HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

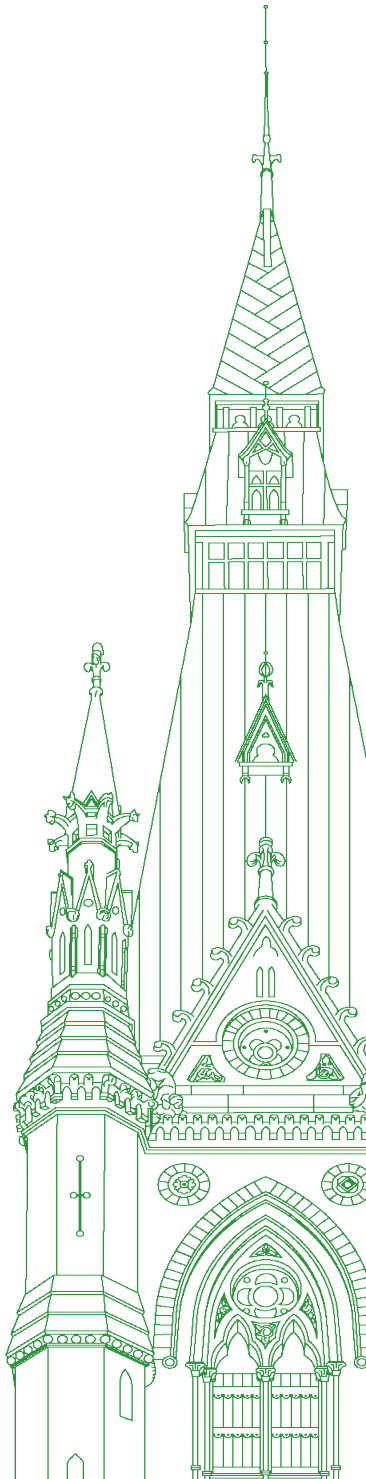
44th PARLIAMENT, 1st SESSION

Standing Committee on the Status of Women

EVIDENCE

NUMBER 115

Tuesday, June 11, 2024



Chair: Mrs. Shelby Kramp-Neuman

Standing Committee on the Status of Women

Tuesday, June 11, 2024

● (1105)

[*English*]

The Chair (Mrs. Shelby Kramp-Neuman (Hastings—Lennox and Addington, CPC)): I call the meeting to order. Welcome to meeting 115 of the House of Commons Standing Committee on the Status of Women.

Before we begin, I ask all members and all in-person participants to consult the cards on the table for guidelines on how to prevent audio feedback incidents.

Please take note of the following preventative measures in place to protect the health and safety of all participants, including the interpreters. Please use only the approved, black earpieces. The former grey earpieces must no longer be used. We need to be mindful to keep the earpieces away from the microphones at all times. When you're not using your earpiece, please face it down on the sticker placed on the table for this purpose. We thank you in advance for your co-operation on this.

To all members, please wait until I recognize you by name prior to speaking. For members in the room, please raise your hand if you wish to speak. For members on Zoom, please use the "raise hand" function. The clerk and I will be managing the speaking time, and I remind you that all comments need to be addressed through the chair.

For the benefit of the witnesses, before speaking, please wait until I recognize you by name. For those participating by video conference, click on the microphone icon to activate your mic and please mute yourself when you are not speaking. For those of you in the room, your mic will be controlled by the proceedings and verifications officer. You may speak in the official language of your choice. Interpretation services are available. You have the choice of floor, English or French for your earpiece. If the interpretation is lost, please inform me right away.

We have a number of wonderful witnesses present and online, and because of the volume of witnesses I am going to be relatively precise on time, just to respect everybody's time here today. Pursuant to Standing Order 108(2) and the motion adopted by the committee on Tuesday, June 4, 2023, the committee will commence its study in response to the call for public comment on the breast cancer draft recommendations from the Canadian Task Force on Preventive Health Care.

Today's meeting will take place in the form of a two-hour panel with our witnesses so that we can maximize the time on this very important topic.

I now welcome and introduce our witnesses. As individuals, we have Shira Farber, by video conference; Dr. Ify McKerlie; Dr. Jean Seely, professor of radiology, University of Ottawa, by video conference; and Dr. Moira Rushton, medical oncologist. From the Canadian Cancer Society, we have Helena Sonea, director of advocacy; David Raynaud, senior manager, by video conference; and Ciana Van Dusen, advocacy manager, prevention and early detection. We also have, from CancerCare Manitoba, Dr. Pamela Hebbard, head, surgical oncology, joining us by video conference; and Dr. Donna Turner, chief, population oncology, joining us by video conference as well. Lastly, from the Coalition for Responsible Healthcare Guidelines, we have Dr. Shiela Appavoo, chair.

If you're appearing as an individual, you have five minutes for an opening statement. If you are appearing on behalf of an organization, you have five minutes shared with your colleagues.

At this point, I give the floor to Ms. Farber to start. You have the floor for five minutes.

Ms. Shira Farber (As an Individual): Thank you.

My name is Shira Farber. I'm here today to share my own story, but I represent a sisterhood of breast cancer patients across Canada who give of their own limited time and energy to improve breast screening guidelines for all Canadians.

Today is an important anniversary for me. Three years ago to this exact date, I was at Princess Margaret Cancer Centre in Toronto, undergoing a biopsy confirming my cancer diagnosis. I can recall the visceral sensation of hearing the words "breast cancer" and believing in my heart of hearts that everything would be okay, because I thought I had caught it early. However, diagnostic testing revealed three large tumours in my right breast and stage 3 breast cancer—what my surgical oncologist described as a cancer found not too late, but one she wished she had found earlier.

What I have learned and what the task force has not paid enough attention to in these guidelines is that stage does matter when it comes to quality of life and reducing some of the side effects associated with more aggressive treatments.

The chemotherapy I received was a dose-dense treatment, which made me so ill I could not work, and I spent most of my days in bed. I could not care for myself, let alone my children or mother. My mouth was full of sores. I lost all of my hair, and my joints were severely impacted. I developed iron-deficiency anemia and tachycardia, and I became extremely ill and was hospitalized with acute constrictive pericarditis. I almost required emergency open-heart surgery.

I couldn't walk short distances without being winded, and I was forced to use a wheelchair. Forty of my lymph nodes were removed, resulting in permanent lymphedema. The mobility in my arm is severely restricted. I get run down and tired easily. I do what I can with physiotherapy, but I'm living with chronic pain. The treatment protocol for a more advanced stage of cancer also limited my options for reconstruction and required multiple surgeries. My body image was shattered, and my mental health was severely impacted. I live with PTSD and fear of recurrence.

The task force guidelines refer frequently to shared decision-making between patients and doctors. When I turned 40, I recall asking my former family doctor, who was a wonderful family doctor, if I needed to have a mammogram. I was advised that women with average risk didn't need them according to the new Canadian breast screening guidelines. I recall asking again closer to the age of 45 and receiving a similar response.

I did not understand that risk factors like breast density, which can only be discovered with your initial mammogram, placed me at higher risk. I was not aware that most women with breast cancer do not have a family history. I didn't push back or self-advocate because I trusted my doctor implicitly and was fearful of the pain I had associated with mammograms erroneously. I had faith that these guidelines, if they were Canada's recommendations and those of my medical practitioner, were the gold standard and would keep me safe.

Women's voices are simply not reflected sufficiently in the Canadian Task Force on Preventive Health Care guidelines. There is a major disconnect between what they are recommending and what actually occurs in family doctors' offices. They fail to take into account the power imbalance between doctors and patients. I speak to women with later-stage diagnoses all the time. Some describe having to advocate for themselves to get a screening referral and being denied because their doctors believe they know best or are not up to date on the latest research and evidence. Some are fearful of pushing back too hard and being labelled a difficult patient and potentially losing the privilege of having a family doctor.

The task force also infers one of the harms associated with screening as anxiety associated with callbacks. I would give anything in the world to experience the transient anxiety of a callback over the physical pain I have experienced and the fear I have of leaving my children without a mother or my husband without a partner.

Women are resilient. We can handle anxiety with the right tools. Over the past year, I watched as the task force, while in the process of conducting an evidence review, made numerous public statements to the press on social media and lectured about what they refer to as the “harms of screening”. I have no faith in a process where members who claim to be objective have publicly declared and maintained their bias.

When I was diagnosed with cancer, I did the same thing I did for family and friends in similar situations. I researched my doctors. I found a cancer care hospital I trusted, and I spoke to others with similar experiences. Isn't that what every Canadian woman deserves? Why are family doctors and Canadians taking directives from non-specialists in the field of detection? Why aren't we listening to the screening experts and surgical oncologists who are at the front lines of this disease? Why aren't we learning from patients' lived experiences? Where are our voices?

Canada has the ability to make this change now. We have an opportunity to give women modern, evidence-based guidelines that could protect some from later-stage cancers. We can't undo the past harms, but we can prevent future unnecessary suffering and deaths.

Thank you.

● (1110)

The Chair: Thank you very much for that.

Next we will pass the floor to Dr. Ify McKerlie.

I will kindly remind everyone speaking and all our witnesses, especially those online, to speak a little bit slower so our translators can accurately do their work.

Dr. Ify McKerlie, you have the floor for five minutes.

Dr. Ify McKerlie (As an Individual): Good morning. Thank you.

I'd like to thank the members of the Standing Committee on the Status of Women for this incredible opportunity to speak about the current Canadian breast screening guidelines.

My name is Dr. Ify McKerlie. I've been a general radiologist with a focus on breast imaging for over 20 years. I co-chair the patient engagement group of the Canadian Society of Breast Imaging. In my practice over the years, it has become increasingly obvious that patients who are affected by breast cancer are getting younger and younger. In addition, the increased incidence of breast cancer has also been shown in recent Canadian research.

My daily practice includes diagnosing and performing biopsies on these patients and, as such, I'm often the first point of contact and the deliverer of bad news. Breast cancer in younger women tends to grow faster and is more aggressive.

The task force has recently released its recommendations for breast cancer screening. It is important to acknowledge that the task force members do not specialize in the field of medicine—breast cancer screening—for which they have set the guidelines. They have mistakenly placed higher emphasis on the potential harm that early screening may cause rather than the life-saving benefits.

Breast cancer is a disease that has a far-reaching impact. The brutal harm of a late-stage diagnosis is significantly more severe than the potential harm of undergoing additional imaging. The outdated study from the 1980s, which the task force continues to use to make its guidelines, comprises a population that is 98% white women.

Forty years later, however, Canada is a much more racially diverse country. Over 9.5 million Canadians were identified as a member of a visible minority group in the 2021 Canadian census, making up 26.5% of the total population.

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. The task force was aware of this recent yet-to-be-published paper from Statistics Canada, but did not lower the screening age.

In the recently released guidelines, the task force notes that the lifetime risk of breast cancer in these populations is lower than the risk in white populations. They go on further to note that non-white populations in the 40 to 49 age group are diagnosed more with breast cancer, have a higher proportion of aggressive subtypes of cancer, are less likely to have hormonally sensitive cancers and are less likely to have stage 1.

Black women have an even more sobering outlook, with a 42% higher mortality than white women, more aggressive cancers and worse outcomes stage for stage. For the 40 to 49 age group, the task force notes:

> There are data showing variability in incidence, mortality, subtype and stage at diagnosis (e.g., higher mortality in Black women....

Despite listing all the disadvantages facing racialized women, it put a strong emphasis on informed patient choice, which would require an educated discussion with a family physician. The task force promotes a one-size-fits-all approach, which counters the observed variability in values and preferences. If a woman chooses to be screened, it still recommends screening every two to three years.

When the U.S. guidelines were announced, the U.S. task force stated that “New and more inclusive science” had led it to call for screening at 40. In Canada, where is the use of new and inclusive science? 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.

The task force also discriminated against women with dense breasts by not recommending supplemental screening. Breast density is highest in Asian, Black and Hispanic women.

It's 2024. We must include the 40 to 49 age group in the screening population, particularly given the incidence in racialized women and higher mortality in Black women, as well as the high risk to women with dense breasts. Lives depend on it.

In the absence of proper governance and an accountability structure for the task force and indeed for any organization, there is chaos. Women in their forties are not acceptable losses.

Thank you.

● (1115)

The Chair: Thank you, Dr. McKerlie.

Next, we have Dr. Jean Seely.

You have the floor for five minutes.

Dr. Jean Seely (Professor of Radiology, Faculty of Medicine, University of Ottawa, As an Individual): Members of the Standing Committee on the Status of Women, thank you for the opportunity to comment on the draft task force breast cancer screening guidelines. As a breast imaging specialist, I diagnose women along their entire cancer journey. I detect breast cancer from screening, or I diagnose it after a woman presents with a palpable lump. I perform breast biopsies, and I localize breast cancers for the surgeons. I interpret the imaging of women diagnosed with late-stage or recurrent breast cancer. I speak to women at all stages of breast cancer.

Screen-detected cancers found before symptoms occur have a very different diagnosis than one found because of symptoms at stages 2 or 3, or already metastatic at stage 4. The task force falsely states that an additional imaging test is a harm comparable to a delayed diagnosis of a late-stage breast cancer. My patients attest that the severity of the harm of a delayed diagnosis vastly exceeds any stress associated with an additional imaging test.

The recent draft guidelines released by the task force for breast cancer screening have sparked significant concern within the medical community, and as an expert included on the evidence review panel, I found their recommendations profoundly disappointing. These guidelines ignore robust recent evidence that supports the initiation of screening at age 40, a standard now adopted by the U.S. task force and by numerous other countries worldwide.

The task force recommendations are anchored in studies that date back 40 to 60 years using obsolete technologies such as screen-film mammography. This reliance on outdated data overlooks monumental advances in breast cancer treatment, including hormone receptor-positive treatments, less invasive surgical options like lumpectomy, sentinel lymph node biopsy and all the modern immunologic and chemotherapeutic agents that have completely revolutionized breast cancer management.

The task force approach diminishes the importance of recent observational trials that involve millions of women comparing screening to no screening using updated diagnosis and treatment. This includes a large Canadian study of over 2.7 million women screened over 20 years showing a 44% reduction in breast cancer mortality in women who began screening in their forties. Similar studies in Sweden show an even greater benefit, with reduction in mortality of 50% to 60%.

Breast cancer is a devastating diagnosis, but the harms are mostly preventable when it is detected early. The survival rates are starkly different across the stages. It's nearly 100% five-year survival for stage 1 detected by screening compared to only 22% five-year survival for stage 4 when the disease has spread and become incurable. Further, the treatments are much less intensive and less costly when treated early. Stage 1 costs an average of $36,000 Canadian to treat as compared to stage 4, which can exceed half a million dollars per patient diagnosed. These statistics underscore the critical importance of early detection, which the task force draft guidelines fail to adequately prioritize.

The task force disregarded data that showed that women of race and ethnicity other than white are more likely to be diagnosed with breast cancer in their forties. This one-size-fits-all approach to recommending screening starting only at age 50 discriminates against these women and contributes to their twice higher rates of advanced breast cancer due to delays in diagnosis and lack of access to screening mammography programs.

The task force also acknowledged that women with dense breasts were twice as likely to develop breast cancer than women with non-dense breasts, but it failed to recognize the reduced sensitivity of mammography in these women, which drops from as high as 90% in women with non-dense breasts to a low of 60% in those with the densest breasts. The task force ignored very high-quality randomized trials that showed that adding screening with MRI reduced interval cancers, those that are found by symptoms after a normal mammogram, by 80% with MRI and by 50% in those screened with supplemental breast ultrasound. These interval cancers have been shown in evidence-based medicine to be acceptable surrogates for breast cancer mortality, which may take 10 to 20 years or more to demonstrate. They failed to acknowledge the importance of supplemental screening in these women and, again, are not following international standards.

We must demand that our health policies be reflective of the latest scientific evidence and best practices in medicine. As a medical community, we owe it to every woman in Canada to advocate for guidelines that are not only scientifically sound, but also reflective of modern medical technology and treatment advances.

● (1120)

Let us stand together to call for an immediate review and revision of the task force guidelines to truly reflect what is best for women's health today.

Thank you very much.

The Chair: Thank you, Dr. Seely.

Dr. Rushton, you have the floor for five minutes.

Dr. Moira Rushton (Medical Oncologist, As an Individual): Thank you.

Honourable members, thank you for your invitation to testify today on breast cancer screening.

As a medical oncologist as well as a 41-year-old woman, concerned for both the well-being of my patients and the health of my generation, I was deeply disappointed with the draft report from the Canadian Task Force for Preventive Health Care last month.

The report significantly overstates the harms of screening while ignoring the benefits of early detection. What has been missing from the ongoing public discourse are the benefits of early detection of breast cancer from a treatment perspective. We hear frequently about the harms of screening, but there's been little discussion about the differences in treating a cancer that is clinically evident versus screen detected.

Treatment of breast cancer is complicated, and it is expensive. Beyond surgery and radiation, I offer patients medical treatments to reduce their risk of recurrence or dying of cancer. While the task force mentioned chemotherapy and no chemotherapy, our treatments today go far beyond that, including things like immunotherapy, targeted therapies, antibody-drug conjugates, cell cycle blockers and up to 10 years of hormone-blocking therapy for patients with stage 3 hormone-sensitive breast cancer.

Catching a breast cancer at an early age when it becomes clinically detectable reduces the need for extensive medical treatment and lowers the risk for distant recurrence and death. A larger tumour with lymph node involvement, which has become clinically evident to a patient, means higher risk disease and, therefore, more treatments to achieve similar outcomes, leading to higher costs for both individuals and our society.

Individual costs include time out of work, hair loss, cognitive dysfunction, chronic fatigue, sexual dysfunction, infertility, premature menopause, nerve damage, cardiac complications and mental health issues, not to mention the constant fear of recurrence.

The financial toxicity of breast cancer treatment is real and is carried by all of us in our publicly funded health care system. As was just mentioned, we know that the costs significantly increase by stage, with screen-detected stage 0 cancer costing only about $14,000, whereas stage 3 cancer management in Ontario today, based on the treatments we use and publicly funded, costs nearly $400,000.

This year we took those numbers and put them into cost-effective analysis using the same OncoSim modelling that CPAC has endorsed. We found that not only is this cost-effective; it's cost saving because the treatment of breast cancer at stage 4 is so very expensive.

Screening typically diagnoses breast cancers at an early stage. Only 35.7% of women age 40 to 49 in Ontario are diagnosed with stage 1 disease in the absence of an organized screening program, whereas, for those who participate in the Ontario breast screening program between ages 50 and 74, nearly 87% will be diagnosed with stage 1 or stage 0 cancer.

The communication tool provided by the task force meant to inform discussions between patients and their primary care providers about the risks and benefits of screening at an earlier age makes no mention of the downstaging that's achieved by early detection with a screening program.

The updated guidelines raise many questions. There are major discrepancies between the Canadian and U.S. task forces in terms of the benefits estimated for population-based screening. The U.S. task force predicts more deaths averted and lives saved than the Canadian task force by reducing the age of screening to 40, but even with the conservative Canadian estimate, lowering the age of screening to 40 from 50 would prevent an additional 2,600 deaths over the 10 years of screening in the demographic of women aged 40 to 49.

The task force has opined that this benefit does not justify the harms of additional testing and a few overdiagnosed cases. On this point, I disagree as does the literature, from which we know that women will accept up to six overdiagnosed cases to save one life.

The task force has also ignored the long-term benefits of early detection by focusing only on a 10-year time frame in terms of both the report and the discussion tools to evaluate the benefits of screening. The reality is that, for the most common type of breast cancer, which is hormone sensitive, even if you have a stage 2 or stage 3 breast cancer that may come back some way, probably, even if it does recur within that 10-year time frame, in 10 years you're still going to be alive. You'll just have stage 4 disease and be living through chronic treatments.

As my patients will tell you, living with cancer is not the same thing as surviving it, but the tools being provided to our family physicians make no differentiation of the two points.

Until we figure out a way to prevent breast cancers from developing, the only way to reduce morbidity and mortality as well as the cost to our health care system is with early detection. The task force has significantly minimized the benefits of early detection and has not provided transparent modelling data about the downstaging that can be achieved with an organized screening program. Without this crucial part of the conversation, we are only informing women about half of the story.

● (1125)

I hope my testimony today will start a broader conversation about the harms of breast cancer treatment and the risks of delayed diagnosis.

Thank you.

The Chair: Thank you so much, Dr. Rushton.

At this point, I would like to give the floor to the Canadian Cancer Society.

Your organization now has the floor for five minutes.

[*Translation*]

Ms. Ciana Van Dusen (Advocacy Manager, Prevention and Early Detection, Canadian Cancer Society): Hello. My name is Ciana Van Dusen and I am the manager, prevention and early detection. With me today, virtually, is David Raynaud, who is the senior manager for Quebec. We are part of the advocacy team at the Canadian Cancer Society, the CCS.

The CCS is the voice of Canadians who care about cancer. As part of our commitment to improving and saving lives, we are happy to make recommendations about breast cancer screening.

Cancer is the leading cause of death in Canada. Two in five people are expected to receive a cancer diagnosis over their lifetime, and approximately one in four people will die of the disease.

In Canada, it is estimated that one woman in eight will receive a breast cancer diagnosis in her lifetime. Breast cancer is the type of cancer most often diagnosed in women in Canada, and even though there are fewer cases among women under age 50, it is still the leading cause of deaths from cancer among women aged 30 to 49 years. While the data show that the incidence of breast cancer among women in their forties has risen over the last 35 years, the overall incidence of breast cancer and the mortality rates in Canada are dropping, with improving early detection, treatment and care being significant contributors.

However, international data indicate that more Black, Asian and Hispanic women who have breast cancer receive a diagnosis before the age of 50. In addition, they often receive a diagnosis when the disease is at an advanced stage compared to other women. That means that starting breast cancer screening at age 50 is a missed opportunity to do early screening among the women in those communities.

The data have shown the benefits of starting regular, systematic breast cancer screening starting at age 40. Timely screening is essential in order to detect breast cancer early, when treatments have more chance of being effective.

We will keep hearing about people who have breast cancer whom the current guidelines do not take into account, because those guidelines do not reflect their lived experience.

As well, a national survey has shown that most respondents said they support expanding access to systematic breast cancer screening by setting the age to start screening at 40.

Our organization supports systematic breast cancer screening for women at average risk aged 40 to 49. We also have to make sure there are clear guidelines for people at high or very high risk of developing breast cancer, such as people who have certain genetic mutations, family histories, or dense breasts.

I will now give the floor to Mr. Raynaud.

● (1130)

Mr. David Raynaud (Senior Advocacy Manager, Canadian Cancer Society): Thank you, Ms. Van Dusen.

Thanks also to the members of the committee.

A growing number of Canadian provinces have begun expanding access to breast cancer screening services to people starting at age 40, or have said they would expand access. While the provinces and territories are examining the new national guidelines on this subject, the CCS is calling on governments that have not yet done so to include women aged 40 to 49 who are at average risk of breast cancer in their organized cancer screening programs. This change also reflects the new evidence that has been published between the last update of the guidelines in 2018 and the guidelines that were presented a few weeks ago.

The data about participation in the breast cancer screening program in Canada will be updated shortly by the Canadian Partnership Against Cancer. Our most recent figures date from before the pandemic, and at that time, breast cancer screening programs were not hitting the national target of a 70% participation rate. It is therefore important to expand the capacity to meet the needs of Canadians while at the same time adapting our services to address the needs of underserved populations.

As well, the CCS recommends that the federal government invest more in research, to expand our knowledge about screening and the risks associated with cancer. It is also important to close the gaps in the data so we have a better understanding of the impact of breast cancer in Canada. The pan-Canadian Cancer Data Strategy and the pan-Canadian Health Data Strategy offer good opportunities for improving the data in Canada.

In addition, governments must invest in prevention, early detection and treatment, and reducing the effects of the labour shortage. Those investments include new investments in human resources, integrating new technologies, digital infrastructure, and modernizing care paths to meet the present and future needs of Canadians.

As a final note, I would like to thank you for taking the time to listen to our recommendations. We are eager to continue working together to offer better support to people affected by cancer, because to take on cancer, it takes a society.

[*English*]

The Chair: Excellent. Thank you, Mr. Raynaud.

At this point, I would like to give the floor to CancerCare Manitoba.

Your organization has five minutes.

Dr. Donna Turner (Chief, Population Oncology, CancerCare Manitoba): Thank you very much, Madam Chair.

Thank you also to the committee for the opportunity to speak about the draft guidelines prepared by the Canadian Task Force on Preventive Health Care, also known as the task force on breast cancer screening.

This is an important topic, and all of us here today want to reduce the impact of breast cancer on Canadian women. It's important to remember that we are united in this goal, even if opinions and perspectives differ.

I am Dr. Donna Turner, an epidemiologist and the chief of population oncology at CancerCare Manitoba. Joining me today is Dr. Pamela Hebbard, who is a cancer surgeon and the head of surgical oncology for CancerCare Manitoba.

Breast cancer is a complex subject, and considering breast cancer screening, we find there's often confusion about what is screening and what is not. Screening is a test offered to all women who do not have symptoms and who have an average risk of breast cancer. Women who find a lump in their breast or who are experiencing symptoms that are not normal for them need a diagnostic workup. Women who are at higher than average risk, due to family history or genetic predisposition, are often best served by tailored or individualized screening.

Regardless, our message to all women is that, if you experience something that is not right for you, please see your health care provider right away.

In our province, CancerCare Manitoba works to deliver evidence-based programs, while supporting Manitobans throughout their cancer journey. For example, as a result of the evidence coming forward related to screening, we are promoting screening where the evidence is strongest, including for women aged 50 to 74. I note that, like other Canadian jurisdictions, we have not achieved the 70% target rate among women who are most likely to benefit from screening, which are those in these age groups.

Second, we work with communities and Manitobans who are at risk of being underserved by our health care system, including those who are racialized, gender diverse and/or residents of geographically remote communities, to reduce inequities in breast cancer screening access and ensure improved health outcomes.

Third, we are acting with our health care partners to provide avenues to best support all women to make informed decisions about their health. Based on recent evidence, this includes women aged 40 to 49 who may want to explore their options for mammography by further understanding the benefits as well as the harms.

At this time, I'll turn it over to my colleague, Dr. Hebbard.

● (1135)

Dr. Pamela Hebbard (Head, Surgical Oncology, CancerCare Manitoba): Thank you, Chair, for the opportunity to be here today.

As Dr. Turner mentioned, I am the head of surgical oncology, and my clinical practice is dedicated to the treatment of breast cancer and gastrointestinal cancers.

Particularly with breast cancer, the number of scientific studies is immense and varied. It is important that we don't make health policy decisions based on personal bias or even on a well-meaning desire to make a difference. You need experts who are impartial. They need to not have skin in the game. The statistics that go into these recommendations are complex, and you need experts to interpret the data correctly.

There is a misconception that mammography will prevent cancer or significantly de-escalate the treatment required. This is actually the exception rather than the rule. Breast cancer is not a single disease. We tailor breast cancer treatments based on protein profiles, which is the largest determinant of their treatment. Based on cancer subtype, there are some five-millimetre cancers that will get chemo, and some five-centimetre cancers that will not.

In the modern era of breast screening, this largely impacts how many women are diagnosed with stage 1 versus stage 2 cancers, with stage 3 and 4 cancers largely unaffected by screening programs. The treatment of stage 1 and 2 breast cancer is largely the same.

I believe the harms of screening are real. We know younger women are more likely to have an abnormal screen, which results in multiple follow-up tests and biopsies. Women commonly report this process as highly distressing. In some women, it is so distressing that they never go for screening again and miss out on future benefits.

However, on a health care system level, an increase in mammograms is a large financial and human resources problem, but the outflow of follow-up testing and biopsies is the greater problem and risks creating new and very significant delays in the diagnosis and treatment of those who actually have cancer.

What would be the most impactful to the breast cancer landscape in Canada? We need to increase screening in our current age groups, include women who are remote and those who have social disadvantages and belong to minority groups. In my practice, I see women who die of colorectal cancer at a young age, and people with cervical cancer and many other diseases. I personally see the lack of access to primary care driving more deaths in young women and young men due to this health care crisis.

We also have too few studies on breast cancer prevention, and there really needs to be a renewed focus on this.

In conclusion, I thank the committee and all the people here today who have a passion to improve the future of this disease, even if we see a different way forward.

My final comment is that I'm a 47-year-old mother, breast cancer surgeon and health care leader, and I have not personally had a mammogram, because I do actually believe in the work of the Canadian task force.

Thank you very much.

The Chair: Thank you, Dr. Hebbard.

Lastly, we have Dr. Shiela Appavoo.

You now have the floor for five minutes.

Dr. Shiela Appavoo (Chair, Coalition for Responsible Healthcare Guidelines): Thank you very much.

Honourable members of the Standing Committee on the Status of Women, thank you for convening this important study with such urgency. I spoke yesterday at HESA, so any resemblance between today's statement and my statement from yesterday is purely coincidental.

I'm Dr. Shiela Appavoo. I'm a general radiologist with an interest in breast imaging. I founded and co-chair, along with Dr. McKerlie, the Canadian Society of Breast Imaging patient engagement working group. I also founded and chair the Coalition for Responsible Healthcare Guidelines.

I speak today about my serious concerns about the recent draft guideline issued by the Canadian Task Force on Preventive Health Care regarding breast cancer screening that is recommending against screening women 40 to 49. This guideline stands in stark contrast to those provided by the U.S. task force, the Canadian Cancer Society and the majority of Canadian provinces, all of which have recognized the need to lower the screening age to 40. The Nurse Practitioner Association of Canada has also recently withdrawn their endorsement of the similar 2018 task force guideline.

The decision to not screen women 40 to 49 is biased. The May 30 news that the task force had again refused to recommend screening for women 40 to 49 was not a surprise to those of us following along with the guideline development process. This result was predetermined. The task force leadership indicated in the media in early May 2023, immediately following the release of the U.S. task force guideline draft, that there was no need to change the Canadian guidelines. This was before the evidence review began. Lo and behold, this prophecy was fulfilled almost exactly a year later.

How does the task force come to such different conclusions from the rest of the modern world? Without the context provided by the fulsome guidance of experienced content experts, they amplify harms, such as overdiagnosis, benign biopsies and callbacks for additional imaging, and they minimize the benefits of early detection. In their calculations they do not include important morbidity benefits of screening, such as decreased rates of mastectomy, chemotherapy or lymphedema, a permanent, disabling and disfiguring form of arm swelling caused by aggressive lymph node surgery needed for later-stage cancers.

The task force's focus on the harms of screening, particularly the anxiety of recall, is paternalistic. The paternalism of making decisions for women because of their concern about the possible reaction of anxiety to a recall is disturbing. It's tantamount to saying, "Don't worry your pretty little head about breast cancer."

If instituted, the consequences of these new task force guidelines will be dire. Many young women will potentially pay with their lives. Most provinces and territories have recognized this and have allowed self-referral for women aged 40 to 49. However, the recommendation of a primary care provider is still the strongest predictor of whether a woman will actually go for screening. As long as doctors are being given the task force message that women in their forties don't need screening, many of those women won't get access.

By continuing to make the same breast cancer screening recommendation that the task force has made since 2011, Canada's national guideline is falling farther and farther behind the provinces, other countries and expert recommendations. Unfortunately, these guideline problems are not isolated to breast screening and are a pattern seen in multiple other guidelines, including those that directly affect women's health.

Please bear with me as I veer slightly off the topic of breast cancer, as this is important for context. The task force's pregnancy and postpartum depression, lung cancer and cervical cancer screening guidelines are similarly dismal. All of these affect women.

The cervical cancer guideline has not yet been updated since 2013, despite multiple landmark studies that should have prompted a revision. It does not recommend HPV screening, although this was recommended nationally and instituted in such countries as the U.K., Australia, Norway and the Netherlands dating back to 2017. While Australia is on its way to being the first country to eliminate cervical cancer through vaccination and HPV screening, women in Canada have been getting invasive cervical cancer—avoidably—for the greater part of a decade because of this weak task force leadership.

We must not allow these guidelines to stand as they are. We must have a breast screening guideline that is informed by the latest evidence and not by paternalism, one that truly serves the best interests of Canadians. With respect, looking at its record, we must dismantle and rebuild the Canadian Task Force on Preventive Health Care to safeguard Canadians in the future.

Thank you for your attention to this critical issue.

● (1140)

The Chair: Thank you all very much for your opening remarks.

At this point, we will move on to our rounds of questioning from members.

I'd like to begin with Anna from the Conservative Party, for six minutes.

Mrs. Anna Roberts (King—Vaughan, CPC): Thank you, Madam Chair.

Thank you to all the witnesses for being here. This is an important topic, especially for women.

I have a question for Dr. Shiela Appavoo.

I'm wondering if you can explain this to me. If someone has been adopted and they have no family history, what is the best test in ensuring the prevention of breast cancer?

Dr. Shiela Appavoo: Screening is considered secondary prevention. As opposed to preventing the cancer, it prevents late-stage cancer diagnosis. In general, for people who have no available family history, so whether they're adopted or estranged from their family, we treat them as average risk. Again, our recommendation is to start at 40 and screen annually until they are within 10 years of life expectancy.

Mrs. Anna Roberts: My other question is this...and this has happened to someone I know. If there's a family history of breast cancer and breast cancer is detected in one of the breasts, in Ontario they'll remove that breast but not the other one because that would be considered cosmetic. However, with this particular individual, two years after the breast was removed, she received a diagnosis of stage 3 breast cancer in the second breast. Why wouldn't they have removed both?

● (1145)

Dr. Shiela Appavoo: I can't speak to Ontario, and I'm not a breast surgeon or involved in treatment. I'm more involved with diagnosis. However, perhaps I could defer to one of my colleagues who is more of an expert in that field.

Dr. Rushton...?

Dr. Moira Rushton: Sure. I'm not a surgeon, but I do see a lot of patients with early-stage breast cancer.

The current guidelines for surveillance after a breast cancer diagnosis is annual breast imaging of both breasts. Having a singular breast cancer diagnosis does increase your risk of having contralateral breast cancer, so for our breast cancer survivors, our recommendation is to have annual mammography screening for, essentially, the rest of their lives.

Typically, patients who have undergone treatment would have their first mammography screening.... At least here in Ottawa, our standard would be to do it six months after the completion of radiotherapy, as their baseline.

I agree with Dr. Appavoo that it's very difficult to comment on an individual case, and I think some of our guidelines have evolved over the years. Now we're doing a lot more MRIs for patients at time of diagnosis, especially if they have risk factors like dense breasts, to ensure that there are no small contralateral lesions that are being missed.

However, it is currently not the standard of care to automatically do a prophylactic contralateral mastectomy because it has not been demonstrated to improve survival. The focus, rather, is annual screening in all breast cancer survivors, which is also a problem in our breast screening programs because in most provinces breast cancer survivors are excluded from screening, meaning they have to go back to their primary care providers year after year to get those screening mammograms.

Mrs. Anna Roberts: In this particular situation, the mother had breast cancer, and two of the three siblings had breast cancers. The doctors of the siblings have recommended that the female grandchildren—because it is a pattern because the great-grandmother also had breast cancer.... They were refused by their family physician to have the screening because they were under the age of 40.

However, because they have a history of multiple diagnoses going back, you know, 100 years, why would we not go ahead and do the mammograms?

Dr. Moira Rushton: Family doctors in Canada go through four years of medical school and two years of residency training for their specialty. They have extremely limited exposure to any sort of education around oncology, and breast cancer is no exception. At the University of Ottawa, they get about one week of oncology lectures in their time during medical school, and there is no mandatory training in oncology.

The real biggest issue with the task force is that the task force guidelines are about as much as the family doctor has time to understand and process. If a big national organization recommends against routine screening, then they are not going to do routine screening because they do not have the time, and nobody has taken the time to educate them or include this in their medical education over the years.

That family that you speak of should have been referred—or if they have not, should be referred—to medical genetics for genetic screening. Those members of that family should be in a high-risk screening program.

Mrs. Anna Roberts: Would you agree that we have to put the patient care back onto the patient? I agree with you. I mean, let's face it. There's a shortage of family doctors, a shortage of experience. However, do you agree that lives are more important than skipping a step?

Dr. Moira Rushton: Absolutely.

I do think that this discussion around screening and health screening is an opportunity for us in Canada to think about more meaningful health care reform. We can think of what the evidence-based ways are that we can help save lives and about how we can skip that step outside of a primary care provider, because our family physicians are burning out. They do not have the capacity for us to be putting more on their plates by saying, “Now please have detailed risk-benefit ratios.”

With regard to government organizations, I'd really like to see the government, public health and provincial health providers providing screening programs that patients can self-refer to, much like what is about to start in Ontario in the fall, so that they can make that decision and then follow up with their family provider to review the results.

Trying to make family doctors continually be the gatekeepers to all medical care in Canada fails so many because, even in Ottawa, about 30% of people don't have a family doctor.

The Chair: Thank you very much.

At this point, we'll move on to Sonia.

You have six minutes for the Liberal Party. Thank you.

● (1150)

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 the representative from the Canadian Cancer Society and then all the witnesses who want to reply can contribute to that. I would like to know about the differences across provinces and territories in their outreach approaches to testing women and the treatment of breast cancer.

Ms. Ciana Van Dusen: We know that the recommendations are as such. They're guidelines. The provinces have the ability to make informed decisions for their populations, and they are doing so across Canada.

In the last few months, we've seen various provinces make the decision to expand access, whether self-referral or systematic screening. It is important to note that there is a difference there and that self-referral does still require women to know that they have access, that they have a right to it and that they can go and get it, as well as a certain amount of education and resilience in pursuing that, as opposed to a systematic approach where the invitation comes to you and it's a lot more streamlined and clear.

Those are some differences as far as how we carry out access to breast cancer screening, but both are certainly steps in the right direction. I'm not sure if there was a second part to your question as far as differences are concerned.

Ms. Sonia Sidhu: Thank you. Would anyone else like to contribute on that?

Go ahead.

Dr. Jean Seely: I can tell you that the Canadian practice has been a patchwork of guidelines. Some provinces have been screening women in their forties by allowing self-referral since the program started, like in British Columbia, Nova Scotia and Prince Edward Island. Others have come on board. Currently, as of this date today, that's all the provinces and territories except Nunavut, which does not have a screening program, and Quebec, which is looking at the evidence for screening women in their forties. Manitoba is the only one that has not adopted this policy for self-referral for women in their forties. Alberta starts at 45. The other provinces all start at age 40.

We have had the opportunity to study this differential. What we've shown, in this large study done with Statistics Canada, is that the women who have been diagnosed through screening in their forties in these provinces that have been screening have a significantly higher rate of early-stage breast cancer, and the provinces that do not include those women in their forties have significantly higher rates of those more advanced cancers at stage 2, stage 3 and stage 4. There's also a differential in approach to density.

This is the opportunity we have for the guidelines to make a more standardized approach, and one of the reasons we're so disappointed with the draft guideline.

Thank you.

Ms. Sonia Sidhu: Thank you, Dr. Seely.

As a follow-up—

The Chair: Sonia, I believe Dr. Turner wants to contribute to that as well.

Dr. Donna Turner: Yes. Thank you, Madam Chair.

I just wanted to note that in some provinces, for example in Manitoba, the breast screening programs work very hard to connect with communities of various racialized populations and indigenous populations, in particular in a province like Manitoba.

I think it's really important to note that one of the things we have not done well in Canada is capture information on race and ethnicity or, in fact, in terms of gender identity. This is an area where we see that there is a great possibility for advancement.

In Manitoba, our breast cancer screening program is asking women to self-identify in terms of their race, ethnicity and indigeneity, following a practice that has been developed in Manitoba with communities and in partnership with communities and health care leadership. It's really an important step forward in our getting more information on what we can do for women who are in potentially equity-denied populations.

Ms. Sonia Sidhu: Thank you, Dr. Turner.

You raise a very good point regarding the data collection for racialized or indigenous populations. Do all provinces collect the data? What could you tell us about data collection specifically for racialized women? The Cancer Society or anybody can answer.

Dr. Jean Seely: Perhaps I can answer that because I was involved in a large study with Statistics Canada.

Unfortunately, the data for race and ethnicity is not collected and not correlated with the method of detection of breast cancer, so we had to do a very circuitous registry adjustment and correlate it with the census data to be able to provide that race and ethnicity data. This is really a significant gap, and we need to be able to collect these kinds of data to be able to show the impact of screening in these women of different races and ethnicities.

Our data does show that there is very significant harm being done to the women of races and ethnicities other than white, and that includes indigenous women and women of all ethnicities in Canada, with a higher rate of advanced-stage breast cancer.

This is a call for increasing the data collection in different provinces and territories to be able to capture this more readily and to demonstrate the impact of screening and diagnosis.

● (1155)

The Chair: Sonia, I see that there are several others who want to contribute to this conversation, but your time is up.

Perhaps those who have their hands up can find the room to provide an answer in some of the following questions.

Next, I'd like to invite Andréanne Larouche.

[*Translation*]

It is six minutes for the Bloc Québécois.

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

Thanks to the witnesses for being with us today.

Breast cancer is devastating for women and for entire families. We all know women who have died or are still suffering the consequences. That is the case for me. So I want to thank all the witnesses for participating in this study, in memory of all the women who have died and in solidarity with all the women who hope to continue living.

My first question will be for Ms. Van Dusen and Mr. Raynaud, from the Canadian Cancer Society.

What I am hearing today is that more and more studies are showing the importance of prevention. I would like to hear your views on the guidelines that serve as a manual on the subject of screening for people starting at age 40.

Quebec may not have guidelines about this yet. However, the Institut national d'excellence en santé et en services sociaux is working on revising Quebec's rules on the subject, so something is happening in this regard.

There are also examples at the international level. No one would want to turn back the clock when it comes to the guidelines for people starting at age 40.

[*English*]

Ms. Ciana Van Dusen: There is a growing amount of evidence, reports, data and methodologies across various areas that are demonstrating both the advantages in terms of the lived experiences of these people diagnosed with cancer but also the advantages to our system of catching cancer early when it's most treatable and less expensive.

I think that when we look to the United States, their guidelines having changed most recently, it is a good indicator. We have race-based data internationally that we have not previously seen or had access to, and we know that we have a very diverse population in Canada whose needs we need to meet.

Also, I will just mention that there are women of that age group—50 to 74—who currently have access and are not being screened. It's really important that as we consider expanding access, we're not leaving these people further behind and are supporting this expanded access that women should have with resources, whether that's health resources, human resources, technological resources or financial resources, so that we're delivering this in the way that is intended.

[*Translation*]

Ms. Andréanne Larouche: Mr. Raynaud, do you have anything to add?

Mr. David Raynaud: We are talking about prevention and early detection, which are two different things. As we said in our opening statement, we can also do things upstream from cancer by trying to promote healthy lifestyles, for example. That said, early detection is definitely a key factor, not only for increasing survival rates, but also for reducing the impact of treatments and for the secondary effects. We have seen this in some of the accounts we have heard. Having better early detection means that the burden of treatments on patients and the secondary effects can be limited. This is also a way of reducing costs to the health care system, because there could be lighter treatments.

That is what I wanted to add, to supplement my colleague's answer.

● (1200)

Ms. Andréanne Larouche: Well said. In fact, Ms. Farber's poignant testimony, which we heard first, was to the same effect.

Mr. Raynaud and Ms. Van Dusen, I would like to continue my questions for you.

We are talking about the guidelines for screening starting at age 40. It is all very well for the federal government to establish these guidelines, but ultimately, that will serve no purpose if it does not then provide its share of investments. I am talking about transfer payments here. It has not invested enough in the health care system over the last few years and we are now seeing the tangible consequences. It has allowed the systems in Quebec and in the provinces to grow poorer. It has made cuts to health transfers over the years. It has not met the expectations of Quebec and the provinces in this regard.

As you said, a standard is one thing, but Quebec and the provinces, which control their own systems, then need to have the resources. I am talking here about financial resources, technological resources and human resources.

It is important to reinvest in the health care system to avoid it falling victim to an era of austerity and to have the financial resources to provide appropriate care and treatment.

[*English*]

Ms. Ciana Van Dusen: Do you have your hand up?

Dr. Shiela Appavoo: I may attempt to answer that. Recent studies that I think were done by Dr. Seely and colleagues have shown that, based on screening annually from 40 to 74 modelling and modern treatment costs—which are very expensive—Canada would save about $460 million per year in treatment costs. I think investing in screening will pay off in spades for the government. They need to take the plunge and make the investment up front, and I think they will reap the rewards in the next few years after that.

[*Translation*]

Ms. Andréanne Larouche: I have only a few seconds left, so thank you.

[*English*]

The Chair: Thank you. Unfortunately, that's your time. Well, you have about three seconds.

[*Translation*]

Ms. Andréanne Larouche: To summarize, not only is more money needed, but prevention would also save money and allow more to be invested in treatments for the victims.

[*English*]

The Chair: Next up we have Leah from the NDP.

You have six minutes as well. Thank you.

Ms. Leah Gazan (Winnipeg Centre, NDP): Thank you so much. I want to thank all the witnesses. The testimony is just magnificent. If we can keep our responses brief, I have an agenda.

One of the comments that was really shocking to me is that people making decisions can't have skin in the game. I actually disagree.

My first question is for Ms. Farber. I'm wondering if you could provide a key recommendation to our committee to improve the health care system based on your experience. If you had one key recommendation, what would it be?

Ms. Shira Farber: As it pertains to screening, because that's why we're here today discussing these guidelines, I firmly believe that Canadian women should be allowed to self-refer and be included in a screening program starting at the age of 40. I also believe that women over the age of 74 who want to participate should be able to continue to do so. There are a lot of women in their later seventies who are in great health and would like to have the right to detect their breast cancer early too.

I believe that women who have breast density should know that. I think that's a major risk factor. I didn't know that I had dense breasts until my pathology results came back. How would I ever know that was a risk for me if I had never had a mammogram before my cancer diagnosis?

In my opinion, that's what will empower women and allow them to have these discussions with their family doctors—for those of us who are lucky enough to have family doctors, because, as we know, there are a lot of Canadians without family doctors right now.

Ms. Leah Gazan: Thank you so much.

My next question is for Dr. McKerlie.

Shockingly, but not shockingly, I'm wondering if you are aware of the makeup of the task force right now. Give me a yes or a no, please.

Dr. Ify McKerlie: Yes.

Ms. Leah Gazan: What is the number of folks on the task force who are Black, indigenous and people of colour?

● (1205)

Dr. Ify McKerlie: I am not actually sure what their ethnicities are, but I think it's very few of them.

Ms. Leah Gazan: Okay. How many of them are women?

Dr. Ify McKerlie: I'd have to check.

Ms. Leah Gazan: I asked that because I think inclusion is intentional, and sometimes we don't look at specific factors if certain people are excluded from tables. I am concerned about it.

Dr. Appavoo, you spoke about paternalism and saying, “Don't worry your pretty little head” about it. Can you expand on that? What is a key recommendation you would make to address that level of paternalism that seems to be costing the lives of women and gender-diverse people?

Dr. Shiela Appavoo: Thank you for asking that question.

I think there's paternalism at several levels. One of the most obvious is the idea that recalls are a harm that should be weighed against the possibility of an avoidable late-stage diagnosis, which may mean harsher treatment and potential death.

A recall is where somebody gets pulled over after their mammogram to go back for extra testing. I liken it to going through security at the airport. They put your carry-on through the X-ray, and every once in a while they'll see something in your bag, ask you to come over and check your bag. Then most of the time you're not carrying anything dangerous, and you can just go on your way.

That's very much similar to what the process is with mammography. A recall is not a harm. It's unpleasant. I do not diminish the level of anxiety and shock that there is in finding out you have to go back for another look, but it's transient. The reason people are worried is that they don't want to die of cancer, and that's what this is all for. We are trying to avoid having people die of cancer, so they get worried when we call them back, but that's part of the process. It's a lot of hard work not to die of cancer.

Ms. Leah Gazan: What would your key recommendation be?

Dr. Shiela Appavoo: My key recommendation would be to acknowledge the anxiety, but not put it into an equation where you weigh that against the potential benefits of not having late-stage treatment or potential death. It is something to acknowledge, to warn people about, but it has no business in an equation.

Ms. Leah Gazan: Okay. Thank you.

Do you have something to add?

Dr. Ify McKerlie: Yes, I was thinking about that question in terms of knowing what the specialties of the people who comprise the task force are, particularly with your comment about having skin in the game and the bias for breast experts. I've always thought about that and wondered what the bias is.

We as radiologists in probably most institutions out there are known as people who are busy, and we always say no. On that skin in the game, we want what's best for our patients, and we wouldn't do anything just for.... I think I can speak for most radiologists. I'm not exactly sure what that bias is. Is it monetary? It's one thing to be sitting and making these guidelines and thinking about one in *x* number of people. It's another thing to be actually dealing with people individually and seeing them as people, not numbers on a paper. It's different.

Ms. Leah Gazan: Thanks very much, because I am concerned about the lack of data and the fact that the lack of data is impacting certain populations, because we don't have the research that's needed.

I'm going to Dr. Seely. It's shocking that Nunavut is the only territory that doesn't have breast screening. We know that Nunavut, in terms of access to essential services, is lacking housing. We're often turning a blind eye to the folks of Nunavut.

The Chair: Leah, you have exhausted all of your time, and then some.

Ms. Leah Gazan: Oh, wow. I never look at the chair.

The Chair: She avoids looking at me.

I was a little bit generous, but we need to move on. Perhaps we can incorporate that question Leah was alluding to further on in the discussions.

At this point, I'd like to start our second round with Dominique with the Conservatives.

[*Translation*]

The floor is yours for five minutes.

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

So much intelligence today! We often hear highly intelligent things from witnesses appearing before this committee, but today you are all truly very inspiring. Thank you for being here and for your testimony.

I am going to try to speak slowly so the interpreters are able to convey my thoughts to you well.

To begin, I have to tell you that I have a personal experience that I will not recount here, but my colleagues are aware of it. Among my family and friends, I also have women who had to have mastectomies in their thirties. I can confirm that you are telling the truth when you say that more and more young women are facing the problem of breast cancer. Ms. Roberts cited the example earlier where cancer is diagnosed in one breast but the other is healthy. Sometimes, the person might nonetheless decide to have the second breast removed as well. We can see how very difficult these situations are.

I was surprised by something I heard this morning and I had seen in my reading, which is the talk about harms caused by early detection. I am flabbergasted. Personally, I started having mammograms when I was a young woman, which makes for a few years now. How can anyone talk about harm in screening? Explain that to me. I do not understand how anyone can reach that conclusion.

Dr. Appavoo, what are the disadvantages or harms associated with early screening? I cannot believe that the disadvantages or harms come down to simply getting telephone calls to tell us to go and get tests done or redone. For myself, I was quite happy that they called me back and they insisted.

What, then, are these harms that the task force is taking into consideration?

● (1210)

[*English*]

Dr. Shiela Appavoo: Thank you for asking that question.

Everything has pluses and minuses. There are a few downsides to screening.

One of them is that about 7% to 10% of women who get a mammogram may get called back to have a second look. About 95% of those women will get a double-check, be able to breathe a sigh of relief and go home knowing they got a little bit of extra care and attention. They're good until their next screen. Most of them will be fine.

I don't like to diminish the worry. I mean, mental health is important as well. I don't diminish it, but in comparison with a delayed diagnosis, I think it's trivial. That's my own personal opinion about that.

I would say there is a more significant harm in the form of something called overdiagnosis, which is essentially the chance that your cancer is found. You poked the bear. You went hunting for cancer and you found one, but that cancer could have sat there until you died of other causes and you would have never had to have the treatment. The treatment itself is unpleasant, to say the least.

However, the good news is that, for the youngest women, that is a very trivial likelihood. It's around 1% or less than 1%. That is because your chance outliving your cancer, basically, is based on whether or not that cancer is aggressive. Is it one that's going to grow? Also, how much lifespan do you have left?

On the one extreme end, if you do a mammogram on somebody who's 85 and she has heart disease, that's overdiagnosis, but for somebody who's 40, it's not going to—

[*Translation*]

Mrs. Dominique Vien: I am going to have to interrupt you, because I do not have much time left and I would like to add a brief word. I apologize.

You said earlier that the working group should be dismantled and another one appointed. What are the main characteristics or the main reasons that led you to say that? Who do you think should sit on that committee?

[*English*]

Dr. Shiela Appavoo: For the new task force, first of all, it's not for me to actually do that. I think that would be a project of its own. However, we do have some recommendations.

I think that we need to rebuild it with accountability. We need to rebuild a new task force with accountability, with transparency and with experts. The idea of bias and eliminating the need for experts is based in a logical fallacy, an ad hominem attack and an appeal to motivation, which is—I'm sure most of you have debated here at some point—really not a valid argument. Everybody has bias. There's some sort of bias in everybody and you have to work around it.

You can't throw out expertise in trying to eliminate bias.

[*Translation*]

The Chair: Thank you, Mrs. Vien.

Mrs. Dominique Vien: Have I already used up all my time?

The Chair: Yes, your five minutes are up. I'm sorry.

[*English*]

Next we have Emmanuella for five minutes.

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

I'd like to thank all our witnesses for being here today. All of you are great.

Dr. McKerlie, Dr. Rushton and Dr. Appavoo, I want to particularly thank you because I was the person who submitted your names. Jennie Dale from Dense Breasts Canada was the one who had sent me your names.

In honour of her and of all of the women fighting to improve the outcomes for women with dense breasts, I'd like to ask you if there's any evidence that has come out in the last decade that you think should have been considered by the task force when putting out the report.

In the report, it actually says that “for women with moderately increased risk due to high breast density...[they] did not find find any evidence on the benefits of supplemental screening”. That's not what we heard today. If anybody can explore that a little bit more and provide some more details, that would be great for a first question.

Go for it.

● (1215)

Dr. Ify McKerlie: I'll just start by saying that they did put it in the guidelines. There's been a lot of research done in the States to show that women with dense breasts have at least a four to six times higher risk of getting breast cancer.

If you add MRI to supplemental screening, I think you pick up at least 80% more cancers, where in a mammogram it would have been normal. If you add ultrasound, you'd pick up at least 50% more. There is for sure some evidence to show that supplemental screening would help pick up more cancers and that should have been factored into guidelines.

I'll stop there.

Ms. Emmanuella Lambropoulos: Dr. Rushton.

Dr. Moira Rushton: In discussion with one of my colleagues, part of the issue with a lot of these studies is that the end point perhaps is not the right end point we need to look at. The end point is often a hard end point of survival, instead of looking at the stage migration that we achieve with early detection.

I would disagree with the chief surgeon from Manitoba who indicated that the treatment of stage 1 and 2 breast cancer is essentially the same. Historically, that may have been true, but every year we're achieving advances in systemic therapy of breast cancer, where that's no longer the case. Even in the worst actor of triple negative breast cancer, where even a small subcentimetre node-negative tumour gets chemotherapy, one that's larger than two centimetres or has lymph node involvement will have immunotherapy and a more aggressive chemotherapy. Systemic therapy is really working to de-escalate treatment where we can in earlier-stage disease, but also very much escalate for stage 3 disease across the board.

Stage does matter, and I think end points matter. The problem with the evidence review and the lack of expertise is that there is no one there to put it into the context of what it means to treat breast cancer today.

The Chair: Emmanuella, Dr. Hebbard would like to contribute as well.

Ms. Emmanuella Lambropoulos: I'm sorry. I have another question.

I actually took a look at the composition of the task force. It appears that there are quite a few women. It seems like it's almost equal in women and men. However, there is only one Asian woman and one Asian man. Besides that, everybody is white.

Do you think that had any effect on what those recommendations looked like?

Dr. Shiela Appavoo: I can answer that.

I don't think there were actually any women of colour on the working group that actually addressed breast cancer. I don't think that necessarily influenced what they said. I will grant that they weren't making racist recommendations because no people of colour were in the room. However, I do think that it's symbolic of a disregard for racial equity.

One of the things that I think is also indicative of that is their use of GRADE to elevate the ancient RCTs above the observational studies. Ninety-eight per cent of those RCTs were done from the sixties to the eighties on white women. They put that evidence as the top level of evidence, and everything else, which may have been much more diverse, was given a lower importance, so there is a systemic form of racism there.

I think the fact that there were no women of colour on the working group is possibly a symptom of the same disease.

Ms. Emmanuella Lambropoulos: Thank you very much.

I don't have much time, but I would like any stats that you can send to the committee on dense breasts, any facts that we can include afterwards in our report.

By what date do they have to submit?

Ms. Clare Annett (Committee Researcher): It's tomorrow.

● (1220)

Ms. Emmanuella Lambropoulos: They're due by tomorrow, so if at some point today you could send in some statistics on dense breasts, which you mentioned, Dr. McKerlie, and anything else that you have, that would help us send the right information to the task force.

This is what's going to happen with this study. It's going to end up being sent there so that they can consider this. Please do send it in.

The Chair: Thank you, Emmanuella.

Next, Andréanne, you have two and a half minutes.

[*Translation*]

Ms. Andréanne Larouche: Thank you, Madam Chair.

Before asking my question, I would like to check one thing. You all seem to have studied the subject extensively. Can you tell me, by raising your hand, whether some of you were consulted by the working group?

Ms. Sonea, were you consulted?

Ms. Helena Sonea (Director, Advocacy, Canadian Cancer Society): Yes.

[*English*]

La présidente: Andréanne, I think Jean Seely has her hand up as well online—just so that you are aware.

[*Translation*]

Ms. Andréanne Larouche: Perfect, thank you.

I would like to know, in the case of the people who were consulted by the working group, what they had the opportunity to tell it. I would ask that they give me a summary, since I do not have much time.

We could start with Ms. Sonea and then hear Ms. Seely, who is joining us by video conference.

[*English*]

Ms. Helena Sonea: Thank you very much for the question.

We were consulted along the way. For us, it was really important to ground this entire experience in what patients are experiencing, making sure that, as part of their considerations as they were building out their guidelines, the patient experience was front and centre in their considerations and making sure that we were being holistic in that approach.

Dr. Jean Seely: I was one of the expert advisers on the evidence review, and the advice we provided was rejected by the task force on multiple occasions. Anyone who was able to be an adviser to the working group had to sign a non-disclosure. They could not disclose what their input would be. It was something that I did not do for that reason.

I can tell you that, on numerous occasions on the evidence review panel, we could see the lack of understanding of the screening and of the understanding of the studies we were talking about, so it was really not well regarded and not well taken into consideration.

[*Translation*]

Ms. Andréanne Larouche: Forgive me, I am a bit in shock. You were consulted and you made recommendations, but you were disregarded and you were made to sign a non-disclosure agreement.

Can you tell me, in two or three seconds, what the reason for that was?

Mrs. Dominique Vien: And yet it is a public issue. That is unbelievable.

[*English*]

The Chair: Thank you, Andréanne.

Leah, you have two and a half minutes.

Ms. Leah Gazan: Thank you so much.

I agree with my colleague Andréanne Larouche. It is totally shocking, this whole notion. It's like this hysterical woman's syndrome. We know that the health care system has historically reeked of sexism, which is why I ask the question.

I certainly don't think that representation doesn't exclude expertise, but in having other folks making decisions about my body as a woman, I'd like to see some women around the table and certainly women around the table who reflect my background and ethnicity.

In saying that, I want to ask Dr. Seely a very basic yes-or-no question, and then I want to ask you another question. In Nunavut, do you think it's critical that they immediately implement a breast screening program? Please answer yes or no.

Dr. Jean Seely: Yes.

Ms. Leah Gazan: Okay, you would recommend that.

Dr. Jean Seely: Yes. In fact, I do interpret those mammograms, and I've been working to try to implement this in Nunavut. We're working toward that.

Ms. Leah Gazan: Okay. Thank you.

You also spoke about data, that there's not a lot of data on Black people, indigenous people and people of colour. Would you recommend a major federal investment to do more research geared towards breast cancer as it impacts Black people, indigenous people and people of colour?

● (1225)

Dr. Jean Seely: Absolutely. There is an urgent need to collect these data and to add this to how we track breast cancer and other cancers in Canada so that we know who is getting breast cancer and at what stage.

Ms. Leah Gazan: I have only 25 seconds left.

Dr. Appavoo, you mentioned that you have a list of recommendations for the task force. Could you please submit those recommendations to the committee?

Dr. Shiela Appavoo: I will.

Ms. Leah Gazan: Do you believe that sexism has impacted decisions made by the current task force?

Dr. Shiela Appavoo: You know, in all fairness, I think they are equal-opportunity bad guidelines. The prostate cancer guidelines are similarly distasteful to people who know about prostate cancer. I would have to say that I don't see it as being specific to gender. I see as it being specific to incompetence.

The Chair: Thank you, Leah.

Next we have Michelle for five minutes.

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

Thank you so much to our witnesses for this really important study.

Thank you to my colleagues for sharing their personal stories. There's certainly no shortage of people who have been impacted by breast cancer.

We're here trying to get some information about screening at an earlier age, in particular age 40. I will start with Ms. Farber, who has shared her personal experience of being diagnosed.

You wanted a mammogram at 40, but you were discouraged. What was the reason for this?

Ms. Shira Farber: When I talk about this, I want to really make it clear that this wasn't a case where I was advocating hard and my doctor denied me something. Every year I go to see my family doctor. There are certain things we've done—a pap, for example. By the way, I've never been asked about my personal preference or my values and whether or not I want to have a pap. That's kind of interesting to me.

It was just about the things that needed to be done. I needed blood work. I needed my tetanus shot. When I asked if I needed to have a mammogram, since I was 40, the response was, no, the Canadian guidelines now say that you don't need to have one until you're 50. I asked again later on, I believe when I was 45, and received a very similar response. It was a very casual discussion. I think that's probably more reflective of the types of conversations that are happening between patients and doctors in busy family doctor offices.

I was also told that I had no family history, and therefore I was very low risk, which I have now found out is not true. We know that the majority of breast cancers that are found in women are found in women without a family history.

Ms. Michelle Ferreri: What's interesting there is how you kind of rationalized that you didn't have to advocate hard. I find that bizarre when we're dealing with our doctors. It's our body. We live with it all day, yet we have to sort of fight to be heard. I feel that a lot from folks.

Dr. McKerlie, you said that the guidelines currently are based on a study from the 1980s, and this study is flawed. How is it flawed?

Dr. Ify McKerlie: Thanks for the question.

A number of things went on, including a randomized controlled trial, which is supposed to be the gold standard. There were issues with that randomization. There are papers that have shown that to be the case. There were other issues as well as that non-randomization.

Of course, one of the main things, even if the study was equal and perfect, was the fact that they used 98% white women—Dr. Narod agreed in the House of Commons last time—when we know that this is not reflective of the Canadian population today.

Ms. Michelle Ferreri: Thank you for that.

I think what's kind of shocking for a lot of provinces is that you can only get a screening mammogram if you have a referral from family physicians. One in four Ontarians are without a family doctor and 6.5 million Canadians don't have a family doctor. On the Ontario website, it says that if you don't have a doctor, phone this number—like you're going to get one. I think that's pretty hysterical.

This is a big problem. I know that you can self-refer in some provinces where that's changed, but the reality is that, if the waitlist is too long and there's a backlog, what does that even do?

I have a question for whoever wants to answer it, but I guess I'd look to Dr. Rushton on this. If we move this number back to 40 right now...but even say that it is 50. You don't even get it at 50, because there are not enough doctors. There are not enough spaces. I think even moving it back to 40, you might not even get it at 40, if I do the math.

I'm not sure who wants to answer that.

● (1230)

The Chair: Michelle, if I may—

Dr. Jean Seely: Maybe I could take it.

The Chair: —there are three individuals on the screen behind you who do want to chime in. I don't think you can see the screen from there.

Ms. Michelle Ferreri: I can't.

Dr. Jean Seely: I'd be happy to comment on that. It's a great question, and it addresses some of the concerns from Manitoba.

In Ontario we are planning, and we are allocating resources, to increase the screening program to include women in their forties. We know, based on British Columbia and Nova Scotia data, that the first screen has the highest abnormal recalls. Then it drops to the same if you're in your forties, fifties or sixties. It's not higher if you're in your forties.

You do need to allocate resources, but we are going to be able to do that in Ontario by increasing the training of technologists, more mammography units and more access to these diagnostic tests. This will be beneficial.

The Chair: Thank you for that.

I know we have a lot of information that we're trying to get out. Unfortunately, the five minutes is exhausted. If any of you could submit any additional information that you have in response to that question, that would probably be helpful for the analysts.

I'd now like to welcome Anita.

You have five minutes.

Ms. Anita Vandenbeld (Ottawa West—Nepean, Lib.): Thank you very much. I just have to say that I think this is probably one of the most impactful panels we've had in this committee, and I am incredibly grateful that we have had the ability to create the platform to bring your voices into a process that clearly has been lacking those voices.

Ms. Farber, I just wanted to say to you that I have a feeling that lots of us around this table, and those who are watching, are thinking precisely what you just described. I think you're describing what is probably, in reality, the lived experience of most women. Thank you so much for that testimony. I'm so sorry for what you had to go through.

I want to start my questions with Dr. Seely, because you mentioned that the task force was looking at obsolete technologies and old reports, sometimes decades old, and that it ignored recent observational trial data I think you said that 2.6 million women were in that. I just wonder if you could elaborate a bit on the methodology and the reports and the actual data and information that were addressed by the task force and how that may have led to the flawed results of the task force.

Dr. Jean Seely: One of the recommendations that I and two other expert advisers made to the evidence review team is that using the old randomized trials would really be an error in looking at the new evidence. The reason for that is that the methodology called GRADE, which Dr. Appavoo referred to, automatically characterizes that as the highest quality evidence. It doesn't matter if you include another 90 studies after those randomized trials; it automatically downgrades that.

What we showed in our evidence review is that, if you look at the observational trials, you see that the benefit of reducing mortality was 50%. It is a huge benefit. However, if you only look at the randomized controlled trials, you see that it lowered it to about 20%. This methodology, which was insisted on by the task force, downgraded all of these very large extensive trials that included more modern treatments. That was one of the points that we recognized they had disregarded.

Ms. Anita Vandenbeld: You also briefly said that you had a non-disclosure on inputs that you would want to provide to the task force. Can you elaborate on that? It doesn't seem quite transparent.

Dr. Jean Seely: The task force had a call for experts to be consultants and advisers, but the condition of being one of those advisers had to be that you signed a form that removed any possibility of your disclosing what the process was and was involved with. These experts also were non-voting members. I decided that was a risk that I was not willing to take, but I was able to work with the evidence review team and to really see what the working group was insisting on by this evidence review.

I could see their interference, really, and their direction, which really hampered the evidence review team from doing the work that had been proposed, which was to look at the recent evidence, which was what was done in the United States. They only looked at studies from 2016 on. This protocol was not adopted by the working group, and I think that is one of the reasons we have these recommendations.

● (1235)

Ms. Anita Vandenbeld: In fact, there was a disincentive for experts to participate in this. That's quite alarming.

I did want to go quickly to Ms. Van Dusen, because—

The Chair: Anita, just so you're aware, Dr. Turner does have her hand up as well. I didn't know if you saw it.

Ms. Anita Vandenbeld: Yes, I want to try to get to as many as possible.

The Chair: Of course.

Ms. Anita Vandenbeld: I did want to ask Ms. Van Dusen quickly about international data. You said that there was international evidence that was not taken into account. Could you explain that?

Ms. Ciana Van Dusen: We have a whole list of data that we informed our recommendations on, both in Canada and internationally. I'd be happy to provide that.

Ms. Anita Vandenbeld: Perhaps you could actually submit that in writing.

Ms. Ciana Van Dusen: Yes.

Ms. Anita Vandenbeld: It was Dr. Turner, I guess, who wanted to speak.

Dr. Donna Turner: Yes. Just very briefly I wanted to note that I really would encourage people to go and have a look at the task force's website. They did collect information on the feedback they had from people, including their responses. As you know, these are draft guidelines, and right now they are currently open.

When you look through, I think you'll see they have been quite transparent about the studies that they included and didn't include, and they've expanded their look. I think actually that's one of the reasons why the discussion around 40 to 49 has actually been more on the table now in terms of enabling people to have those conversations. I just wanted to encourage that.

Ms. Anita Vandenbeld: I'm so limited in my time, and I did want to go to Dr. Appavoo because you—

The Chair: Anita, I'm sorry to share with you that I tried to get in an extra 30 seconds but it's not working.

Because of the efficiency of all of you around the table, we do have time for an entire fourth round, so I'd like to start.

Anna, you have five minutes.

Mrs. Anna Roberts: Thank you, Madam Chair.

I'm going to ask everyone a simple question: Do you consider it to be a risk, as according to the task force, to have a family history carrying the mutation gene of BRCA1 and BRCA2 or to have dense breasts? If everyone could just say yes or no, that would be great.

Dr. Ify McKerlie: Yes.

Mrs. Anna Roberts: I think we all agree with that. We're all in agreement.

The Chair: Dr. Turner has her hand up.

Mrs. Anna Roberts: Does she not agree with that?

The Chair: I don't know.

Dr. Donna Turner: No, I do agree. I just want to note that it is increased risk. Those are not average risks, which is what the guideline—

Mrs. Anna Roberts: Okay, that's increased risk.

Would you agree, if that is the case, there should be mandatory genetic testing, yes or no? I'd like just a yes or no from everybody.

Dr. Moira Rushton: No.

Dr. Jean Seely: No, I think risk assessment should be done. That's very important, but not necessarily genetic testing.

Mrs. Anna Roberts: Okay. I just did some research with the Cancer Society. Breast cancer is the second cause of cancer death among women. It is 25% of new cancer cases in females. In 2024, it is estimated that 5,500 Canadian women will die, so 15 women will die of breast cancer every day.

This is something I think all women—all of us—feel: In order to prevent the mortality rate, we should push the task force to increase the testing at age 40. Does everybody agree with that?

Voices: Yes.

Dr. Jean Seely: If I could just make a comment, unfortunately, the genetic testing only identifies 50% of women at high risk, and the majority of women do not have any risk factors that would tell them they're at high risk. They wouldn't carry the genetic mutation, but they would still get breast cancer.

Risk assessment is what we're recommending, starting at age 25 to 30, as a way to demonstrate when they should start screening. I think that is really an essential component that we should be recommending, and this guideline did not address that.

Thank you.

Mrs. Anna Roberts: Would you say that the task force needs to be updated with the more pertinent information? I'll be quite honest with you, as a woman, these numbers scare the hell out of me. I think I'd rather know early how I prevent cancer or how we can detect it in the early stages, so that I have a long enough life to see my grandchildren grow.

Anyone can answer.

● (1240)

Dr. Pamela Hebbard: If I can start, I think we have to look at.... We all, everyone around here, want there to be no breast cancer deaths, and so how do we achieve that? Screening has a very important role in that, so does advancement of treatments. I think there is a role for certain populations to have better access to genetic testing and prevention.

Prevention itself has been largely understudied, and poorly studied, in breast cancer, but just the task force recommendations themselves are a very limited single tool. Whether or not we should move from 50 to 40, we have a multitude of different views around that, which I won't get into for brevity, but I think it's always important to know that, actually, over 90% of women with breast cancer in Canada will be cured. It is—

Mrs. Anna Roberts: Okay—not to cut you short, but I do have limited time. I'm so sorry.

Is there a fee for genetic testing?

Dr. Pamela Hebbard: There is a fee.

Mrs. Anna Roberts: Can you tell me what that would be?

Dr. Pamela Hebbard: Yes, if you want private genetic testing.... If the government pays for it, each government will have a different amount for not the fee to patients but how much it costs them. In my practice, I do counsel patients who aren't candidates for provincially funded [*Technical difficulty—Editor*] testing to pay for it themselves. In the two groups that I tend to lead them towards, the last time I looked, it was $299 U.S. and that is a common ballpark for genetic testing that someone would pay for out-of-pocket at a medical-grade lab.

Mrs. Anna Roberts: What I'm thinking here is that, if I had a situation where there was a family history of it, I would try to find the money somewhere to help the individual get that genetic testing, if we could avoid—

Dr. Pamela Hebbard: If you don't mind, because I think this is fruitful point about getting genetic testing. The challenge is that genetic testing always works best if someone in your family who has had the cancer is the first one to get genetic testing. Actually, across Canada, which would be a whole other discussion for us, there is a varied landscape of how easy or how hard it is to access that testing, and provincial guidelines do not agree.

When you haven't had cancer and you opt for a genetic test, then there is some nuance to it, because if you come back with a gene, that's helpful. However, if you come back without a gene it doesn't tell us whether your family is carrying a gene and you didn't get it so that you're actually relatively low or population risk, or whether there is something else going on in your family—all the mix of small genes that we can't measure, lifestyle choices, our environment—that goes into your risk and you are still at elevated risk for breast cancer.

Testing people who haven't had cancer comes with difficulty, and that's where our medical genetics colleagues are really important in that, and I do think it probably.... I'll stop now because it's a bit different.

The Chair: Thank you, Dr. Hebbard.

Thank you, Anna.

Marc, you have five minutes.

Mr. Marc Serré (Nickel Belt, Lib.): Thank you, Madam Chair.

Thank you to all. I echo what was said earlier. I've been here on the status of women committee now for seven years, and this is probably the most insightful panel of witnesses that we've had—I mean, we had some good witnesses in the past—and I want to thank you for the work and commitment.

Also it's shocking, I think, what we're hearing today.

Dr. Appavoo, we talked about the guidelines of the U.S. and some of the recent evidence that the Canadian task force didn't take into consideration. I want to talk about that, but first, you talked a bit about the composition of what the membership should be.

Can you enlighten the committee with your recommendation on what the composition of the task force should look like? There seem to be some issues there.

Dr. Shiela Appavoo: Right now the task force is deliberately made up of people who are not content experts. They are experts in their own fields, you know, but they are not experts in the topic that they're handling. They do that because, again, it's this idea of not having skin in the game or not having bias or conflict of interest, but I think it's throwing out the baby with the bathwater because, then, you not only eliminate bias or at least specialist bias.... Actually, you don't eliminate bias because they're biased. Everybody has bias.

In my opinion it should be—and I think this is probably what most Canadians believe to be true already—experts in the topics who are leading the guidelines, and methodologists at their side assisting them, sort of shoulder to shoulder, working together towards good guidelines for Canadians, and not this idea of leaving the experts out of the room.

I always liken it to school kids marking their own homework and shutting the teacher out of the room. They give themselves good marks, so it seems well and they have good marks, but they don't know what they don't know. Unfortunately, they need better guidance from people who do understand the context and nuances. You cannot use a blunt tool like GRADE, which allows you to include only, for example, not diverse data—it's a very blunt tool—and expect to get a good understanding of what the nuances are.

● (1245)

Mr. Marc Serré: Thank you.

Dr. Appavoo, you mentioned the studies on cervical cancer and others.

To Dr. Rushton and Dr. McKerlie, we saw other reports that for women's health, in general, studies have been at the bottom of the list, either from NSERC, university or government studies. It seems like we have the group here from Manitoba who seem to agree with the task force recommendations, but in general the data seems to be either not there or not being looked at.

What are your recommendations to the federal government here, the committee, to really...? I know there's more money needed for women's health on the study side, but what recommendations...? What seems to be the glitch here between the task force and the lack of studies, or even not following the U.S. guidelines?

The Chair: MP Serré, you have two individuals online as well if you'd like to engage.

Dr. Moira Rushton: I'll be brief.

I think one big gap that I would like to identify out loud, and I can send more information, are the disutilities that are used to assess the quality of life that is gained with early detection. I was looking at this recently for the disutility.... If you treated someone for a cancer in health economics, you'll apply a certain, “What percentage of quality of life are they living during that treatment period?”

For breast cancer, and probably for many cancers—but I don't treat those, so I just looked at breast cancer—the disutilities during the treatment period are very finite and really limited to a very short period of time, which really does not reflect the patient's experience. I think if there is going to be work done, it will be looking at the disutilities of the real quality of life and the long-term quality of life impacts of our treatments, which span, in some cases, up to a decade after a cancer diagnosis.

Mr. Marc Serré: Ms. Shira Farber, answer quickly—in 30 seconds—please.

Ms. Shira Farber: I just really want to quickly address this idea that the task force is objective because they don't have skin in the game. With all due respect, the task force has been lecturing on social media, has been interviewed by the press and has published papers about the myths of the benefits of screening and the harms of screening this entire time. At least the specialists are specialists in that area. As a patient, that's who I would like making decisions about these guidelines, not people who are propelling their careers and their academic careers based on something called the myths of screening and debunking screening.

The Chair: Thank you so much.

Next, we have Andréanne Larouche.

You have five minutes.

[*Translation*]

Ms. Andréanne Larouche: Thank you, Madam Chair.

Since this is probably my last turn to speak, I would like to thank all of the witnesses for being here. It was both instructive and disturbing, shall we say, to see a bit of what is happening at present.

I would like to address Ms. Van Dusen and Mr. Raynaud from the Canadian Cancer Society.

I found an article dated the beginning of May that was published after the Canadian Cancer Society called publicly for the age to start breast cancer screening to be lowered to 40. That is a pretty big thing. The Canadian Cancer Society felt the need to speak out in the media because, evidently, it had not been consulted by the working group. That is what I asked the witnesses earlier to tell me by raising their hand. So you were one of those who were not consulted, since you had to go to the media to voice your request. The article reports the response your request received: “The Canadian Task Force respects the Canadian Cancer Society and its important work … We look forward to discussing the draft recommendations on screening for breast cancer from our comprehensive evidence review later this spring.”

I imagine you have not yet had any news and you are still waiting to discuss preventive health care with the Canadian Task Force.

What do you expect, since that article reported that the working group had replied that it wanted to discuss it with you?

● (1250)

[*English*]

Ms. Ciana Van Dusen: That's an important question, and I think it's a bit of a difficult one. We want to keep working with the task force while they are in the position that they are to create the guidelines that they are creating. We do think that improvements were made since the last iteration, and we appreciate at least the acknowledgement that women who want access should have access.

We just feel that it doesn't go quite far enough because it still places the onus on women to, again, know that they have access to breast cancer screening and to ask for it in a context in which.... We've acknowledged that many Canadians don't have access to health care providers. We've also heard today that, if it's not the standard, then you think that maybe you don't need it, so it undermines the inclination that we need care. We will continue to work with the task force whenever possible. We have echoed calls from other organizations to increase transparency, but obviously there are concerns with the way this has all transpired.

I don't know if you have something to add, Helena.

Ms. Helena Sonea: Really briefly I'll add that we also really hope that the public consultation they are currently going through as a result of these guidelines will be made public.

[*Translation*]

Mr. David Raynaud: I would like to add something very quickly.

Our organization is the voice of people affected by cancer, so it is important to us that those people's experience be taken into account and be reflected in these studies. That is also fundamental to our work.

[*English*]

The Chair: You still have two minutes left, Andréanne.

[*Translation*]

Ms. Andréanne Larouche: Ah, okay. I was thinking my time was two and a half minutes, Madam Chair. That's great, thank you.

Earlier, in response to my question, some people raised their hand to let me know they had been consulted by the working group. Ms. Van Dusen and Mr. Raynaud, forgive me, I didn't see you nod your head earlier. So you were consulted. Thank you for the clarification. I had seen Ms. Sonea's hand up, and Ms. Seely's, who is with us by video conference, and we heard their answers.

So you spoke about your expectations.

Mr. Raynaud and Ms. Van Dusen, in the article, it also says that these are guidelines. Women aged 40 to 50 are given the opportunity, or the right, to request screening. Previously, in reply to a question, we were told this was not a matter of interfering or prohibiting. Ultimately, nothing is being made mandatory; you just want to offer it. This is an effort to avoid the battle that women might have to wage to be entitled to this test. It is important to clarify that, and in fact it is in the article.

Do you have anything to add?

I see you nodding your head, Ms. Van Dusen.

Ms. Ciana Van Dusen: Was there a question in what you were saying?

Ms. Andréanne Larouche: I would like to hear your opinion about the fact that having guidelines for women aged 40 to 50 does not mean that anything is being made mandatory, women are just being offered the choice.

[*English*]

Ms. Ciana Van Dusen: The recommendations are there, but if they create a barrier to other provinces to making this decision, I think that's a problem. I also think that it's a problem if doctors are individually using this as a recommendation in how they operate in their own practice. If you do happen to be lucky enough to have a health care provider, and your doctor says that you don't need access because the recommendations don't say so, then you happen to be out of luck or you are forced to look elsewhere for somebody who will support you in that feeling or inclination that perhaps you should be receiving screening earlier.

The Chair: Thank you so much for that.

Leah, you have the last five minutes.

Ms. Leah Gazan: Thank you so much.

Thank you to all the witnesses today.

It is just so shocking to me that people making decisions about life and death matters are not experts in the field.

There's this whole notion of bias. I spent almost 20 years in academia. There is no research that is unbiased, and you have to identify that bias. It is a non-relevant argument, in fact, that's being used. I find it horrifying.

I also found it horrifying, Dr. McKerlie, that they're using research from the 1980s that was comprised of 98% Caucasian women. If we want to talk about bias, that screams bias to me.

Would you recommend that the federal government make major investments in genetic research to identify hidden genetic factors for Black people, indigenous people and people of colour?

Dr. Ify McKerlie: I would absolutely agree. Right now, there's a lot of research going on in the States that shows that a large part of the issue in the racialized population, especially Black people, relates to genetics. There's a call for racialized women and Black women to engage in those clinical trials. I absolutely agree that there needs to be some investment in that, especially in Canada.

● (1255)

Ms. Leah Gazan: Thank you very much.

My question is for you, Dr. Appavoo.

You said that the people currently on the task force are not experts. Can you expand on that? I want to understand the level on which they are not experts. Who is on this task force? I would never put myself on the task force, for example.

Dr. Shiela Appavoo: Again, I want to give them their credit. They are experts in their fields, but their fields are not the fields of the guidelines. For instance, the 2018 breast cancer screening guideline was chaired by a nephrologist, a kidney doctor. The guideline this time was chaired by a family doctor.

They are experts in their fields and they're experts in guideline methodology, but I think that guideline methodology needs to be the assistant to the guideline. We need to have methodologists helping to make guidelines but not completely making the guidelines without any expert guidance and without understanding, for instance, the nuances of the disease behaviour, the nuances of treatment and so on.

Ms. Leah Gazan: I ask that because we're all experts in something. I'm an expert in adult education. I'm certainly not questioning their qualifications as an individual.

What I am questioning, however, are their qualifications as experts to make decisions about matters outside of their expertise. Would you say that their expertise falls outside of the expertise related to cancer, certainly breast cancer? Please answer yes or no.

Dr. Shiela Appavoo: Yes, there's something called epistemic trespassing, which is the phenomenon of somebody who's, say, a doctor of geology—and this happened during the pandemic—talking about vaccines. Now, this is definitely not the same case. They are experts in medicine, but they really have no expertise in the areas that they're making national rulings on. They're basically practising specialty medicine out of their fields.

The Chair: This is your last minute, Leah.

Ms. Leah Gazan: Okay. Thank you.

Yes, that's very troubling.

My last question is for Dr. Seely.

You did research on genetics. Why wasn't it accepted? I still don't understand this. It included over two million women. What was the argument for it not being accepted? I find this shocking.

Dr. Jean Seely: Again, that has to do with methodology. The use of randomized trials always takes precedence over a study as large as 2.7 million women.

It is shocking; I completely agree with you. Those recent studies looked at more modern diagnoses and treatments using more up-to-date technology. This, I think, has to do with a lack of expertise and the lack of knowledge about what screening is and how it functions in Canadian programs. Canadian programs are extremely well run. We monitor the abnormal recall rates and the positive biopsy rates.

All of that was done and shown in this beautiful study, but because we didn't have experts who understood the impact of this, it was downgraded in favour of the randomized trials that were 60 years old.

The Chair: Thank you very much for that.

I would like to thank all of our witnesses. This does conclude our meeting on the breast cancer draft recommendations. On behalf of the committee, I would certainly like to thank all of you for your testimony and for contributing to our work as a committee.

As a reminder for all members, on next Tuesday, June 18, we will be studying the draft letter that will be prepared on this topic using today's testimony. That's next Tuesday. At the next meeting, Thursday, we will be coming back to our red dress report.

Thank you, everyone.

Is everyone in agreement to adjourn?

Some hon. members: Agreed.

The Chair: The meeting is adjourned.