House of Commons
Chambre des communes
CANADA

Standing Committee on Justice and Human Rights

JUST • NUMBER 037 • 1st SESSION • 42nd PARLIAMENT

EVIDENCE

Thursday, November 24, 2016

Chair

Mr. Anthony Housefather

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● (1105)

[*English*]

The Chair (Mr. Anthony Housefather (Mount Royal, Lib.)): Ladies and gentlemen, I am going to call this meeting of the Standing Committee on Justice and Human Rights to order as we continue our study of Bill S-201, an act to prohibit and prevent genetic discrimination.

I would like to welcome our witnesses for today. We are joined by the Canadian Medical Association, represented by Dr. Cindy Forbes, who is the past president, and Cécile Bensimon, who is the director of ethics.

Welcome, ladies.

We're also joined by the Canadian College of Medical Geneticists. Dr. Gail Graham, the past president, is joining us.

Thank you very much for being here.

We've agreed that you will begin, Dr. Forbes.

Dr. Cindy Forbes (Past-President, Canadian Medical Association): Thank you very much.

Thank you, Mr. Chair, and thanks to all of you.

I'm Dr. Cindy Forbes. I'm a family physician from Nova Scotia and the past president of the Canadian Medical Association. As you may be aware, the Canadian Medical Association represents 83,000 Canadian physicians. I'm joined today by Cécile Bensimon, who is the director of ethics.

The CMA very much welcomes this opportunity to appear before the committee as part of your study on Bill S-201, the genetic non-discrimination act. As part of my opening statement, I will focus on the national importance of federal legislation preventing genetic discrimination.

At the outset, however, let me state that the CMA strongly supports the enactment of Bill S-201 in its entirety, that is, maintaining the three core elements of this bill. At the core of the CMA's support is the fact that this legislation addresses discriminatory barriers related to genetic testing, an emerging issue that is about patient care.

Genetic discrimination, and the fear of this discrimination, may potentially negatively impact the patient-physician relationship. This is a concern that I encourage you to consider carefully, and I welcome your questions on that.

Genomic medicine holds great promise in the diagnosis and therapeutic treatment of many known and new diseases and, ultimately, in enhancing the quality of life of many patients. We are witnessing the transformative development of genomic medicine, with a rapid expansion in genetic testing. This transformation and the availability of new genetic tests are allowing for the discovery of new genetic conditions, as well as early diagnoses that will benefit patient care.

Before us is the prospect of transforming clinical medicine and patient care at a pace that will only accelerate in the foreseeable future. Today, genetic testing is aiding in the early diagnosis of numerous conditions, including many forms of cancer, heart disease, and dementia, to name only a few. As well, our ability to genetically test for new conditions is continually increasing.

Of great concern to Canada's doctors and their patients is the fact that public policies and legislation have not kept pace with this transformation. Genetic discrimination is both a significant and an internationally recognized phenomenon. As you heard from other witnesses, Canada stands alone amongst the G8 as the only country that has not established legislative protections in the face of this major transformation.

While genomic medicine will continue to have broader clinical applications, the fear of genetic discrimination is both widespread and real. As a primary care provider, I have experienced, in having conversations with my patients, their very real fear of discrimination.

As Canada's doctors, it is the CMA's position that Canadians deserve to have access to the best possible health care without fear of genetic discrimination.

Genetic discrimination presents several negative consequences. The most concerning consequence may be patients who feel they must hide their family history from their health care providers, who may never be referred for a genetic assessment, or who may avoid care or treatment for fear of discrimination. These consequences are simply unacceptable in Canada's universal public health care system.

Six out of every 10 Canadians will be affected during their lifetime by a health problem that is genetic in whole or in part. It's important to recognize that genetic testing will no longer be limited to rare, esoteric genetic diseases occurring in patients seen by a handful of specialists across the country. Rather, it's becoming an integral part of broad medical care and, as such, is expected to become mainstream medicine.

While genomic medicine is still in its infancy, it's already changing the face of modern medicine. Every year, every month, and every week, new genetic conditions are discovered using these tools. Patients who were undiagnosed for years are now finally receiving diagnoses thanks to these genomic advances. Early diagnoses are actively influencing medical management.

The way we deliver genetic care to our patients has radically changed over the last decade, and there's no reason to believe that this growth will plateau anytime soon.

There are obvious economic and productivity impacts if patients are not able to be diagnosed and we are not able to provide appropriate care. Ironically, at a time when genomic technologies have broader clinical applications than ever before, the fear of genetic discrimination is preventing some Canadians from benefiting from these advances. For these reasons, the CMA strongly supports the enactment of Bill S-201 without amendment.

My colleague and I would be pleased to address any questions you may have. Thank you.

The Chair: Thank you very much, Dr. Forbes.

Now we will move to Dr. Graham.

Dr. Gail Graham (Past-President, Canadian College of Medical Geneticists): Thank you very much.

First of all, thank you to Dr. Forbes and the CMA for taking a very reasoned and proactive stance on Bill S-201, and thanks to all of you for the privilege of addressing this committee on behalf of the Canadian College of Medical Geneticists.

We are the doctors who diagnose and treat patients with genetic diseases. In preparing this statement, we asked ourselves what can we possibly tell you that you have not already heard from informed individuals such as MP Oliphant, Senator Cowan, and Bev Heim-Myers, from esteemed researchers, and also from very learned constitutional experts.

We can speak as doctors across our country who care for patients with genetic conditions. We can say very clearly that genetic discrimination and fear of discrimination are not just theoretical, as some have argued. We can say that it truly changes behaviour. We can say that it influences patients' decisions in clinics across the country every single day. We can say that it sits in the clinic room between us and our patients when they consider the pros and cons of a predictive genetic test for hereditary cancer, for example.

We can say that it lingers forever when a patient declines a test that had a 50% chance of demonstrating that she does not have a hereditary cancer syndrome and therefore might not require the imaging surveillance that her doctor will be compelled to recommend for the rest of her life. We can say that it sometimes wastes health care dollars, and we can say that it prevents some of our patients' family members from ever seeking or following through with a referral to our clinics. I know that Dr. Forbes has had that very experience.

We can say that it deters patients from participating in the very research that might further our understanding of their genetic condition. We can also say that genetic testing is not always valid and not always straightforward, because our interpretation of test results is in its infancy and is evolving rapidly over time. Sometimes, genetic testing mislabels individuals with genetic conditions or predispositions to a particular disease, when in fact they are healthy and will remain healthy.

For all of these reasons, the CCMG unequivocally supports Bill S-201. We commend the senator and his policy adviser, Barbara Kagedan, for their tireless work, which has recently been recognized internationally in the form of an Advocacy Award from the American Society of Human Genetics.

You have already heard that we are the only G8 country that does not enjoy this protection, and I find it ironic that this initiative is celebrated by another country before it has even been enshrined in law here in Canada.

Our first message, which is not new to you, is that we must act now, not months from now and not years from now. The complete sequence of the human genome was drafted in 2000. Just over 15 years later, we have already linked 5,000 of the estimated 20,000 genes to so-called rare human genetic diseases, and we know of thousands more gene variants that influence predispositions to common health conditions such as diabetes and heart disease.

Those numbers are rising every single day. Genetic testing has become a critical tool in many disciplines of medicine, not just to diagnose disease, but also to guide the selection of personalized treatments. That includes imaging surveillance and medications.

This is the very promise of the human genome that Francis Collins spoke of in his historic announcement of the completion of the human genome project just over 15 years ago. It is incredibly empowering, both for patients and for their doctors, but as long as there is no legislative protection for genetic information, patients are vulnerable, and if our experience to date is any judge, many of them will forgo the benefits of genomic medicine. I feel very strongly that we have a duty to change that.

Our second message is that you are our patients. Most of you, at some point in your lifetimes, will have the ability to determine your susceptibilities to common diseases through genetic testing. Would you prefer to have this information to yourselves and act upon it to mitigate your risks, or would you prefer that it is also in the hands of your insurers or your employer? How comfortable would you be in subjecting yourself to a genetic test without this protection? How comfortable would you feel if I asked you to provide a sample of your saliva to a genetics laboratory before this legislation has passed?

● (1110)

Our third message is that, yes, it is important to alter the Canadian Human Rights Act to include the words “genetic characteristics”. Canadians believe that it is equally as abhorrent to use one's genome against an individual as it is to use their race or their disability. Canadians believe in protecting our most vulnerable, whether they are disabled by birth or by accident.

These are values we embrace, and our human rights act should reflect that, but that is not enough. Without the other two pillars of the stool, the non-discrimination act and the amendments to the labour code, there will be no deterrent to insurance or employment discrimination on the basis of genetic test results.

I've read the transcripts of these hearings. I know that you have already heard that the Office of the Privacy Commissioner has two studies that do not predict that the insurance industry will be harmed by this legislation, and that similar legislation in other countries has not hampered that industry. You have already heard from three of four constitutional expects that this bill is soundly within the purview of the federal government.

You have already heard that the provinces have not raised concerns about this legislation, despite being given ample opportunity to do so. You have already heard that Ontario is moving to support the concept of protection against genetic discrimination with Bill 30, which would amend the provincial human rights act, and that you have heard that Bill 30 is designed to work in partnership with Bill S-201—they need each other.

The CCMG urges you to do the right thing for Canadians and endorse this bill without amendments.

What I want to be able to say to my patients is that you don't have to worry about this anymore. You can make the choice that's best for you and for your family without fear. You can base your decisions on sound medical evidence.

Thank you very much. We appreciate the opportunity to offer our perspective.

● (1115)

The Chair: Thank you very much, Dr. Graham.

Thanks to all of you for your testimony. We're now going to questions.

We'll start with Mr. Falk.

Mr. Ted Falk (Provencher, CPC): Thank you, Mr. Chairman.

I echo the chairman's sentiments. Thank you for your testimony here this morning. Like all of you sitting at that end, I'm excited about this legislation. In general, I support it; it may require a bit of tweaking yet.

As technology develops and there are advances in what we're able to do from a medical perspective in gene testing and DNA testing, I think it's important that we also create the proper parameters that as a society and as a country we decide we want to operate within.

All of you so far have indicated that you provide wholehearted support for the bill as presented, without amendment. I do have some questions. I want to refer specifically to clause 6, which is an exception clause. This particular legislation provides very clearly that anybody is prohibited from providing goods or services or requiring people to undergo DNA tests with the exception of the health care community: health care practitioners, researchers, physicians, or pharmacists.

Help me understand why they should be exempt from exercising discrimination against individuals.

Dr. Gail Graham: Thank you for that question.

Physicians must discuss genetic testing with their patients when there is an indication for that test. That's exactly what I do. I see patients who may have genetic conditions. I do a medical assessment, I counsel them about the likelihood that they might have a genetic condition, and I discuss a genetic test with them. You can imagine why that kind of interaction with a patient would have to be exempt from discrimination.

Dr. Cindy Forbes: Perhaps I could also reinforce the fact that this information within the patient-physician relationship is confidential. That's not changed at all in that exemption.

Mr. Ted Falk: I can appreciate exactly what you've indicated and what you've said, but my concern goes a little deeper and a little further than that because, as researchers, pharmacists, and physicians, you actually have the ability to discriminate. According to this legislation, the way it's drafted today, you have the ability to withhold goods and the ability to withhold services from individuals based on whether or not they've submitted to a DNA test.

I'm wondering whether, as a group or as an association, you would have any recommendations for us there. I understand that people are well-intentioned, well-meaning, and that from a Puritan's perspective, we shouldn't need to have a safeguard there. But as a community of health care providers, you have a blank cheque here to discriminate if you choose to. I'm not saying that your intention is to do so. That would be the furthest thing from me.... It appears as though this exception clause allows you to do that if there are individuals who choose to do that.

● (1120)

Dr. Gail Graham: I guess one response to that would be that in the absence of any legislation we have that ability as well. As you know, physicians are regulated through the college of physicians and surgeons. For us to discriminate against our patients would be considered gross misconduct. There are already safeguards in place to prevent physicians from discriminating against their patients, whether it's for genetic reasons or any others, such as, for example, discriminating against patients because they're of a different race. I'm not sure if I understand the concern.

Mr. Ted Falk: I understand that, and I understand the ethics boards and associations that you're subject to, but it does seem to provide a very blank cheque for individuals within your community. I'm not saying that the community as a whole would discriminate, but we're providing legislation that would protect people from being discriminated against, and now there's a segment of people who have been given an exception clause to discriminate without penalty. I'm concerned about that.

Dr. Cindy Forbes: It was really our interpretation that this allowed physicians to have the discussions with their patients—

Dr. Gail Graham: That's right.

Dr. Cindy Forbes: —and is not in any way exempting them from discrimination. That was really our interpretation.

Mr. Ted Falk: I recognize the intent of why it's there, but when I read it and I try to make sense of it, I think it's broader than what the intent was. I'm wondering whether there needs to be some kind of safeguard or....

Dr. Cindy Forbes: That certainly wasn't our interpretation.

Mr. Ted Falk: Okay.

Dr. Gail Graham: No, I think the intent is to allow for appropriate health care to go ahead and not be hampered.

Mr. Ted Falk: I really appreciate that. It's just that I see that the window is open further than that, and it's something that I think may need to be addressed.

I have another question. Any of you can answer. Could you give me any examples of discrimination that you've witnessed and that this legislation will address?

Dr. Cindy Forbes: I think that mainly what I've seen as a family physician is the fear of discrimination, with patients not being tested for genetic abnormalities because they're fearful that they won't be insurable or they won't be eligible for employment in a certain field. That fear is very real, and they act on that fear.

I can give you some examples. We have patients in our practice who are twins. One was diagnosed with breast cancer at the age of 43, and the other twin at the age of 44. There likely could be a genetic cause, but neither of them is willing to be tested because of the fear of uninsurability and the implications for their children as well. Their decision not to be tested has actually caused quite a rift in the family; there are various opinions because it affects so many different people.

If these women were tested because of the nature of the gene they have and if they were positive for the nature of the cancer they have, they would be offered treatments—surgical treatments, perhaps removal of their ovaries, or mastectomies and other treatments—that would not be available to them if they were not—

Mr. Ted Falk: Part of that testing.

Dr. Cindy Forbes: Yes, if they were not tested.

Those are the kinds of examples that I would see of people refusing.

I have another example in my practice of a family with a hereditary heart disease. The father has the gene. There are three children. One has decided to be tested, and she is positive, so she's under close surveillance. The other two have not because of fear in terms of employability.

Mr. Ted Falk: Okay.

Dr. Cindy Forbes: That's not to say that they can't be followed, but perhaps they don't need to be. They're even fearful of being assessed regularly for fear that will indicate that they won't be able to be employed.

Those are very real things that are happening in our practices. Some of the things that happen never come to our attention. The conversations are taking place before we see them in our offices. Also, many of them never reach the geneticists, because those decisions are made before they've had a chance to have proper genetic counselling.

● (1125)

Dr. Gail Graham: Yes, although we also hear from family members who do come to us that their relatives are choosing not to solicit or not to act on a referral. In that regard, even as recently as two days ago I was paged by one of my colleagues whose child is due to be seen in our clinic regarding the possibility of a condition called neurofibromatosis. It's relatively common. About one in 3,000 people have it. Most people do pretty well, but there is a risk, especially in adulthood, of some nasty tumours associated with this condition that are occasionally life threatening.

She called me specifically to ask me if she came to the genetics clinic and her child was diagnosed with this condition, would that impair her insurability? I said that I had to answer truthfully that it could. It could impair her insurability. She's only 13. If she is diagnosed with that condition, then it may become very difficult for her to obtain life insurance, disability insurance, and so on. That child will not be coming to see us, for that very reason.

I have a number of patients that I see because of the possibility of a hereditary cancer syndrome. One of them who I saw fairly recently is a lady who has temporary employment and moves from employer to employer. I saw her because she has a 50% chance of having a hereditary cancer syndrome that's associated with a very aggressive form of kidney cancer. She decided not to have the test that would diagnose that syndrome or, on the other hand, free her from that concern, because she's afraid that she will be subject to employment and insurance discrimination associated with her employment.

The Chair: Thank you very much.

We're going to Mr. Fraser.

Mr. Colin Fraser (West Nova, Lib.): Thank you, Mr. Chair.

Thank you very much for being here today and for your excellent testimony. It's much appreciated.

Some of what has been mentioned today is the anecdotal sort of evidence. I'm wondering if you have any information about statistics or even about looking to other jurisdictions with regard to the numbers of people who would take advantage of genetic testing but who don't now because of the fear of discrimination.

Dr. Gail Graham: Yes. I think the best data is evidence that has already been presented to this committee both by Dr. Cohn from SickKids and by Dr. Yvonne Bombard, who has done research in this area. I'd make reference to both their testimonies.

Mr. Colin Fraser: Thank you.

Dr. Forbes, from the Canadian Medical Association's point of view, do you know of any work being done in the provinces on this? I know that reference was made to Bill 30 in Ontario, but is there other work being done in the provinces that you feel is helpful but not quite getting to the point where we would have a national overarching framework for the country? Why do you feel that it would be important to have this done nationally rather than province by province?

Dr. Cindy Forbes: I'm not aware of work being done at other provincial levels, other than what's already been presented. I think that from speaking with physicians, we know, from our day-to-day work, that it is a real problem. It's not easily measured, if you can imagine the nature of it, of patients.... We're really talking about very personal health care decisions that may or may not even come to our attention.

Ms. Cécile Bensimon (Director, Ethics, Canadian Medical Association): What I can add is that we feel it's very important to have national standards because, as we know, if we leave it to provincial regulation we can end up with a patchwork of regulations. That's not consistent with the spirit of the Canada Health Act, which wants to guarantee portability and, for example, access to care.

There are many reasons why there should be national standards. One of them is the question of access, as well as protections for Canadians. One thing I can say in my capacity as an ethicist is that genetic discrimination is fundamentally an ethical issue. We know that discrimination is addressed at a federal level, because we need that consistency and uniformity across the country.

● (1130)

Mr. Colin Fraser: Thank you for that.

When Professor Hogg was here on Tuesday, he talked about the legislative agendas in each province as well and the fact that having an ability to put into place a national overarching framework for this would be useful, because each province may have different priorities and it may take time to get it uniform across the country. Would you agree with that statement?

Dr. Cindy Forbes: Absolutely.

Dr. Gail Graham: Yes, absolutely.

Mr. Colin Fraser: Thank you.

With regard to the constitutionality of it, does either of your organizations have an opinion on that? Can you shed any light with regard to it being more properly addressed through provincial legislation?

Dr. Gail Graham: Not being lawyers and not being constitutional lawyers, we're at a disadvantage, but I've spoken to the senator and I've also read the testimony from the very esteemed lawyers who presented to this committee. Our organization has no concerns whatsoever about the constitutionality of this legislation.

Dr. Cindy Forbes: I would agree with that.

Mr. Colin Fraser: You mentioned, Dr. Graham, the colleges of physicians and surgeons, which in one form or another exists in every jurisdiction in the country. Have they expressed to either organization any challenges or problems with regard to encroaching on provincial jurisdiction?

Dr. Cindy Forbes: No, they have not.

Dr. Gail Graham: No, not to us.

Mr. Colin Fraser: All right.

Do I have more time?

The Chair: You have one minute.

Mr. Colin Fraser: With regard to supporting early diagnosis, which you mentioned, Dr. Forbes, can you give some indication as to how this bill would encourage people to get the genetic testing and how that would support an early diagnosis and would help them make medical choices for themselves?

Dr. Cindy Forbes: Absolutely. I think the example I gave was one that would illustrate that point. The conversation that we have at the primary care level is often very introductory, recognizing that there are pros and cons to genetic testing, and one of the obvious negatives is insurability.

If we can take that out of the equation and that's no longer part of the conversation, then we're looking at purely the medical issues and no longer at the societal issues that may involve employment, or insurance, or repercussions that will follow for generations. Then we're really looking at what is best for the health care of that patient. It really narrows it down. It makes it that much more simple, and even though those are complex discussions, it removes that fear.

Mr. Colin Fraser: Very good.

Dr. Gail Graham: If I may, I could offer an example. The inherited arrhythmias, such as long QT syndrome, are a good example. Let's say one's parent has the condition. Then one is at a 50% risk to have it. A genetic test can say yes or no as to whether that person has a predisposition to potentially life-threatening arrhythmia that can be treated with anti-arrhythmic medication and sometimes an implantable defibrillator.

If somebody refuses to have that genetic test simply because they're afraid of employment or insurance discrimination, they forgo that treatment. They don't discover whether they need that defibrillator. It makes a very real difference.

Mr. Colin Fraser: Thank you so much.

The Chair: Thank you.

Mr. MacGregor.

Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP): Thank you very much, Mr. Chair.

Thank you to the witnesses for appearing today.

It's good to see you again, Dr. Forbes. I remember our meeting earlier in the year.

As you've correctly referenced, we've had some very illuminating testimony on this bill from constitutional experts. The government feels that this particular bill is going to be imposing federal jurisdiction in an area of traditional provincial jurisdiction, in contracts and services; however, that view has been counteracted by none other than Professor Hogg. Professor Hogg is probably the most-referenced constitutional scholar in Canada, and I think that when he speaks, he speaks with a certain amount of authority. It is clearly within his view that the constitutionality of this bill falls strictly within federal criminal law power. He feels it's a valid exercise.

However, to be fair, I do want to read out to you some of the opposing legal arguments that have come from the Torys law firm, which was hired for the insurance industry. They feel that courts have relied on the criminal law power to uphold a variety of federal statutes on the basis of a “public health evil”. In each of the cases, the criminal law power has been directed at human conduct that has “an injurious or undesirable effect on the health of members of the public”. Their conclusion is that they feel that the first clauses of Bill S-201 do not address a public health evil.

Dr. Forbes, I'd like to get your response to that.

● (1135)

Dr. Cindy Forbes: Obviously, I would disagree with that. It is a public health issue. It is a health care issue. I think it's a very personal issue for everyone; I think that was well said, you know, if you think about it for yourself.

I see it as a national issue. Each of us has a genetic code. It is universal. As for how we deal with that, I think we need to do it as a nation. Also, there's the issue of portability of health care and universality. If you had testing done in one province under the opinion that it was safe and that you would be safe from discrimination, and you then reside in another province where you have to reveal that, or where it's suggested that you have to take a test to be insured, then you're playing under two different sets of rules.

I think that as Canadians we value our Canadian health care system. I think this is a really good example of an issue where federal legislation will serve everyone well.

Mr. Alistair MacGregor: Thank you.

Ms. Bensimon, I'm very interested in this. So far, we have just been looking at the constitutionality of this bill, and there have been so many legal arguments, but seeing as you hold the very interesting position of director of ethics, I'm wondering if you could inform this committee of how you approach viewing Bill S-201 from a purely ethical standpoint.

Ms. Cécile Bensimon: Thank you for the question. I'm very happy to answer this.

As I touched on earlier, we can say that in Canadian society the question of discrimination is recognized as a fundamentally ethical issue. Discrimination can lead to a violation of one's integrity or one's autonomy, and those are principles that we value in Canadian society. Those are principles that are integral to our health care system today.

What I can say is that if we understand genetic discrimination as being part of what constitutes discrimination, it touches on what we consider to be some of the most fundamental ethical issues in health care, which are questions of equity, of access, of equitable access, of appropriate care, and, from a public health perspective, I would even add appropriate use of scarce resources.

To summarize, this question of genetic discrimination, if we understand it to be as constituting discrimination—and I think we can all agree that discriminating against someone based on their genetic characteristics is discrimination—really touches on the most fundamental ethical issues that we value in Canadian society.

Mr. Alistair MacGregor: Thank you very much for that.

Dr. Graham, you gave some very interesting testimony. If I heard you correctly, you really want this bill to come into place in its present form and not amended at all, because you see the fear that people have. You want to get rid of that fear of discrimination that people have.

Given the position you hold and the knowledge you hold, can you paint a picture for this committee of what we are on the cusp of in terms of genetic testing going forward in the 21st century and, really, what kind of potential this may hold for the future of the Canadian medical system as a whole?

Dr. Gail Graham: Absolutely. I think it's hard to overstate what's happening. It's a real revolution in medicine. It is something that we had hoped and anticipated would happen when all of the three billion letters in the human genomic code were put together in a draft sequence in 2000 and then finalized in 2003. We are now seeing that promise.

Genetics will become a core component of all of medicine, so that when you go to your family doctor and you're found to have hypertension, your family doctor will have a point-of-care tool that allows him or her to decide which of the dozen or so anti-hypertensive medications you are most likely to respond to, in addition to advising you to lose weight and exercise—all of those things. It will literally become part of every branch of medicine. It's what we call “pharmacogenomics”: using the variants in our genome to decide how to target medications to that person. We will no longer be taking the one-size-fits-all approach for medications, which is that if you're a male you start with this medication and then work through a series of them. We'll be able to go to medication number five right away because that's what works for you.

It really is hard to overstate how it's going to change things. We're just starting to see this infiltration of genomics into the rest of medicine. In my world of relatively rare genetic conditions, we've been using genetic tests for a couple of decades, but now we're starting to see this infiltrating into the rest of medicine, which is what we wanted, but that's why the timing is so critical. We can't afford to wait, because patients need to be able to make decisions on the basis of medicine and evidence and set aside the fear of discrimination by their employer or their insurance company.

● (1140)

The Chair: Thank you very much.

Ms. Khalid, you're next.

Ms. Iqra Khalid (Mississauga—Erin Mills, Lib.): Thank you, Chair.

Thank you for coming in today and presenting some very compelling testimony.

Dr. Forbes, initially in your testimony you mentioned that Canada is the only country in the G8 that does not have some form of regulation of genetic discrimination. With this proposed legislation, we would create imprisonment as a possible penalty for those who discriminate based on genetics. Looking at international law and trying to compare where Canada would stand, I see that the U.S., Austria, Finland, and Ireland have monetary penalties. France and Israel have imprisonment as penalties. I could go on.

Have you seen effects in the international community with respect to how it impacts discrimination whether monetary penalties only are involved or whether it's imprisonment as well as monetary penalties?

Dr. Cindy Forbes: I'm going to let Cécile answer that.

Ms. Cécile Bensimon: We don't know that there's really any systematic data on this. What we do know, based on international evidence, is as Dr. Forbes said: genetic discrimination is a significant and internationally recognized phenomenon. It requires a multi-level response at the policy level and at the practice level. Legislation is also integral to that response. We would need legislation that has teeth, so to speak. I think there is international evidence for that.

Ms. Iqra Khalid: Thank you.

Dr. Graham, how far behind is Canada with respect to genetics and research in genetics because we don't have laws that tackle the problem of discrimination?

Dr. Gail Graham: You would have heard earlier from my colleague Dr. Cohn, who has data that indicate that between 30% and 35% of individuals who would have been eligible and interested in participating in genetic research and genomics research declined to participate specifically because of this. We are risking the promise of the Human Genome Project, basically. If we can't move ahead with that kind of research, and if we can't use this information for the benefit of our patients without these concerns, we are missing out on the entire promise of that huge multi-billion dollar investment.

The answer is, we are starting to slip behind, and we will slip further behind very quickly if this worry about discrimination continues to exist for Canadians.

● (1145)

Ms. Iqra Khalid: Thank you. Just to follow up, then, are the other G8 countries that do have these discrimination laws in place ahead with respect to their research on the Human Genome Project?

Dr. Gail Graham: Certainly, they have much less trouble enrolling patients in genomics-type research studies.

Ms. Iqra Khalid: Ms. Bensimon, if I could come back to you, there's no definition of what “genetic characteristics” means in the legislation as proposed. What is your take on that? I was reading through the comparative law of international legislation on this. I see that many countries do define what “genetic characteristics” means with respect to applying that to potential discrimination. Can you explain why you support the lack of a definition in the bill?

Ms. Cécile Bensimon: Thank you for the question.

Supporting the bill without amendment does not necessarily mean that we wouldn't welcome an addition such as the defining of genetic characteristics. If that were deemed to be required, it can certainly only strengthen the bill.

Ms. Iqra Khalid: Thank you.

I don't have any more questions.

The Chair: Thank you very much, Ms. Khalid.

We're now going to start our second round of questions with Mr. Hussen.

Mr. Ahmed Hussen (York South—Weston, Lib.): Thank you, Chair.

Thank you, panel, for coming in and giving us your very useful testimony.

My question is related to the accuracy and effectiveness of the genetic markers that are used in current genetic testing. This committee heard on Tuesday from the Canadian Institute of Actuaries that the presence of certain genes within individuals is vital information for insurance companies when assessing their risks of mortality or of contracting critical illness.

Can you speak to the degree of accuracy of these tests? Upon testing positive for a certain gene, can an individual be certain or near certain that they will in fact contract the disease associated with the gene in the future?

Dr. Gail Graham: Thank you for that question.

There are two categories of genetic tests with respect to this question. One of them is the single gene test, such as the test for Huntington's disease, where there is a definitive test result: you either will or will not develop that disease, depending on that test result. Those are very reliable tests that we use in the context of our medical relationship with patients.

The second category, which you alluded to, are genomic variants, the little variations in each of our 20,000 or so genes that may contribute a small amount toward what we call a “complex disease”, such as heart disease. There are probably many genomic variants that contribute to the predisposition to heart disease, and that aspect of genetic testing is still very much emerging.

The best example I can give you of the unreliability of that information is that direct-to-consumer genetic test companies are using those variants to offer patients. Patients swab their mouth, send it off in a kit to a company, and get back a report about all the variants in their genome and ostensibly what their risk is of having heart disease, Parkinson's, and various other things.

If you take the same person's swab and send that to six different direct-to-consumer test companies, you will get six completely divergent results. You will get one company saying that the person is at high risk for heart disease, another saying they're at average risk, and another saying they're at low risk. This is published. There are published studies, as well this being anecdotal.

In fact, I just read a published study last night that speaks to this very issue. It is extremely dangerous for insurance companies to base their assessments of risk on this kind of data. It is not ready for prime time.

Mr. Ahmed Hussen: Thank you.

I'd like to share the remainder of my time with Mr. McKinnon.

Mr. Ron McKinnon (Coquitlam—Port Coquitlam, Lib.): Thank you, Chair.

Mr. Falk touched on an interesting line of questions that I would like to continue. Clause 3 states:

> It is prohibited for any person to require an individual to undergo a genetic test as a condition of
>
> (a) providing goods or services to that individual;

I can see medical treatment as a service, so that makes sense to me. Also, it states:

> entering into or continuing a contract or agreement with that individual;

If that kind of contract is related to the providing of treatment, that makes sense to me. As well, there is:

> offering or continuing specific terms or conditions in a contract or agreement with that individual.

Again, if it were all about treatment, that would make sense to me.

However, the exclusions in clause 6 are far broader than that, in my view. I would agree with Mr. Falk on this point. If that exception were to be reduced to the aspect of providing treatment to an individual, I think I'd be okay with that. Would you like to comment on that?

● (1150)

Dr. Gail Graham: I think a rewording of that section could be entertained. Again, I don't have a legal background. One would want to protect the ability of pharmacists, for example, to prescribe and to use a point-of-care genetic test to prescribe the correct dose, for example, of the medication that the physician has requested. I think we have to be careful not to narrow that so much that we do risk interfering with medical care, but I understand the spirit of what you're suggesting.

Mr. Ron McKinnon: On the example of the pharmacist, that would be part of providing treatment, I should think.

I'm sorry, Dr. Forbes. Go ahead.

Dr. Cindy Forbes: I was going to add that when I read clause 6, it does implicate the physician, pharmacist, or other health care practitioner as providing health care services, and that the person doing the medical and scientific research is in respect of the individual who is participating in the research. There is already a professional relationship there.

I guess I'd just like to remind the committee that, in addition to the college, as physicians we abide by the Hippocratic oath, which is to do no harm. Also, of course, our college regulations would insist on all of the other principles that we practise by every day, which include confidentiality and only doing things in the best interests of the patient. I think there is a lot of protection already in existence for those relationships.

Certainly, with medical research, there are a lot of protections with ethics boards and many safeguards that protect participants. In those cases, participants sign very clear consents that they understand what the research is about and what their role is. I think there are a lot of safeguards. I don't really agree with there being a lot of concern about that.

The Chair: Thank you very much.

We're going to move to Mr. Cooper.

Mr. Michael Cooper (St. Albert—Edmonton, CPC): Thank you, Mr. Chair.

Thank you to the witnesses.

It's good to see you again, Dr. Forbes. I think you appeared numerous times on Bill C-14.

Dr. Cindy Forbes: Yes.

Mr. Michael Cooper: I want to begin by looking at clause 5 of the bill, which prohibits collection, use, or disclosure without the written consent of the patient. That makes sense, in my opinion. There's nothing wrong with that clause, but I think it's a fact that when an individual undertakes genetic testing, for example, it may show that he or she has a predisposition to a disease or something, and as a result of that predisposition, it may also demonstrate that family members have a similar predisposition. It could be argued that, to some degree, the clause doesn't go far enough to protect other persons who might in some way be impacted as a result of an individual giving their consent.

Do any of the witnesses have any thoughts on that? Is it a concern? Is there something that perhaps should be considered in the way of an amendment to the legislation? Or are you satisfied that it's good as it is?

● (1155)

Dr. Cindy Forbes: Certainly, under the patient-physician relationship and confidentiality, we would be bound not to disclose that information without the patient's consent, regardless of whether other family members may have that gene.

These situations are sensitive and complex, and involve conversations with our patients about the implications, and whether they wish to disclose that information to other family members. Again, I'll pass that over to our genetics specialists, because I would be relying on them as well to have those conversations.

Dr. Gail Graham: Yes, that's very much a part of what we do. When we're discussing a predictive test with a patient—I'll use Huntington's disease as an example—we discuss not only the implications for that person of a positive or negative test result, but depending on the family structure and how they are connected to an affected member of their family, we discuss what their test result will and won't tell them about other family members.

We discuss if and how they would disclose their test result to other family members. All of that is called "genetic counselling". It's very much a part of the contract that I have with my patients. As Dr. Forbes said, if a patient tells me that they want their test result to be kept confidential, then I must respect that.

Mr. Michael Cooper: Thank you for that.

I want to turn to a different issue, and in particular the Torys opinion. I don't know if any of you have had an opportunity to review it. I certainly am not necessarily endorsing the legal analysis, but it's their argument that, in order for Parliament to properly exercise its criminal law power in matters relating to health, there must be a public health care "evil" or a health care "evil", and that's right. That's accurate. They try to distinguish the underlying purpose of Bill S-201 as not combatting a "public health evil", but rather promoting "beneficial" medical health practices.

I know you have alluded to the different negatives or consequences of someone forgoing genetic testing, but maybe you could put on the record what it might mean for the health of an individual who, for whatever reason—because of fear of discrimination—decides that they don't want to undertake a genetic test. What might that mean for that patient's health?

Dr. Cindy Forbes: I think a couple of things are involved in what you're saying. We have the broader issue for the whole system of public health, and then the issues for the individual.

Specifically for the individual, it may mean they will not avail themselves of what would be the best medical care available to them, given their condition. They may not be offered treatment such as something radical like surgery or something very invasive, because it wouldn't be justified without a positive test. They may not be offered the appropriate treatment. As mentioned, when we start to see the pharmacology based on the genetic code of an individual, that will not be available to patients as that becomes more common. They may have a delayed or absent diagnosis. They may never actually get diagnosed with their underlying condition, because they have not had the testing that would show that. By not availing themselves of the best treatment, they may have increased mortality and morbidity, so they may die younger. They may be more ill. There may be other consequences for the health care system in a delayed diagnosis.

I have a colleague who actually has a family history. Her father is from a family of 10 in Prince Edward Island. All 10 developed early-onset dementia: 10 out of 10. The gene has been identified. She is not willing to go into clinical trials. Actually, there are none here, but in the States there are clinical trials for treating patients like her before they develop symptoms. But she's not willing to be tested because of concerns about insurability. It brings up another public health issue of patients not willing to become part of research projects. There is no benefit to her at this point without any proven treatment. There is only the downside of the insurability issue. That's a broader issue of not having people entered in clinical trials because they are not willing to take that risk.

I think I've outlined quite a few of the issues that patients would really would be facing.

● (1200)

The Chair: Thank you.

Because of time, I'm going to Mr. Bittle.

Mr. Chris Bittle (St. Catharines, Lib.): Thank you so much.

I only have one question. If it's all right with the chair and the committee, I'll be splitting my time with Mr. Casey.

We heard from the insurance industry at the last meeting. They proposed what in my mind is half-baked, because they haven't really come up with the details yet. They would prefer to self-regulate genetic discrimination. They promised to announce the details sometime soon, maybe, but I was wondering if you could comment and give us your thoughts on self-regulation by the insurance industry.

Dr. Gail Graham: Well, for insurance companies, their duty is to their shareholders. My duty as a doctor is to my patients. You've heard multiple examples today, and previously as well, of the way in which this issue interferes in patient care and how it can cost the health care system more money because people don't want to have the test that shows they don't need the extra surveillance. I think this is far, far too important to be put into the hands of the insurance industry for them to undertake some kind of voluntary moratorium....

Dr. Cindy Forbes: I would simply agree with that.

The Chair: Does anyone have any objection to Mr. Casey taking the rest of Mr. Bittle's time?

Mr. Casey, you're on.

Mr. Sean Casey (Charlottetown, Lib.): Thank you, Mr. Chair and colleagues.

My first question is for Dr. Graham. We heard what I thought was some pretty compelling testimony on Tuesday from the Institute of Actuaries. They talked about a situation in which a patient has an EKG that indicates a diagnosis and where there could be a genetic test that could result in the provision of the same information. One needs to be disclosed. The other doesn't.

That brings me to the whole question of the nature of the genetic information, in that certain information is for diagnostic purposes, certain information is for predictive purposes, and certain information is for research. Bill S-201 does not differentiate between any of the proposed purposes, but in England, for example, they do.

I'd be interested in your perspective on the value of differentiating within the legislation the purposes for which the genetic information is being used and adopting or tailoring rules around its disclosure based on its use.

Dr. Gail Graham: It's an excellent question.

The dilemma, really, is that many of the genetic tests that we discuss with patients are predictive tests. Take the example of Huntington's and someone at the age of 20 who has a test for Huntington's that shows they will get the condition, probably in their forties or fifties. That's going to happen. That's certain information. Take the example of someone who has a cholesterol test as part of their annual physical with their doctor and gets as a result a risk for heart disease, that is a risk that can be influenced by a whole bunch of other things. It can be influenced by what the patient does between then and 10 years from then.

I think the distinction we need to make is not so much how the test is being used. I think that we have to protect all genetic information regardless of in what context it came to light. Because the concern is still there: regardless of whether it was a diagnostic test or a predictive test, that person is still subject to discrimination.

● (1205)

Dr. Cindy Forbes: I want to take a bit of a different tack on that. I think there's a danger in breaking this down into categories. It would not ameliorate the issue of the fear of discrimination. It would not be clear to the general public, to most people, that some of the information could be used and some of it wouldn't be used. I think the message would still be that it's not safe. There wouldn't be certainty as to which information would end up going to the insurance company legitimately and which wouldn't. I think we should avoid confusion. For that reason, I would say that it should be all genetic information, in addition to what you've mentioned.

The Chair: You have time for one more small question.

Mr. Sean Casey: Thank you.

There's a perception out there that if insurance companies get their hands on someone's genetic information, they're going to be ineligible for insurance. If it became broadly known that you will always have the right to withhold genetic information if the value of your insurance policy is, let's say, under $250,000, or if you're to be part of a group insurance plan, and if that were widely known in the medical community and widely shared with their patients, would that have an impact?

Dr. Cindy Forbes: I think that if it were clearly understood, if I understood you correctly, it would not impact your risk of insurance. Is that what you just said?

Mr. Sean Casey: The proposal, as I understand it, whether it be by self-regulation or by government regulation, is that genetic testing would not be required to be disclosed for any policies under $250,000. It's only for big insurance that it's relevant.

Dr. Cindy Forbes: I honestly don't think that would change anything. I think it would be the same issue.

Also, not everyone knows at what point in their life they're going to be considered for a policy of any value. If you're having the testing done when you're 18, you're not even thinking about insurance. You really don't know what the repercussions could be later on when you're actually someone who needs to apply for a much larger amount.

I don't think it would change people's concept of the risk of discrimination.

Do you have any thoughts on that, Gail?

Dr. Gail Graham: No, I agree completely. It wouldn't change anything.

The Chair: Thank you very much.

Mr. MacGregor.

Mr. Alistair MacGregor: Thank you. I have just a couple of minutes, I guess?

The Chair: Yes. Take what you need.

Mr. Alistair MacGregor: Your answers to my previous questions were certainly very illuminating for me and, I think, for this committee. If I had to ask one more question, I would like to get a response from each of you in turn in terms of comparing what your thoughts are on previous testimony that we've heard.

One of our first witnesses came from the Canadian Human Rights Commission. The last section of this bill deals with amendments to the Canadian Human Rights Act, and that witness felt that the change by itself would not be enough and that criminal sanctions are definitely needed to prevent genetic discrimination.

Just to get it on the record, do you agree with that statement? That's for the three of you.

Dr. Gail Graham: Thank you.

I wholeheartedly agree with that statement. I believe that the amendment to the Human Rights Act is important and that it should enshrine these values as Canadian values, but by itself it will absolutely not be sufficient to protect patients. It won't give them a recourse in terms of employment or insurance discrimination.

Dr. Cindy Forbes: I would agree with that. I think that's what gives it the teeth. We may be talking about large corporations that have deep pockets, and if it's not considered a serious offence with serious consequences, that may not be a deterrent.

● (1210)

Ms. Cécile Bensimon: I completely agree as well. I would say that amendments to the Human Rights Act to include genetic characteristics lay the foundation for understanding that discriminating against someone based on genetic characteristics constitutes discrimination.

Mr. Alistair MacGregor: Thank you, Chair. That's all I have.

The Chair: Colleagues, would you be okay with my following up on Mr. Falk's question? I would like to follow up on what Mr. Falk and Mr. McKinnon were asking about, because I'm not sure that it came out as clearly as I would like.

In essence, as Mr. Falk pointed out—there are things that get pointed out that you suddenly recognize when a colleague brings it up—clause 6 gives a wide latitude of protection to medical practitioners and researchers to be exempt from clauses 3 through 5 of the bill.

Dr. Forbes correctly stated that medical practitioners have ethical obligations within their profession that also regulate them, but the same could be argued of lawyers and accountants and many other professions, yet they are not exempt. Clause 3 of the bill—and I want to read it clearly because I want to understand, and maybe there's a really clear reason why—states:

> It is prohibited for any person to require an individual to undergo a genetic test as a condition of

Let me ask you this. Would there be any reason why a physician would say to someone, “I will not treat you if you will not undergo a genetic test”?

Dr. Cindy Forbes: I can't imagine that myself right at this moment, but I also would suggest that if a physician were to do that they would possibly be in violation of their ethical code, so they would be subject to discipline.

The Chair: So would an attorney. I understand that. There are other professions that are regulated in the same way. I was just asking because there may have been something that wasn't apparent to me on the face of it where you might tell me that a doctor may require a genetic test and would say “ I will not treat you unless you undergo it”. You can't see that.

Dr. Cindy Forbes: I personally can't.

Dr. Gail Graham: I'm sorry, but I can't think of a single example where that could happen.

The Chair: Okay. That's what I wanted to understand, because I think the exemptions may be, as Mr. Falk said, perhaps overly broad. They may cover certain clauses and may be meant to cover the confidentiality clauses and the ability of the patient-doctor relationship to exchange information about the tests, but may not have been meant for the general prohibition related to a failure to provide services if somebody didn't undergo a genetic test.

Dr. Gail Graham: Yes, I think the idea itself was so foreign to us that we couldn't imagine it.

The Chair: Thank you. I think that clarifies that issue for me much better.

Go ahead, Mr. McKinnon.

Mr. Ron McKinnon: I think the point for me is that it's a reasonable exclusion if the requiring of the test is essential or important for the treatment that is going to be rendered, or in order to decide on a course of treatment, but beyond that, it seems to be unnecessary. It seems to be, as was observed, a little bit broad.

The Chair: [*Inaudible—Editor*] part of the bill. It was just a question since you are physicians, and this goes to the physicians especially.

Did anybody else have any short questions?

Ms. Bensimon.

Ms. Cécile Bensimon: Yes, thank you.

If I may return to the point that two of you made. I'd like to return to the point about the Torys's legal analysis that this is not a “public health evil”. I'd like to make the point that whether or not this is a public health evil—and I think there are many compelling reasons why there would be implications for public health that transcend a legal analysis—the question is that genetic discrimination gets to the heart of patient care and the implications for patient care. I think that's really where we need to focus our analysis.

The Chair: Thank you very much.

For all of those watching at home, “Torys” in this case means the Torys law firm, not the Conservative Party.

Voices: Oh, oh!

The Chair: I want to thank all of you. Your testimony has been enormously helpful to the members of the committee.

We're going to go in camera, so we'll have a short break for everybody to clear the room.

Again, thank you so much, ladies.

[*Proceedings continue in camera*]

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