



HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

44th PARLIAMENT, 1st SESSION

Standing Committee on Health

EVIDENCE

NUMBER 092

Wednesday, November 29, 2023

Chair: Mr. Sean Casey



Standing Committee on Health

Wednesday, November 29, 2023

• (1930)

[English]

The Chair (Mr. Sean Casey (Charlottetown, Lib.)): Welcome to meeting number 92 of the House of Commons Standing Committee on Health.

Today's meeting is taking place in a hybrid format pursuant to the Standing Orders.

For those who are participating remotely, be sure to click on the microphone icon to activate your microphone, and mute yourself when you're not speaking.

Regarding interpretation, for those of you on Zoom, you have the choice at the bottom of your screen of either the floor, English or French. I will remind you that screenshots or taking photos of your screen are not permitted.

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.

Appearing as individuals, we have Dr. Elaine Jolly, professor emeritus, Department of Obstetrics and Gynecology at the University of Ottawa, and Dr. Fiona Mattatall, obstetrician-gynecologist, appearing by video conference. Representing EndoAct Canada, we have Dr. Catherine Allaire, co-chair, who is on the screen, and Kate Wahl, executive director, also on the screen. Representing the McGill University Health Centre, Endometriosis—Centre for the Advancement of Research and Surgery, we have Dr. Don Bach Nguyen and Dr. Andrew Zakhari.

Thank you to all of you for taking the time to appear today. We look forward to hearing what you have to say. We're going to begin with opening statements of five minutes each, starting with Dr. Jolly.

Welcome to the committee. You have the floor.

Dr. Elaine Jolly (Professor Emeritus, Department of Obstetrics and Gynecology, University of Ottawa, As an Individual): Good evening, Mr. Chairman, committee members and fellow witnesses. I am honoured to have this opportunity to present to the standing committee on women's health.

Endometriosis is a condition that I have been advocating for throughout my 50-year career in medicine, first, as an obstetrician and gynecologist, then as a reproductive endocrinologist and as the founder of the Shirley E. Greenberg Women's Health Centre at the Ottawa Hospital. Although treatment options for endometriosis have advanced for women in Canada, progress on research, early diagnosis and surgical treatment has been slow in comparison to other countries.

I began my medical practice as a gynecologist and established the Ottawa infertility program. Later, I started a pediatric and adolescent gynecology service at the Children's Hospital of Eastern Ontario. I saw first-hand frightened young adolescents living with menstrual disturbances and chronic pelvic pain—yes, even at this early age.

In my infertility practice, I saw the heartbreak of women unable to conceive, as 40% of these fertility patients suffer from endometriosis. This chronic condition, if left untreated, often plagues women throughout their reproductive lives, even up to and beyond menopause.

In my menopause program, which I founded at the women's health centre in Ottawa, there were significant numbers of patients with premature menopause due to early ablative surgery. Providing these young women with hormone replacement for quality of life is extremely difficult since endometriosis may be restimulated by hormones. If they cannot take hormone replacement there is an increased risk of cardiovascular disease, stroke, osteoporosis and even premature death.

In the early 1970s, laparoscopy and imaging by pelvic ultrasound assisted in the diagnosis of endometriosis. By the eighties we had the first minimal invasive surgery treatment by laparoscopy. In the nineties, fellowships in minimal invasive surgery were offered at teaching hospitals in Canada and in many places around the world. Furthermore, in Ottawa, we did not get supreme imaging that was enhanced by MRI until the 2000s. Sadly, today, advanced diagnostic imaging is not equally accessible throughout Canada. There are only a few centres of excellence in major urban centres. Persons living in remote communities and ethnic minorities are under-served. I have had patients visit my Ottawa clinic from northern Ontario, Quebec, the Maritimes and Nunavut.

In departments of OB-GYN across Canada, funding for gynecology is a problem. Funding is prioritized to obstetrics, leaving gynecological problems struggling to have clinics and OR time. The development of sub-specialized programs, such as minimally invasive surgery and chronic pelvic pain, remain unfunded. This bias needs to be addressed nationally and ASAP.

First and foremost, I wish to acknowledge and fully support the excellent and timely submission of "Endometriosis in Canada" and its recommendations.

I also suggest the following 10 actions be taken to support women with endometriosis in Canada:

One, establish a national education program for all women, with government funding of lay organizations to promote awareness and to start a standardized high school curriculum on menstrual disorders. This should be a national outlet.

Two, expand the gynecology curriculum across all medical schools and teaching hospitals to include endometriosis, with an updated and standardized curriculum for undergraduates and post-graduates.

Three, have continuing medical education and support for health care providers.

Four, give financial support for endometriosis centres of excellence with a multidisciplinary approach.

Five, the recognition and support of allied health practitioners.

Six, investments in innovation and research for advanced diagnostics.

• (1935)

Seven, amend the immigration policy to fast-track qualified foreign medical graduates, prioritizing those with advanced medical skills.

Eight, increase funding for women's health research on endometriosis.

Nine, propose national guidelines on endometriosis, written by experts, with expanded Canadian health data.

Finally, 10, develop a national action plan on endometriosis diagnosis and management, which is done in a few countries. We must catch up.

In conclusion, now is the time to study endometriosis fully and to make policy decisions that will advance the prevention, care and treatment of women facing this chronic condition. All women have the right to live full, productive lives that are pain-free.

Thank you for your attention.

• (1940)

The Chair: Thank you, Dr. Jolly.

Next, we're going to hear from Dr. Fiona Mattatall.

You have the floor, Dr. Mattatall.

Dr. Fiona Mattatall (Obstetrician-Gynecologist, As an Individual): Thank you, chair and members, for this opportunity to speak.

I'm Dr. Fiona Mattatall, and I've worked for two decades as an obstetrician-gynecologist in Calgary, Alberta. As such, I am a specialist in both the medical and the surgical care of the organ system that includes the vulva, vagina, uterus and ovaries. I am one of your frontline workers in women's health, but this also extends to the care of gender-diverse Canadians. I am a clinician, but also an educator and an assistant professor at the University of Calgary.

It is refreshing to see the standing committee address women's health and specifically not focus solely on pregnancy. All too often, women's health is reduced to maternal health only. An example from here in Alberta is that our strategic clinical networks focus on maternal health, and there is no place for advocacy for non-pregnant women's health issues, such as contraception, heavy periods, pelvic pain, menopause or pelvic organ prolapse.

Although it was reassuring in Monday's meeting to learn about the recent work and funding through the sexual and reproductive health fund, we see a lack of prioritization of sexual and reproductive health across the country. Again, here in Alberta, the surgical metrics that we see tracked are cataracts, knee replacements and hip replacements. We see no tracking on things such as wait times for hysterectomies or any other gynecological procedures.

Every day in my clinic, I witness Canadians who cannot fully participate in life or work due to gynecologic issues. Patients are affected by the lack of health prevention, the lack of health awareness and delayed diagnosis. Many times, I feel that my hands are tied, as patients cannot afford medical options or they sit on my surgical wait-list for over a year.

I am sure you will hear specifics from experts tonight with regard to endometriosis, but this also extends to heavy periods, menopause and, again, pelvic organ prolapse. This is further exacerbated by the difficulty accessing evidence-based holistic care for these conditions, such as pelvic floor physiotherapy.

I am sure that your committee is aware of the historic and current issues of gender inequality in medicine. Pelvic pain has long been dismissed, and I am one of those physicians who has been on both sides of the diagnosis.

Endometriosis, as a disease, has for too long been neglected as a priority in research and in treatment. While this has improved slightly in recent years, there remains a significant and unaddressed gap when it comes to other areas of medicine. As you will hear today, endometriosis is a complex disease for which treatments are focused on medication and surgery, but there is also a longer-term chronic pain aspect that requires multidisciplinary teams, and many aspects of these are poorly supported in Canada.

Specific to gender inequity and surgery in our own country, you might be interested to find out that reimbursement for surgeries on Canadian women pays 26% less than that for the equivalent surgeries on Canadian men. The study that cites this data is attached to my notes. That gynecology is the only majority female surgical specialty is a double hit of gender inequity to both the patient and the physician.

I have three suggestions for the standing committee this evening. Number one is to include key performance indicators for women's health in all system evaluations. Number two is to require provincial health organizations to apply a gender lens to health care resource allocation. Number three is to support the passage of a national drug plan, and specifically include contraception and medications that treat pelvic pain and heavy periods.

Thank you.

The Chair: Thank you, Dr. Mattatall.

Next, from EndoAct Canada, are Dr. Catherine Allaire and Kate Wahl.

I understand that you have a joint statement. Between the two of you, you have five minutes. You have the floor. Welcome.

• (1945)

Dr. Catherine Allaire (Co-Chair, EndoAct Canada): Thank you, Mr. Chair and members of the committee for the opportunity to provide evidence today about endometriosis for the women's health study. We are grateful to the committee for prioritizing this issue.

I am Dr. Catherine Allaire. I'm a gynecologic surgeon. I'm also head of the UBC division of gynecologic specialties and medical director the B.C. women's centre for pelvic pain and endometriosis, an interdisciplinary centre we have in Vancouver for endometriosis care. I'm also co-lead of EndoAct Canada, an organization created to drive action on endometriosis in Canada, which was co-founded by the Endometriosis Network Canada and is a patient group, and the Canadian Society for the Advancement of Gynecologic Excellence, which is a physician group.

I am joined today by my colleague Kate Wahl, a Ph.D. candidate at the University of British Columbia and executive director of EndoAct. We look forward to sharing and clarifying our points of view and hope that the committee will also have the opportunity to hear directly from people living with endometriosis.

Endometriosis is a complex, chronic disease that affects at least one in 10 women of reproductive age and an unmeasured number of transgender, non-binary and two-spirit people. That's approximately two million Canadians. The disease occurs when tissue that is similar to the lining of the uterus forms lesions, cysts and deep

nodules on other parts of the body, including the ovaries, bowel and bladder. Symptoms of endometriosis often begin in adolescence and include severely painful periods, chronic pain and infertility. There is currently no cure for endometriosis, and the disease is managed through expert surgery, medications and complementary care.

Historically and to this day, endometriosis symptoms have been dismissed as just part of being a woman or a bad period. This is rooted in the widespread normalization of women's pain and neglect of conditions that affect women and leads to delays in diagnosis and treatment as well as adverse outcomes. For example, teens with symptoms of endometriosis are 10 times more likely to miss school, impairing their ability to obtain their educational goals. Adults with unmanaged endometriosis are less able to participate in their work, community and family.

Beyond the physical impact of the disease, people with endometriosis also experience higher rates of mental health conditions. Endometriosis is not just a women's health issue; it is a societal issue. In fact, the cost of endometriosis to the Canadian economy has been quantified as \$2.5 billion annually, primarily due to lost productivity.

Despite its high prevalence and the burden of endometriosis on Canadians, access to care remains poor. People wait an average of at least five and as long as 20 years to receive a diagnosis. This delay is attributed to poor public awareness of the disease and low knowledge among health care providers. Once people do receive a diagnosis, our recent informal survey of surgical experts across Canada found that patients are waiting six to 18 months to see an appropriate specialist and a further six to 24 months for surgical management. That's a wait of up to three and a half years.

The reasons for this delay include an insufficient number of properly trained surgeons and inadequate remuneration for this type work, but, most importantly, lack of adequate OR access for those surgeons who choose to do this work. There is a consistent and concerning discrepancy in wait times for non-cancerous gynecologic conditions when compared to other non-cancerous surgical specialties. This is gender-based discrimination.

Ms. Kate Wahl (Executive Director, EndoAct Canada): The shocking consequence of these delays is that more and more Canadians are paying out of pocket to access the endometriosis care they need outside of the country. To be clear, these are not experimental or unnecessary procedures; they are standard and life-changing surgeries. It is also not just wealthy Canadians who are seeking care internationally. We have spoken to people who have drained their savings or taken out second mortgages to make treatment possible.

Fortunately, there are opportunities to make real change in the lives of women and gender-diverse Canadians with endometriosis. Looking internationally, our peer nations like Australia, France and the United Kingdom have all identified endometriosis as a pressing women's health issue and developed policies to tackle the disease. The common theme of these policies is investment in three areas: first, improving timely access to appropriate care; second, enhancing knowledge of the disease among health care providers and the public; and, third, investing in research to identify the cause and cure of endometriosis.

We strongly urge the committee to consider how Canada can join our peer nations in taking coordinated and strategic action on endometriosis. In our view, the first and critical step would be to consult with Canadians who have endometriosis as well as clinicians and researchers to better understand the contributors to the current challenges and create a national action plan on endometriosis to address this problem. Together, we can make real change on this pressing health issue.

Thank you.

● (1950)

The Chair: Thank you, both.

Last but not least, we have the McGill University Health Centre.

Dr. Nguyen and Dr. Zakhari, you have the floor. Welcome.

Dr. Andrew Zakhari (Co-Director, Endometriosis Centre for the Advancement of Research and Surgery, McGill University Health Centre): Thank you very much to the House of Commons for extending an invitation to Dr. Nguyen and myself.

We are gynecologic surgeons specializing in endometriosis, and we are the co-directors of EndoCARES, which is a specialty clinic for advanced endometriosis surgery and research.

We'd also like to thank our fellow witnesses for their powerful statements today.

I'll let Dr. Nguyen take it from here.

Dr. Dong Bach Nguyen (Co-Director, Endometriosis Centre for the Advancement of Research and Surgery, McGill University Health Centre): Thank you, Mr. Chair and members of the House of Commons.

All of us here know someone affected by endometriosis, whether we realize it or not. That's because even though it affects one in 10 women and countless gender-diverse individuals, it often leaves people silently suffering with debilitating pain and absenteeism from work or school.

Imagine having plans of building a family but not being able to conceive because of endometriosis, or losing a kidney because of endometriosis, or having a blockage of the intestines.

When you consider that over one million people in Canada have endometriosis—which may take years to diagnose—this represents a huge economic burden on the health care system and on our society. It's estimated to be over \$2 billion per year.

Dr. Andrew Zakhari: When it comes to endometriosis in Canada, we are fortunate in many ways. We do have experts in endometriosis from coast to coast. We have 14 fellowship programs for gynecologists to subspecialize in complex pelvic surgery. We have a national body, known as CanSAGE, that oversees these training programs and that organizes boot camps and workshops, as well as conferences, in gynecology. We're also fortunate to have organizations committed to spreading awareness and to fundraising, such as EndoAct Canada and the Endometriosis Network Canada.

Dr. Dong Bach Nguyen: Many countries around the world—such as France, Australia and Denmark—have set national action plans for endometriosis care. While in Canada we have expertise in endometriosis, what is missing is a comprehensive action plan to allocate funds and resources to centres with endometriosis expertise. We believe that empowering these centres is the most effective way to address wait times for diagnosis and treatment.

There are three main domains in which support is needed.

First, there is an urgent need to improve access to surgery. Surgery is essential for many patients, whether to relieve symptoms, improve fertility or reverse damage to organs. What is missing is not surgical expertise but rather adequate operating room time to address growing wait times.

In our centre alone, there are nearly 1,000 patients awaiting surgery in the department of gynecology. This means that patients who are referred to us wait six months to be seen, followed by an additional one year of waiting if they need surgery. This backlog is frustrating for patients and providers, and it's disheartening, obviously, for patients living with terrible symptoms.

Dr. Andrew Zakhari: Besides improving access to surgery, the second key domain is supporting multidisciplinary care teams, as we've heard tonight.

Endometriosis can negatively impact so many aspects of life besides causing pelvic pain. It can affect sexual function. It can affect urinary and bowel function, reproductive health and mental health. A multidisciplinary team is, therefore, essential for endometriosis care. We should be emulating successful clinical models, as we've seen with cancer care, diabetes or orthopaedics.

Endometriosis is a complex and chronic condition no less deserving of such a model of care. For endometriosis, such teams would include nurse navigators, pelvic physiotherapists, nutritionists and psychologists. They would all be part of the team. Until we ensure adequate public funding for all these services, proper endometriosis care will remain accessible only to those able to pay in the private system and will remain fragmented for the rest of the population.

Finally, as we've also heard here tonight, endometriosis research is underfunded, particularly when compared to other chronic conditions. I'll put this in context: In 2022, there were approximately \$4 per patient per year allocated to endometriosis research compared to \$31 for diabetes or \$130 for Crohn's disease, which affects less than 1% of the population. While we are encouraged by the recent announcements of federal support for endometriosis through the Endometriosis Network Canada and the Society of Obstetricians and Gynaecologists of Canada, more funding allocated to research in endometriosis and women's health will help drive innovation and discovery in this field, and hopefully open up new diagnostic tests and treatment options.

To summarize, we need resources to follow the patients who are seeking care in centres with expertise in endometriosis, specifically improved access to surgery, public funding for all the allied health care workers needed for high-quality endometriosis care, and more research funding focused on endometriosis and women's health. While taking these steps will not solve the challenge of endometriosis care, it will certainly go a long way to bridge the divide between where we are today and where we should be in Canada.

Once again, we'd like to thank the House of Commons for the invitation to appear here today to advocate on behalf of our patients.

• (1955)

The Chair: Thank you very much.

We're now going to begin rounds of questions, beginning with the Conservatives.

We have Ms. Vecchio, please, for six minutes.

Mrs. Karen Vecchio (Elgin—Middlesex—London, CPC): Thank you so much, Chair.

I would really like to thank all of the witnesses who are here today. You've really brought your expertise. I really appreciate all of the knowledge you have.

I want to read just a quick quote for you. I think that after speaking to you we can see that there's absolutely some disconnect here, because we could do more.

As noted in Policy Options:

Canada is known by advocates around the globe for having some of the worst endometriosis care in the developed world, a situation made worse by gatekeeping at the family medicine and generalist OBGYN levels, a stubborn lack of ex-

pertise on how to treat this complex illness, and some of the longest specialist wait times on record.

I think you've touched on many of these things.

I'll start off with you, Dr. Jolly.

Thank you. For 50 years of working on this, you deserve a massive pat on the back from every woman who has ever gone through this. Thank you so much.

I heard from McGill, though—and I want to switch around to all of you—that one in 10 women, from what I understand, has endometriosis. When do the first signs start to appear? Is it at the time of the first menstruation that they would be finding that something might be bad?

I'll move into these questions.

Elaine, can you share that with me? When does endometriosis start? When would people start thinking that there's something different with their period or that it's abnormal?

Dr. Elaine Jolly: Well, definitely, it can start in adolescence, so we need these young women to be aware of what the signs and symptoms are.

Number one, it is pain: pelvic pain, pain with your periods, pain if they are having intercourse and pain with regard to bowel function and to ovulation. It can also be associated with heavy bleeding and irregular bleeding.

If we can get this early—and treat it early and think about it early—the gatekeeper is the family physician. Many family physicians don't have time and they normalize this: “Oh, this is just what happens to girls, so suck it up, buttercup.”

You need to listen, because the family doctor or somebody in emergency may have said that you can take NSAIDs and that would help. Sometimes it helps a bit, but it doesn't help that much. If in three months you're taking your initial NSAIDs along with even more serious pain medication, then the physician should think about it. Could this be endometriosis? Should they examine this patient, which they often don't do? Might that patient need diagnostic imaging like ultrasound?

It can also be asymptomatic, which is difficult. When you see this young woman—not the same one, another one—in your infertility practice and you do all of the workup for her and then do maybe a diagnostic laparoscopy, and oh my goodness, you see that she has a pelvis that may not be full of endometriosis but may be at the beginning of endometriosis.

It is pain: pain, pelvic pain, which eventually turns into chronic pelvic pain, but that can take quite a while depending on the serious nature—

Mrs. Karen Vecchio: There was something that EndoAct Canada said, that Catherine had mentioned here, which was that it was seen as “a bad period”. That is so subjective: What is a bad period?

Is there something when it comes to a length of a period so that if a young woman.... I've done some research that they may have a shorter time span. Five days are what you regularly would be menstruating for; they talk about it being shorter. As you indicated, they may go into menopause earlier as well. Can you share a bit about that?

I'll pull over to you. I'm looking at the six months to be seen, followed by the one year for surgery. If you're 12 years old or 13 years old and getting your first period, you have no idea how to compare this. You're comparing apples to oranges, because nobody's period is the same. When is it going to be the first time that one of these young women actually starts seeing an OB-GYN because this has actually been referred further?

I know that's a lot to pile on. Please, anyone take charge, but Elaine, if you could start with that, I'd really appreciate it.

Then we'll go over to EndoAct, and then back to McGill, if you don't mind.

• (2000)

Dr. Elaine Jolly: It doesn't usually start right away unless there's obstruction to the pelvis. Sometimes that happens, and it's a congenital issue, so that as soon as you have a period, you start to have pain. This is something that builds up slowly. The pain initially may be minor. Of course, this is normal; this is just what happens to girls. However, when it becomes so serious that they have to miss school, they see the school nurse.

Periods last five to seven days. If you are bleeding for 10 days or 11 days and you're having pain for all of that time, then you know there is something wrong.

You need to take a good history. You need to take a gynecological history, and for this you need time. You need to have some idea about endometriosis: pain, heavy bleeding—

Mrs. Karen Vecchio And more pain....

Dr. Elaine Jolly: —and more pain.

Mrs. Karen Vecchio: I want to pass it over to EndoAct, because I had the opportunity to meet with EndoAct as well as young women who came and shared with me their experiences. Can you provide some insight on this as well?

Dr. Catherine Allaire: I'd be happy to. I think your points are very well taken, and certainly the teenager who has abnormal periods may not know they're abnormal. There is certainly a difficulty with sharing that information. Sometimes there is still a certain mystery and certain taboo about discussing menstruation. That's problematic, and that's one of the points that has to be addressed in understanding what a normal period is and what an abnormal period is.

I would take Dr. Jolly's point, which is that when the period is interfering with the person's quality of life and they are unable to function during the time of menstruation, that's a problem. To me, that's the simplest way to put it. If they're unable to function and having to plan their life around their periods and are missing school, work, etc., then that's a red flag, essentially.

That's what I'd say about that.

The Chair: Thank you, Dr. Allaire and Ms. Vecchio.

Next is Dr. Bennett, please, for six minutes.

Hon. Carolyn Bennett (Toronto—St. Paul's, Lib.): Thank you all very much. It seems everybody wants a national action plan, and I know that the September funding was mainly about access, but how would you see some of that money going to actually map out what's there and not there? From what I'm hearing from Dr. Jolly, I think if young women knew about it.... As a humble family doctor, I had lots of patients come in and say, “Do you think it could be endometriosis?”

If you build that health literacy, sometimes it shortens how long it takes to get the imaging or all of that. My question is on what would be in an action plan.

Also, in the specialized imaging, it sounds like it's only going to be in certain places across the country. Is there a way that could happen virtually with technicians in various places, but the actual imaging happening in the specialized sites? In the referral system, again, how do we make sure it's equitable across the country, without people having to get on a plane? Is it just that it's not on the billing schedule, or is it that there are wait times and people then choose to go private or go to the States?

Anybody can have a go at any of it.

Dr. Catherine Allaire: I'll speak to the national action plan, because that's certainly something EndoAct has put forward as something that can be emulated following the example that Australia has set for us. They have been very successful so far with their plan at obtaining funding. The three arms are always awareness education, access to quality care or for evidence-based care, and research funding.

The funding that was released in September was targeted to awareness, so that's the first part of what we're hoping for. It was targeted toward increased awareness among the patients and the population of Canada, as well as some educational initiatives for physicians and gynecologists by SOGC. That part seems to be a beginning. It certainly may not be enough money, but it's certainly a start.

I do believe that a national plan requires consultation, and a bit more identification and study of the actual barriers. We think we know the barriers, but we need to be more scientific about understanding really where the barriers are so we can address them in a more fulsome way.

• (2005)

Dr. Elaine Jolly: If I may, having read the two action plans—the one in Australia and New Zealand and the one in the U.K., which goes up to Scotland—I would say they are amazing, so we certainly would consult. As a matter of fact, I think that a visit to one of these places would be ideal.

In Canada we need to know what is happening and we need, before we have the action plan, to have our own guidelines. This was the start they took, and actually they called them “nice” guidelines because of what is in the parentheses. In similar situations, we would look at the major parameters and come up with guidelines for Canada, and then have this national action plan. So it would be a series of funds.

What struck me is the similarity. They have both have had very successful integration of endometriosis information in the schools, so there is a pattern and there is information that is shared, but it is specific. In Wales, in Ireland, in Scotland and in the basic U.K., in all of the schools they have put this in and the funding has been from Parliament. As a matter of fact, when you look at this, it's a parliamentary report. It's not quite the same in Australia.

We have differences. We have a big country. They have a small country. We have to go from sea to sea and we have to look at centres of excellence to lead some of this, and there needs to be a coming together of experts in endometriosis and all of the areas we have represented here so they can come up with a really good document.

This isn't going to happen overnight. Would you say this is going to take a little while?

Dr. Andrew Zakhari: Absolutely.

At this time I'd like to add that part of the national plan should address what we're already doing well, because we keep saying that we have problems, but we also have success stories.

We heard a quote tonight about it being some of the worst care in the world, but I would argue that we also provide some of the best care in the world, so I think we're on both ends of the spectrum. That's what we need to mediate with a national action plan to identify our strengths and the gaps in care, and to build systems to make sure every patient has access to the good story and not the bad story.

Dr. Elaine Jolly: We need education, though, for the primary care physicians and the patients. They need to fit into this, and the education comes from the wonderful supports we have here in Canada.

I would say that we don't have bad care. We don't have enough physicians. We don't have enough health care workers. We can't even put this action plan into place until we have some support.

Just to give you an example, we have a women's health centre in Ottawa that was supported by a very wonderful woman who gave a lot of money. That was matched by the hospital and by the province, but this needs to be carried on. You must have a priority in your department, because you can get the start, but then you must produce. The production is part of the national action plan, because we know what is good, but we don't have enough centres

of excellence. We have some—14—and just now we need some in every province so that people don't have to travel miles and don't have to do medical tourism.

I'll say just one thing about imaging. Pelvic imaging has to be done with a diagnostic pelvic ultrasound, so you can't do that virtually. You have technicians and the technicians learn old endometriosis information because they have not been brought up to date. In some cases, yes, they have wonderful imaging.

In Ottawa, my colleague, Dr. Sony Singh, just recruited a physician from—

The Chair: Dr. Jolly, thank you. We're well past time.

There are a whole bunch of other people who want to ask some questions here too.

• (2010)

Dr. Elaine Jolly: —Kuwait, who has diagnostic imaging expertise that no one else we could recruit here from Canada has, so we need to look at all of this as well.

[*Translation*]

The Chair: Ms. Larouche, you have the floor for six minutes.

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

I want to thank all the witnesses for being here today and for taking close to two hours to talk about endometriosis.

We know that the stigma surrounding women's illnesses is still very widespread in our communities.

I have a number of questions and I know we will have a few rounds to ask them.

I will begin with you, Dr. Jolly.

You were on a roll regarding the recognition of credentials.

What needs to be done in this regard, knowing that some aspects are under government control and that some professional bodies might have reservations at times?

Who has to come back to the table? What discussions are needed to facilitate the recognition of credentials?

You raised the issue of staffing, which is crucial in our health care system.

[*English*]

Dr. Elaine Jolly: I have to give that answer to someone else. I didn't turn on my French button, so I didn't understand exactly what—

[*Translation*]

Ms. Andréanne Larouche: Perhaps someone else would like to answer.

[*English*]

The Chair: If you could turn on—

[*Translation*]

Dr. Catherine Allaire: I would be pleased to answer in French if you wish.

Let me get back to your question, which is similar to what someone else asked about access to care. Access to surgeons was mentioned, among other things.

Many surgeons have received excellent training in Canada. Fourteen research grants have been awarded in laparoscopy and endometriosis, but the surgeons end up working in the communities and no longer have operating time.

One of my colleagues who studied with me and works in a city in Alberta was given one day of operating time per month. She has a two-year waiting list, but does not get enough operating time. That is the first problem.

Not much can be done by well-qualified people who are not given operating time. The first step is to give them the necessary access. Once they have sufficient access, we have to look at staffing issues and the recognition of credentials.

We have to consider people from other countries who have the necessary degrees, while ensuring that their training is equivalent to what we offer in Canada. Due diligence has to be shown and we have to check their credentials to ensure that their skills meet our standards.

Ms. Andr anne Larouche: Dr. Allaire, I would like to continue with you.

In your presentation, you mentioned salaries for health care professionals and doctors. You also talked about access to operating rooms, in particular.

The Standing Committee on the Status of Women conducted a study on the disproportionate effects of the pandemic on women. We also suspect that the pandemic had an impact on health care and resulted in delays.

Organizations such as the Canadian Cancer Society have indicated that there were delays in obtaining certain diagnoses.

I would like to hear your thoughts on the pandemic's impact on treatment delays, recognizing that we should have invested more in Canada's health care system, and that has been the case for a very long time.

The pandemic simply highlighted the cuts that were made over time, in the name of austerity, to our health care system and to health transfers.

What link has to be made between the pandemic and the emphasis the government must place on adequately funding the health care network, in spite of periods of austerity and the pandemic's impact?

This is the time to send the public the clear message that massive reinvestment in our health care system is needed in order to increase staffing.

It is not simply a question of recognizing credentials; we must also offer good salaries to attract and retain health care workers. Greater access to operating time is needed.

Can you make a connection between the pandemic and the issue of investing in our health care system?

My question is a bit long, but I would like some information nonetheless.

Dr. Catherine Allaire: Everyone knows that the pandemic was devastating to the medical system. All non-urgent cases were set aside during the pandemic. Only cases of cancer and trauma were treated. This created major problems in health care, and we are struggling to get back to normal. We are trying to catch up, but are not there yet.

This highlighted the weaknesses of our system, which was already stretched to 110%. So when the pandemic hit, we were unable to absorb the additional pressure on us. We have all seen the effects of that.

Certain things can be done, however. Some centres in Canada have invested in women's health, including ours. I have to say that we are very lucky in Vancouver because B.C.'s women's hospital recognized the importance of women's surgery. It created a surgical program specifically for women and their illnesses. It made available a number of operating rooms for day surgeries and minimally invasive procedures that did not require major surgery. So we can do our major procedures at the hospital where they should be done, and minor procedures elsewhere.

Such models exist, but it takes motivation and money to develop them. We were lucky that our hospital and the B.C. government recognized the importance of this.

• (2015)

The Chair: That's all the time we have, Ms. Larouche.

[*English*]

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

Ms. Lindsay Mathysen (London—Fanshawe, NDP): Thank you to all of the witnesses for joining us this evening.

This will be for Dr. Allaire and Ms. Wahl from EndoAct, first of all.

In the submission to this committee, you note, "Federally, endometriosis is not included in the Canadian Chronic Disease Surveillance System, and the Canadian Institutes of Health Research...have not invested in endometriosis as a priority area."

You also stated—and I think all of the witnesses commented on this—the high number of women who suffer from endometriosis. It's one in 10 women, and the research is not even done on those who are transgender, non-binary and two-spirit.

Why is endometriosis not included in the Canadian chronic disease surveillance system and why hasn't it been a priority for that federal funding?

Ms. Kate Wahl: I think that's an excellent question.

On the research front, it's probably a multi-faceted problem. On the one hand, to make real changes in endometriosis we need to see sustained investment in research areas. Certainly, the Canadian Institutes of Health Research have been investing more in women's health research more recently, which is really wonderful to see. I think to catch up on this issue, continued ongoing investment in areas that are prioritized, particularly by the patient community, would be important for change.

There's also a little bit of a researcher pipeline problem in the sense that when there's unawareness of a disease, you're not necessarily bringing people into that field to investigate the issue.

It's at once about how our research funders can invest in the problem, thereby contributing to solutions, and also about bringing folks into the field who might not have been there before.

On the chronic disease surveillance front, I think that's a question we would almost have for the committee. It's very difficult for us to understand how those priority areas are set, given how common endometriosis is among Canadians and the burden that it has over the course of a lifetime. We're talking about a disease that can start when you're 12 or 13 and continue to menopause and beyond.

Certainly, understanding how to make changes in that area would be important. We say that if you can't measure it, you can't fix it. Having a better sense of what the burden is and how it's changing over time would be really important for making change.

Ms. Lindsay Mathysen: That CIHR funding is tri-council funding. I mean, that's directly from the federal government.

I've certainly heard that from a number of grad students. Those who rely upon that funding in my home town at Western University and the Schulich School of Medicine have commented on that directly. It's incumbent upon the federal government to increase that as well within that tri-council funding.

Would you agree with that?

• (2020)

Ms. Kate Wahl: Yes, I think that's fair.

Ms. Lindsay Mathysen: Also, EndoAct in Canada called on the federal government to ensure there are provisions for endometriosis in transfer funding agreements, particularly to enable improvements in access to expert surgical and multidisciplinary care.

To your knowledge, has the federal government raised such provisions in its ongoing negotiations to finalize bilateral health-funding agreements with the provinces and territories?

Ms. Kate Wahl: I'm not aware that has happened. That's one of the points we made in our brief, which was attached.

Until we consider endometriosis benchmarking as a priority similar to what we've done for other things like hip replacements, etc.... Those have been set as priority areas. It is high time endometriosis

surgery is set as a priority area with associated benchmarks, and with expectations for provinces to fulfill those benchmarks.

Ms. Lindsay Mathysen: My colleague Don Davies introduced a motion, M-52, which tries to establish a national action plan for endometriosis. New Democrats certainly support that. One of the key points of a national action plan, of course, is the universality of care, which ultimately falls within the Canada Health Act.

Would everyone agree with that, as well?

Perhaps I can hear from Dr. Jolly.

Dr. Elaine Jolly: New Zealand, Australia, U.K. and now France—which just announced it is going to do this—have universal funding. Therefore, they can, from the federal position, support what is asked for or what is pointed out as vital to decrease the gap. In the U.K. and Australia, it takes eight years to be seen. We're much better than that. We're at 5.4 years, but that's old data. Maybe it has gone up to six.

We are doing some things right. We have universal care, but we don't have access. That is the problem. As well, we don't have people. Not everybody who goes to an endometriosis centre of excellence is waiting for surgery. It is diagnostic. Why is this not helping...so they get the super-duper imaging? They may get laparoscopic diagnosis and they may get treatment in a minor way, but no diagnosis. We do not, now, need to have a laparoscopy to make the diagnosis. We need the signs and symptoms. It's pelvic pain that is unadulterated and continues.

You need to fill in the gaps and get manpower. That manpower comes from the universities, medical schools, and obstetricians and gynecologists. There are three action plans with regard to seeing patients. There is the family doctor. Sometimes the family doctor is the local clinic. Sometimes the clinic is good and sometimes it's very full—or often. Then there is referral to a gynecologist. Often, the situation is very much improved, but that takes time. Finally, if they can't help, you go to the super-duper endometriosis specialist.

We must make sure there are enough of these across Canada, not just four, five or six in Ontario and two, three or four in Quebec. We don't all have that. We have one just starting now in Nova Scotia—

The Chair: Thank you, Dr. Jolly.

Mrs. Roberts, please go ahead for five minutes.

Dr. Elaine Jolly: Thank you. I get a little passionate.

Mrs. Anna Roberts (King—Vaughan, CPC): Thank you so much.

I wish, Dr. Jolly, that you'd been around when I went through it. My own personal experience wasn't fun. I know that I'm a little older than most of the women here. Years ago, nobody believed us. It was just, "Oh, well, it's one of those things."

Thank you for bringing light to this whole situation.

I want to ask you a couple of things.

Can endometriosis be caused after you have children?

Dr. Elaine Jolly: Yes, you can certainly have endometriosis after that.

Having children is good, because the hormones of pregnancy help allay the situation. You may have an asymptomatic situation if you're lucky enough to get pregnant.

Of course, you can have endometriosis in your forties. The good thing about menopause.... It doesn't often start after menopause. It's the continuation when it gets severe. It causes the menopausal situation. Then it's very hard to treat the menopause because of the endometriosis. The key years are 20 to 30. That's where you have most of your endometriosis.

We would have diagnosed you. You should have come.

Voices: Oh, oh!

• (2025)

Mrs. Anna Roberts: I am going to share something personal with you. I lost five children, and it wasn't diagnosed. After God blessed me and gave me two healthy children, that's when it was diagnosed, and they attributed it to being part of the miscarriages, but that's enough about me.

Dr. Elaine Jolly: I'm not sure about that.

Mrs. Anna Roberts: I just think it's important.... Let's be totally frank here, and no offence to the gentlemen in the room, but if it weren't for us, they wouldn't be here. I'm just saying.

You mentioned a lack of education. I think we also need to bring that into the curriculum in schools to make them aware.

You mentioned the lack of doctors. I met with doctors, just a few months ago, who came from all over the world. Some of them had as much as 20 years' experience in all different areas of medicine, and they're driving cabs. They've passed their boards, but they're driving cabs. I met one doctor who really shocked me when he said that he taught at the University of Toronto, but he's not allowed to practise in this country.

When I hear about the situations we have with endometriosis and with the lack of health care for women, I question what we are doing as a government that we're not able to ensure we can get those doctors practising so that we don't have those wait times and so that we can do a better job. How can we change that system? What ideas can you bring to this committee to help us understand that?

Dr. Elaine Jolly: There is progress being made in Ontario to fast-track individuals so that they don't have to drive cabs and don't have to wait, if they have the training and if they pass the medical exams, because the council of medicine must have Canadian participation. However, many of those people do. They pass the exams. They have study sessions.

There's a piece missing to direct them. That is a provincial matter. We must have somebody, an ombudsman, who can fast-track the areas we need doctors in. It's very obvious, when you look at their CVs, what the situation is.

The fast-tracking has started, not with immigration but within the system. Once you pass your exams, then where can you go and how much do you have to train? We're very specific, and so it should be. We can't allow every doctor in, but we can allow in the ones who have trained and the ones who are good. That requires some assistance or an appointee at the provincial level who can direct them, or a committee that directs them.

Mrs. Anna Roberts: Do you not agree that we have to do a better job of assessing the individuals who come here? Some doctors I met have 20 years' experience in their home countries. A couple were from the U.S., a couple were from Dubai, India and all over. They come here, pass the boards, and then they are told they can't practise. I shake my head, and I think to myself that I have constituents who can't even find a family physician, and therefore, they're struggling through their medical situations. They have to go to either the hospital or a walk-in clinic, and it could be a different doctor—

The Chair: Mrs. Roberts, I'm sorry, but that's your time.

• (2030)

Mrs. Anna Roberts: They got six minutes, and I only got five.

The Chair: Yes, that's right. A couple of your colleagues farther down are only going to get two and a half.

Mrs. Anna Roberts: Oh, I'm sorry. Thank you.

The Chair: Ms. Vandenberg, go ahead for five minutes, please.

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

I'd like to direct my questions to Dr. Mattatall.

Fiona, it's nice to see you again in this context.

I just want to pick up on something you said that, frankly, is a bit shocking. You mentioned that we track wait times for things like hip surgeries, but not for gynecological procedures. Then you also mentioned something about surgeries done on women being reimbursed less than surgeries done on men, if I heard you correctly. It just begs the question: Why is this happening?

You talked about performance indicators. If we're not tracking or measuring this, what is the issue now in terms of data? Are there barriers to getting this data? Is there anything the federal government could do to improve both of those situations?

Dr. Fiona Mattatall: Thank you, Anita. What a nice treat to see you.

I think it is historical gender equality. It's 2023 and it's time for that to be called out.

The issue with data is that we do not have it. I went online today to see what my wait time is for hysterectomies here in Calgary compared with other colleagues, and the data is blank. It is not there. Without asking the question, we don't have the answer.

The suggestion I have is to make a push to the provincial ministries of health to quantify this, to prioritize gendered procedures and ask the question.

Hopefully members of the committee have time to take a look at that excellent Canadian study that did look at the cost per surgery and what physicians and surgeons are paid for surgery. When you look across the country, surgery for endometriosis is not paid well.

To the last point, we can bring in more surgeons for endometriosis—excellent surgeons from outside of Canada—but without operating room time and access, it does not change the wait times for patients, so bringing in more physicians can't be stand-alone.

Ms. Anita Vandenberg: Those are excellent suggestions. I appreciate that very much.

My next question is for Dr. Jolly.

I am an Ottawa MP, so I know very well the incredible value of the women's health centre and the work you do.

I want to pick up on what you said about centres of excellence. You talked about sea to sea and how big a country we are.

As a federal government, how we would be able to support the establishment and ongoing support for these kinds of centres of excellence?

Dr. Elaine Jolly: They're so important. They are training centres as well. They are training physicians at all levels and training in medical schools.

What happens is, it's a wonderful surgery. The residents love it and they want to take extra time because it's like “wow” surgery. Menopause is...not so much. Everybody has menopause. It's a difference.

What is a centre of excellence? Well, it is something or some place that is run by or operated by experts in endometriosis. Surgical experience is the first thing that happens. Medical treatment for endometriosis is quite exciting. It's not perfect, but it can certainly get you through without surgery. You have the option, as a woman, to try. Surgery is really still the last resort, unless there's a big ovarian cyst or the typical chocolate cyst.

It's very important to have the education at all levels—in the medical school curriculum and the nursing. We had fantastic nurses who were certified and credentialed, for example, in menopause. There are nurses, probably in your institution, Dr. Zakhari, who help with the patients and they are taught about endometriosis. They go to endometriosis meetings. They are part of the research. The whole team comes together. It's multidisciplinary.

The other thing is that it should be associated with a university with regard to the education. Remember that we're not talking about 100 of these. We're talking about one in every medical

school. We have 16 medical schools and I understand there are three more on the way.

Each one of these should be mandated and there should be funding for this. It's a centre of excellence, so there should be an endowed chair. The endowed chair can be someone who has excellence in leading this, but also has funding to do research. That research may \$100,000, \$200,000 or \$300,000, but that chair is endowed. That is very important.

The Chair: Thank you Dr. Jolly.

Dr. Elaine Jolly: There's other stuff, too.

• (2035)

The Chair: Thank you.

[*Translation*]

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

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

I would like to go back to something. It was you, Dr. Nguyen and Dr. Zakhari, who talked about funding.

Something could be done with regard to research. Moreover, the World Health Organization, or WHO, has recognized that not enough research is being done and that there are many knowledge gaps in certain areas, particularly for the development of potentially less invasive diagnostic methods, especially treatments that would not prevent women from becoming pregnant. In many cases, that is a dramatic outcome of endometriosis treatments.

What are your thoughts on such research and the need to invest in research related to such treatments?

Dr. Dong Bach Nguyen: Thank you for the question.

[*English*]

I absolutely agree with what you're mentioning.

When patients come to see us and we give them a diagnosis of endometriosis, one of the first things they ask is why they have endometriosis. There we are all looking at them and trying to give an answer when we really don't know why. We have many theories why this disease is occurring, and it's probably a combination of all, but we don't exactly know the perfect pathogenesis, nor do we find perfect DNA or genetic answers for patients. I think, from the get-go, research needs to tackle that. When we know the origin and exact cause, that would also help us develop research in developing medications or targeted medications toward endometriosis. Currently, all medications treating endometriosis are hormonal-based, because we know that this condition is a hormone-dependent disease. Invariably, if we do advance research more, we will be able to find ways of treating endometriosis better.

We always talk about three areas or barriers to care: number one is awareness, number two is diagnosis and number three is treatment. In diagnosis as well, currently we're relying heavily on imaging, on MRIs—ultrasound mainly, if not MRIs. Now, laparoscopy is really used mostly to treat endometriosis, but if we can find diagnostic methods that are less invasive, then even the people in the remote areas can have access to these and have a quicker diagnosis.

Dr. Andrew Zakhari: What I would like to add, too, which has not been mentioned before, is that we talk about ultrasound used to diagnose endometriosis, but it's actually quite a difficult thing to do in the community, because it requires a specific skill set with ultrasound. It's much easier to diagnose a gallstone by ultrasound, because you see the stone. With endometriosis, you may see a chocolate cyst, but you may not, so negative scans are often not negative.

At our centre, we often are repeating ultrasounds ourselves, and we're getting outside MRIs reread by our radiologists. These are duplicate amounts of work. They're not remunerated fairly either. We're often asking radiologists at our meetings if they would mind taking a look at an MRI, which has already been reported, but the report is not accurate. There's no standardization of ultrasound reporting in Canada that I'm aware of, or in Quebec for sure, so lots of ultrasound reports we get will just say that there is a normal uterus present, but they lack all the signs that we look for for endometriosis. We have to repeat a lot of work, which is another barrier for patients.

The Chair: Thank you.

We have Ms. Mathysen, please, for two and a half minutes.

Ms. Lindsay Mathysen: Dr. Mattatall, you had mentioned in many of your recommendations the need for coverage for prescriptions and medications. As someone who has pushed really hard on the idea of pharmacare and the government providing pharmacare, I'd love to hear more about that. In addition, I think you also mentioned that that include, of course, the specifics around contraception.

I've just put a motion forward in the House that calls for that universal access to contraception as well, and that the federal government provide that, much like we see in B.C.

Maybe you can talk about some of the positives of that and the need for that.

● (2040)

Dr. Fiona Mattatall: Thank you for the question.

The arenas around contraceptives and endometriosis do overlap. Sometimes oral contraceptive pills or the Mirena progesterone IUD are adjuncts that can be used to treat pain with endometriosis and to control bleeding that can be associated with it as well.

The standard and approved medical treatments for endometriosis are expensive medications. I have many patients who do not get coverage for these medications. Whether it's through plans at work or our Blue Cross here in Alberta, these will not cover our approved medications for endometriosis. Also, we really struggle with off-label treatment with other medications for it. We've talked a lot about surgical access and barriers there, but there are significant medical barriers to endometriosis to get pain under control—and

it's not just pain. It's about preventing that disease from getting worse over time and trying to prevent that chronic pain state.

As Dr. Jolly mentioned earlier, getting that diagnosis early for that younger patient, and getting them on a medication to prevent some of the later complications from endometriosis will ultimately save our health care system money.

The Chair: Thank you, Ms. Mathysen.

Dr. Kitchen, please, for five minutes.

Mr. Robert Kitchen (Souris—Moose Mountain, CPC): Thank you, Mr. Chair.

Wow, thank you all for being here. This is tremendously educational. I feel like I am back in university again. I need an instantaneous note service for everything being covered here. I haven't written this many notes in I do not know how long.

Dr. Jolly, I wish you would have been my professor when I was doing female care 40-some odd years ago. I do appreciate your comments. There is so much knowledge here.

A couple of things have been brought up. We have people watching today who have written and sent a lot of letters to the committee, etc., dealing with the issue of endometriosis, and recognizing it and getting that early diagnosis. You've all talked about that.

Dr. Jolly, you had 10 points. The first one was about education and basically getting into the schools to educate youth on what could possibly happen. I think that is great. The other part you talked about is expanding that medical education. I am going to throw this out there, because one of the things I brought up in the study is the reality that when I went to school, probably only 20% of the students were female. Today at medical schools, it's 50%-plus. That is great to see. We are seeing closer to 48%, 49% female practitioners.

What our constituents who are watching want to know is how we get those doctors who have graduated to take an interest in this subject. I got into sports medicine and various aspects. I streamed into orthopaedics. That was my interest. Everyone tends to do that. But how do we get these doctors to say that this is something they need to know, so when that youth or menopausal lady comes in, they know that this is part of what they need to know.

I will start with you, Dr. Nguyen, and then I will go to Dr. Jolly.

Dr. Dong Bach Nguyen: I think this comes down to CME, continued medical education. To be able to teach, you need the experts.

One of the big things that we need to look at, when we look at endometriosis, is that the care for endometriosis today is very different from what it was 20 years ago. Twenty years ago we had a handful of people who were experts, but like a tree that grows, one branch becomes two becomes three and those divide further. Now, coast to coast, we have a large number of experts.

How do we transfer that knowledge from the experts to the general population and to physicians who have graduated, for instance? That is done through CME. I think it is very important to fund CME so that it entices people to continue offering those courses; but also, if we're able to fund these expert centres, then these centres can then provide teaching and education for a larger number of people and a larger number of trainees.

• (2045)

Mr. Robert Kitchen: Thank you.

I apologize. My time is short, and I'm going to go to Dr. Mattatall first and then to Dr. Jolly.

Dr. Mattatall, what are your thoughts on how we can do that?

Dr. Fiona Mattatall: You're speaking to the converted here.

I am a patient who had a laparoscopy at age 19, and I became a gynecologist. Now I teach pelvic pain at the medical school. There are efforts on the ground and advocates like those who are sitting in front of you who are doing this work to educate fellow physicians, medical students and family physicians. We just need to continue to do the work and get the support.

Mr. Robert Kitchen: Getting that CME out there is so important, such that people recognize that.

Doctor Jolly, do you think it would be worthwhile to make it a mandatory program in continuing education for practitioners?

Dr. Elaine Jolly: Well, there are mandatory programs and you get certain points for going to certain CMEs, so you have to apply for this. It's important to know that if you don't attend a certain number of CMEs, you don't get your professional points. I've not heard of anything very bad that happens if you don't get these points, but they certainly are important.

Through the Society of Obstetricians and Gynaecologists of Canada, obstetrics and gynecology has all kinds of guidelines for everything. There are guidelines for endometriosis, which need to be updated, and we need to then have those, as I said, as a basis for our national action plan, because everything is in that with a review of the literature. The physician is out there and he, she, or they must attend certain numbers of CMEs, and they can do it virtually now. That's one thing we're thankful for that happened with COVID, that we learned how to do this. It was not terribly easy, but we did it.

The CME is excellent now, but in order to attain the CME, our doctors have to be paid for what they do. They don't have enough money sometimes to do all of this, especially the family physicians who are out there struggling with too many patients and too much of a load. Of course, now there's the rule in Ontario of one problem per visit, so if you have two problems, then you have to make another appointment, and this is such a silly thing. There are many areas that are working now, but we have to act on those.

The Chair: Thank you, Dr. Jolly.

Next, from Whitehorse, will be Dr. Hanley.

Go ahead, please, for five minutes.

Mr. Brendan Hanley (Yukon, Lib.): Thank you very much.

I want to add my thanks to all of the witnesses for some incredibly enriching testimony.

Robert talks about taking lots of notes, but I've been changing my question every, I think, two or three minutes based on the testimony.

I want to ask my questions mainly from a rural practice point of view, especially as you're all from urban areas and from areas of centres of excellence, so I really want to try to paint that link between centres of excellence and rural care.

Dr. Jolly, I really appreciate your 10 points, and many of your recommendations speak to rural practice: CME and support for health care providers, financial support for centres of excellence, empowering allied health professionals, innovation and advanced diagnostics, proposed national guidelines.

Dr. Allaire, maybe I'll go to you, since you're from my end of the country. How do you see yourself as supporting quality rural health care and women's health care in general, but also, perhaps, endometriosis in particular?

Dr. Catherine Allaire: Thank you. That's a very important problem considering the size of our country. Having centres of excellence is one thing, but having access for the whole community and the whole province is very important.

I think there are basically the frontline providers. We have to mention the family physicians, who will be the ones who have to be educated to recognize the possibility of endometriosis, to initiate first-line treatment and then to really promptly make a referral once the first-line treatment doesn't work. I think there's a huge education piece on that side. We're trying hard. We put an article in the CMAJ; we do CME events; we reach out in various ways to family practice meetings, but more has to be done.

Once that first-line provider has referred someone, you need the gynecology expert in the local area. Now, many communities in rural areas do have gynecologists, but they also have to have their skills upgraded to a certain degree so they know the proper chain of treatments and when to refer. There's a certain subset of patients who need a referral for treatment in tertiary care centres. Those are the ones who are going to have quite severe endometriosis, with invasive disease and the challenging surgeries that require that kind of expertise or those who have chronic persistent pain who really need that holistic, interdisciplinary, multi-faceted approach. If the general gynecologist is clear on that and knows what works in that setting and who to refer, then having access to those centres becomes a bit more efficient.

• (2050)

Mr. Brendan Hanley: Thank you very much.

Dr. Mattatall, maybe I'll go to you. I think all of this is in recognition that access to primary care in general in the country is really stressed at the moment, and even more so in rural health care. I'm thinking that as we, hopefully, fund and rebuild primary care that we can make sure some of the inequities you talk about, Dr. Mattatall, are addressed in primary care and team-based care.

Specifically, I want to reflect on two aspects. You mentioned chronic pain management and how that's an area that we know we need to improve in, and you also mentioned the importance of pelvic floor physiotherapy. I know we have an excellent service here. I imagine it's quite stressed at the moment. How do you see those around the country and, particularly in those two areas, how do we build those up so we have access to those universally as well?

Dr. Fiona Mattatall: I think that, with both of those areas, whether it's pelvic floor physiotherapy or looking at chronic pain and specifically chronic pain in the pelvis, we do see an inequity and quite a lack of equal access across the country, even within large centres like Calgary, Montreal or Vancouver.

We are blessed in Calgary. We have a large number of pelvic floor physiotherapists. We have a specific chronic pain centre.

I think that the challenge is access and money. For pelvic floor physiotherapy, the only patients I have who can access that are ones who have their own private coverage. Patients who are not covered by a private plan through work don't have access to pelvic floor physiotherapy at all. They're left to looking on YouTube for videos.

When it comes to the chronic pain aspect, sadly, the remuneration for that work for physicians here in Alberta is deplorable. It's hard to keep good, skilled people doing the hard work of chronic pain. It is not easy medicine. Anybody who has looked after patients with chronic pain knows that it's very hard medicine, and it is paid very poorly because it is not a procedure.

I think there needs to be a discussion about how we pay for those things properly, support patients in accessing them and then make sure that they are available, not only in rural and urban areas but also across the country.

Mr. Brendan Hanley: Thank you very much.

The Chair: Thank you, Dr. Mattatall.

Next we're going to Dr. Ellis, please, for five minutes.

Mr. Stephen Ellis (Cumberland—Colchester, CPC): Thank you very much, Chair.

Thanks, everybody, for being here.

I have so many questions and so little time.

I think, Mr. Mattatall, it was you who talked about medications for the treatment of endometriosis. In one minute or less, maybe you can talk about the medications and then maybe talk about the laser therapy thereof and briefly about the surgery as well, just so that people listening at home get an education this evening.

Dr. Fiona Mattatall: Respectfully, I'm going to punt this question over to Dr. Allaire. She is more expert than I.

Dr. Catherine Allaire: The first line medical therapy that family physicians would start with would be something simple: oral contraceptive pills, even taken continuously, progestin-containing IUDs, which can help quite a bit with dysmenorrhea, or sometimes progestin-only therapies, which is the next level of therapy.

Gynecologists might entertain stronger medications like progestin therapies and then move on to some stronger therapies, which are quite fraught with side effects but may be quite effective in some patients. They put them in a semi-menopausal state, which sounds extreme, but in some patients, is life changing to really suppress the symptoms.

You mentioned surgery. Surgery becomes, certainly, a treatment option for patients. We don't use it for diagnosis only. We want to do an excellent surgery and plan to remove endometriosis and to excise the adhesions that we see. Secretions can be very simple and superficial perineal.

We have some pictures that we put in our slide deck that we sent. We can see very flesh-like lesions that, really, a community gynecologist would likely be comfortable treating.

When mention laser, that's just one of the tools we use. Not everybody uses a laser. We can use cautery, etc. It's just a tool. Treatment should usually involve removing the disease to confirm the pathology, but it can also be a more severe disease where we have involvement with bowel, bladder or ureter that requires a certain higher level of skill to be able to do safely and laparoscopically so that the patient doesn't have to have a big incision. It can be done with a minimally invasive approach and quicker recovery.

• (2055)

Mr. Stephen Ellis: I must say, through you, Chair, thank you. That was absolutely impressive. Hopefully folks at home will benefit from that.

One thing that I think is important is talking a bit about infertility associated with endometriosis. It's a topic that I don't think we've touched on this evening.

I don't know if anybody here is an expert in that, but again, if someone could give a bit of a primer on infertility and endometriosis, whoever wants to jump up, that would be great.

Dr. Elaine Jolly: Well...

Mr. Stephen Ellis: Don't all speak at once. It's good.

A voice: Oh, oh!

Dr. Elaine Jolly: Looking in Canada and abroad at some of the data we have, 40% of infertility patients have endometriosis. The endometriosis can be minimal, or it can be moderate. It's staged from one to four, and you can guess that four is the worst. If you have stage four with chocolate cysts, there's no question you need to have surgery, because it is often symptomatic.

However, there's an enigma. A patient can have terrible endometriosis with no symptoms—no pain or problem with periods. We just find the endometriosis. We've been trying to answer that question for a long time. I'm not sure if it's going to be easily answered, but we still need to know. What is that patient doing, within her body, so that she does not have the rigours of endometriosis?

Once you have endometriosis with infertility, you treat it the best way you can. Most people would like to give treatment a chance, but not right away. When you do the laparoscopy, you check for fertility. The uterus looks good. The tubes are open, because you can put dye through them. Even with a bit of endometriosis, within six months, you may be lucky enough to get pregnant. With moderate endometriosis, the same is true, so you don't want to rush into treatment. However, if there is terrible pain, without suppressing the hormones so that you are able to get pregnant, you then can go ahead.

It is individualized. Endometriosis is sometimes a little different for everyone. You specifically look at what the issues are: how much pain there is and whether there is a bleeding problem. You should treat a bleeding problem. With minor endometriosis, you complete the workup because.... Remember that 50% of the time men have a low sperm count. You need to look at the problem in a holistic fashion. Then, treat the endometriosis appropriately, individually. Infertility specialists are pretty good at laparoscopy. When they're making diagnoses, they can treat the endometriosis—do the laser and the buzz. Then, if there's a pregnancy, they say, “Oh, isn't that wonderful? That was because of the endometriosis.”

Voices: Oh, oh!

Dr. Elaine Jolly: Well, okay, God, how did you know?

It's an interesting problem.

The Chair: Thank you, Dr. Jolly.

Next, we have Dr. Powlowski for five minutes.

Mr. Marcus Powlowski (Thunder Bay—Rainy River, Lib.): Thanks for getting a whole stream of doctors here. For many years, I was an emergency doctor, and I worked in developing countries. I'm certain I have a certain bias about this.

As I recall, in medical school, we had a one-hour lecture on endometriosis. It seems rather bizarre that, now that I'm in Parliament, I'm hearing more about endometriosis than I ever did in medical school.

Voices: Oh, oh!

Mr. Marcus Powlowski: In my mind, I see endometriosis as a bit of a diagnostic quagmire. When somebody who has chronic pelvic pain and dysmenorrhea comes in, there's a workup and you do an ultrasound. Already, as you said, this can be a problem, because it depends on who's doing the ultrasound or the MRI. Even that may not be reliable. However, say you do an ultrasound, MRI or laparoscopy, and they have endometriosis. How do you know that's the cause of the pain? You've told us some people can have quite severe endometriosis and have no pain at all.

Again, I'm admitting my bias from the population I used to see. It seems to me it wasn't that unusual to see a woman with chronic

pelvic pain who'd been diagnosed as having endometriosis or an irritable bowel, or they were NYD. They'd seen a gynecologist. They'd had an ablation and nothing changed. You wonder whether it was endometriosis at all.

Were those people under-treated? Is it being over-diagnosed when you have ultrasonic or laparoscopic evidence of endometriosis, but in fact that isn't the cause of pain? Can you talk a bit about diagnostic ability, and the false positives and negatives?

• (2100)

Dr. Andrew Zakhari: Thank you for the question. Maybe I'll jump in here.

It speaks to the complexity of endometriosis. As was mentioned before, a lot of times it starts off with endometriosis and painful periods. If left untreated for a long time, that will evolve into pain that's not just during the period, but also between periods. Now suddenly you've gone from having an endometriosis-only patient to having an endometriosis and chronic pelvic pain patient. The two are related and similar, but they're not identical.

That's why treating endometriosis is so difficult. At some point you can't just be treating the endometriosis; you have to treat the chronic pain as well, which then means you need a multidisciplinary team. You need to set up with probably physiotherapy, which can help manage the pain. You need a chronic pain centre. You need a multi-faceted approach using all sorts of different techniques to manage pain, whether it be cannabis, acetaminophen or anti-inflammatories and the whole gamut, while trying to avoid narcotics and their complications.

A lot of times, when we're consulting with patients for surgery, we'll tell them that we can guarantee that we can remove the endometriosis, check their tubes, take out the cysts and do that sort of thing. We can never really guarantee that we can cure the pain.

Often we will improve the pain. Sometimes we'll cure the pain, but sometimes we don't. We set expectations very clearly with patients at the outset. Often we're very happy with the outcomes, but they're not always perfect.

Mr. Marcus Powlowski: If you're saying it starts off with endometriosis and then can become chronic pelvic pain, how do you know that's the case? How do you know it wasn't endometriosis to begin with and it just happened to be incidental endometriosis?

Dr. Andrew Zakhari: It's sort of a chicken and egg situation. Once you're faced with a patient who has both, it's hard to say whether this is a chronic pain patient who developed endometriosis later in life or an endometriosis patient who got diagnosed and treated so late in the process that it developed into chronic pelvic pain.

Mr. Marcus Powlowski: I'll refer to our chair. I spoke to him. He is a former litigation lawyer. We talked about the diagnosis of endometriosis. Apparently he was involved in a few cases where a diagnosis of endometriosis was made and later it turned out that there was a more sinister cause of the pain.

How much of a problem is it that, where pain gets attributed to endometriosis when perhaps at one point they've had an ultrasound or a laparoscopy showing that they have endometriosis. Then four or five years later, they're having pain that's attributed to endometriosis and it turns out to be something else?

Dr. Andrew Zakhari: I'd say that the reverse situation is probably much more common, where you have patients whose pain is attributed to normal menstrual pain when really it's missed endometriosis. I think that's much more common than having someone with endometriosis who has a secondary pain diagnosis.

The Chair: Thank you, Dr. Powlowski.

[*Translation*]

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

Ms. Andr anne Larouche: I don't know if I will have another turn to speak, Mr. Chair, so I will be as quick as possible.

This evening, a number of witnesses have talked about a national endometriosis strategy. Australia, France, Ireland, Wales and Scotland were mentioned as examples. Yet Canada does not have the same political framework as those countries, specifically in terms of the division of powers. For example, Quebec is responsible for the recognition of credentials and the management of health systems. Ottawa is responsible for procurement. The federal government can also invest in health care research.

Like other witnesses, Dr. Mattatall talked about funding. In Canada, the funding comes from health transfers which, since the 1990s, have been gutted.

How could we benefit from the experience of other countries that have that kind of national strategy, while working within our framework, which can be different?

• (2105)

Dr. Catherine Allaire: Will my answer be interpreted into English?

Ms. Andr anne Larouche: Dr. Allaire, you talked about what happened in B.C. and the fact that certain provinces have already launched some interesting initiatives.

Please go ahead, if you wish.

Dr. Catherine Allaire: As you said, not all countries can be directly compared to Canada, of course.

That said, we looked carefully at the program in Australia. We even met some people from Australia who came to spend some

time with us and talked with them a lot. Their political system is quite similar to ours, including federal health transfers.

So I think if we were to look at a program more closely, it should be theirs. I know the health sector is very complex in Canada, but we can still draw fairly strong parallels between the two countries' systems.

The Chair: Thank you, Ms. Larouche.

[*English*]

Next is Ms. Mathysen, please, for two and a half minutes.

Ms. Lindsay Mathysen: We haven't spoken much.... I'll leave it to whoever wants to address it, but we haven't really referred to multi-organ endometriosis. I wanted to talk to and hear from the witnesses about the dangers, how that goes undiagnosed, of course, and all the things related to that.

Dr. Dong Bach Nguyen: Thank you for your question.

As you know, when endometriosis becomes severe, it can start invading the adjacent organs, whether it's the bladder, the bowel, the diaphragm or even the pelvic nerves. The symptoms the patients will present are slightly different, depending on the organ that is injured. Surgery becomes that much more complex, because if it requires that we remove part of ureter or the bladder, then urologists have to be involved. If it involves removing part of the bowel, then the bowel surgeon needs to be involved. When people have recurrent pneumothoraces—air that goes inside the chest because of endometriosis going into the diaphragm and the lung—then you need a thoracic surgeon involved as well.

This is why there's the need for these centres that have all of these people under their umbrella, which we call multidisciplinary care, to be able to tackle this disease.

Ms. Lindsay Mathysen: That's a huge and significant cost if we don't address the situation when they—

Dr. Dong Bach Nguyen: Absolutely, and countless times we have had referrals of patients who have undergone resection of the bowel nodule, thinking it was cancer and finding out it was endometriosis, and they have been sent to us to treat.

Again, it's taking care of something that was treated differently, because treating cancer is not the same as treating endometriosis. You need to have margins. You remove a much larger part of the bowel, and the symptoms' improvement is not that great if you removed that nodule but left all of the endometriosis behind.

This is where awareness coming in is important, but also, if we have better diagnosis and we're able to realize that the endometriosis—the bowel nodule—comes from there, we're able to better treat the patient.

The Chair: You have 30 seconds, if you want them.

Ms. Lindsay Mathysen: I know you did additional studies in Europe. What were your experiences there and how do they compare with Canada? What can Canada learn?

I'm not sure if you can answer all of that in the 15 seconds you have left.

Dr. Dong Bach Nguyen: Thanks.

I trained in a centre that did a few hundred bowel surgeries a year. In France, care has been very centralized toward centres that they call "of excellence", where they have all these multidisciplinary approaches. What's really beautiful about the process is that there's a pathway for every patient. When they come in, they expect to have such imaging, they expect to see the surgeon and they have the fertility specialist right next door. For the surgery, everything gets combined and they're all in the same vicinity.

This is possible in academic centres here in Canada as well. It's a model that we can definitely reproduce—and we have with the opening of our centre, so we're very happy about that. We're not the only ones in Canada; many people here have done an excellent job as well.

I think all of these are attainable goals as long as the government sees the importance of investing in this.

We alluded to the provincial and federal governments having different roles in all of this, but I think if the provincial sees the importance, the province will necessarily follow.

• (2110)

The Chair: Thank you, Dr. Nguyen.

Next is Ms. Vecchio, please, for five minutes.

Mrs. Karen Vecchio: Thank you very much. I just want to build on from where Lindsay started.

Thank you very much to our witnesses for all of the incredible work you have done.

Dr. Nguyen, looking at this, you are also a co-author of something called "Bowel surgery for endometriosis". I assume this is where we start talking about the adjacent organs that are being impacted.

From what we've heard, the delay in diagnosis can create a lot of other issues. If you could provide for me some timelines.... We started this conversation an hour and a half ago. It's six months to be seen and a year for surgery. There are all of these things and the time frame is very difficult.

When would we start seeing the adjacent organs been impacted by endometriosis? When we talk of one in 10 women having endometriosis, what are those statistics when it comes to secondary organs?

Dr. Dong Bach Nguyen: That's a very good question.

It's hard to know, because many women with endometriosis are very asymptomatic. That even means that people who have horrible disease—when we enter the pelvis, they have stage four endometriosis—may be asymptomatic. They may have no symptoms.

That being said, if we look at studies, probably 15% to 20% of endometriosis cases are more severe, so they're stage three to four. Among those people, it's hard to say when they first developed the severity of the disease, because often, we catch it when it's already severe or when it's superficial. We don't have enough data to follow and see what the timeline is that it takes for someone with superficial endometriosis to develop something more severe.

Every person is different. Endometriosis in some women recurs very quickly after surgery, versus other people, who don't see it recur. I think all of this points toward the need to have more funding for research so that we can elucidate these answers and give better care for patients.

Mrs. Karen Vecchio: We've all spoken a lot about pelvic pain today. I'm sure that many of us women in this room have had what we would see as cramps, muscular cramps.

When you talk about this pelvic pain, is it similar to the cramping that one would get during a period or the severity of that type of cramping?

How would someone know the difference between pelvic pain and five-day pain during their period?

Dr. Dong Bach Nguyen: That's also a very good question, because everybody feels pain differently. Depending on where the endometriosis occurs, if it affects the nerves; then it can cause different pain as well.

What I can say is that, when somebody doesn't respond to anti-inflammatories such as Advil plus Tylenol, the first line is birth control. With both of those, if they continue to have debilitating pain, that is when they need to be investigated further with imaging and see a specialist.

Mrs. Karen Vecchio: Thank you so much.

Dr. Jolly, I want to move over to you because I want to talk about menopause and the early menopause that endometriosis can cause.

Menopause is usually in that 50 age range. When would you start seeing women who have endometriosis start going into an early menopause? Are we talking about 35 or 40? What's the age group?

Dr. Elaine Jolly: Premature menopause is defined as menopause that occurs before age 40. We know that. Ages 40 to 50 is the perimenopausal range. Most of the patients with endometriosis who enter into menopause have to have ablation surgery, which means having a hysterectomy and their ovaries out. If they are lucky, any endometriosis is completely removed. That is not so difficult to treat, because you can put this patient on low-dose estrogen to prevent the ravages that can occur that I talked about with regard to cardiovascular disease, stroke, osteoporosis, etc.

When somebody is in menopause because they've had severe endometriosis and have had surgery, which is a surgical menopause, that can occur any time. These wonderful surgeons can tell you that once in a while they have to do it between ages 20 and 30—hopefully not very often, because we're getting better and better. Certainly, in the olden days, it was more common, so we are making ground on that.

Let me just say, listening to all of this, that you must understand that endometriosis is a condition that is stimulated by estrogen. Women produce estrogen every month. At ovulation, they produce progesterone, which can temper it.

If you control this estrogen, it is important to realize that it's a lifelong treatment. You diagnose endometriosis as an adolescent. You treat it appropriately because you suppress the estrogen. You can make it so that the patient doesn't have any periods at all, which is quite wonderful. Not everybody believes that is holistically good, but that's a different thing.

• (2115)

Mrs. Karen Vecchio: Dr. Jolly, I want to ask a few more questions specifically on this.

We talked about bowels being affected by this. You just mentioned early menopause. A lot of other things can happen to a woman.

What are some of the other impacts or effects if a diagnosis of endometriosis is delayed? What are some of those other impacts to women's systems that you see?

The Chair: Give a brief answer, if you could, Dr. Jolly, please.

Dr. Elaine Jolly: Okay, I'll try.

There are issues regarding cognitive function—fear, depression, anxiety, living with the fear of the pain every month and the sequelae of that. It's gritting your teeth when you have sexual intercourse and not having the ability to have a comfortable bowel movement. These pains are very difficult. When imprinted on that woman, they can do a huge amount of damage so that you need your psychologist, you need counsellors, and you need help from the holistic point of view. If untreated, it can result in losing your uterus and your ovaries.

The Chair: Thank you, Dr. Jolly.

Ms. Sidhu, please, go ahead for five minutes.

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

Thank you to all of the witnesses for your insightful testimony.

I want to build on Ms. Vecchio's questions. According to a study published in the National Library of Medicine, anxiety disorders and depression are more frequent among women with endometriosis than in the general population.

Can you please talk about the importance of an approach with psychotherapy or counselling?

Dr. Jolly, you can start, then, Dr. Nguyen, you can add on.

Dr. Elaine Jolly: It must be nipped in the bud so that you have, with the early diagnosis, that support system from an empathetic,

kind physician, who understands and doesn't normalize it and say, "There, there, that's what women have to have. Go and get pregnant and that will take care of everything." That is not the answer.

You need support in the home. You need the parents and the significant other to be part of this whole treatment, with timely referral to an appropriate counsellor, psychologist or possibly even a psychiatrist, because we certainly have seen women have severe effects and take their life. There's data to support this.

You bring up something that's very important, and it's the whole approach. Because that woman isn't going to be going right now to the big centre; she needs her family doctor to support her, the specialist to support her, and she needs to be able to reach out to the other community members to know they are all looking after her.

Dr. Dong Bach Nguyen: Yes, thank you for bringing up mental health as one of the big concerns, because it is. It is under-represented and undertreated.

In our centre, we try to have physiotherapists come on board with us as well. We had several back-and-forth discussions because they were all very interested in the subject and wanted to help. The first question they asked us was, do you have funding? For us, we managed to get funding through generous patient donations and the foundation. Through those we were able to fund a nurse navigator role for us. Then in the next steps we have several things that we have under the budget, but a psychotherapist was definitely one of them.

In Quebec, and I think in most of Canada, psychotherapy is not covered, so you need to be privately funded. It would be approximately \$150 to \$200 per session.

While I don't think this is an elective thing, I really do think it's mandatory and essential. Again, it comes down to the fact we're now able to recognize this and know that it is important, but how do we get the funding to people to help these women to get the help for their mental health?

• (2120)

The Chair: Ms. Sidhu, I think Ms. Wahl wants in on this discussion.

Ms. Wahl, please. You're on mute.

Ms. Kate Wahl: We couldn't go one meeting without someone being on mute.

I just want to say quickly that I think when you speak with people who have endometriosis, a lot of the mental health concerns they experience come from being disbelieved by their health care providers, by their families, by their friends, by their communities. A lot of the burden comes from that.

I think in addressing some of the delayed diagnosis issues, we'll also have an opportunity to mitigate the effects on mental health—not completely but certainly, I think, in a significant proportion.

Ms. Sonia Sidhu: Thank you.

My next question is about ovarian cancer and public awareness. There are several types of ovarian cancer, which account for 140,000 deaths each year, making it the fourth-largest cause of cancer death in women. How can we enhance public awareness about endometriosis to ensure early recognition of the symptoms so that we can save lives? Then we heard about the \$2.5 billion cost, which is a lot of burden on the health care system.

Dr. Nguyen can start.

Dr. Dong Bach Nguyen: Ovarian cancer is increasing in women with endometriosis. It is anywhere between one-and-a-half times to twice the relative risk of having cancer. It comes down again to the importance of imaging and being able to recognize it, because the first signs are typically seen on imaging, and being able to have the resources to follow these patients over time to make sure that cancer doesn't develop.

The Chair: Thank you, Ms. Sidhu.

Next, we'll go to Ms. Roberts, please, for five minutes.

Mrs. Anna Roberts: Thank you, Mr. Chair.

I have a question and I'm not sure if anyone has the answer for it. How many pelvic floor physiotherapists are there and, if so, how well trained are they?

Dr. Andrew Zakhari: I'm not sure of the number.

Go ahead, please.

Dr. Fiona Mattatall: In Calgary, we have about 40, and to my knowledge, there isn't a qualifying certificate to call yourself a pelvic floor physiotherapist, but we do have a large number here.

Dr. Catherine Allaire: In British Columbia, I think we're probably unique in Canada in having probably the most pelvic physiotherapists. Our physiotherapist told us there was a certificate she had to do to get that designation, although some may choose to call themselves that without the designation and without the certificate, because there's no governance of that, I believe. But there certainly are some extra courses they can do to have that expertise.

Mrs. Anna Roberts: I have another question, but I am not sure who can answer it.

Has endometriosis been related to cancer of the bowels?

Dr. Andrew Zakhari: It has not that I'm aware of. It's mostly ovarian or peritoneal cancer, which is sort of the lining that's near the bowels or the uterus.

Mrs. Anna Roberts: Okay. So would you say that if caught early enough, it would avoid the issue with the bowels?

Dr. Andrew Zakhari: It would most likely. As Dr. Nguyen said earlier, we don't really know the full natural history of endometriosis and the rate of change, and often we catch things late because of all the problems we've talked about for two hours. Definitely catching things early and intervening early can make an impact, which is why it is important to look at this.

Dr. Dong Bach Nguyen: For instance, some bowel lesions are small. Then they can be excised with a technique that spare the back of the bowel, versus once the lesion has gotten to be very large, then we have to do a larger resection of the complete bowel. So there are two different techniques. One is associated with half

the risk of complication that you can see after. So, if you're able to pick it up when the lesion is still small, the patient can undergo a surgery that is less risky to the patient.

• (2125)

Mrs. Anna Roberts: I have another question.

I think, Dr. Jolly, you mentioned that 40% of people in Canada have endometriosis.

Dr. Elaine Jolly: No, the 40% was 40% of infertility patients—

Mrs. Anna Roberts: Okay. I misunderstood.

Dr. Elaine Jolly: —have endometriosis. It is one in 10 women. Ten per cent of women in Canada have endometriosis if we look at the total population, but 40% of infertility patients is quite a lot.

Mrs. Anna Roberts: Will women with endometriosis, if it's curable or treatable, be able to have children?

Dr. Elaine Jolly: To keep endometriosis under control, you have to look at this as a lifelong matter, and very often—most often—you go to a gynecologist, you have your endometriosis surgery and then you go back to your family doctor without any appropriate follow-up.

The follow-up should be some treatment, especially if there are symptoms. The treatment can be as simple as an intrauterine device, a Mirena. You don't get pregnant with this, but hopefully between pregnancies you are maintaining a milieu for the endometriosis that is suppressing estrogen. The same thing can be done with a low-dose birth control pill. These are both easily obtainable. If the endometriosis is more severe, then you have to bring out the bigger guns, and funding is a problem with that.

You need to have an understanding that endometriosis can rear its head anytime before menopause, so you need to follow that patient. You need, in this case, to do a pelvic examination, because that is the easiest. The pelvic examination includes a rectovaginal examination because that's where endometriosis flourishes, in nodules that cause pain.

There is a follow-up procedure to endometriosis, and unfortunately, in the countries that we mentioned, it is not perfect either because it is not a one-stop thing. It is something that goes on until your periods stop.

The Chair: Thank you. I am sorry, but that is your time.

The last round of questions for this panel will come from New Brunswick—Fredericton or Oromocto.

Mrs. Atwin, please go ahead for five minutes.

Mrs. Jenica Atwin (Fredericton, Lib.): Thank you very much, Mr. Chair.

Thank you to the witnesses for being with us this evening.

I was at a different committee. I just popped in for the second half, but, my goodness, I've learned a lot in this short period of time. I think that speaks to just how important the awareness piece is and how there is such lack of awareness, in general, in Canada about this.

I'm struck by the first time I was ever introduced to the issue of endometriosis. It was through a friend of the family—a Mi'kmaq woman here in New Brunswick—and her journey in finally receiving an endometriosis diagnosis, after years of that denial we talked about. I'm thinking particularly of the mental health impacts of not being believed. Then, of course, add that to the layer of being a Mi'kmaq woman.

I wonder if any of our witnesses this evening would like to address this topic—how we need to look at the issue with a lens of intersectionality, as well, in order to understand some of the systemic barriers and discrimination within our health care system, and how much harder it is for indigenous and, in particular, racialized women to receive this diagnosis.

This is for anyone and everyone who would like to comment on that.

Dr. Elaine Jolly: We need data. We need to know what the incidence of endometriosis is in areas where we have not looked. This even includes the United States and their indigenous populations. Once you get that data—this could be commissioned by the federal government—look at what the impact is on women of aboriginal status, or on those who have an increased risk, if you wish, of endometriosis. Black women have that.

There certainly needs to be some idea of what the incidence is.

• (2130)

The Chair: Ms. Wahl has her hand up, Mrs. Atwin.

Go ahead, Ms. Wahl.

Ms. Kate Wahl: Thank you, Mr. Chair.

Something we hear from women with endometriosis is that the very first step is believing them when they say they're in pain. We know people from different underserved groups are believed less commonly in the health care system. We know, for example, that Black women talk about the narrative of “the strong Black woman”—that they feel pain differently or don't feel pain. A lot of folks with endo talk about being accused of drug-seeking when they go to the emergency room looking for care.

We already know those biases exist in the system, and they just stack up with endometriosis. Already, if you're a woman, there might be a feeling that you're being “hysterical”. You might then also be considered to be drug-seeking.

There are so many biases that pile up for this population. We have a good sense of what they are. I think the next step is to start addressing them in different ways in the health system.

Mrs. Jenica Atwin: Excellent. Thank you very much.

If any other witness would like to add to that, please feel free to do so.

I certainly have another question, as well.

The Chair: Dr. Mattatall is applauding, but I'm not sure if that means she wants in.

Dr. Fiona Mattatall: No, I was just impressed with Ms. Wahl's comment.

The Chair: Thank you.

Mrs. Jenica Atwin: Thank you very much.

Dr. Zakhari, my time is wrapping up, but you mentioned some of your experiences, I believe, in the European health care system.

I'm wondering if you can pull from that experience and draw on some of the things we could be focusing on with regard to a national action plan. You mentioned models exist and there are some things we can learn from them.

In our final minutes here, what are some key things we need to focus on for a national action plan that perhaps could be pulled from some of those European models?

Dr. Andrew Zakhari: While I completely agree with Dr. Allaire that the Australian model is probably our best bet of what we can emulate, I think the key thing is this: The first step is bringing together a working group of people who have a vested interest and the expertise, and to have patient advocates on board who can help us identify their priorities, as well. I don't think we need to completely reinvent the wheel. We have, as we said, good models that we can work off to create something unique for Canada that fits our structure and system, and that fills in all the gaps we've discussed at this meeting today, among others.

Then, make sure that, if Canada sets forth endometriosis as a priority... I'm sure that, if we lead, the provinces will follow. Every province will find a way to structure their care, incentivize hospitals to make endometriosis a priority, identify key centres that have expertise, and invest heavily in them. That way, patients and resources will know where to go to keep building our endometriosis framework in Canada. A lot of it comes from gathering data and statistics, and from understanding our population. The second part of that is going to be action, of course.

If there's more time, I'm happy for anyone to jump in and throw in their two cents.

The Chair: Dr. Zakhari, you got the last word. Thank you so much.

Colleagues, just before we wrap-up, this is a reminder that when we get together on Monday, it's going to be for three hours. In the first two hours, we will begin our study of the opioid epidemic with departmental officials, and at one o'clock, we'll be hearing from witnesses for the study of the advance purchase agreements with Medicago.

To our panel with us this evening, your expertise, your experience and your passion are evident. We thank you so much for being with us. I think absolutely everybody here—even the medical doctors—learned a lot. It will be of significant value as we go forward with this study on women's health.

Thank you so very much for being with us.

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

Some hon. members: Agreed.

The Chair: We're adjourned.

Published under the authority of the Speaker of
the House of Commons

SPEAKER'S PERMISSION

The proceedings of the House of Commons and its committees are hereby made available to provide greater public access. The parliamentary privilege of the House of Commons to control the publication and broadcast of the proceedings of the House of Commons and its committees is nonetheless reserved. All copyrights therein are also reserved.

Reproduction of the proceedings of the House of Commons and its committees, in whole or in part and in any medium, is hereby permitted provided that the reproduction is accurate and is not presented as official. This permission does not extend to reproduction, distribution or use for commercial purpose of financial gain. Reproduction or use outside this permission or without authorization may be treated as copyright infringement in accordance with the Copyright Act. Authorization may be obtained on written application to the Office of the Speaker of the House of Commons.

Reproduction in accordance with this permission does not constitute publication under the authority of the House of Commons. The absolute privilege that applies to the proceedings of the House of Commons does not extend to these permitted reproductions. Where a reproduction includes briefs to a committee of the House of Commons, authorization for reproduction may be required from the authors in accordance with the Copyright Act.

Nothing in this permission abrogates or derogates from the privileges, powers, immunities and rights of the House of Commons and its committees. For greater certainty, this permission does not affect the prohibition against impeaching or questioning the proceedings of the House of Commons in courts or otherwise. The House of Commons retains the right and privilege to find users in contempt of Parliament if a reproduction or use is not in accordance with this permission.

Also available on the House of Commons website at the following address: <https://www.ourcommons.ca>

Publié en conformité de l'autorité
du Président de la Chambre des communes

PERMISSION DU PRÉSIDENT

Les délibérations de la Chambre des communes et de ses comités sont mises à la disposition du public pour mieux le renseigner. La Chambre conserve néanmoins son privilège parlementaire de contrôler la publication et la diffusion des délibérations et elle possède tous les droits d'auteur sur celles-ci.

Il est permis de reproduire les délibérations de la Chambre et de ses comités, en tout ou en partie, sur n'importe quel support, pourvu que la reproduction soit exacte et qu'elle ne soit pas présentée comme version officielle. Il n'est toutefois pas permis de reproduire, de distribuer ou d'utiliser les délibérations à des fins commerciales visant la réalisation d'un profit financier. Toute reproduction ou utilisation non permise ou non formellement autorisée peut être considérée comme une violation du droit d'auteur aux termes de la Loi sur le droit d'auteur. Une autorisation formelle peut être obtenue sur présentation d'une demande écrite au Bureau du Président de la Chambre des communes.

La reproduction conforme à la présente permission ne constitue pas une publication sous l'autorité de la Chambre. Le privilège absolu qui s'applique aux délibérations de la Chambre ne s'étend pas aux reproductions permises. Lorsqu'une reproduction comprend des mémoires présentés à un comité de la Chambre, il peut être nécessaire d'obtenir de leurs auteurs l'autorisation de les reproduire, conformément à la Loi sur le droit d'auteur.

La présente permission ne porte pas atteinte aux privilèges, pouvoirs, immunités et droits de la Chambre et de ses comités. Il est entendu que cette permission ne touche pas l'interdiction de contester ou de mettre en cause les délibérations de la Chambre devant les tribunaux ou autrement. La Chambre conserve le droit et le privilège de déclarer l'utilisateur coupable d'outrage au Parlement lorsque la reproduction ou l'utilisation n'est pas conforme à la présente permission.

Aussi disponible sur le site Web de la Chambre des communes à l'adresse suivante :
<https://www.noscommunes.ca>