required for the first screen, but women may self-refer thereafter.

Cancers in the 40s can grow aggressively, but only PEI, NS, YT, and AB allow women to selfrefer for mammograms annually. All women are directly informed of their breast density in only six provinces: BC, NS, AB, MB, PEI, NB. Only women in the highest category are informed in SK, ON, NL, NWT, and YT. Only six provinces recall women with the highest density category for annual mammography: ON, PEI, NL, SK, NWT, and YT.

Breast screening practices are failing Canadian women. For more details about screening in your province, visit mybreastscreening.ca



Lack of access and confusion around screening at age 40

47% of overall respondents were unaware that having a mammogram starting at age 40 is a woman's decision.

For women aged 40-49 in Canada, most women (58%) were unaware they could decide whether to have a screening mammogram. In Ontario, this percentage was even higher (66%). This demonstrates a significant gap in the information conveyed to women and health care providers.

The Canadian Task Force on Preventive Health Care guidelines for women in their 40s state that the decision whether or not to have a mammogram depends on the values a woman places on any possible benefits and harms of screening (15). According to the Task Force, "The new guidelines are intended for an empowered position, which puts the decisionmaking in the hands of the individual woman in terms of what she prioritizes." (16)

This information has not been effectively communicated to women in their 40s.

Survey results and comments also indicated that some women who were aware that they could request a mammogram were denied their requests. Accessing a requisition is also problematic for women who do not have a family doctor.

"It might be my decision, but I still have to insist, pretty much cry and beg."



11% of women aged 40-49 have been refused a mammogram requisition for screening in their 40s. The reason given to these women is the Canadian Task Force on Preventive Health Care recommendation against screening in the 40s.

Canadian women are being denied screening in their 40s even when they have decided they would like to be screened. Because of the recommendations in the 2018 Task Force report, some woman must convince their physician to provide a referral and are often met with resistance.

This demonstrates the lack of awareness among health care providers of the statement from the Canadian Task Force that the decision of whether or not to be screened is based on a woman's priorities. This information has not been clearly communicated to all health care providers.

By allowing women to self-refer, this issue can be avoided. Women in their 40s represent 17% of breast cancers and 24% of the years of life lost from breast cancer (17), (18). It is essential that any woman in her 40s who wishes to be screened has the opportunity to do so.

> "As a nurse though, I have seen too many times doctors refusing to send women for screening or the requisition being refused as the woman doesn't fit into the guidelines for screening."



97% of respondents stated that women over the age of 40 should be able to book their own mammogram.

Since only four provinces/territories permit self-referral for women in their 40s, women across Canada do not have the same opportunity for early detection.

"The lack of available practitioners leaves a lot of people without a family doctor, so unable to get a referral for a screening."

Fourteen percent of Canadians do not have health care providers, leading to further inequity (19). Allowing women to self-refer at 40 would give equity to those who cannot access a requisition because they do not have a health care provider. In some provinces, when women receive a requisition in their 40s, their mammogram is performed outside of the organized screening program at a diagnostic centre. When this occurs, there are no reminder letters sent, no results letter sent, and women are not informed of their density, even if their province has implemented notification. So, it is important that all women be allowed to self-refer to the screening program.

"[We] 100% need to remove the paternalistic influence of the current screening guidelines. Women can make an informed choice."

Screen Program Practice





believe women over the age of 40 should be able to book their own mammogram

Calls to Action



Decision makers need to ensure equitable access and standards of care for women's breast screening across Canada

Allow self-referral at age 40 in all jurisdictions. Currently, only four jurisdictions allow women to self-refer for a mammogram at age 40. In AB and NWT, they require a requisition for their first screen, but can self-refer thereafter. The ability to detect cancer early should not depend on one's postal code or access to a family doctor.

Offer annual screening for women aged 40-49, given that 17% of breast cancers occur age 40+ and tend to be more aggressive (20). Women from minority groups, such as Black, Asian, and Hispanic can get cancer earlier and should start screening at age 40, not 50. Breast cancer in Black women peaks in the mid-forties, and it can be more aggressive; Black women are 30-40% more likely to die of breast cancer than white women (21).

Did you know?

Canadian Task Force guidelines are made by non-subject experts and do not reflect expert guidance by breast cancer screening specialists

Canadian Taskforce Guidelines

- Screening for women aged 40-49 is not recommended
- Women aged 50-74 should screen every 2-3 years with mammography
- There are no recommendations for screening women over age 74
- Supplemental screening is not recommended for women with dense breasts
- Risk assessment is not recommended
- Clinical breast exams not recommended
- Breast self-exam is not recommended

Canadian Society of Breast Imaging

- Women aged 40-49 should screen annually with mammography
- Women aged 50-74 should screen every 1-2 years with mammography
- Women over aged 74 should screen every 1-2 years with mammography as long as they are in good health with life expectancy of ~7+ years
- Women with dense breasts can benefit from supplemental screening
- Risk should be assessed by age 25-30 to determine if early screening is appropriate
- Mammography may miss breast cancers and clinical breast exam is complementary to mammography
- Breast self-awareness is recommended



This is failing Canadian women.

Dense Breasts Canada Advocate Gaynor Hart, diagnosed at age 48. Here with her daughters, aged 6 and 9.

B

Limited awareness about breast density risks and screening options

Of all women who had mammograms, 30% were not informed of their density and 10%could not recall.

It is encouraging to see the percentage of women who had been informed of their breast density. However, potentially lifesaving information is being withheld from a significant proportion of women.

Approximately 43% of women over age 40 have dense breasts (22). Dense breasts are a more prevalent risk factor than family history (23) and pose two risks: an increased risk of breast cancer and an increased risk that cancer will be masked on a mammogram by dense tissue. Only six jurisdictions provide information on breast density directly to all women having a screening mammogram. In five jurisdictions, only women in Category D of density are informed, even though both Category C and D are considered dense.

So, a large percentage of Canadian women are still not being informed of their breast density and are denied the opportunity to be proactive about their breast health. "I was diagnosed with breast cancer in 2018. I'd been having mammograms for about 14 years at that point and had NEVER been told that I had dense breasts and was therefore at increased risk of breast cancer. I was NEVER offered an ultrasound because of dense breasts either. I feel I should have been told & made aware of the increased risks to me, due to having dense breast tissue."



Almost half of the respondents (44%), did not know about the two risks associated with dense breasts.

A significant number of respondents were unaware of the increased risk of developing breast cancer and the increased risk that breast cancer can be hidden by dense tissue on a mammogram, highlighting a gap in information. It's encouraging to see, that of the women who knew of the risks, 43% had heard about them from their health care provider.

It's also encouraging that women in some provinces/territories are now being told about their breast density in the letter they receive, but not all provincial letters give a clear explanation of the associated risks of dense breasts. Women should also be encouraged to do a breast self-examination (or "be breast aware") since that is how cancers are often detected in dense breasts. Women with dense breasts are significantly more likely to be diagnosed with an interval cancer (a cancer detected as a lump between screenings) (24).

Women who are unaware of the risks can have a false sense of security after a normal mammogram and may not bother with selfexam or may even ignore a breast cancer symptom because of a *normal* mammogram.



Women with dense breasts are unable to access supplemental screening.

Many women with dense breasts, who were aware that cancer can be hidden by dense tissue on a mammogram expressed concern they could not access supplemental screening and were only offered mammograms. Others commented that their cancer was hidden by mammogram and only detected by ultrasound or MRI.

Women are becoming educated about the risks of dense breasts but feel they are at risk because they cannot access screening that can help detect cancer earlier. Evidence from 1995-2021 shows that ultrasound finds additional cancers missed by mammograms (25). Secondary analysis from the only Randomized Control Trial of ultrasound being performed was published recently. The J-START study found that in Japanese women undergoing routine breast cancer screening, supplemental ultrasound helped reduce interval cancer rates and the rate of late-stage disease, and will, in time, likely show reduced mortality (26).

Women with dense breasts, whose cancer was missed on mammograms and found later when a lump was detected and seen with ultrasound, are often still only offered mammograms in their follow-up care. Access to screening ultrasound varies by province.



Breast Density - Provincial Comparison Chart



Calls to Action

Decision makers need to provide optimal screening for women with dense breasts

Inform all women having a screening mammogram of their breast density and the associated risks of dense breasts within the mammogram results letter mailed to them. Early detection saves lives.

Offer annual mammography screening to women with dense breasts. Seely et al. (2021) showed fewer interval cancers in Canadian jurisdictions that screen women with dense breasts annually, compared to provinces that do not (27).

Offer supplemental screening like ultrasounds, in addition to mammography to women with dense breasts. Ultrasound detects cancers missed on mammograms in women with dense breasts. Educate women about the importance of being 'breast aware' due to the increased risk of interval cancers.

Increase equipment and labour resources to reduce wait times for screening ultrasound in women with dense breasts.

Educate women and health care providers about the risks of dense breasts.



Let's stop failing Canadian women.

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The Voices of Canadian Women

"I had a clear mammogram in January 2018 and was diagnosed with a 6 cm tumour 10 months later. I had dense breasts and the tumour went undetected. Thank God for self-breast exams or I probably wouldn't be here 3 years later."

"My breast density is D. I wasn't offered an ultrasound-I had to push for one. I was told the wait is up to a year and that although I have a referral I'll most likely only be contacted some time in 2022."

"I wish I had known about breast density sooner. NS does not offer women breast ultrasounds . Even after being diagnosed with breast cancer and knowing that I have level C dense breast tissue, I had to go to Ontario for an ultrasound , at my own expense."

"Holding on to the guidelines as much as some doctors do, puts more young women at risk of a late/delayed diagnosis and death. It's absolutely frustrating, navigating this here."

All quotes are from a 2021 survey of 2,530 women in Canada.

"I'm a practicing ultrasound tech in Alberta. Many of my patients have no idea about breast density.

I think education is so important. There needs to be better access to education so more women know about breast density.

Also, many women don't know they can start screening for breast cancer at 40."

"Younger women need screening. I am surrounded by women in their 30s with advanced breast cancer. It's all grade 3 and aggressive. They are dying. Devastating. Young children without moms. Spouses without partners. Younger women are told "we're too young for breast cancer" and yet we're getting diagnosed during and after pregnancy. The worst is when some physician tells us not to worry, "just enjoy your new baby. It's a clogged milk duct."

Awful how we're infantilized with our real concerns. And now we die because we're not taken seriously. A simple ultrasound would have alerted to the malignancy. I am so angry and lost. And I'm "lucky" because I found it early, but many don't.

And now I watch those women who helped me through the nightmare die horrible deaths. All because they were "too young to have cancer". They are not too young to have cancer. They are too young to die from cancer."

Advocacy at Work

In the past three years, Dense Breasts Canada (DBC) has successfully advocated in six provinces that women be directly told their breast density in their mammogram result letters. In five other provinces and territories, women with the highest density are now informed.

As a result, hundreds of thousands of women in Canada have now been informed that they have dense breasts and can be proactive about their breast cancer risk.

We are dedicated to do more.

DBC has recognized the significant gaps and disparities in breast screening as shown by the women's voices within this report.

Our mission has expanded to raise awareness and advocate for optimal and equitable breast screening practices for Canadian women so that every Canadian woman has a chance to detect breast cancer early.

DBC launched a second site <u>mybreastscreening.ca</u> in September 2021 to educate and empower Canadian women to take control of their breast health.



Acknowledgements

We gratefully acknowledge that the headquarters of Dense Breasts Canada is on the traditional territory of many First Nations, including the Ho de no sau nee ga (Haudenosaunee), Anishinabewaki ⊲σĴċV·⊲P, Mississaugas of the Credit First Nation and Wendake Nionwentsïo.

In the spirit of reconciliation, we honour Indigenous histories, worldviews, and cultures, and acknowledge the enduring presence of First Nations, the Métis Nation, and the Inuit Peoples.

Dense Breasts Canada wishes to thank our medical advisor, Dr. Paula Gordon, for her tireless efforts to raise awareness and advocate for evidence based practices to ensure the best health for Canadian women.

Thank you to our advocates and team members for their passion and dedication.We are grateful to the many women that have shared their experiences.

We dedicate this report in memory of the women that are no longer with us today but whose advocacy legacy will live on through Dense Breasts Canada.

Janie Dale Michell Forvoso

Jennie Dale and Michelle Di Tomaso Cofounders, Dense Breasts Canada October 2021

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