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Chair: Mr. Sean Casey



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• (1240)

[English]

The Chair (Mr. Sean Casey (Charlottetown, Lib.)): I call the meeting to order.

Welcome to meeting number 113 of the House of Commons Standing Committee on Health.

Before we begin, I'd like to remind all members and other meeting participants in the room of the following important preventative measures. To prevent disruptive and potentially harmful audio feedback incidents that can cause injuries, all in-person participants are reminded to keep their earpieces away from all microphones at all times.

As indicated in the communiqué from the Speaker to all members on Monday, April 29, the following measures have been taken to help prevent audio feedback incidents. All earpieces have been replaced by a model that greatly reduces the probability of audio feedback. The new earpieces are black, whereas the former earpieces were grey. Please only use an approved black earpiece. By default, all unused earpieces will be unplugged at the start of a meeting. When you are not using your earpiece, please place it face down on the middle of the sticker for this purpose that you will find on the table, as indicated. Please consult the cards on the table for guidelines to prevent audio feedback incidents. The room layout has been adjusted to increase the distance between microphones and reduce the chance of feedback from an ambient earpiece.

These measures are in place so we can conduct our business without interruption and to protect the health and safety of all participants, including the interpreters. Thank you all for your co-operation.

In accordance with our routine motion, I am informing the committee that all remote participants have completed the required connection tests in advance of the meeting.

Pursuant to Standing Order 108(2) and the motion adopted on May 16, 2022, the committee is resuming its study of women's health.

I would like to welcome our panel of witnesses and thank them for their patience. We have, appearing by video conference, Dr. Neeru Gupta, professor in the department of sociology at the University of New Brunswick. Also by video conference, we have Dr. Ruth Ann Marrie, a professor in the department of medicine, Max Rady College of Medicine at the University of Manitoba. With us here in the room we have Dr. Deborah Money, professor and head of the department of obstetrics and gynecology at the University of

British Columbia. Representing MS Canada, we have the president and CEO, Dr. Pamela Valentine.

Thanks to all of our witnesses for being here. Thanks for your patience as we had to observe the established rules of this place in terms of votes taking precedence and the time allotted to allow for members to cast their votes.

We have resources here until two o'clock, colleagues. I suggest we get the opening statements from the witnesses, proceed with one round of questions, and then we'll test the will of the room as to whether we want to go further than that. I would think we should be able to get at least that far without issue, or at least I hope so.

With all that by way of introduction, we're now ready to begin with opening statements of five minutes, starting with Dr. Gupta.

Welcome to the committee. You have the floor.

Ms. Neeru Gupta (Full Professor, Department of Sociology, University of New Brunswick, As an Individual): Thank you very much.

My name is Dr. Neeru Gupta. I'm a professor of sociology at the University of New Brunswick. I'm also the equity lead with the Canadian Health Workforce Network. As such, I would like to share with you some of my thoughts on how we can improve women's health research, and in particular I would ask the committee to consider that ending the neglect of women's health research necessarily entails ending the neglect of research on women in the health workforce.

We know there is no health care without a health care workforce, and we also know that we're experiencing a health workforce crisis. Indeed, this very standing committee published a report in 2023 addressing the health workforce crisis, and yet, like much health research, that report was gender-blind. In other words, there was no mention of women, and there was no mention of any potential unintended consequences of gender-blind or one-size-fits-all policies to recruit and retain health care workers.

We know that half of the Canadian population is women, and we also know that four out of five health care workers are women, so how health research considers or neglects the health of women in the workforce as both recipients and providers of care itself is an impediment to improving health care that works for all Canadians.

The Standing Committee on Health has also heard, to my understanding, from various speakers before about a number of persistent research limitations in terms of better understanding the health of women, in particular in relation to health conditions that are specific to biological females, including ovarian cancer or menopause; those health conditions with risk factors, symptoms or modifiers that more often go under-recognized in women, such as heart disease; or those that might disproportionately affect women because of a multitude of socio-cultural factors such as depression or intimate partner violence.

All of these issues, therefore, also affect four out of five health care providers, and a double impact is the neglect of research on women in the health care workforce itself.

While health care services and health research are often considered insufficiently responsive to women's specific health needs, they are also highly dependent on women as providers of care. However, gender-based analyses of the impacts on women are much less prevalent in research and funding of research on the health workforce and the associated implications for health care improvement, including improving patient experiences, the health of populations, value for money and health care provider experiences.

That last item I mentioned is implicit in the quadruple aim, which has been adopted by health care organizations across Canada and around the world, and yet women's experiences as health care providers are understudied and undervalued.

Research is scarce on how factors salient to women drive health workforce outcomes. We know that in Canada, and around much of the world, data to support research and policy on the health workforce tend to be siloed and incomplete. The Standing Committee on Health has already endorsed the need for better, more robust and comprehensive health workforce data to help address the health workforce crisis. This includes the sharing and use of comprehensive workforce data as part of a world-class health data system as identified in the Standing Committee on Health's previous report.

The recent establishment of Health Workforce Canada offers a valuable opportunity to strengthen collaborative work on health workforce data and planning. Optimizing women's contributions and research on women's contributions to the health sector must be central in these conversations.

I would ask the federal government what role we can play to help improve Canada's health care system through improving gender equality. I would argue that prioritizing research investments on women in the health sector is essential to making health care work better for women and for all Canadians.

● (1245)

Closing the gap on women's health research includes scaling up research on women in the health workforce. In particular, to borrow a framework from the World Health Organization, I would suggest that there are four main areas where we can work together to help improve women's research, research on women's health and research on women in the health workforce.

The first is gender occupational segregation. We know that four out of five health care workers are women. Integrating gender sci-

ence into health workforce research, therefore, is imperative to disentangling occupational segregation, which is the unequal distribution of women and men within particular job types.

If our goal is to increase the numbers of practising health care providers in Canada to help address the health workforce crisis, then we must be driven through research that helps to disentangle and understand gender norms and stereotypes, so that we can—

The Chair: Dr. Gupta, if I could, I'll get you to wind up. We're a bit past time. You'll get a chance to expand upon your opening statement in response to questions, but please bring it to a close.

Ms. Neeru Gupta: Okay.

I would suggest then that pay gaps, leadership, gender occupational segregation and safe environments for women in the health workforce are critical to improving the health workforce, yet research is lacking.

The Chair: Thank you, Dr. Gupta.

Next, we have Dr. Marrie from the University of Manitoba.

Welcome to the committee. You have the floor.

Dr. Ruth Ann Marrie (Professor, Department of Medicine, Max Rady College of Medicine, University of Manitoba, As an Individual): Thank you to the chair and the committee for the invitation to present today about the topic of women's health research.

I'm a neurologist and, as you heard, a professor of medicine and community health sciences at the University of Manitoba, where I hold the Waugh Family Chair in Multiple Sclerosis. I also serve as the director of the provincial health program for multiple sclerosis.

For the past 20 years, my clinical practice and research have focused on people living with MS, including the topic of women's health. Three-quarters of people living with MS—three-quarters of the people I care for—are women at all life stages.

Today, I will share key reasons why research related to women's health is a critical issue that must be addressed for women with MS and other chronic diseases.

First, women with MS must manage the challenges of decisions regarding family planning, pregnancy and menopause while concurrently managing a chronic disease.

Second, many knowledge gaps exist regarding women's health in the context of MS and chronic disease.

Third, existing knowledge tells us that women with MS experience important disparities related to women's health.

Allow me to elaborate on these points.

MS most often presents between the ages of 20 and 40 years. However, it can present in children in about 5% of people, and in later life. This means that women with MS are dealing with a disease at a time when they are completing their schooling, starting careers, building relationships and planning families. They must make complex decisions about stopping or changing their disease-specific therapies if they decide to have children. They must figure out how to parent or sustain relationships while potentially dealing with pain, fatigue and depression, as well as physical or cognitive impairments.

In a recent review of the world literature, we found that relatively few studies—about 350 out of more than 100,000 publications—focused on the topic of women's health in MS. Most of these studies focused on pregnancy. Very few studies addressed menopause—which is a life stage that all women experience if they are biologically female—gynecologic cancers, cancer screening or biologic effects of sex hormones.

The participants in these studies did not fully represent all women with MS. Most participants were white. Few were living with severe impairments due to their disease.

Focus groups have told us that these topics—menopause, cancer, sexual dysfunction, parenthood and pregnancy—in the context of chronic disease are the top priorities for future research.

Women with MS, like other women with physical impairments, are less likely to undergo cancer screening tests, such as mammograms or Pap tests. This is particularly true for women of lower socio-economic status.

Some of these disparities reflect the difficulty in finding health care providers and health systems equipped to deal with women with physical impairments who may not be able to stand unassisted for a mammogram or who need a lift to transfer them to an examination table. Women with MS, as a consequence, are more likely to be diagnosed because they have symptoms of breast cancer, rather than through cancer screening. They are also less likely to survive breast cancer.

We need far more research addressing women's health issues in women with MS and other chronic diseases. Women with MS deserve to know how their reproductive life stages and the related biological, sociological and social changes interact with their disease, and how best to manage these life stages and their chronic illness together. They deserve to have effective, accessible care, regardless of health status, that ensures they get equitable health outcomes. That research must be inclusive, reflecting the perspectives of women with many different characteristics, backgrounds and life experiences.

Thank you for your attention.

• (1250)

The Chair: Thank you, Dr. Marrie.

Next is Dr. Money from the University of British Columbia.

Welcome to the committee. You have the floor.

Dr. Deborah Money (Professor and Head, Department of Obstetrics and Gynaecology, University of British Columbia, As an Individual): Good afternoon. Thank you for the invitation to speak with you today.

There are many strategic documents that have been developed in Canada and globally since the recognition of the importance of sex- and gender-based research into many conditions, including, as mentioned previously, cardiovascular diseases; cancers; metabolic diseases; mobility issues, including sports-specific studies; infectious diseases specific to women; mental health conditions and conditions of aging. In addition, as previously mentioned, there are very specific conditions: gynecologic and breast cancers; menstrual cycle disorders; endometriosis and pelvic pain; and management of fertility, preconception, pregnancy, postpartum, menopause and post-menopause.

This is a daunting and entirely incomplete list of conditions that have only been partially addressed through attempts to increase women's inclusion in clinical trials, cohort studies and female-specific approaches in fundamental science. In addition, the disparities in Canada experienced by rural and remote populations, indigenous peoples and those experiencing poor socio-economic challenges are amplified in the women's health space.

Instead of bombarding you with more statistics, I'd like to share three specific anecdotes from my experience as a women's health researcher. My first example draws on my experience where I had the privilege of participating in a bold trial studying the impact of the first licensed HIV drug, AZT, in pregnancy in a placebo-controlled study. The interim analysis came out in February 1994, and we immediately received the data in our clinic showing that the transmission rate of HIV from mother to infant was only 8% in the treatment group compared to 25% in the placebo group. This was the first demonstration that HIV drugs could be used for treatment as prevention. It was an extraordinary moment in medical research, and it was globally pivotal. I returned to Canada in September 1994, and we launched routine antenatal screening for HIV and standard treatment to prevent the transmission of this then-deadly virus. I was forever convinced of the value of pregnancy-specific and women's health-focused research.

My second example is that of the HPV vaccine and HPV screening towards the elimination of cervical cancer. The discovery of the HPV virus as the near-universal cause of cervical cancer was not only pivotal for women's health but also brought us to the opportunity to have a vaccine-preventable cancer. Despite major advances in understanding the biology and in how to prevent this disease, it continues to kill relatively young women worldwide—one every two minutes and still more than one death per day in Canada.

Canadian research has, however, contributed to understanding the two key strategies: vaccine programs and HPV screening instead of Pap smears. This is a proven strategy. We've just deployed it in British Columbia and will hopefully move across the country soon. This is a research success story that has driven global strategies from Canadian-based research.

The third example is from our recent pandemic experience. You will recall that, at the beginning of the pandemic, most of the focus—probably appropriately—was on the general population and vulnerable elderly. However, we didn't know the impacts on women, pregnancy, the fetus and the newborn infant. We were able to pull together many experts across Canada to form a network to study this. Our data showed that pregnant women had a substantially higher rate of hospital and ICU admission and preterm birth rates. This immediately informed clinical care, and when the vaccine became available, Dr. Theresa Tam recommended specifically offering pregnant women the COVID-19 vaccine to prevent these adverse outcomes.

Now our data shows not only that the vaccine is safe but that adverse outcomes are substantially reduced in vaccinated versus unvaccinated women. The key point here is that without Canadian teams ready and able to pivot to study diseases in women and in pregnancy, we would not have even appreciated the substantive differential effects.

Finally, I would like to propose some recommendations to move women's health research forward in a strategic and focused way. I believe we need to develop a strategic plan for women's health research in Canada. Part of that, in my opinion, is that we need to invest in key scientists who will focus on women's health research, and we can do this by creating more salary awards for scientists and clinician scientists. Ultimately, we need to break down barriers between provinces to share data and understand cofactors.

• (1255)

To conclude, I would like to quote the ambassador for women's health for the U.K., Dame Lesley Regan. "When we get it right for women, everyone in our society benefits."

Thank you.

The Chair: Thank you, Dr. Money.

Last, but not least, representing MS Canada, we have Dr. Valentine.

Welcome. You have the floor.

Dr. Pamela Valentine (President and CEO, MS Canada): Good afternoon.

Thank you to the chair and members of the committee for the invitation to speak today on the topic of women's health.

I am a trained neuroscientist and have the distinct honour of serving as the president and CEO of MS Canada. I am here today to share the importance of prioritizing and investing in women's health research specifically for the community I represent, those impacted by multiple sclerosis.

As you probably know, Canada has one of the highest rates in the world, and MS is a disease that differentially affects Canadian women. Women are, as you heard from Dr. Marrie, up to three times more likely to be diagnosed with MS than men. Every day in this country, 12 Canadians are diagnosed with this disease. On average, nine of them will be women. That means that every two hours in this country someone has to hear, "You have MS".

MS Canada is committed to changing the face of MS today and tomorrow. We're making incredible progress towards our impact goals of advancing treatment and care, enhancing well-being, understanding and halting disease progression and ultimately preventing MS.

We have cultivated a network of MS researchers that has become a leading contributor to discovery in the field of MS. The Canadian MS research community is made up of remarkable clinicians and researchers who are contributing to accelerating our research progress in MS, including Dr. Ruth Ann Marrie, who you've already heard from today.

As you heard from Dr. Marrie, there is a pressing need for research focused on women's health issues in MS to address health disparities, knowledge gaps and decisions for MS disease management around family planning, pregnancy and menopause.

I would like to speak for a moment about the emerging area of research that is gaining momentum in the area of prevention. Breakthrough research has shown infection with Epstein-Barr virus as an early trigger required for MS development. This discovery has given us an unprecedented opportunity in preventing MS.

For Julia, a mom living with MS, this research could directly impact her, as she said, "As a parent living with MS, the possibility of my kids developing MS weighs heavily in the back of my mind." It was a question that she and her husband Matt had for my doctors when they decided to try to start a family. "Could our children develop MS? Is it hereditary?"

These recent research advances are changing the way we think about MS. Where MS prevention was once a distant aspiration, today we see prevention as an attainable goal. To reach that goal for moms like Julia, we need to maintain the momentum of these recent discoveries and accelerate research.

At MS Canada, we know the power of collaboration. With the experience and expertise within the MS research community here in Canada and around the globe, working together will lead to transformative progress. Together we will be able to turn our vision of a world free of MS into reality.

With your work here at the committee and as parliamentarians, you can help raise awareness and propose concrete actions, particularly as they relate to MS prevention. This is particularly important when assessing the individual and economic burden of MS.

A recently released Deloitte Access Economics report estimates the annual cost of MS at more than \$3.4 billion and rising.

Please allow me to give you an example of this burden.

Amanda, who was diagnosed just 10 years ago, says, "There is no question that living with MS is costly to an individual, but the productivity lost and the health care costs affect our economy as well. As a 36-year-old woman living with MS on long-term disability with increasing health costs, I am one of 90,000 Canadians already costing our system. The toll MS has on our economy is why research for prevention is imperative for our government to invest. More Canadians are being diagnosed every day, and Canada leads the rates of MS globally. We should be taking the lead in partnering globally to answer why MS has become Canada's disease."

- (1300)

The federal government has an important opportunity to invest \$15 million in MS research funding in partnership with MS Canada, leveraging our connections and expertise to focus and further our understanding of MS; to pursue leading-edge research on repair and regeneration; and to explore strategies to prevent MS such as identifying risk factors, understanding pre-clinical MS and testing interventions to prevent MS.

With less than 1% of the current federal health research dollars being currently earmarked for MS research, this is simply too little for Canadian women suffering from this life-altering disease, a disease that could arguably be prevented.

In closing, we would like to reiterate the urgency of investing in women's health research, which will benefit all Canadian women, including those who live with MS.

Thank you.

The Chair: Thank you, Dr. Valentine.

Thanks to all of our witnesses for their opening statements. We're now going to begin with rounds of questions, starting with the Conservatives.

We'll go to Ms. Goodridge for six minutes, please.

Mrs. Laila Goodridge (Fort McMurray—Cold Lake, CPC): Thank you, Mr. Chair.

Thank you to all of our witnesses for being here today.

It's very fitting that we're here in May, the MS month, and have two witnesses to come to speak to us on MS. I've been shocked every time I think about MS and the fact that three quarters of the people who are diagnosed are women.

Dr. Valentine, how many people in Canada have MS, and how many of them are women, in the peer numbers?

Dr. Pamela Valentine: Currently we can estimate that the number of Canadians living with MS is 90,000. That might be an underestimate, given that there are likely to be individuals in the country who don't get diagnosed. It's often a fairly complicated path to getting diagnosed. As we know, for many people, it takes years.

We also have come to understand that there is a prodrome, or a pre-clinical state and we can see individuals with a distinct health utilization pattern as many as five to 10 years out before the state of diagnosis.

Mrs. Laila Goodridge: Thank you, I appreciate that.

Dr. Marrie, I was really taken aback by your statements regarding the screening for cancers and the lack of research when it comes to women with MS. I was wondering if you had any recommendations about how we could improve guidelines or research to be able to improve those outcomes.

Dr. Ruth Ann Marrie: From a care standpoint, we need to ensure that the tools or systems we have in place allow people with physical or cognitive impairments, or who live remotely, to access things like mammograms and Pap smears. We need to ensure that every community has access to mammogram tables that are adjustable for people who need to be in wheelchairs, and that there are lifts and people to do that. That's an inventory that could be done within health authorities across the country. There shouldn't be disparities because you have those impairments.

From a research perspective, our challenges have been that, like much research done in Canada and around the world, the people we end up including in studies are those who are best educated, most affluent, able to miss time from work and those kinds of things. We need to be able to fund studies that are more complex so that we can reach out to people in their first languages rather than the languages they acquire when they come to Canada, so that we can have study sites that are remote from academic centres that still allow us to collect information and address the barriers of underserved populations, so that we can figure out how to address their needs from a health care perspective. That really requires a concerted effort across all levels of funding.

• (1305)

Mrs. Laila Goodridge: Thank you.

As a rural and remote member of Parliament, that's something that definitely does speak to me. That's an incredibly important piece.

Dr. Money, you also touched on "rural and remote". You talked about the HPV screening that is being done in British Columbia. I don't have much time left, but I was wondering if you could expand on what's being done in B.C., what you would recommend to women and what you would recommend to other governments when looking at HPV, specifically.

Dr. Deborah Money: We have really good data that shows that primary testing for the virus that causes cervical cancer, the HPV screen, is actually better than the Pap smear, as much as we were very proud of that from before. In the way we've deployed it, it's actually a self-swab that is very simple for women to do. They can do it in their home. They can mail it in to the central laboratory. It really does reduce those barriers.

If there's a fear of having these kinds of examinations, a history of trauma, if they're very remote—any of those barriers that have made it difficult for women to get in for Pap smears—we are confident that this will reduce those. We'd love to see it rolled out across the country.

Mrs. Laila Goodridge: How complicated is the self-screening for HPV?

Dr. Deborah Money: It's actually really very simple. It's a simple vaginal swab, and almost all of the labs across the country are capable of doing the HPV screen panel. We're looking specifically for types of viruses that are known to be cancer-causing. It triggers an algorithm for those who are negative, and they can go for a five-year gap. Those who are positive need more additional attention. We're then focusing on the people most at risk of cancer.

Mrs. Laila Goodridge: That's really interesting. You were talking about your early research into HIV drugs and pregnancy. I'm finding, in some of those links that we've heard about many times in this committee, that there's a disparity when it comes to research for that period of time. I was wondering if you have any suggestions as to how we could improve access to women's health research funding, specifically for women in those stages of life.

Dr. Deborah Money: I think it's really about how research funding is allocated and prioritized. We certainly see that pregnancy is often the stage of life where women are excluded from clinical trials. The reason I called this a bold trial is it was incredibly ground-

breaking to have the guts to try an early-stage drug. However, it was because of the high rate of infection in the infants and the death rate associated with that. It forced a really bold and advanced move. Unfortunately we haven't seen that follow-up. New medicine, new vaccines over and over again...we're not seeing the trials in pregnancy early enough to understand safety.

Mrs. Laila Goodridge: Chair, I know my time has lapsed, but I have one quick question.

What would you recommend to young girls who are looking at getting an HPV vaccine?

Dr. Deborah Money: I would say please do it, because it can prevent cancer.

Mrs. Laila Goodridge: Thank you.

The Chair: We have Ms. Sidhu, please, for six minutes.

• (1310)

Ms. Sonia Sidhu (Brampton South, Lib.): Thank you, Chair. Thank you to all of the witnesses for being here. My question is to Dr. Gupta.

Dr. Gupta, I hosted the Celiac Canada breakfast this morning, and they mentioned that women are far more likely to have celiac disease than men. It was the same thing today with MS Canada. Dr. Valentine, you said that women are three times more likely to have MS than men. Given your extensive research, have you found barriers to health care for women more than men? If you find that, can you also tell us how women and men differ in the detection and the prevention?

Ms. Neeru Gupta: I do want to preface that I'm not a biomedical researcher or a clinical care researcher; I'm a social scientist. We bring a different perspective, perhaps, from some of the other witnesses who have spoken today and in some of the other sessions that I watched online.

My perspective is that on gender itself, one of the big contributions of social sciences to the health care research field is disentangling gender from a socio-cultural angle versus that biomedical or clinical angle. Absolutely, we know there are health conditions that are exclusive to biological women, and we know that others are understudied in women. That's often rooted in the power dynamics associated with gender. That dynamic then extends across the field from undervaluing research to undervaluing women as scientists, to undervaluing social science perspectives of how we can improve health care and access to health care services across the genders.

I'm speaking also as somebody coming from a more rural-dominated province—half of our population is rural. These barriers are all intertwined with the ongoing health care crisis, and yet the conversation around women being the majority of health care providers is itself absent from many of our discussions on improving access to health care for all Canadians.

I would suggest that if we are looking to improve access to health care, that means reducing the barriers to women accessing health care occupations. It also means reducing barriers to men entering into predominantly female health care occupations themselves, unconsciously or consciously.

Ms. Sonia Sidhu: Thank you.

Ms. Neeru Gupta: Understanding how the dynamic works in rural areas is completely under-researched and without any type of dedicated funding structure to look at this.

Ms. Sonia Sidhu: Thank you.

The questioning goes over to MP Brière now.

[*Translation*]

The Chair: Ms. Brière, you have the floor.

Mrs. Élisabeth Brière (Sherbrooke, Lib.): Thank you, Mr. Chair.

Ms. Gupta, during your presentation, you named four globally recognized objectives. Could you tell us more about them?

Ms. Neeru Gupta: Thank you very much for giving me the opportunity to give you a few more details on the subject. It's a conceptual framework developed by the World Health Organization and it helps put a bit more emphasis on these four dimensions.

First, there is segregation, which I talked about earlier. We know that 80% of health staff are women, due to differences within professions. For example, surgical care specialists are still men for the most part, whereas most of the nursing staff are women. If we want to increase health personnel overall, we have to find a way to help women enter specialized professions, as well as encourage men to become nurses.

Second, it mentions a safe workplace for women working in the health system. As we know, women are more likely to be victims of violence, particularly at home. However, throughout Canada, there is no method for collecting relevant data to determine workplace safety for women working in the health sector. To do so, more research is needed. Lack of safety in the workplace affects not only women's physical and mental health in the health sector, but also the health system itself.

Third, there's the issue of women's pay in the health sector. Canadian women earn less than men on average. In fact, our research shows that within the health system, which is supposed to be universal and fair, there are income disparities between women and men. Why? Is it because of payment structures? Are there other factors? For example, is money really what will encourage more women to work in this sector in a rural area, or is it instead factors like access to day care for their children? We have no—

• (1315)

The Chair: Thank you, Ms. Gupta.

Ms. Larouche, you have the floor for six minutes.

Ms. Andréanne Larouche (Shefford, BQ): Thank you very much, Mr. Chair.

The witness testimony is really quite interesting. A lot of themes were raised, including many of those brought to our attention this week.

Since my question focuses mostly on the area of research, my questions will initially be for professors Money and Marrie. That said, other witnesses may answer my question as well.

Like Ms. Sidhu, I attended this morning's interactive round table on the state of celiac disease in Canada. We were told that, to reduce gaps between women and men in the field of health, research work is the key.

Scholarship amounts for higher education and postdoctoral studies haven't increased for the last 20 years, but finally, there was an announcement this week on the subject. We managed to increase scholarship amounts for graduate and postgraduate researchers at long last. We're talking here about a significant win for research. In fact, I want to highlight the work done by my colleague, Maxime Blanchette-Joncas, the Bloc Québécois critic for science and innovation and a member of the Standing Committee on Science and Research.

How did those 20 years of underfunding, during which scholarship amounts didn't go up, undermine research? We must take into account the fact that a substantial health research gap between women and men must be addressed.

[*English*]

Dr. Deborah Money: I'm happy to start. I'll try to be brief.

I think that research funding has not emphasized the lifespan of women who are living with these different disorders that need to be studied. That's a granting of project challenge, but the piece that I think is also very much a challenge... As much as it's wonderful to hear of additional funding for trainees, we have a great deal of difficulty with the way we fund research faculty. Young and mid-career faculty, who are often women coming up in this world, are not well funded. It's hard to get funding for them, and it tends to be—though not uniformly—women researchers who will prioritize women's topics, even within diseases like MS or celiac, and so on.

I think we really need to have a look at proportionality and the way we support investigators who are coming up.

• (1320)

Dr. Ruth Ann Marrie: I agree with Dr. Money. I think it's how we fund research. I agree that lots of support is needed for young investigators, but we need to adequately support trainees if we want to have a new pipeline of individuals to carry on that work. We need to be able to support people from training into their faculty positions and onward so that those early investments yield the results that we can then translate into practice. We need to make a better effort at funding research that takes us from learning about the results to actually making change at the policy level, because that's often where the important findings that we do have tend to fail.

[Translation]

Ms. Andr anne Larouche: It could even make us more competitive and help us catch up at the international level.

Ms. Valentine, it's multiple sclerosis awareness month. I don't have my flower with me today, because I gave it to my daughter last night, and she really had a lot of fun with it. I'll have to get another one.

You talked about the financial impact of multiple sclerosis. In my office, I've met with representatives of multiple sclerosis organizations in Quebec. For the most part, they told us that employment insurance should be reformed to reduce the number of work hours needed to access it. It's the federal program we have to help people get through hard times because of health problems.

Why does employment insurance reform, which would also have great benefits from a feminist point of view, matter for people with multiple sclerosis who need to overcome financial obstacles?

[English]

Dr. Pamela Valentine: What we know about individuals who have MS is that they often present with what we call relapsing or remitting forms of MS. Somebody can be quite well in one period of their life, and the next month, it could be a totally different story.

We've been asking for a reform to reduce the number of hours to qualify for EI so that people can manage an often episodic form of their disease and get enough hours to qualify for EI. The request has been to drop the numbers of hours from 600 to 400.

It's a real challenge for individuals living with episodic forms of the disease because they don't need the same benefits all of the time. Some individuals will progress and pull out of the workforce. We also know that there's a very high percentage of individuals with MS who, at some point in their life, are going to be in need of support structures because they're just not well enough to contribute to the workforce, yet they don't want to come out completely. They don't want it to be a binary system in which you're in or you're out.

The Chair: Thank you, Dr. Valentine.

Next we have Ms. Kwan, please, for six minutes.

Ms. Jenny Kwan (Vancouver East, NDP): Thank you very much, Mr. Chair.

Thank you to all of the witnesses for sharing your expertise with this committee.

I'm particularly interested in what work you think can be done and what the government should do, particularly in looking at the issues through the lens of under-represented communities, for example, in the racialized community, the LGBTQ2+ community and, I would even venture as far as to say, for seniors, who are often put on the back burner, especially as they age. What are some of the health concerns, both on the research side, as well as on the side of actually providing real supports?

That is to all of the presenters, please.

Dr. Pamela Valentine: I'll jump in. I don't know if anybody else will make the same comment.

We have a real problem with information and data in this country. I sit as the CEO for MS Canada, and I cannot answer what the diversity of our population living with MS in this country looks like. I can give gender—it's fantastic to know that there are three times as many women as there are men—but after that, it's really difficult to answer those questions.

To get data in this country that crosses provincial borders is exceptionally difficult. That will not be a surprise to you. That definitely costs us more time, money and energy to get the solutions that we have today, as Ruth Ann has suggested, into the hands of the people who are going to put that information to work.

It's a very real barrier for us.

• (1325)

Dr. Deborah Money: I'd like to pick up on that theme.

What we know is that with many diseases, particularly as they affect women, they're definitely overrepresented in racialized communities and in rural and remote communities. However, we have a terrible problem with getting accurate data, really, on any health condition in this country that covers the whole country and that tells us where people live, what their cultural or racial background is, what their first language is and so on.

The lack of ability to link data within health authorities across the province and across provinces and territories is an enormous barrier to moving the dial in this area.

Ms. Jenny Kwan: Thank you for that.

What do you suggest to address this issue? Should there be dedicated funding targeted toward this data collection and research in this area?

What would you say needs to be done? What is the number one priority that the government should undertake to address this?

Dr. Money.

Dr. Deborah Money: Funding is always helpful, but to be perfectly honest, the barrier is legislation. We are not permitted to share data without enormously complicated agreements. Every single time we try to look at another thing—be it COVID, syphilis, congenital syphilis or whatever—we have to go through new individual-level agreements to get permission to share what is actually de-identified data, but has some information on it around, say, rurality.

That's our biggest barrier.

Ms. Jenny Kwan: To that end, the federal government should take a national approach and coordinate this effort between provinces and territories through legislation or whatever is needed so that it doesn't become a barrier to addressing women's health.

I'm seeing nodding heads. We will make sure that....

Dr. Deborah Money: Absolutely.

Ms. Jenny Kwan: That's your recommendation for a priority item that the government should undertake.

Dr. Deborah Money: It's a big priority for me. That's for sure.

Ms. Jenny Kwan: Dr. Valentine, do you have anything to add?

Dr. Pamela Valentine: I was just going to ask Dr. Marrie if she wanted to comment, as a researcher who very regularly tries to get data across provinces.

Dr. Ruth Ann Marrie: Thank you for that.

Yes, I agree with the regulatory barriers issue. We know why they're there. It's important to protect the privacy of health information.

Unlike countries in Scandinavia, where you can have all the national data all at once through a single process, we have multiple processes, as Dr. Money said. Even within provinces, I had one study that needed 13 regulatory approvals to do one study in one province. This adds to costs, it reduces the productivity that we have for the amount of research dollars invested and it limits our ability to do things that are relevant on a national scale.

In addition, we have a fundamental data harmonization problem. We collect information differently in different regions about these key socio-demographic and diversity characteristics.

Ms. Jenny Kwan: Thank you very much that. I really appreciate it. I hope we'll make sure that we can advance that as a recommendation from this committee.

One of the issues that women often tell me is forgotten or is even hard to diagnose is endometriosis in women, and particularly young women. They're in such pain. Do you have any advice or action that needs to be taken to address that?

Dr. Money.

Dr. Deborah Money: We do have research in this space looking at biomarkers—so markers in the blood—to pick up endometriosis in its early stages. It can be diagnosed surgically, and that requires a specialized centre and individuals with expertise. Again, focused research in areas like this are making a difference, and I think if we can get to the point of non-invasive markers that make it simpler in-

community to make these diagnoses, it will help these young women.

• (1330)

The Chair: Thank you, Ms. Kwan.

Colleagues, we have resources and sufficient time for one more round of questions from each party if the witnesses are prepared to stay for another 15 or 20 minutes. Does that suit you? Great. Thank you.

Ms. Roberts, please go ahead for five minutes.

Mrs. Anna Roberts (King—Vaughan, CPC): Thank you very much, Mr. Chair.

I'm really disgusted to hear that we can't share among provinces. Isn't it more important to save lives? I think it should be a recommendation that we change that legislation ASAP because we're important. I think all of us women here would agree to that.

I want to get my head around this, so please help me with this: What research has been done to discover why Canada has the highest number of MS individuals? How do we compare to other parts of the world? What can we learn from best practices used by other countries?

Dr. Valentine, do you have any comments on that?

Dr. Pamela Valentine: Allow me to start, but I will toss it to Dr. Marrie.

I like to describe MS as a perfect storm. What we do know is that it's a complex disease. There are 230 genetic loci that have been identified and are associated with the disease, and then if you stack on top of that environmental circumstances over the life-course of an individual and it is that perfect storm, then you tend to see the expression of the disease.

What we know today is we could identify it much earlier—in fact years earlier—than we probably can today. We don't really know why Canada has the highest rates in the world, but it's likely a combination of those factors of genetic predisposition and environmental circumstances that has led to that. If you look around the world, there's a northern country band, a latitude band of the kinds of countries that have the highest rates in the world.

I ask Dr. Marrie to comment as well.

Dr. Ruth Ann Marrie: As Dr. Valentine mentioned, we think of MS as needing an underlying genetic template that you're born with, and then exposures over the course of your life that lead to disease.

If we think about who many of the first people were who settled in Canada, many of them have genetic backgrounds that are shared with other parts of the world with high risk, like Scandinavia, western Europe and the U.K. as examples. Then we can think about the environmental risk factors. We don't know all of them, but there are some that are common in Canada that are associated with risks: smoking; obesity, particularly in childhood; low vitamin D levels, which you see in northern climates, where the sun is further away for much of the year; as well as infections such as the Epstein-Barr virus infection.

If we want to think about changing that, we need to think about trying to act on the risk factors we can change. It's hard to change your genes, but we can take action to make sure people know that smoking is a risk factor for MS and work on trying to help people quit, with both policy measures as well as education and targeted efforts to people who may be at higher risk because they're known to have a family member with MS or another immune disease. We can work on childhood obesity. Again, there are lots of policy levers around availability of foods that have sugar, fats and all of those things, accessible to children and school programs. We can look at studies in which we can actually test whether interventions with vitamin D or trying to prevent or treat Epstein-Barr virus might prevent disease. These may allow us to move forward in terms of reducing the risk of MS that we see.

This is a critical issue. The number of people with MS is going up in Canada, not so much because the risk is going up but because we're doing better at diagnosing people earlier, and people are living longer, so the burden is going to continue to rise. It is really important for us, in terms of the country's well-being, to try to mitigate, as much as possible, the risk to future generations of developing MS.

Mrs. Anna Roberts: Do you think that there will ever be a situation in which we have the opportunity to develop a screening mechanism to stop this...well, maybe not stop it, but help identify it early in the stages of MS?

Dr. Pamela Valentine: Yes—

Dr. Ruth Ann Marrie: Yes, I think we are moving—if I may, Pam—in that direction.

We now understand that there are signatures of MS we're starting to pick up in health care use before people present with their first typical symptoms.

As well, we know that we can see markers of brain injury during that period of time.

New research—and this highlights the importance of research—came out just last week that identified a signature in the blood that might help identify people at higher risk.

We need to narrow it down so that we can target investigations to people at higher risk; those are active areas of research that would benefit hugely from additional investment. Because our early work tells us that if we can intervene early, before the typical symptoms of MS develop, we may be much more effective at preventing people from moving along that path.

There are people with brain MRIs who look like they have MS, but they have no symptoms. We refer to them as having “radiologically isolated syndrome” if it's just on imaging.

There have now been two clinical trials that show us that if you treat those individuals you can reduce their risk of going on to symptoms of MS, or at least the first few years, by 80% to 90%. This is dramatic. If we could identify people like that early, then we can potentially have an enormous impact. We're not yet able, due to the approvals process in Canada, to treat people who have radiologically isolated syndrome for that purpose, but these are things that we need to move towards to reduce the impacts of MS.

• (1335)

The Chair: Thank you.

Moving over to the Liberals, we have Mr. Naqvi, please, for five minutes.

Mr. Yasir Naqvi (Ottawa Centre, Lib.): Thank you very much, Chair.

I will share my time with Mr. Powlowski.

I'll start, Dr. Valentine, with you.

I had an opportunity to meet some incredible folks from MS Canada just a few days ago, as I was mentioning to you earlier. Part of our conversation that took place was around the prevalence of MS in women. That came as a surprise to me. I had never thought about it in those terms.

I wonder if you can expand on that. What data and evidence do we have in that regard? Do we know the causes—are these environmental, genetic—that result in more incidents of MS in women than men?

Dr. Pamela Valentine: I'll start, but I will toss it to Dr. Marrie again.

I don't think we really know why it's so prevalent in women versus men, but again, it's going to come down to that genetic milieu that a person has that they're born with, and then the set of circumstances or risk factors.

Dr. Marrie, perhaps you want to comment.

Dr. Ruth Ann Marrie: I think this points to part of what we heard from Dr. Money earlier.

There is what we call a sexual dimorphism in the brain and differences in the immune system, so things like hormones will influence manifestations of disease. We don't fully understand why, but knowing that those things are different, we can see that they may, then, interact with genetic factors and some of the other environmental factors that lead to the disease.

This is not a unique problem for MS. There are many other what we call “immune-mediated diseases” where there is some immune dysfunction leading to disease where women are more likely to be affected.

Understanding that interface between the sex-specific biology and disease risk is really important to allow us to successfully target prevention efforts, as well as learn how to treat disease based on an individual's characteristics.

Mr. Yasir Naqvi: As a follow-up question, Dr. Marrie, is there sufficient research taking place in Canada to determine those causes as they relate to women? In other words, is there more women-focused research in MS taking place right now, or does more need to happen to better understand the factors?

Dr. Ruth Ann Marrie: I think more needs to happen. I don't think this has been a focus of enough research in Canada or elsewhere in the world.

Mr. Yasir Naqvi: Thank you.

Mr. Powlowski.

Mr. Marcus Powlowski (Thunder Bay—Rainy River, Lib.): Concerning the link between EBV infection and MS, how certain are we of that? Is there an EBV vaccine?

I think you mentioned that it was a necessary causal factor for multiple sclerosis. I would assume it's not so easy as, okay, we've got a cure and we vaccinate everyone for EBV.

Is there a vaccine, or how close are we to a vaccine, and is there that kind of causal certainty that we can take that approach?

Dr. Pamela Valentine: There's been a growing body of literature over a very long period of time that has linked EBV to MS. I think that the push in the field, the belief that this is really important and the strongest risk factor that we might be aware of today, was at a military database. They had biological samples and could look back 20 years, and it was the single viral indicator for everybody who ended up getting MS. I think that has really pushed forward the EBV story.

There are three EBV vaccines currently under development, one of which is an mRNA vaccine like a COVID-type vaccine. Importantly, there are other antiviral medications, many of which are available to us today, that might play as important a role as perhaps a vaccine will.

I don't believe it's realistic to think that, if a vaccine became available tomorrow, we would vaccinate the whole population. I don't think that's the most successful prevention strategy that we'll have available to us, but if you know that at-risk population that Dr. Marrie just talked about, then maybe you can deploy a vaccine or an antiviral, particularly early in the disease core. I don't think there will be one strategy at the end of the day; I think there will be multiple strategies.

• (1340)

The Chair: Thank you, Dr. Valentine and Dr. Powlowski.

[*Translation*]

Ms. Larouche, you have the floor for two and a half minutes.

Ms. Andréanne Larouche: Thank you, Mr. Chair.

Ms. Gupta, I'd like to discuss a subject that hasn't been touched on as much during questions, until now. In your opening statement, you talked about the issue of intimate partner violence and the consequences it can have on women's psychological and physical health. More and more places throughout the country are stating that intimate partner violence is a serious problem, and some are even talking about an epidemic.

Is this really a good way to start drawing connections between women's health and the issue of intimate partner violence, as well as its impact?

Ms. Neeru Gupta: From my point of view, research on the effects of intimate partner violence is underdeveloped, which also has an impact on the health system. That's some of what I wanted to put out there. We know that 80% of health staff are women. So, we can't talk about an epidemic for the general public without also talking about the impact of this epidemic on the health workforce. Furthermore, women who work in the health sector often—more often than men—experience violence from their patients and their families. So, I think that's a dual vulnerability.

However, we don't have a research system, and we don't really have a funding system for the research to look into those types of subjects.

Ms. Andréanne Larouche: Dr. Money, you were nodding. Do you have anything to add?

[*English*]

Dr. Deborah Money: I was just really agreeing with the situation that partner violence is definitely experienced to a great degree by women, although not exclusively, and we see then what the juxtaposition of a disease is on that vulnerable population. We see higher rates of HIV, sexually transmitted infections and other disease states, so it multiplies the damage and the problems.

We have a great deal of difficulty in quantifying partner violence because of the very nature of it, and women tend not to come forward, but more research into how to understand it better and obviously how to prevent it is critical.

The Chair: Thank you, Dr. Money.

[*Translation*]

Thank you, Ms. Larouche.

[*English*]

The last word goes to Ms. Kwan, please, for two and a half minutes.

Ms. Jenny Kwan: Thank you very much, Mr. Chair.

I just want to follow up quickly on my last question.

It's good to hear that there is perhaps more research and potentially emerging research coming forward. In the meantime, what should women do? Often it's just sort of overlooked, and it's hard for women to tell their physician to look into the issue, so what can they do? What can they do practically at this point?

• (1345)

Dr. Deborah Money: I think there are two sides to it. One is that women need to be empowered with the understanding of what this condition is and how it can manifest, and then they can self-advocate.

The side I sit on is as an educator for women's health for obstetricians and gynecologists, primary care providers and so on. We have spoken about this a great deal. We need to increase the general understanding by practitioners of how this manifests and ensure that these women are taken seriously when they present with symptoms that may be a little bit non-specific but can sometimes be very devastating.

We need to increase the number of practitioners in OB/GYN who can do the current surgical diagnostic procedures that are needed until we get research into non-invasive options.

Ms. Jenny Kwan: I note in the MS Canada presentation the need for research and the call for a \$15-million investment in research. Of the different recommendations that you want to make to the Canadian government, would this be your number one request by way of research investment?

Dr. Pamela Valentine: What we do know is that less than 6% from the major MS research organizations around the globe—both governmental and not-for-profit organizations like mine—is spent on prevention. I think this is an unprecedented opportunity to pre-

vent a debilitating neurological disease, which largely affects women, in the next generation, and probably in 10 years.

I think about where we've gone in the last 15 years; we have gone from three to 20 disease-modifying therapies that have produced the kinds of health outcomes that have reduced mortality by 30% and offset disability by 10-plus years. To be able to make those investments today is going to change the face of MS 10 years from now. There isn't another neurological disease, I don't think, in which you could make that claim with the evidence that's available to us today.

We're certainly asking the federal government to come in on that as a partner with a lot of concerned citizens who are going to give us money to partner on that. That's one of the specific requests that we've been making.

The Chair: Thank you, Ms. Kwan.

Thank you, Dr. Valentine, for allowing us to finish on such an optimistic note.

This concludes the time that we have, and it also concludes the testimony that we intend to receive on this particular study. Next week, we'll be giving drafting instructions to the analysts.

Thank you for sticking with us and putting in the extra time. It will be of significant value to us. We appreciate your patience and professionalism.

Is it the will of the committee to adjourn the meeting?

Some hon. members: Agreed.

The Chair: I see consensus. The meeting is adjourned.

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