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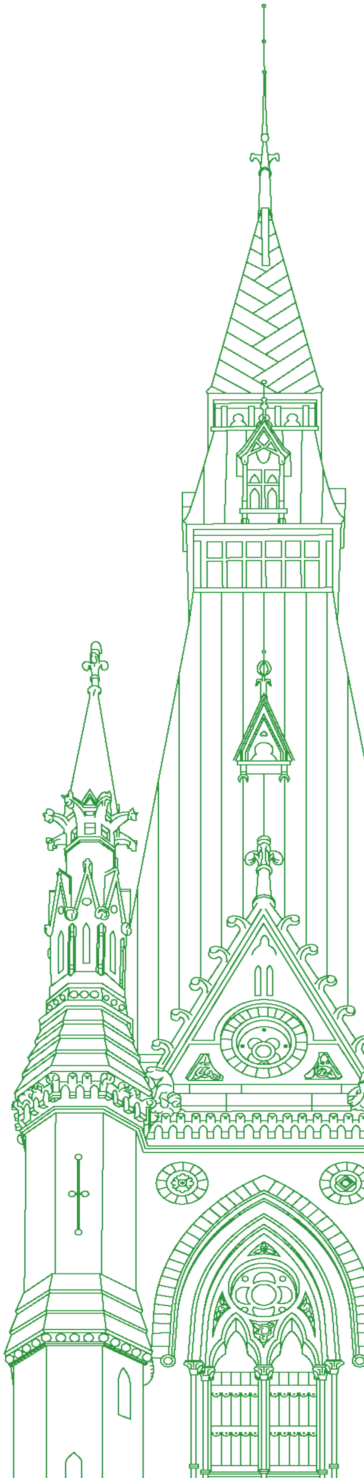

Standing Committee on the Status of Women

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• (1635)

[*Translation*]

The Chair (Mrs. Shelby Kramp-Neuman (Hastings—Lennox and Addington, CPC)): I call the meeting to order.

[*English*]

Welcome to meeting 124 of the House of Commons Standing Committee on the Status of Women.

I would like to remind all members of the following points.

Please wait until I recognize your name before speaking, and as a reminder, all comments should be addressed through the chair.

[*Translation*]

Thank you for your co-operation.

[*English*]

Pursuant to Standing Order 108(2) and the motions adopted by the committee on Tuesday, June 4, and Wednesday, September 25, 2024, the committee will commence its study of breast cancer screening.

Before I begin, I would like to ask all in-person participants to read the guidelines written on the updated cards on the table. These measures are in place to help prevent audio and feedback incidences and to protect the health and safety of all participants, including the interpreters.

I would like to welcome our witnesses. Appearing as an individual, we have Cheryl White. Appearing by video conference, which we're trying to get set up and connected, is Dr. Jean Seely, professor of radiology in the faculty of medicine at the University of Ottawa, and Kimberley Wahamaa-Deschenes, founder of Trust Your Bust.

From Dense Breasts Canada we have Carolyn Holland and Jennie Dale, co-founder and executive director. She is joining us by video conference, which we're trying to coordinate as well.

At this point, we will begin with our opening statements.

Ms. White, you will have the floor for up to five minutes.

Ms. Cheryl White (As an Individual): As a patient who has been negatively impacted by difficulty accessing mammograms in Canada due to task force guidelines, I would like to thank this committee for inviting me to speak today. Many women have found themselves in similar circumstances who will feel seen and heard. Through treatment, I heard many stories of fellow patients, friends and families with the experience of delayed diagnosis. Many Canadians have lost a young woman in their life.

When I was 39, my doctor told me that she had been reading, and that since screening at 40 was a shared decision, she wanted me to start thinking about it. She suggested that a benchmark at 40 would help us watch for changes and be proactive. I agreed—that sounded very wise. Unfortunately, within the year she suddenly retired and closed her practice. It took me some time, but eventually I found a young doctor accepting new patients.

One of my first requests was for a screening mammogram. She refused, explaining that it was not recommended. I insisted, but again she refused. I would ask again the following year—but again no. I knew I couldn't get a second opinion, as I was asked to sign a contract that I would not use walk-in clinics. I knew if my doctor removed me from her roster, I would be unable to find another due to the doctor shortage.

Then I found a lump. At first I dismissed it. I felt that since she had been so firm on not authorizing a mammogram, the appointment would be challenging. Eventually I did go, and two weeks after my 43rd birthday I was diagnosed with a locally advanced cancer with lymph node involvement. My family doctor called me between appointments. She was crying on the phone, but I didn't have the time or energy to comfort her. I think the guidelines cause harm to the doctors who follow them too.

Sure, the biopsy scans and all of the processes of diagnosis were stressful, but so was trying to advocate for my care to my doctor in the first place. I wonder about what if my first doctor hadn't retired or if I'd taken the chance and gone to a walk-in clinic to ask for a requisition. There is a power imbalance between doctors and patients, which makes shared decision-making impractical. Unless patients can access screening without their doctor's permission, it is essential that women in their forties across Canada be allowed to self-refer. If I had been able to self-refer, my cancer may have been caught earlier.

The consequences of delayed diagnosis for me may not end my life prematurely. However, the treatment effects are awful and my quality of life has been impacted. The chemotherapy may have damaged my heart and other organs. I needed surgery to remove the tumour and affected lymph nodes, 29 consecutive days of radiation and a full year of targeted therapy infusions. I am currently in my fifth year of hormone treatment, which causes achy joints, mood changes, brain fog and other unpleasant side effects. I'm lucky. I may live to old age. I may even live the rest of my life without a breast cancer reoccurrence.

When I was undergoing chemotherapy, I read the Pulitzer Prize winning book *The Emperor of All Maladies*, and there are four pages on the Canadian breast screening randomized controlled trial from the 1980s. I was so saddened to learn that it is widely known that the study was sloppy or maybe even fraudulent. The people involved explained the problems with randomizing patients, and still there is no indication that scientists, the University of Toronto or the journal CMAJ, where the study was published, are planning to retract the RCT.

I hope my story helps the committee in their important work. It is so reassuring that the people in your position care about the health and lives of women like me.

Thank you.

● (1640)

The Chair: Ms. White, you're in a safe spot here. Thank you for sharing.

At this point, I would like to welcome Dr. Seely. You have up to five minutes.

Dr. Jean Seely (Professor of Radiology, Faculty of Medicine, University of Ottawa, As an Individual): Thank you, dear committee members, for the opportunity to testify today on this critical issue.

I am a breast imaging specialist at the Ottawa Hospital, where I diagnose women at every stage of breast cancer. Early detection is key. Screening detects cancers at stages 0 and 1, while cancers detected once symptoms appear are often advanced—stages 2, 3 or even 4—requiring aggressive, life-altering treatments. Seventeen per cent of breast cancers occur in women in their forties. These are often aggressive, fuelled by ovarian hormones, and there is minimal overdiagnosis in this age group. Without screening, these cancers will continue to grow unchecked. Breast cancer is the leading cause of death for Canadian women aged 40 to 55.

I was invited as an expert to work with the Ottawa panel reviewing the evidence for the breast screening guideline update. What I witnessed was deeply concerning. The task force ignored recent, robust evidence that supports lowering the age for screening to 40, evidence that the U.S. task force and numerous other countries have already embraced.

I've had the privilege of collaborating with Statistics Canada and other Canadian researchers on multiple studies. The research is clear and points to the same conclusion: The age for screening in Canada must be lowered. Our research with Statistics Canada showed a dramatic increase in breast cancer incidence over the past 35 years, with a significant 9.1% rise in women in their forties.

Last month, we published a study—again with Statistics Canada—highlighting that younger women, particularly those aged 40 to 45, are more likely to be diagnosed with aggressive breast cancer subtypes. These cancers, like triple negative breast cancer, have a poorer prognosis when detected late, with only 47% of women surviving five years after being diagnosed with stage 3 disease. However, our study also revealed hope. Early detection can play a pivotal role in improving survival outcomes. Across all subtypes, when cancer is detected at stage 1, the five-year survival rate is greater than 96%.

Any argument that stage doesn't matter because we have good treatments today is very misleading. In Canada, the five-year survival rate for stage 1 breast cancer is nearly 100%, but it plummets to a devastating 23% when the disease is stage 4.

In another study, we analyzed provinces with screening programs for women in their forties, like Yukon, P.E.I., Nova Scotia and British Columbia, and we found a significant reduction in stage 4 cancers among those in their forties simply because they lived in a province that screened women at 40. Women in these provinces are diagnosed at earlier stages, saving lives and reducing suffering. This applies not only to women in their forties but also to women in their fifties whose cancers are caught earlier thanks to screening in their forties.

Another of our studies showed that screening in the forties was associated with a marked improvement in 10-year net survival and a reduction in breast cancer mortality. This isn't just about saving lives; it's also about reducing the massive financial burden of treating advanced cancer. In 2023, we published research showing that in Canada, the cost of treating a stage 1 breast cancer diagnosis is under $40,000. However, for stage 4, that cost skyrockets to an average of $370,000 due to expensive treatments like chemotherapy and immunotherapy.

In addition, we looked at cost effectiveness in Canada. We found that screening women every two years from ages 40 to 74 is not only life-saving but also cost-effective compared to screening from ages 50 to 74. Screening every year is even more cost-effective, saving $31,000 per death averted and $1,889 per life year saved. It's estimated to save over $417 million Canadian every year, which is a huge benefit in terms of cost effectiveness.

One thing that some people fear is that increased screening will increase the number of cancers and therefore increase costs. However, our research found the opposite. When we compared provinces that screen women in their forties to those that don't, we found no increase in breast cancer incidence. This is because if you don't screen in the forties, the cancers don't disappear. They keep growing and are eventually diagnosed at later, more dangerous stages.

Lastly, I'd like to emphasize the profound disparities that exist in breast cancer diagnosis across race and ethnicity in Canada.

● (1645)

In our study with Statistics Canada, which was recently accepted for publication, we found that while the peak age of diagnosis for white women is in their sixties, non-white women are far more likely to be diagnosed in their forties. We found that 41% of cancers in non-white women are diagnosed before age 50, compared to just 16% for white women.

Also, Black women are 1.4 times more likely to die from breast cancer. These women often develop aggressive subtypes of the disease, but even these aggressive cancers can be treated effectively when caught early. Screening at age 40 isn't just a matter of science; it's a matter of equity.

We cannot allow outdated guidelines to persist when the evidence is clear, overwhelming and urgent. We must demand that our health policies reflect the latest scientific evidence and best practices. We must act now in Canada. Many lives depend on it.

Thank you very much.

The Chair: Thank you, Dr. Seely.

Next I welcome Ms. Wahamaa-Deschenes.

You have up to five minutes.

Ms. Kimberley Wahamaa-Deschenes (Founder, Trust Your Bust, As an Individual): Good afternoon. *Bonjour. Aaniin.*

Madam Chair, vice-chairs, committee members, fellow witnesses and guests, my name is Kimberley Wahamaa-Deschenes and I'm from Sudbury, Ontario. I'm here today not only as a witness for the study of breast cancer screening for women age 40 and over, but as a breast cancer survivor. I was diagnosed at the age of 47, when mammograms were recommended for those 50 plus.

On April Fool's Day in 2013, I found a lump the size of a ping-pong ball on my left breast. It was no joke. In May, I had a biopsy. In June, I was diagnosed with stage 2 breast cancer. In July, I had a lumpectomy. From October to December, I received four chemotherapy treatments. My hair started falling out 12 days after my first chemo treatment. I literally pulled out and shaved the rest of my hair. I started my radiation therapy in January 2014, and finished 30 radiation sessions by the end of February.

Eleven years ago, with 11 months of treatment, under the age of 50 and with no family history of breast cancer, my life changed forever. I asked myself, “Will I survive this diagnosis? What can I do?”

First, I purchased my family tombstone and plot and put my name on it with a cancer ribbon, because who knows? I worked throughout my treatments. I was an events manager. I couldn't afford not to be and I had events to run. I created the Trust Your Bust fund through the Northeast Cancer Centre and raised over $18,000 by producing awareness events, such as a high tea, a Halloween party, a pink-labelled beer and a skate with my pink wig and my Trust Your Bust jersey at a Sudbury Wolves game, to name a few things. Funds went to breast cancer research, awareness and families in need.

I did some local research and found that many women in my community had developed breast cancer under the age of 50. I invited 12 women and one man—as 1% of men will develop breast cancer—to share their story in my “Calendar of Hope”. I sent a copy of my calendar to the minister of health at the time, the Honourable Deb Matthews, asking why mammograms were only given after the age of 50.

With no response, I continued my advocacy. Through my “Trust Your Bust” fund, I helped a young woman, Janicka Faye, who was diagnosed with breast cancer on her 27th birthday. She started a journal, entitled “Fight to 28”. She reached her 28th birthday but later passed away, leaving three young girls, a husband, her parents and her siblings behind. She died at the age of 28—not 40 and not 50. I can't imagine losing a child at the age of 28. When my son turned 28 two years ago, I thought about us and Janicka Faye and her family.

I presented my raw story as a survivor to high school students and women's groups and was asked to present at NOSM University to first- and second-year learners. My presentation is now part of the NOSMU curriculum, showing a patient's perspective for the first time. The students came up to me crying and thanking me for my story of the good, the bad and the ugly so that they could be more prepared as they become doctors.

We've come a long way in education, research, treatment and screening for breast cancer. Early detection is key. Many women with dense breasts avoid mammograms, so companies like Radialis in Thunder Bay have developed a non-invasive PET screening process for breast cancer patients, and Rna Diagnostics in Sudbury has developed a technology that will lighten the treatments of breast cancer. Imagine if I had only had to have two chemo treatments instead of four. The harsh impact of side effects would have been minimal.

Had I not trusted my bust at the age of 47, I might not be here today. I celebrated my 59th birthday last week.

My question to all of you is this: Why should there be a minimum age barrier for mammogram testing? Wouldn't more lives be saved if the test was made available to people regardless of age? What if the focus, instead, was on providing more education to increase awareness, self-examinations and early testing?

● (1650)

In my courage, strength and hope, I believe that removing the age barrier from mammogram testing and breast screening would result in early detection. Thus, more lives would be saved.

Thank you. *Meegwetch*.

The Chair: Kimberley, thank you very much for joining us and sharing your story today.

I would like to invite Ms. Holland and Ms. Dale to speak for up to five minutes.

Ms. Carolyn Holland (Dense Breasts Canada): Thank you so much.

My name is Carolyn Holland. I'm here today not just as a 46-year-old breast cancer patient, but as a mother, wife, sister, daughter, colleague and friend.

As a volunteer with Dense Breasts Canada advocating for earlier screening, I'm thrilled that Ontario lowered the age to 40 yesterday. Unlike the Canadian Task Force on Preventive Healthcare, Ontario listened to experts and followed current evidence.

I'm excited for women to have the opportunity to detect cancer early and avoid the lifelong repercussions I face from not having had the chance. My doctor never raised the topic of screening in my forties, and by the time I discovered a lump at the age of 43, the cancer had already spread to my lymph nodes. My life has been forever changed by these dangerously outdated guidelines.

The 2024 guidelines are similar to those my family doctor followed three years ago. I am concerned that recent gains from more provinces adopting self-referral at 40 will be undermined by the ongoing influence of misinformation from the task force, which may dissuade women from screening.

Task force representatives insist that women discuss the so-called harms and benefits of mammograms with their doctors before booking. Informed decision-making requires accurate information, yet doctors are not being instructed to tell women the truth: that cancers are often more aggressive in the forties, with the highest years of life lost to women diagnosed in their forties. Instead, doctors are instructed to say that the risk of breast cancer is low in this age group and that screening is less beneficial than for older women. They share the task force's exaggerated harms of false positives, which are really just callbacks for more images, and they flag theoretical overdiagnosis, a risk that is minimal for women in their forties.

Doctors also rely on the task force's 1,000-person tool, but its flawed one-size-fits-all approach ignores personal risk factors like ethnicity, family history and breast density. The only benefit this tool considers is the decreased risk of dying of breast cancer and not the years of life gained or the benefits of avoiding mastectomy and chemotherapy. It presents women with a limited view of the benefits of screening over the next 10 years instead of much greater lifetime benefits. This messaging misguides doctors and patients and denies women the full picture they deserve to make a truly informed decision.

As long as the task force guidelines remain unchanged, Canadian women will continue to receive misleading information that downplays the life-saving benefits of early detection.

Thank you.

● (1655)

Ms. Jennie Dale (Co-founder and Executive Director, Dense Breasts Canada): This misinformation campaign extends beyond doctors' offices to the way the task force frames its methods, communicates in public forums and dismisses legitimate concerns.

The task force misled the public by claiming that experts were meaningfully included in the guideline update process. However, expert advisers revealed that their input was often dismissed, with the task force dictating which evidence to consider, including outdated trials from 40 to 60 years ago that don't reflect current technology or treatment advancements. These experts were excluded from voting on the guidelines. The task force cast doubt on the integrity of these experts in the media by suggesting they have conflicts of interest. The task force claimed only its members are neutral.

In reality, even before the evidence review began, the task force co-chair stated to the media that the guideline against screening in the forties did not need to change. This resulted in a predetermined outcome orchestrated by a panel with a troubling anti-screening bias. PHAC refused to remove the co-chair despite repeated evidence of her lack of objectivity.

The task force would have Canadians believe that early cancer detection is unimportant because we have effective treatments. In reality, the stage of diagnosis is critical to survival, regardless of treatment advancements.

Data from Statistics Canada contradicts the task force's claims. When aggressive triple negative cancer is detected at stage 1, the five-year survival rate is 96%, but at stage 4, it plummets to 7%. Early detection is life-saving.

The task force misled Canadians by claiming that it included current evidence in its update. In reality, its grading system undervalues current observational studies, as well as studies that highlight critical trends, like the rising incidence of breast cancer in younger women and the racial disparities. The U.S. task force recognized the credibility of this evidence and lowered the screening age to 40.

Although our task force acknowledged that many ethnic groups face earlier onset and higher mortality rates from breast cancer, it chose to leave the guidelines unchanged and discriminatory, calling for more research while ignoring the existing data that demands immediate action.

Our examples today show how the task force misled the public and health care professionals, operating without accountability, ethical oversight and scientific integrity. The evidence for screening at age 40 is irrefutable. Current guidelines must be suspended and revised to reflect modern inclusive evidence. We must act now to stop avoidable late-stage breast cancer diagnoses and the needless loss of life of Canadians.

Thank you for allowing me the honour of testifying today, and thank you for all the work you're doing for the well-being of Canadians.

The Chair: Thank you to all witnesses for your testimony and your remarks.

At this point, we will move to rounds of questions from members. I would like to acknowledge to members that Dr. Seely needs to sign off at 5:30, so just keep this in mind when you are posing your questions.

I'd like to start with Michelle, for six minutes, please.

Ms. Michelle Ferreri (Peterborough—Kawartha, CPC): Thanks, Madam Chair.

Thank you to our witnesses for their powerful testimony today. It's obviously emotional too. October is Breast Cancer Awareness Month, so it's fitting that at the status of women committee we are delving into this. Thank you for being here.

Cheryl, if I can call you Cheryl, your testimony about your experience was emotional and powerful, and I think pretty much anyone who's been through the medical system, regardless of having breast cancer or not, and is trying to advocate for something when they know something is not right with their body can really resonate with what you spoke of today.

How old were you when you first started advocating to get breast screening?

Ms. Cheryl White: My previous physician was talking to me about it when I was in my late thirties. I'm not sure, but I was probably 38 or 39, and she retired shortly after. Then I found a new doctor, so it was probably at 40, maybe 41, that I was asking for that. It was because my prior physician had encouraged me to do so. She'd been doing some reading, and she said, “I think you do need to be screened at 40.” It was around 40, and I was diagnosed two weeks after my 43rd birthday.

● (1700)

Ms. Michelle Ferreri: I feel like there's a bigger conversation that you've brought up. We're talking about breast cancer, and the statistic dropped here today that breast cancer is a leading cause of death in women ages 40 to 55 is pretty shocking. What's left out of that stat is the number of women, families and children who are negatively impacted, not just by death but by the sickness itself and the disease itself. That is also a statistic we should be considering.

The bigger picture that I feel you have dropped in this committee, which needs serious evaluation, is from the words you used: power imbalance. I think a lot of us sitting around this table have aging parents or we've seen this. If you do not advocate and fight, you don't get anything. We don't have enough doctors. There's a massive imbalance because you're afraid, and you'll take whatever you can get.

Your testimony is very powerful. The answer that I hear from you—and what I'd like to see put in the report we're going to do—is the concept of self-referral. This is your body. I'd love you to expand on how you feel about that.

Ms. Cheryl White: I don't understand why we can't. People talk about the harms of mammograms, but the only harm I can think of is the $75 cost of getting one. Being told that you might have cancer and that you need a biopsy is terrible, but it's much worse to miss that.

Lots of people I know have heard my story. They've self-advocated and they've struggled. They've had a hard time getting a mammogram because their doctors have also told them no. I just don't understand why Canadian women can't access the care they need, which is a mammogram at 40 or even younger.

Ms. Michelle Ferreri: I agree with you. You hit the nail on the head. What I think is one of the underlying causes, which I think they're hiding behind, is, as you said, the $75 cost. They want to hide behind science but I think it's numbers.

I'm wondering if anyone on this committee knows—and I would point to Dr. Seely, being that she's a doctor—whether cost is an issue. Is it thrown at you that we can't do these screenings because it's going to cost the system too much money? Is that ever brought up?

Dr. Jean Seely: Thanks for the great question.

This is not directly brought up, but it's always an underlying concern that the costs of screening outweigh the benefits. We showed with a cost-effectiveness study that it would save over $400 million per year if we screened women, because we're shifting the cost away from treating breast cancer at advanced stages to being able to diagnose more women at early-stage breast cancer.

There's still a great deal of resistance about understanding this. We have to really emphasize that the costs we've estimated for cost-effectiveness underestimate the cost of advanced-stage breast cancers.

Ms. Michelle Ferreri: Dr. Seely, I do not want to interrupt you, but I only have 30 seconds left.

Saying “underestimate” is being kind. You're not accounting for the lost work. I don't even know how you would do a cost analysis of that. I'm looking at you guys shaking your heads, and to say that the cost outweighs...is bonkers to me. It doesn't make any sense.

I'd love to see more push-back and see some economics and stats come forward on the lost revenue, the work production and all of the things you have to do. There is travelling to doctor's appointments, parking tickets, being in hotels and all of the other things that accumulate when you are dealing with sickness. We don't have a health care system; we have a sick care system.

Thank you.

The Chair: Thank you, Michelle.

Next I would welcome Emmanuella.

You have six minutes.

Ms. Emmanuella Lambropoulos (Saint-Laurent, Lib.): Thank you, Madam Chair.

Thank you to all of our witnesses for being here today to share your stories with us. I know that it takes a lot of courage to do so. These are really difficult topics, and they have affected your lives in a very negative way. We appreciate learning from your experiences here today.

My first question—and anybody who has the answer can answer it—is about the task force claiming there's not enough Canadian evidence to make changes. What would you recommend the federal government do? In what ways can the federal government help that situation to change so there is enough evidence going forward?

● (1705)

Dr. Jean Seely: If I can politely state it, there is overwhelming evidence, and there is absolutely no need for further study. The claim the task force makes that there is insufficient evidence flies in the face of all of the incredibly strong evidence that made up the reason the U.S. lowered its screening age to 40. It's why many Asian countries and European countries start at age 40. To delay changing these guidelines for a claimed lack of evidence is simply a tactic to avoid facing the reality of what exists. I would strongly urge the committee not to look at doing any further research when there is so much evidence to support making this change.

Ms. Emmanuella Lambropoulos: I agree with you that there is evidence out there. That's why the U.S. made those changes. Clearly it's pointing to something.

We spoke a lot about how different communities are affected in different ways and how certain communities peak at age 40 while white women peak at age 60. Does Canada have research studies that have been done on that?

Dr. Jean Seely: We just had our paper accepted for publication. It was shared with PHAC and the task force, so they are aware of it. What the data shows, what this research shows, is that out of over 117,000 women diagnosed with breast cancer in Canada, Black women, Asian women and non-white women have a peak incidence of breast cancer at under age 50 in a majority of women and are more likely to be diagnosed with stage 3 breast cancer under age 50 than white women are.

The ethnicity and race genetic factors at play in the U.S. are the same ones we're seeing in Canada. This also affects indigenous women. We have very strong evidence that this is the same issue, and again, it is why there's such an equity issue at play in Canada. By not lowering the screening age, we discriminate against these women and prevent them from being diagnosed at an early stage.

Ms. Emmanuella Lambropoulos: Thank you.

We know that sometimes mammograms are not necessarily the best test to do for women who have dense breasts. What would members of the Dense Breasts Canada organization recommend to our committee regarding women with dense breasts?

Dr. Jean Seely: I can start and then I'll turn it over to Jennie Dale.

Dense breasts absolutely are an issue. For us, it means that our mammograms are not as effective at diagnosing breast cancer. We know that, overall, about 40% of women have dense breasts, and under the age of 50, about 50% of women have dense breasts. That means 50% of women have non-dense breasts, and the mammogram works beautifully in those women. For women with dense breasts, we recommend additional screening. You have to start with a mammogram because it's the only way that's been shown to reduce breast cancer mortality, but we need to add other screening tests. Very strong evidence exists to add either a breast MRI every two years or a breast ultrasound every year. That's the best way to identify early-stage breast cancer.

I'll let Jennie Dale add to that.

Ms. Jennie Dale: Thanks, Dr. Seely.

We have the technology in Canada to detect additional cancers in dense breasts, but we are not using it. Only Alberta uses 3-D mammography for screening and uses it in about half the clinics it has. We have the MRI. We have the ultrasound.

Women across the country have difficulty accessing even an ultrasound, and in many provinces, they're flat out refused. It's inequity across the country. We don't have the same chance to find cancer early. It's dependent on where you live. We would like to see more use of the technology we have, to help find cancer early.

One of the reasons the provinces are not offering supplemental screening for women with dense breasts is the task force. It recommended against supplemental screening, and it did not do its own evidence review on dense breasts. It just followed what the U.S. said.

Ontario did a comprehensive 300-page review on density. It recommended supplemental screening for women in category D. The task force totally ignored it. It ignored the randomized control trials on density. That's the major reason we can't access the screening we need.

● (1710)

Ms. Emmanuella Lambropoulos: Thank you very much. I know my time is up, but I appreciate your answers.

The Chair: Thank you.

[*Translation*]

Ms. Larouche, you have six minutes. Go ahead.

Ms. Andréanne Larouche (Shefford, BQ): Thank you, Madam Chair.

Ms. White, Ms. Holland, Ms. Wahamaa-Deschenes and Ms. Dale, thank you for your presentations.

Today's topic is somewhat distressing. We all have a woman in our lives who's had breast cancer and, in some cases, has passed away—my friend, for instance. Also top of mind are all those women battling cancer right now, one I know personally.

[*English*]

The Chair: Andréanne, I'm sorry to interrupt you. We have two different people interpreting right now. We'll just pause for a moment.

Andréanne, do you think you could speak in French for a couple of seconds to see if there's double interpretation?

[*Translation*]

Ms. Andréanne Larouche: I'll say a few words to see whether it's working.

Is the interpretation coming through?

The Chair: That's better.

[*English*]

I'll just make sure the witnesses are able to hear.

I've pressed pause on your time, Andréanne.

Please continue.

[*Translation*]

Ms. Andréanne Larouche: Top of mind are all those women who are battling breast cancer as we speak, including a young mother I know. She was diagnosed in her early forties, when she was pregnant, so she had to give birth while dealing with all that stress. This is an upsetting topic for all those women.

I recently attended an event in my riding put on by the Fondation Louis-Philippe Janvier, which provides support to young adults dealing with cancer. I want to recognize the foundation's work, because it and other such organizations don't get enough help. This came up a bit in the discussion with Ms. Ferreri as well as in your opening remarks.

Something else that comes to mind is the whole debate around providing 50 weeks of EI sickness benefits to ensure that adults dealing with an illness are properly supported and can recover with dignity. Right now, people can't recover from illnesses in 15 or even 26 weeks. Who can reasonably imagine not having that financial burden on their shoulders?

Two weeks ago, I took part in the marche du Grand défoulement in support of the Quebec Cancer Foundation, which also has to try to make up for the fact that the government isn't capable of providing adequate support to young adults suffering from cancer. They have homes to pay for and children to support. Both of those organizations hosted events recently, and I wanted to highlight the work they do.

I've heard all kinds of stories, so I add that to the information and considerations before the committee.

My first questions pertains to a topic we've already talked about, the task force that was formed. Ms. Ferreri asked whether it was a matter of money, and Ms. Lambropoulos asked some questions. There was talk of a lack of evidence. What is that about?

I'll put that to you, Ms. Seely, since you mentioned it in your opening statement and you have to leave at 5:30.

You said you found what has come out of the task force with respect to evidence concerning. Can you tell us more about that? Other than the fact that the task force apparently just relied on what the U.S. said and doesn't have enough evidence, and beyond the cost issue, can you tell us what concerns you about the task force?

● (1715)

[*English*]

Dr. Jean Seely: With evidence, if you use a very strict formulary called a grade format, you can look at thousands of studies, but the highest level of evidence there, which will supersede any other evidence, is a randomized controlled trial. I mentioned earlier that we cannot repeat the studies that have been done for over 40 to 60 years to prove that mammography works. The task force insisted on using the randomized controlled trials evidence, so regardless of all the other studies that came after those old trials, it will always be the best level of evidence if that's the constraint made on the system approach. That has meant underestimating the benefit of screening mammography by almost half.

The reason for the underestimation in those randomized controlled trials is that they used outdated equipment. We don't use the same kind anymore. They also had other significant problems. The Canadian national breast cancer screening trials recruited into the screening arm women who had advanced breast cancers. They also moved patients from one arm to the other.

This constraint meant that, regardless of the outcome, it was predetermined by the task force's selection of randomized controlled trials. With all the evidence, the U.S. did not do that and only used evidence from 2016 on, so we know this was not necessary. The task force was very much insistent that we use that kind of evidence.

As Jennie mentioned earlier, we know that the people on this task force already had a very strong bias against screening mammography. They don't believe it works. They believe treatment is the solution, and it is all that is needed for breast cancer. They have no expertise in diagnosing women like Carolyn and other women who present with advanced breast cancer. There is an incredible, terrible toll it takes on them when they undergo this kind of treatment, with chemotherapy that can be more than 12 months long and all of the downstream negative side effects of chemotherapy. The members themselves, who were selected for that kind of bias, imposed these constraints, which meant that, regardless of what all the experts were saying, they did not listen to them. The experts showed that there were so many changes since those randomized controlled trials that they should not use them.

I don't know whether that answers the question fully, but that's the best explanation I can tell you as to why this was the outcome.

[*Translation*]

Ms. Andréanne Larouche: I have just 30 seconds left. I lost track because of the interruption.

Ms. Dale, you also talked about the task force in your opening remarks. In 30 seconds, do you have anything you want to add to what Ms. Seely said?

[*English*]

Ms. Jennie Dale: The task force lacks accountability. It lacks transparency, as Dr. Seely said, and it has an extreme anti-screening bias. As for composition, there are no experts in breast cancer screening on the task force. There is an ER doctor, a pediatrician and a gastroenterologist making guidelines for Canadians. This is not just an issue that impacts breast cancer; it is an issue that impacts every guideline the task force is making. We need expert input, and the task force lacks that.

The Chair: Thank you, Ms. Dale and Andréanne.

Leah, you have six minutes.

Ms. Leah Gazan (Winnipeg Centre, NDP): Thank you so much.

I want to start out by thanking all the witnesses.

Your stories, Madam White, Madam Holland and Madam Wahamaa-Deschenes, speak to the fact that this is bigger than a physical illness. People need to look at the long-term emotional and physical impacts of cancer on the survivor but also on families. I'm sorry that in your cases that was not respected.

If I have time, I want to ask Dr. Seely some questions, because she's leaving.

Dr. Seely, you have come before to committee to present evidence. We had a witness by the name of Dr. Ify McKerlie, and she stated in a former committee meeting:

> In the U.S., it was noted that in Black, Hispanic and Asian women, breast cancer peaks at an earlier age of 40 when compared to white women. Recent Canadian analysis shows that Caucasian women are the only group whose peak incidence is greater than 50.

She went on to say, “The task force was aware of this recent, yet-to-be published paper from Statistics Canada, but did not lower the screening age”, which was shocking to me.

She added that not only were the studies that were prioritized during the development of draft recommendations out of date, but that they also used a sample population composed of 98% white women. She added, “With knowledge comes responsibility, so knowing the above—acknowledging higher mortality in Black women in the 40 to 49 age group—and not acting on it is simply unethical and discriminatory.”

Do you feel that there needs to be more research done to look at screening ages for populations based on genetic research?

● (1720)

Dr. Jean Seely: Dr. McKerlie was quoting our study, which has just been accepted for publication.

In Canada, all women except white women have their peak diagnosis of breast cancer under the age of 50. White women have their peak age of diagnosis at 60. In those old, randomized controlled trials that I mentioned, 98% of the women were white. Women who are not white are more likely to get breast cancer under the age of 50. This is the biggest reason the U.S. lowered the screening age to 40.

In Canada, if we remove the barrier of age 50 and allow women to self-refer at age 40 and older, we will allow women of all races and ethnicities to participate in screening if they choose to screen. Right now, we only allow that for women 50 years and older.

This is absolutely discriminating against non-white women, and it is why we're seeing that non-white women are three times more likely to be diagnosed with advanced stage breast cancer in Canada than white women. It's so critical that we address this inequity. Simply lowering the screening age to 40 will allow us to remove that major barrier, because a lot of these women don't have a family physician and cannot get a referral to get a screening mammogram even if they are allowed to.

Ms. Leah Gazan: Thank you so much, Dr. Seely.

I want to move to Jennie Dale to build on this, as we're talking about discrimination in the health care system.

One of the things Dr. Seely mentioned was access to doctors and services. I'm wondering, Madam Dale, if you can speak about the health care inequities in patients who live in remote and northern communities. How are they affected in their ability to access screening compared to those in larger cities?

Ms. Jennie Dale: I'm sorry, but I cannot speak directly to remote communities. I can just speak to the inequity of women needing a requisition in their forties who don't have anyone to ask for that requisition.

Women are being denied the chance to get screenings. All I can speak to is the shortage of family doctors, the inability to get a requisition and why we need self-referral to eliminate the inequity.

● (1725)

Ms. Leah Gazan: Thank you so much.

I'm going to move to you, Madam Holland. I believe it was you who spoke about how, when they have cancer, women often have to continue working or the patient has to continue on with surviving and doing things to survive.

Do you think the government needs to look at putting in long-term support programs for survivors of cancer—in this case breast cancer—including mental health supports and programs like that?

The Chair: Leah, unfortunately, your time is up.

I'm going to allow about 25 seconds to answer, because it was a really good question.

I know our next speaker wants to pose one question to you, Ms. Seely, as I know that you need to leave at 5:30. If you can be patient, in just about 30 seconds we'll get moving.

Ms. Holland, if you could, answer in about 25 seconds or less.

Ms. Carolyn Holland: I can pass the question to Kimberley, the other witness. I was fortunate. I had sick leave at my job and had access to long-term disability, whereas I know Kimberley was in a position where she had to continue working.

Ms. Kimberley Wahamaa-Deschenes: I was an events manager. I took one day of vacation for my chemo and went back to work after the weekend. I worked throughout all my treatments. I worked every day through radiation. I had third-degree burns. I finished 30 radiation treatments and went to my remote camp. I wrapped a big bandage around it. You just keep going, so yes, there should be some type of benefit.

One thing that my—

The Chair: If I may, I need to leave it there, but perhaps the title of the report could be “Just Keep Going”.

Dominique, you have five minutes.

[*Translation*]

Mrs. Dominique Vien (Bellechasse—Les Etchemins—Lévis, CPC): Thank you, Madam Chair.

I want to start by thanking each and every one of you for being here this afternoon. I'll go straight to Dr. Seely since she has to leave soon.

Dr. Seely, there is somewhat of a myth out there that overdiagnosis is dangerous or harmful. I'd like to hear your view on that.

There's a second question I'd like your insight on. Let's say women 40 plus in the country could register to have a mammogram if they wanted to. How many lives do you think could be saved, if you were to extrapolate?

[*English*]

Dr. Jean Seely: Let me answer the second question. I think we have very good evidence—with modelling in Canada—showing that if we started screening women at age 40, we would save at least 400 women's lives every year. If you can imagine two jet airplanes filled with women, that's how many lives we would save by starting screening at age 40, and that's even an underestimation.

[*Translation*]

Mrs. Dominique Vien: Tell me, Dr. Seely, is overdiagnosis harmful? Is that true or a myth?

Dr. Jean Seely: I can talk about overdiagnosis. It's the diagnosis of a cancer that would not lead to the patient's death. We refer to overdiagnosis in the case of a woman who is going to die from other causes. The likelihood of a woman in her forties dying from her breast cancer is more than 90%. Overdiagnosis is much more of an issue for older women who are likely to die from other causes, whether cardiovascular or neurological.

● (1730)

Mrs. Dominique Vien: Thank you, Dr. Seely.

Now I'll turn to Ms. White.

Ms. White, we were all quite moved by your story earlier. Women carry an enormous mental load. When it comes to a woman's health, there is no one better—

[*English*]

The Chair: We're having some trouble with interpretation.

Mrs. Anna Roberts (King—Vaughan, CPC): We're back.

The Chair: Okay. We're good.

[*Translation*]

Please continue, Mrs. Vien.

Mrs. Dominique Vien: When it comes to their health, women are in the best position to recognize the signs that something is wrong. They know their bodies. Oftentimes, they are taking care of their families. Whether they're experiencing a urinary tract infection or a symptom of menopause, it isn't in their head—it's in their body and they are feeling it. When they suspect something is wrong and they tell their doctor about it or ask their doctor to check whether everything is okay, the doctor should listen to them.

Ms. White, to pick up on what Ms. Wahamaa-Deschenes was saying earlier, I'd like to know what stages you went through. No doubt you were angry and experienced a range of emotions. You probably felt vulnerable, stressed and anxious. Your mental health was probably affected. You may have had financial problems. What happened to you next?

Ms. Cheryl White: May I answer in English?

Mrs. Dominique Vien: Yes, that's fine.

[*English*]

Ms. Cheryl White: It's very difficult. I've been trying to advocate for better so that other women don't have to go through this.

I apologize for being emotional, but this is very helpful, because if we can improve things, other women won't have to go through this. That's what I'm hoping to achieve.

[*Translation*]

Mrs. Dominique Vien: It's important for us to know what women who have to deal with breast cancer go through. I'm talking specifically about women who shouldn't be in the situation they're in because their cancer should have been diagnosed and treated sooner. That's my question. I'm sure you went through all kinds of stages of suffering, and we need to keep the same thing from happening to other women.

Ms. Cheryl White: Yes.

Ms. Carolyn Holland: I can answer that.

Mrs. Dominique Vien: Yes, of course, Ms. Holland.

Ms. Cheryl White: Thank you.

Ms. Carolyn Holland: I don't want to speak for Ms. White.

Just as you described, in the beginning, I suspected something was going on. How was it possible, I thought. It wasn't. You always think it doesn't happen to women in their forties. It affects older women.

I ended up falling into a depression. After being diagnosed, I didn't know what to do. I didn't eat, sleep or move for an entire weekend. I didn't even cry. I thought about my son, my family. What was I going to do? What were the three of us going to do? My cancer was diagnosed late, so it was more advanced. I was thinking about undergoing the mastectomy, going through chemotherapy, being sick, not being able to work anymore, dying, possibly leaving my 13-year-old son without a mother—and all because people thought they knew better or felt it wasn't worth the expense. I went through the whole gamut of emotions, from anger to sadness. I didn't think this could happen to me.

Mrs. Dominique Vien: Thank you.

[*English*]

The Chair: Thank you very much.

Pam, I'm going to give you about five and a half minutes, because I was quite generous with Dominique's time.

Ms. Pam Damoff (Oakville North—Burlington, Lib.): Thank you to all the witnesses for being here today.

Kimberley, I'm replacing Marc Serré. He was very disappointed that he wasn't here today. He's out of town. Thank you for being here. I'm sending along Marc's gratitude for you being here.

I think we've lost Dr. Seely, unfortunately.

There's a doctor at McMaster, Dr. Juliet Daniel, who's doing incredible research on triple X breast cancer in Black women. I think it was Dr. Seely who mentioned that women who get triple X breast cancer are more likely to die.

I visited Dr. Daniel's lab and met with her team. She's underfunded in her research. I'm not surprised by what we're hearing today about Black women, indigenous women and non-Caucasian women being excluded from research. It doesn't surprise me in the least. If the committee is looking for a Black woman to come and talk about it, Dr. Daniel would be an exceptional witness, if you have time.

My sister was diagnosed in 2019 and has had surgery, chemo, radiation and tamoxifen. It sucks. I'm sorry, but there's no other way to describe the ordeal that you go through.

Cheryl, I think you're very strong. I'm a crier too, so I can relate. It's okay.

I want to talk about the task force, because I have had issues with it for years. I've met with Canadian perinatal mental health folks. They have issues with the guidelines as well. We're talking about breast cancer today, but just the methodology. I'm sure you all saw that today, the health minister announced the external expert review panel, and I think we're all happy to see that.

I'll start with Dense Breasts because I've met with you for probably five or six years now.

What would you like to see? Should the task force be disbanded? How do you get expert input into the task force? How would you like to see it work to come up with the guidelines? They are separate from government.

● (1735)

Ms. Jennie Dale: Yes, absolutely. It's an arm's-length body. We agree there's a place for an arm's-length body when it comes to scientific evidence, but an arm's-length body needs to have accountability. This body does not have accountability. When it was restructured and brought back in 2009, it was missing the accountability and oversight aspect of it.

We need task force reform and we would like to see the guidelines suspended. It's going to take time for the external expert review to file its report. It's not due until spring.

In the meantime, we have women getting later-stage diagnoses, so we need these guidelines suspended immediately. They can be replaced with provincial guidelines. The provinces are moving forward. The provinces are following the science and following the experts. All provinces—except we're waiting for Quebec—have announced or have implemented screening at 40.

We can follow the provinces and can also replace the task force.

Ms. Pam Damoff: Who would you like to see the task force accountable to?

Ms. Jennie Dale: The health minister is not able to get rid of the chair of the task force, who has shown anti-screening bias. PHAC was not able to get rid of the chair.

The health minister has to have the ability to act when dangerous guidelines are being implemented, not just for breast cancer but for different areas. We need somebody to oversee this. We need a governance structure.

This is beyond my pay grade, but we need something in the interim that includes experts. There's the [*Technical difficulty—Editor*], which is full of experts. You could make a panel that includes experts and patients. Right now, we don't have expert input into the guidelines. We need a whole restructuring.

Ms. Pam Damoff: Do you think it should be one task force, or should the task force be tasked with creating an expert panel for...? It's not just breast cancer screening they do. You don't want to put breast cancer experts on the panel providing advice on perinatal mental health.

Would it make sense for the panel to appoint individual panels of subject matter experts to do the guidelines?

Ms. Jennie Dale: That would be great. That really would.

Ms. Pam Damoff: I personally have a problem with them reporting to a politician. I don't think politics should be involved. I think it should be someone independent, because you don't want politicians interfering in scientific evidence.

Ms. Jennie Dale: Right.

Ms. Pam Damoff: I agree with having accountability, but the structure needs to change and there has been a lack of experts.

Kimberley and Cheryl, you've come here and told your stories. Do you have any advice on what we should do with this panel?

● (1740)

Ms. Kimberley Wahamaa-Deschenes: Have experts, have more witnesses and have other people share their stories. Look at Janicka. She was 28. I had my son when I was 27; he would have been one.

Hear the true raw—the good, the bad and the ugly.

Ms. Pam Damoff: It wouldn't be the first time that patient advocates were part of decisions. They wouldn't be the only people involved, but would you support patient advocates being part of a review of guidelines?

Ms. Kimberley Wahamaa-Deschenes: I would.

Ms. Cheryl White: Could I add something?

Ms. Pam Damoff: It's up to the chair.

The Chair: Go ahead, Cheryl. Please be quick.

Ms. Cheryl White: I'm an engineer. We have to measure results all the time. I would like the task force to have transparency, measure the results and involve the people who will be affected by the guidelines—patients and experts.

Ms. Carolyn Holland: Chair, may I add to that?

The Chair: Sure. I'm generous today.

Ms. Carolyn Holland: We've heard from the task force that the working group did include patient advocates; there were patients involved. However, we heard from those patients that their input was disregarded, that they were essentially window dressing and that they were asked to weigh in on things that were completely beyond their scope of understanding. It reads as a box-checking exercise. When we're talking about accountability and transparency, and the task force comes out and says they consulted with experts and patients, it's really just in name, not actually in function.

The Chair: Thank you very much.

Andréanne, please go ahead. You have approximately two and a half minutes.

[*Translation*]

Ms. Andréanne Larouche: Thank you, Madam Chair.

We are hearing a lot about the task force and its guidelines.

Ms. White, you brought up something that, I think, goes to the heart of the issue: your struggle to find a family doctor. The task force recommends that women have mammograms done starting at age 50. To what extent does that recommendation reflect a desire to conceal the underfunding of our health care system? To what extent does it reflect the worry that the system unfortunately isn't equipped to provide adequate care and treatment if the recommended screening age is lowered to 40? To what extent have years of underinvestment and insufficient health transfers been harmful to people in this situation?

Today, some try to justify the recommendation because preventive measures targeting women at higher risk can be taken. That's a false argument. Prevention costs less than intensive therapy. We can come back to that.

Basically, what role do you think the financial component plays? Do you think there's a fear of not being able to provide women with proper treatment if screening access is expanded to those 40 plus?

[*English*]

Ms. Cheryl White: If we don't say what the problem is and we're not talking about the fact that the system is underfunded or that we don't have enough resources, then we can't solve that problem. If we say that it's not necessary and we don't need screening for women who are 40 because it won't help much and might cause harm, then no one is working on that problem; no one is trying to find resources. Maybe there is a more efficient way of screening women, but we won't be pursuing it because it all seems fine. The experts are saying don't worry about it; you don't need to be screened.

Until you call out the right problem, you can't solve it. I think that's an important thing for us to do.

[*Translation*]

Ms. Andréanne Larouche: You also did a good job of illustrating that prevention really does save the health care system money and resources in the long run. Waiting until people are older to screen them for cancer costs the system because the cancer will inevitably be more advanced. Not only do we have to look at the task force and the guidelines, but we also have to revisit the importance of properly investing in the health care system. That way, women can be screened earlier, and if cancer is detected, receive proper treatment.

● (1745)

[*English*]

Ms. Cheryl White: For me, it's unknowable how much it would have cost if I had gotten my diagnosis two or three years earlier. It's very likely that I wouldn't have required as much chemotherapy, as much immunotherapy or as much radiation, or had as difficult a surgery. It's very likely that if I'd had access to screening when I was younger, I would have had an easier go of treatment. It also would have saved the province money.

The Chair: Thank you very much.

Go ahead, Leah.

Ms. Leah Gazan: I'm just shaking my head. Every time we've had witnesses come for this study, the stories of people not listening have been horrifying. I want to allow you a chance to finish what you were sharing before because you weren't able to.

Ms. Kimberley Wahamaa-Deschenes: My oncologist wanted me to take injections to help with my white blood count and they were $2,500 a pop, so that would have wiped out my insurance. I did my research and spoke to other survivors, and I chose not to. She was so rude to me it was incredible. I don't know if they get a double-dip on this. I then went to the health food store and got some immunofin to help me with my white blood count and my white blood count was fine.

Another natural therapy that I used was Nature's Aid. I had third-degree burns on my arms, and the doctors were telling everybody that they need another cream. I spoke to two other girls getting radiation who had the cream and they had open wounds from it, so I didn't do the cream. I did Nature's Aid; I applied it every day. I cut my bra so that I could slather it on, almost like vaseline, and kept it like that.

Ms. Leah Gazan: That brings it to a point. I spoke about other sorts of care, but one thing we just started, hopefully, is a pharmacare program, which we have coming through. The fact that you had to suffer because of costs and couldn't get the medication you needed is horrifying to me. I'm hoping we can see a rapid expansion of pharmacare. Your story is awful. I don't want to be patronizing, but it's grotesque that you had that treatment because you couldn't afford drugs.

Do you support an extension of the pharmacare plan so you can get the medication you need when you need it?

Ms. Kimberley Wahamaa-Deschenes: When you need it, yes.

Ms. Leah Gazan: I feel a little emotional as well. I'm very lucky in my family. Both my sisters have had breast cancer. I'm indigenous and I'm the only one—knock on wood—who hasn't. I wasn't screened until 50. This is horrifying.

Madam Holland, I know you you spoke about a one-size-fits-all approach. Can you expand a bit on that?

Ms. Carolyn Holland: For sure I can.

To stay with the task force, the tools they provide for family doctors, or even for women themselves to decide if they want screening, don't take into account additional risk factors. They don't take into account ethnicity. They don't take into account breast density. When you're only looking at the figures that apply to the typical white woman, you're not in a position to make an informed decision, because again, as you said, you're at higher risk for potential incidents in your forties.

If you don't know that, are you going to advocate for screening? If you don't know that, how are you going to make a sound decision? If you don't know your breast density, how are you going to know you're at risk? We know that dense breasts put you at a higher risk of breast cancer, but if you don't have a mammogram, you can't know what your density is.

● (1750)

The Chair: Thank you, Ms. Holland.

Ms. Carolyn Holland: Thank you.

The Chair: Anna, you have five minutes.

Mrs. Anna Roberts: Thank you, Madam Chair, and thank you to all the witnesses.

I wore pink today because cancer has impacted every single one of us here in some form. I can't believe you're 50.

Voices: Oh, oh!

Mrs. Anna Roberts: I want to make a statement, and then my question is going to Cheryl.

It feels like the task force is mistaking women for ostriches. We don't stick our heads in the sand. We face challenges, and knowledge is power. Our health care system has taken the patient out of patient care and is more concerned about financial care. That's how I feel today, and I'm really disappointed because as women, I feel that we've been left out in the cold.

Cheryl, I need to ask you something, because I recently attended a fundraiser for ABC, which is an organization in Ontario called After Breast Cancer. I had the opportunity to speak with a young woman whose grandmother, mother and sister had breast cancer. She was in her late twenties, early thirties, and she was not eligible for a mammogram.

Was there a history in your family?

Ms. Cheryl White: My grandmother had breast cancer and my aunt had breast cancer. I think some of my grandmother's sisters did as well.

Mrs. Anna Roberts: It's in the family. Okay.

Here's my thinking, and maybe I'm wrong: If there's a history—as in your case, in this young woman's case and in the case of some of my family members, whose family, every single person, had cancer—why are we even waiting until 40?

Ms. Cheryl White: I don't understand why. As I said before, I'm an engineer, and we're thinking about things proactively. We're thinking about preventing things and planning ahead. I don't understand why there is so much “wait and see” in medicine. There's so much it: “Well, we'll catch it when it gets bad enough, and then we'll treat you.” It's backwards to the way I think about things and the way I would treat my car. I wouldn't wait until my car broke down to get an oil change .

Mrs. Anna Roberts: No—exactly.

Ms. Cheryl White: I don't understand why it's acceptable. I can't understand why women's health isn't worthy of more prevention and early detection. That would make things a lot better for us.

Mrs. Anna Roberts: I saw your hand, Jennie.

Ms. Jennie Dale: We know the incidence of breast cancer in women in their twenties and thirties is rising, but right now we don't have the technology or tools to detect cancer in women that young. The radiation from mammograms may be negligible around 40, but it can have an impact in the twenties and thirties. Also, the density of the breast is going to be high in the twenties and thirties, and mammograms probably wouldn't be that effective at all. Hopefully, we'll have a blood test soon or other methods of detection, but right now we don't have the means to detect. We have to rely on self-exams and body awareness.

Mrs. Anna Roberts: I'm sorry to interrupt there, Jennie, but I believe we do have a blood test.

Ms. Jennie Dale: It's not ready for prime time yet.

Mrs. Anna Roberts: There's a history and a pattern here, and I think Cheryl said it best: You don't wait to get an oil change; you get it done before the car breaks down.

Ms. Jennie Dale: Certainly, if a woman has a history of breast cancer in her family—a first-degree relative—she's going to be given some form of screening ultrasound or mammography, depending on her age, 10 years earlier. I think you're pointing out a really good thing in that a lot of women are falling through the cracks because they're not being assessed. A lot of family doctors don't know a patient's history; they're not doing a risk assessment. There's a tool that takes about two minutes to do called the IBIS tool. We need every family doctor in Canada using this risk assessment tool on women between ages 25 and 30 so we can determine who is high risk and who needs more screening with an MRI annually or whatever else.

Mrs. Anna Roberts: Maybe what we need to do is go back and provide doctors with the education and understanding they need to listen to patients. After listening to the ladies here, I find it very strange that.... You know your bodies better than any one of us. How many of us knew we were pregnant before we were pregnant? We know our bodies: “Hey, there's something inside of me growing.”

Voices: Oh, oh!

Mrs. Anna Roberts: I'm just trying to state a fact. We need to make sure that we educate doctors so they listen to us when we say, “Hey, I'm demanding a mammogram because this is what I have found.” We shouldn't have to do that. Are they not trained to listen to their patients? Maybe we need to go back to the drawing board and implement that in medical schools. What do you think?

● (1755)

Ms. Jennie Dale: It's not that they are not listening to their patients—

The Chair: I'm sorry to interrupt.

If you could, just answer yes, no or maybe, because unfortunately we need to go on. Anna has exhausted her time.

Mrs. Anna Roberts: That's not very nice.

Voices: Oh, oh!

Mrs. Anna Roberts: Go ahead. Is it yes or no?

Ms. Carolyn Holland: Absolutely.

Mrs. Anna Roberts: Okay, we have a consensus. Let's change it now.

The Chair: That's perfect.

Please go ahead, Sonia.

Ms. Sonia Sidhu (Brampton South, Lib.): Thank you, Madam Chair.

Thank you to all the witnesses for being with us.

My first question is for Ms. Dale.

Ms. Dale, we all know that dense breasts develop more cancer. Women with dense breasts have more chance of developing breast cancer than women with non-dense breasts.

What question can women ask during regular appointments with their health care providers to receive a referral for further screening? Most women with dense breasts don't know what to ask, as you said. Women aged 20 to 30 have more dense breasts, but what should they be looking for?

Ms. Jennie Dale: The only way you can know your breast density is from a mammogram, so it would apply to women 40 and up. Women in the majority of the country are being told their breast density now. It's only in Newfoundland that they aren't.

Every woman can find out their category—A, B, C or D—and if they're category C or D, they need to have a conversation with their family doctor. They need to be informed, they need to be assertive and they need to state that they need more than a mammogram; they need a requisition for additional screening. Again, they need to know their risk. Maybe they need an MRI instead of an ultrasound. They need to speak up for themselves.

Many family doctors are not educated on breast density. They're not getting education in medical school on breast density and breast cancer. They're getting very limited education, so a woman has to be her own advocate. She has to be informed.

Ms. Sonia Sidhu: This raises another question. Do you think doctors need more education on this? You said they need to refer women with dense breasts, and mostly they do not know that. Do you think education should be added to some modules so they can look into that?

Ms. Jennie Dale: Absolutely. There is a huge education gap. This is the biggest obstacle we face. If our doctors were more educated, we would have fewer later-stage diagnoses because more women would be sent.

Right now, doctors are negating the issue with breast density because they are not informed. You have patients who are more informed than their own doctors, and you have a power imbalance. It's difficult for a patient to speak up when a doctor says they don't have to worry about their breast density. It's difficult for a patient to push back on that.

Ms. Sonia Sidhu: Ms. Holland, did your doctor ask for any other tests, like the BRCA1 or BRCA2? It's a genetic test for mutation. Did your doctor ask for that?

Ms. Carolyn Holland: No. My experience with my diagnosis was that my doctor never raised anything about breast cancer or screening, not when I turned 40 or when I was older, between 40 and 43. My family doctor took my history. I do not have first-degree relatives with it, but there is breast cancer in my family. That didn't seem to figure into anything. The other side of my family history is completely unknown, and that being the case, it was very hard for anybody to assess my risk.

I know that genetic testing, obviously, is very expensive. It's my understanding that unless there is a cluster of cases in the immediate family, you probably wouldn't be sent. Ultimately, once I had my diagnosis, I was sent for genetic testing and I do not carry the mutation. Mine is one of the 85% of all breast cancers where there is no family history. On the IBIS risk calculator that Jennie spoke to, I would have scored low.

It's about the mammogram. Had I had access and been able to self-refer at 40, I would have caught this. I'm proactive with my health. I would have caught it at 40 or whenever it came up, and it wouldn't have been as advanced.

To Jennie's point, I understand family doctors have to be jacks of all trades, but when faced with patients questioning, asking or wanting to know more, there's gatekeeping and a refusal to refer. Whether that is a matter of finances, I don't know the answer, but I don't think they're doing a service to patients by gatekeeping care.

● (1800)

Ms. Sonia Sidhu: Thank you.

Madam Chair, do I have more time?

The Chair: That's five minutes, so we'll move on to the next questioner.

Ms. Sonia Sidhu: Okay, thank you.

The Chair: Thank you.

Members, I have been quite liberal and generous with the time. At this point, I will be a bit tighter on time to get a full third round in.

We're going to start—

Mrs. Anna Roberts: Isn't this the fourth round?

Ms. Leah Gazan: Do I get 10 minutes?

Voices: Oh, oh!

The Chair: We're starting the third round. We'll have Michelle next.

Ms. Michelle Ferreri: Thank you so much.

Thanks again, ladies, for being here.

We're talking about breast cancer screening. There are some shocking stats we've heard today. It is my understanding that everyone testifying here would be in agreement with moving the screening age from 50 years old to 40. Is that correct?

I got a nod from everyone here.

Ms. Dale, you said self-referral would be your even bigger ask for the younger age as well. Is that correct?

Ms. Jennie Dale: Yes, and we do have self-referral. It was announced and implemented pretty much across the country, aside from Quebec, which has it under review right now.

Ontario just began yesterday. Because of this move, 845 cancers are going to be found in the 40 to 49 age group, so it's wonderful to see the country moving forward.

The problem is that the task force still has a huge influence on doctors. That's what they are following, so they may not suggest to women that they can self-refer. How are women going to find out they can self-refer if doctors are still following the task force and may try to dissuade them? This was in the testimony already. We still have the obstacle of the task force even though the provinces are moving forward.

Ms. Michelle Ferreri: That's an interesting point you brought up.

You are all amazing. You all had powerful testimony.

Kimberley, we heard directly here today that you were trying to self-refer. You were asking repeatedly, and it still didn't punch through our paternalistic approach to medicine. That has to be put on the record.

There was another point you brought up, Kimberley, that I think is really important. We have a bill in the House right now that aims to put the kibosh on natural health products. I don't believe anybody in the natural health product industry was consulted by anybody with breast cancer on that. Obviously natural health products were a big piece of your treatment and recovery.

Ms. Kimberley Wahamaa-Deschenes: Yes, absolutely, and they still are. I was on tamoxifen for four years and I was bleeding down there, so I stopped because I could have died from uterine cancer. I made that choice, and my doctor was not very happy about it.

Ms. Michelle Ferreri: That's another lesson. I think we could all go out for a coffee after this and have some big conversations. It sure would be nice if naturopaths and doctors would communicate, because there is a lot of value in health professionals who think outside the box, as we have to live and travel with what's happening in our health world and in our bodies.

I just want to leave it with Ms. Holland.

What we just heard from Jennie is very powerful. The task force has influence, and the members on the board are saying 50, but I don't see any survivors on the task force. That is a very critical piece. I think this is at the status of women committee right now because of this panel of experts. This is what I always ask my kids: Who are the experts and where is the data coming from?

I'll give you the floor to put on the record what you'd like to say about the task force.

● (1805)

Ms. Carolyn Holland: I very much appreciate it. Thank you.

You got to the core of it: Who are the experts and where is the data coming from?

As Jennie mentioned earlier, the experts making guidelines for breast cancer—and also, as we've heard, for postpartum depression, prostate cancer, lung cancer and cervical cancer—are family doctors. There is a gastroenterologist. There are nurse practitioners, and there's an ER doctor. These are not subject matter experts. We always hear from them that they're experts in methodology, but they have no understanding of the information, of the evidence or of the data they're getting because it is not their area of practice. We wouldn't allow someone to practice outside their area, yet here we are with a task force made up of folks who aren't in their area of practice.

I think it's a breach of the public's trust when they are getting information they believe.... If you asked any Canadian who is making the breast screening guidelines, I'm sure they would say that it was an oncologist, a radiologist or someone who knows cancer. It is none of those people.

These are very astute questions to ask. Who is providing this information and where is it coming from? We've heard about 60-year-old studies and have heard about flawed, corrupted studies. This is the data being used.

Ms. Michelle Ferreri: Thank you so much for that.

I just want to say that it would be nice to have an economist on the task force to speak about the financial impact of not investing in prevention.

The Chair: Thank you, Michelle.

Lisa, you have five minutes.

Ms. Lisa Hepfner (Hamilton Mountain, Lib.): Thank you, Chair.

I will echo my colleagues and thank you all very much for attending today, for your very important testimony, for being so honest and straightforward and for bearing your souls. That's really important, and it's valuable that you're here today.

I will go to Jennie Dale.

Did I overhear that you're also a physician?

Ms. Jennie Dale: No. I'm a breast cancer survivor, going on 10 years.

Ms. Lisa Hepfner: I thought I heard somebody call you Dr. Dale, and I didn't want to be remiss and give you—

Ms. Jennie Dale: I just want to thank you for having four patients here to allow our voices to be heard.

Ms. Lisa Hepfner: Jennie, I think you mentioned that the task force was revived in 2009. What was it like? What happened before the task force? What did we have before 2009?

Ms. Jennie Dale: We had a task force, but it was disbanded in 2005 by the Liberal government. Carolyn Bennett disbanded it. When it was reinstated in 2009, it was not done through PHAC. It was done through the University of Calgary, and somewhere along the line, an accountability structure was omitted.

Ms. Lisa Hepfner: You already talked a little about how you would like to see the task force set up, how you would like it to be different. Do you have anything further to add on that?

Ms. Jennie Dale: We definitely would like to see specialty societies involved in the guidelines, and patients and content experts as well.

Ms. Lisa Hepfner: We also heard today that Ontario just lowered the guideline to 40. I had a different experience from all of you. When I turned 40, my family doctor in Ontario said, “It's not the guideline, but you're 40 so I'm going to send you for breast screening.” It seems to depend on the family doctor you get.

If the province has reduced the screening to 40—and most provinces have—what is the impact of the federal guidelines? Does it matter? Do doctors listen to them? I'll start with you, Jennie, but then I'll ask the rest of you to comment as well.

Ms. Jennie Dale: It's their bible.

Listen, as Carolyn said, doctors can't be jacks of all trades. They follow those guidelines for prostate, cervical and colon cancers and postpartum depression—the whole gamut—and the guideline says 50. The information they are given is inaccurate and misleading and has been manipulated, but this is the information they're getting. They're being told it's less common in the forties to get breast cancer. They're not being told it's more aggressive. They're being told the harms and balances and that the benefits are not as significant in the forties. That's what doctors are conveying to their patients, focusing on the harms, so they are a huge influence. As long as we have this task force, women are going to be dissuaded and discouraged from and denied breast cancer screening in Canada.

● (1810)

Ms. Lisa Hepfner: Doctors aren't paying attention to the provincial guidelines. Is that what you're saying?

Ms. Jennie Dale: Some of them will still try to dissuade because the information they were given from the breast screening program focuses on the harms. It does not focus on the benefits, and we can show you that.

Ms. Lisa Hepfner: Go ahead, Cheryl.

Ms. Cheryl White: I have a little example that might help. A few years ago I went to my surgeon—it was post-surgery—and I asked him for supplemental screening because I have dense breasts. He said, “No, it's not recommended. The task force says you don't need that.” I told him that there were no oncologists on the task force, and his jaw dropped. He didn't know that. He had been telling all of his patients they didn't need supplemental screening. He said at the next appointment that ever since, he'd been recommending ultrasounds for all of his patients with dense breasts.

Doctors don't have time to be conspiracy theorists about the task force giving them bad advice. They just have to assume they're getting good advice because the Government of Canada stands behind it. This is the official word of the experts, and I don't think a lot of doctors know there aren't any oncology experts on the task force.

Ms. Lisa Hepfner: Carolyn, go ahead.

Ms. Carolyn Holland: Cheryl mentioned that power imbalance, and Jennie brought it up as well. I think the reality—and we all said it—is that despite what is going on in the provinces, which is admirable, laudable and great, and despite the women who are proactive and confident in their decisions and maybe had someone tell them to get it done, there is a material difference in what information you're getting depending on who your doctor is.

The fact of the matter is, the Province of Ontario is still saying, from the narrative and literature surrounding this rollout, that you should have a discussion with your doctor. If your doctor is telling you, based on the information from the task force, that the risk of a false positive, which is a misnomer, is very high and that's scary, or that you might be overdiagnosed and that's dangerous or that there's radiation—all these fallacies—then yes, that does bear on your decision. We know that despite what's going on in the provinces, as we all said, the task force holds clout. It is very well established and deep seated, and it does take a lot to move the needle on people's entrenched beliefs about the value of screening.

The Chair: Thank you, Ms. Holland.

Andréanne, you have two and a half minutes.

[*Translation*]

Ms. Andréanne Larouche: Thank you, Madam Chair.

Ms. Wahamaa-Deschenes, I'd like to end on a positive note. Could you tell us about the fund you created, Trust Your Bust? I want to give you a chance to talk about what you've been able to accomplish despite the ordeal you've been through.

[*English*]

Ms. Kimberley Wahamaa-Deschenes: I created the Trust Your Bust fund through the Northeast Cancer Centre in Sudbury and was able to raise money to help with research through Rna Diagnostics in Sudbury. I was also able to help families like Janicka's. She had three young kids. It was going to be Christmas, so the community got together and got some Christmas gifts for these young kids.

I think there are a lot of funds at the different cancer centres. Again, it's about bringing awareness. Trust Your Bust is about everybody under the age.... They tell their stories.

One other thing I would recommend is including men. What stats do you have on the 1% of men? Again, Greg Baiden was 28.

● (1815)

[*Translation*]

Ms. Andréanne Larouche: Thank you for the work you're doing. It's an admirable thing.

I'd like to end with Ms. Holland.

Ms. Holland, we've talked about research, and the importance of taking action sooner and investing a bit more in research, as well as in treatments and new technologies.

Given what you went through and your experience with treatment, why is it important to keep investing further and not neglect research? Why is that important for the future, for victims and survivors?

[*English*]

Ms. Carolyn Holland: Absolutely. That's a really valid point.

What's interesting is that as treatments are getting better and survivors are living longer, the need for more therapies and more therapeutics to ensure there's a good quality of life really is critical. There are certain drugs now that are beneficial in preventing recurrences, but the studies on them are still limited by the pool samples.

The Chair: Thank you so much, Ms. Holland and Andréanne.

Leah, you have two and a half minutes.

Ms. Leah Gazan: I have a question for everybody. We've heard a lot about the power imbalance. I know we have only two and a half minutes for all the witnesses, but what do power and justice look like for you in that relationship?

We'll start with Madam White.

Ms. Cheryl White: Ultimately, a shared decision has to be the patient's decision. When you go into a doctor's office, they have all the knowledge of the science. They're supposed to coach you, but you're supposed to make the decision: “This is what I want for myself. Based on everything you've told me, this is what I think is best.”

Having access to screening when we want it is what we need.

Ms. Carolyn Holland: I agree, absolutely.

I'll go back to my point about having the appropriate information. We don't suppose that we're experts in medicine, but we do ultimately bear the risk for ourselves. We should be given accurate and true information to make decisions and so we can refer ourselves.

Ms. Leah Gazan: Madam Wahamaa-Deschenes.

Ms. Kimberley Wahamaa-Deschenes: I'd go back to the oncologist. She wasn't listening to me and I had to trust my body with her. When I said no, she blocked me. She almost threatened me. That was before my first chemo.

Ms. Leah Gazan: Madam Dale.

Ms. Jennie Dale: I agree about having accurate information. We need public awareness campaigns. Also, women should not have to advocate so hard. They should not have to be crying and demanding. The onus should not be on women.

Ms. Leah Gazan: We have a little more time.

Does anybody want to share anything else about justice and power? What does that look like for you as a survivor?

Ms. Jennie Dale: You're bringing up another issue of survivorship, which could be another study, we hope, because women with breast cancer are not given the surveillance they need in Canada. The standard of care does not recognize individual risks or differences. It's about mammography. After you've had breast cancer, you get an annual mammogram. What about if you have dense breasts? There are so many other factors to take into consideration. Power and justice also apply to breast cancer survivors. We're not getting what we need with breast cancer—not before and not after.

The Chair: Thank you very much.

Dominique, you have five minutes.

[*Translation*]

Mrs. Dominique Vien: Thank you, Madam Chair.

We've had some very important and enlightening discussions.

Before the meeting, the Library of Parliament provided us with some information on the situation in each province. Our teams have also gathered information in each of the provinces, and it seems to be encouraging.

A number of provincial governments have opted not to follow the breast cancer screening guidelines. I think that's the good news today, with professionals at the local, regional and professional levels deciding to lower the screening age to 40. Some provinces, however, recommend women go for screening at around 45.

Nevertheless, that falls within the average range we would like to get to, according to your recommendations, so it bodes well.

I should note that, in Quebec, the recommended age range for screening is 50 to 74. There is hope on the horizon because it's possible that Quebec, too, could move to lower the screening age to 40.

I've had health issues, myself. I won't get into all that, but I just want to say that some of us around the table and people in our families have also had issues. A few years ago, a cousin of mine who was in her thirties had a double mastectomy. It's awful. It's an absolutely awful thing to go through. The fact that people dealing with these situations experience so much distress is, of course, very understandable.

Dr. Seely brought up equity earlier. She said that lowering the eligibility age for breast cancer screening to 40 was a matter of health, obviously—the effort is worth the cost, and we have evidence to back that up—but also a matter of equity.

How do you see the equity issue?

The question is for whomever of the four of you can answer.

● (1820)

[*English*]

Ms. Cheryl White: I was listening to all of that and reflecting on the fact that the four patients providing testimony are all white women who were diagnosed in their forties.

Even though screening is more important for women of colour, it also affects white women. I don't know if it's enough to just drop it to 40 to make things equitable, but I was thinking about that too.

Ms. Carolyn Holland: It absolutely occurred to me, being diagnosed in my forties, that had I lived in a different jurisdiction, I would have had access to mammography and the cancer would have been caught earlier. It's not lost on any of us. The idea that your ethnicity or genetics could put you at an even larger disadvantage in being able to take care of yourself is unconscionable.

To go back to the one-size-fits-all approach, it's not working for women. It needs to happen on a more individual basis, looking at the risk assessment that can be done by doctors and at public education and being able to advocate so that women know, if they're at higher risk, to do something and, on the other side, are allowed to do it too.

[*Translation*]

Mrs. Dominique Vien: Ms. White, when you told us about your doctor being upset at your cancer diagnosis, I thought you were quite kind. You have a big heart, seriously. If I were in your shoes, I would've been very angry.

What happened with that doctor? Did she change her practices?

[*English*]

Ms. Cheryl White: I think so. The doctor I had before was nearing retirement. She had seen a lot. She gave me advice to get screening. The new doctor I found was much younger and probably has to rely more on things like guidelines because there is so much material and knowledge doctors need to know.

I'm not angry at my doctor for following the guidelines put in front of her. She's told that this is the way of knowing. This is the best evidence we have as Canadians.

I'm not angry with her, but I do think she was badly affected. I was between staging appointments, and from her voice on the phone, she was clearly upset. In conversations since, when I've advocated for care, we've had a different kind of conversation.

● (1825)

The Chair: Thank you, Ms. White and Dominique.

Anita, you have five minutes.

Ms. Anita Vandenbeld (Ottawa West—Nepean, Lib.): Thank you very much.

I want to thank you for your bravery in telling your personal stories because it really does make a difference.

With just a few minutes left, is there any particular thing you feel you didn't get a chance to say today that you want to add and leave with this committee?

I'll start with you, Cheryl.

Ms. Cheryl White: I'm really frustrated that the RCT from the eighties still stands. I'm really frustrated that there is no pressure to have it retracted. We know there was a failure to properly randomize patients.

I read a book during chemo that won the Pulitzer Prize. It talks about that and the study is still standing. That's the thing I would really like to have some light on.

Ms. Anita Vandenbeld: Carolyn.

Ms. Carolyn Holland: To add to that, it's mind-boggling—and I think the public is not aware of what is going on—that this very small group of non-experts controls so much of our fates and have so much power that's unfettered by any kind of accountability. I appreciate that we don't want politics intervening, but there are no mechanisms to remove someone who is overtly biased, is wreaking havoc and is literally destroying lives with deep-seated biases. To me, it's just unfathomable. It really needs to be rectified.

Ms. Kimberley Wahamaa-Deschenes: When I was first diagnosed, I was presenting at the influential women's awards in Sudbury. I had a little pink book because I knew I was getting diagnosed.

My doctor said that I looked very professional, styled in pink, and she gave me a pink bag. I mean no offence to some of the ladies who sew these little pink bags. There was a little pillow in the bag, a poem on cloud paper and one book about the treatments you're supposed to take for chemo. I didn't even know if I had to get chemo yet. I have been in golf tournaments and gotten better loot.

I was given this lame bag and was like, “What's the pillow for?” Well, it's for your lymph nodes. I hadn't even had any surgery. I hadn't had anything yet.

Did others get a package? Did they get any ideas? Did they get any natural remedies?

A voice: No.

Ms. Kimberley Wahamaa-Deschenes: There's no pre- and post-package. What are we supposed to do?

You research. You google. You go to the health food store. You go for reiki. I went for reiki before each chemotherapy. That really grounded me.

Chemo was supposed to heal me. It wasn't “eff chemo”. I had to embrace it.

It's about education. Also, give us some good packages coming in and going out. I'm all about the loot.

Some hon. members: Oh, oh!

Ms. Anita Vandenbeld: You have been amazing in raising awareness, even today, for many of us. There's clearly a need for more education to allow people to do the self-advocacy you're talking about.

I don't think I got to Jennie, so I'll go to her. If there's time, I think Carolyn wanted to say something else.

Go ahead, Jennie.

Ms. Jennie Dale: Just to reiterate, the evidence is very clear. Dr. Seely presented all the Canadian evidence. We have the modelling. We have the U.S. lowering the screening age based on racial disparities and a rising incidence. What is it we're missing here in Canada? Why are we not acting?

We need to take action immediately because lives are at stake. It's just common sense, and we can save a lot of money by doing so because the average cost of treatment for stage 1 breast cancer is $39,000 versus $370,000 for stage 4. We can reduce the burden on the health care system, we can save lives and we can reduce suffering. Let's just do it.

● (1830)

The Chair: I think that's quite a timely finish.

Thank you, Anita.

On behalf of the committee, I extend my thanks to all of the witnesses for being here today and providing their testimony. Indeed, your experiences and stories help shed light on a really difficult conversation, but it's extremely important.

We started at 4.34, so I have about two minutes that I need with the committee.

We have a proposed budget in the amount of $16,200 for the study on breast cancer. A screening was circulated to everyone yesterday for your consideration. Is it the will of the committee to adopt the budget?

Some hon. members: Agreed.

The Chair: Does the committee agree to adjourn?

Some hon. members: Agreed.

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