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Chair

Mr. Bill Casey

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● (0855)

[*English*]

The Chair (Mr. Bill Casey (Cumberland—Colchester, Lib.)): I call the meeting to order. I'm sorry we're a little late getting started.

Welcome to meeting 116 of the Standing Committee on Health. We're studying the motion M-132 on federally funded health research.

We welcome our guests.

Mr. Davis is not here yet, but we understand that he is in transit.

Today I welcome Doctors Without Borders, Dr. Jason Nickerson, Humanitarian Affairs Adviser; Universities Allied for Essential Medicines, Louise Kyle, North American Coordinating Committee Member, and Rachel Kiddell-Monroe, Board Member; and from the Multiple Sclerosis Society of Canada, Benjamin Davis—who is not here yet—National Vice-President, and Dr. Karen Lee.

We're going to start off with each group having 10 minutes for an opening statement.

We'll start with Doctors Without Borders and Dr. Nickerson.

Dr. Jason Nickerson (Humanitarian Affairs Advisor, Doctors Without Borders): Good morning. Thank you for the opportunity to address the committee on this important topic.

I am the humanitarian affairs advisor for Doctors Without Borders, or *Médecins Sans Frontières*, MSF, based here in Ottawa. I am also a respiratory therapist with clinical and public health experience across Canada and internationally, and I have a Ph.D. in population health. I am also appointed as a clinical scientist at a hospital here in Ottawa.

MSF is an international medical humanitarian organization that provides impartial medical assistance to people affected by armed conflicts, natural disasters, disease epidemics, malnutrition crises and other emergencies. Last year, our teams carried out over 10.6 million outpatient consultations, treated more than 2.5 million cases of malaria, and cared for more than 200,000 people on first-line antiretroviral therapy for HIV. We're also the largest non-governmental provider of tuberculosis treatment in the world, and last year started more than 18,000 people on first-line treatments for TB and 3600 people on treatment for drug-resistant TB. We have operations in over 70 countries.

To deliver high-quality medical care, MSF needs both affordable access to and innovation for drugs and other health products, like diagnostics, vaccines and medical devices We have worked for decades to push for more affordable access to them and for health research systems that prioritize public health needs.

I want to first note that the M-132 study has the potential to get to the heart of some of the other issues that the committee is studying or has studied, including access to treatments for rare diseases, antimicrobial resistance and even pharmacare.

While each of these issues is complex, the fundamental question is often similar: How can we best develop and deliver new, needed drugs and other health products, and ensure that patients in Canada and around the world have timely, affordable access to them?

The fundamental issue here is not just high prices. High prices are a symptom of a broken health research and innovation system. The fundamental issue is how the system is working and the outputs it's producing.

The problem is clear. The business model that underpins the health research and innovation system that we have is not delivering drugs and other health products that are affordable and that address global public health priorities. If we want different outputs, we need a different model.

I'm going to give the committee four Ps to consider to better align Canada's health research system with patient needs and access: one, prioritize health needs; two, use partnerships to develop and deliver products to meet them; three, have policies in place to ensure access to new health products developed with public funds; and, four, pay for it.

Canada has the ability to prioritize health research that responds to public health needs and does so through a number of different ways. However, while these priorities may open up avenues of funding for the discovery of new health products, the main mechanism by which drug discoveries move out of labs and into the development pipeline is through commercialization.

Generally, that's using exclusive licensing or sale to the private sector in exchange for royalties, but with few to no safeguards that ensure Canadian and other patients around the world will be able to access the final product, even when the public has paid for the discovery. During the rare diseases study, the committee heard from a witness who noted that because Canada lacks the infrastructure to support research and development, we have become “net buyers” instead of net contributors to drug development.

Drug development is a costly endeavour. However, while the pharmaceutical industry says it costs billions to develop a new drug, that is not MSF's experience. In 2003, MSF, along with five public research institutions, founded the Drugs for Neglected Diseases initiative, or DNDi, an international not-for-profit research and development organization that was created to respond to the frustration of being faced with having to use medicines that were ineffective, highly toxic, unavailable, or had simply never been developed despite a public health need. DNDi has been an experiment in innovation, both in what it did—develop new treatments for neglected populations—and how it did it—by testing a model of drug development that was driven by patient needs and not profit maximization.

To date, with total expenditures of $375 million Canadian, DNDi has delivered seven new treatments for four diseases—malaria, sleeping sickness, viral leishmaniasis, Chagas disease and pediatric HIV—that are affordable, adapted to the places where patients live, and not patented. In addition, DNDi has created a robust pipeline with 30 R and D products covering six disease areas, including 15 potential new chemical entities or new drugs.

Factoring in the usual attrition rates in the field of infectious diseases, DNDi estimates that it can develop an improved treatment, for example, by repurposing a drug—which the committee discussed on Tuesday—for between $14 million to $58 million Canadian, and can develop a new chemical entity for between $144 million and $216 million Canadian. That's much cheaper than the billions of dollars the pharmaceutical industry says it costs them.

How is this possible? Through partnerships and collaboration and guiding principles, the DNDi model is what's known as a product development partnership, or PDP. DNDi does not have its own laboratories or manufacturing facilities. It relies on partnerships to integrate capabilities from academia, public research institutions, non-governmental organizations, health charities, governments, and the more than 20 pharmaceutical companies that DNDi has partnered with on early-stage research, clinical development and implementation. This model creates a framework for collaboration among the actors involved to better leverage research investments to more efficiently address public health priorities. The work is guided by access and affordability principles to ensure the final products are available to patients who need them.

The product development partnership approach, guided by principles of access and affordability, could be adapted to the Canadian context and used to develop and deliver new products that are needed by Canadian patients and which serve a global public good. This could be applied to solving pressing public health problems, for example developing new short-course oral cures for tuberculosis which, as the committee heard during its study on antimicrobial resistance, are desperately needed in Canada and in low- and middle-income countries.

Our policy recommendation number one is to identify priorities for health research and development that address global public health needs. Once priorities are identified, public funders should think through the steps needed to develop and deliver tools to address them from start to finish; act as the coordinator of needed innovation; and experiment with Canadian models of product development partnerships that leverage the expertise and investments of government, universities, industry and civil society to develop new drugs and health products that address these priorities.

This of course needs to have policies in place that ensure access to the innovations developed with public funds. Canada needs policies that articulate not only the desire but also the ways in which funders of health research are maximizing the use of public funds to deliver public goods. The Canadian Institutes of Health Research, or CIHR, the main funder of biomedical research in Canada, has a mandate to support the creation and translation of new knowledge into improved health for Canadians and more effective health services and products.

While this mandate includes reference to developing new and needed health products, what it lacks is a clear commitment to ensuring that Canadians and other patients will have access to the products that are developed with the federal funds provided to researchers and research institutions. Ensuring a public return on public investment should be a guiding principle of publicly funded health research. In the context of the development of drugs, devices, vaccines and other health products, this should translate into timely, affordable access to products developed in whole or in part with Canadian public funds. Profitability for research institutes, for investigators, or for the Government of Canada should not be a guiding principle behind decisions on how or whether to develop or commercialize health products.

Our policy recommendation number two is that federal funding agencies like CIHR and others should require recipients of public funds to have access and affordability policies in place for discoveries that are made with public funds. This could be one of the institutional eligibility requirements for receiving federal funding and could include the broadly applicable institutional plans and principles to guide the way universities manage their discoveries. This would better ensure publicly funded discoveries are affordable, globally accessible, and registered in countries that need them, and that the science used to develop them is made available for others to build on.

Finally, pay for it. Financing and incentive mechanisms must be sustainable and include appropriately designed incentives that delink, or as it was referred to on Tuesday, decouple, the cost of R and D from the price of medicines. Setting priorities and creating a framework to coordinate product development through a principle-driven partnership model is one step towards this, but it is important to also create the appropriate incentives to participate in it. One example is the use of prize funds to reward researchers who reach certain milestones in product development—for example, registering a clinical trial or a new chemical entity—and who agree to license the products to developers who will ensure affordable and accessible pricing and registration. Instead of relying on royalties as a means of revenue generation, Canada could simply replace the royalty incentive and reward researchers and institutes who reach certain milestones with, for example, cash prizes, bursaries or additional grant funding.

Our final policy recommendation, number three, is to experiment with the use of different funding mechanisms and incentives that delink the cost of R and D from the final price of new health products. Consider how funding agencies could reward health researchers who meet milestones for developing new health tools and who agree to access and affordability safeguards. Any rewards that are provided should require recipients to have an access strategy in place for the product to ensure it will be available and affordable for patients.

● (0900)

Thank you very much for having me here today. I want to emphasize that if members of the committee have any additional questions or want clarification, you're welcome to contact me.

I'd also encourage the committee to consider additional hearings on this issue in order to hear from other organizations with experience and expertise in this area that I know would be interested in speaking with you.

Thank you.

The Chair: Thank you very much.

Now we'll go to Universities Allied for Essential Medicines for a 10-minute opening.

Dr. Rachel Kiddell-Monroe (Board Member, Universities Allied for Essential Medicines): Good morning. Thank you for inviting us to be here to present to your committee.

I'd first like to thank MP Raj Saini for all the incredible work that he and his office have done to bring this study to light. I really appreciate it.

It's many years that I've been working on issues of access to medicines. I was involved with Canada's access to medicines regime back in 2002-2003 and was slightly disappointed to see that it actually never really took ground. I think we need to find new ways to try to get at these issues and make sure we address the issues of access to medicines here in Canada.

My background is that I've been working with *Médecins Sans Frontières* for 25 years. I am an international board member of *Médecins sans frontières*. I am also a professor at McGill University in international development, and I was actually the founding president of Universities Allied for Essential Medicines, which is a global student group trying to make sure that their universities fulfill their social missions, specifically in regard to biomedical research and development.

I've lived and worked in many countries throughout the world where people are not able to access the drugs they need.

My first experience with MSF was in Rwanda during the genocide, where I had to watch people die because they could not afford HIV/AIDS medicines in that country. At that time, the drugs cost $10,000 per patient per year. I've also seen children who die of malaria in Congo because the medicines they have are no longer effective and no one was interested in creating better drugs. I've also watched children in Bolivia suffer from Chagas disease because there was no market interest in the drugs that those children needed.

What we know today is that one in three people in the world cannot access basic essential medicines. Many of these people are suffering and dying absolutely needlessly just because they cannot access the drugs they need.

These are all signs that the system, the model, that we have currently just simply does not work. Even here in Canada, we're watching as our Inuit populations are suffering from 300 times the rate of tuberculosis over and above that of the non-indigenous Canadian-born population.

This national crisis that we have here in Canada today around tuberculosis is also reflecting a global crisis that we have around tuberculosis: a global crisis that is killing two million people per year. People with multidrug-resistant tuberculosis today are dying because they do not have access to the treatment they need.

The treatment that exists is over 63 years old, requiring 14,000 pills and multiple injections, which leave one in two people deaf. This is the treatment that most people with multidrug-resistant TB are using today. There is a new drug, an amazing new drug that could really change things, but it's just too expensive; it's out of reach for most of those people.

Why is this happening? As Jason just very clearly laid out, this is happening because the current model that we have, the biomedical research and development model—or the R and D model, as we like to call it—is simply not fit for the purpose. It's failing patients globally. It's failing patients here in Canada. Even the United Nations, on many, many occasions, has made it extremely clear that we need to do this differently. We've been talking about this at the United Nations level since the early 2000s, if not before.

We can do it differently. What's really interesting is that at Universities Allied for Essential Medicines we did a study of all the alternative research and development models that are out there. We found 81. What Jason mentioned—DNDi—is just one of those models, but there are many of them. We know that we can do it. It's just a matter of giving these models the space, the financing and the ability to be able to do what they know they can do. There are ways to do it that are different from what we do today.

What we want to do today—and I'm going to this pass over to my colleague Louise—is propose a practical model that could be part of a new approach to biomedical R and D and that UAEM has been working on for over 10 years now.

● (0905)

Ms. Louise Kyle (North American Coordinating Committee Member, Universities Allied for Essential Medicines): Hello. Good morning, everyone. My name is Louise Kyle. I'm a law student here at the University of Ottawa and a member of Universities Allied for Essential Medicines, or UAEM.

In my spare time, I like to enjoy the great outdoors of our country with my partner and my family. In order to do that, I rely on an essential medicine that was developed here in Canada.

I'm here today to share my story with you. I have lived with type 1 diabetes for 25 years. By a simple accident of birth, I have been fortunate enough to have consistent access to insulin my entire life. In contrast, 99% of children with type 1 diabetes who are living in sub-Saharan Africa will die within six years of being diagnosed—six years.

An accident of birth separates me from a young man about my age who died last year in the United States rationing his insulin after being kicked off of his parents' insurance.

As you may know, insulin was discovered here in Canada by researchers at the University of Toronto, a publicly funded university. After witnessing countless people die from type 1 diabetes, Sir Frederick Banting wanted to see insulin mass-produced and distributed to those who need it. He chose to sell the patent rights to insulin for a symbolic $1 to the University of Toronto. He famously said, “Insulin does not belong to me; it belongs to the world.” That was in 1921. It's incredible to me that today this life-saving medicine is unavailable for one in two people who need it. Let me say that again—one in two.

As highlighted by previous witnesses, we need to continue to support research in the public domain. This provides the foundation on which all medicines will be discovered.

You heard Dr. Nickerson talk about the CIHR. The CIHR invests $1 billion per year in health research, and I pay taxes that go to those dollars. The Canadian government has the capacity, and I would say the responsibility, to ensure that medicines discovered with Canadian taxpayer dollars are available to those who need them.

Many medicines are developed in whole or in part with public funds at universities. Universities have goals that are socially oriented, yet they license promising research to private corporations on an exclusive basis. The problem is that these private corporations do not have the same goals as universities. As a result, private corporations are not making these publicly funded medicines available and accessible to all those who need them. Global access licensing would remove the exclusivity to a single corporation, and universities would therefore retain the right to license to other institutions.

Take sofosbuvir, for example. It cured over 90% of hepatitis C cases, but at a cost. One pill carried a price tag of $1000. That was $84,000 for a full course of treatment. This model does not reflect the goal of universities. Whereas a private pharmaceutical corporation is responsible to its shareholders, universities answer to the public.

Global access licensing aims to change the current dynamic. Global access licensing is non-exclusive licensing that allows multiple companies or institutions to access promising research. Global access licensing is a two-part solution. First, a federal funding agency like the CIHR requires a global access licensing provision in any funding that they provide; then, the university is able to license the research to multiple companies or institutions. This licensing is non-exclusive, meaning it allows for competition. This means that versions of the new medicine or the technology can be made available at an affordable price. To ensure access for populations beyond Canada's borders, federal funding for biomedical research should include obligations to sell final products at cost, or other access provisions.

● (0910)

Dr. Rachel Kiddell-Monroe: What we see is that it's actually a very simple proposition. Basically, it's that medicines funded by the public should be accessible to the public.

UAEM's proposal is also very simple. It's a very elegant, ethically sound solution. It just requires a policy shift. It's an easy fix. It actually doesn't require major legislative change, but it does have the potential to impact people in Canada and all over the world.

What's more, the solution that Louise has just been talking about is a solution that's already in practice both nationally and internationally.

First of all, it was adopted as a recommendation by the United Nations High-Level Panel on Access to Medicines in 2016. Also, over 10 leading universities in Europe have adopted global access licensing. On our continent, there are at least 20 universities that have adopted it, including Harvard University, Yale, Johns Hopkins and the Federal University of Rio de Janeiro.

Here in Canada, one university has also adopted it, the University of British Columbia, which was a real pioneer university in adopting global access licensing in 2007. They've shown that it can be done.

What we're trying to do here by considering this motion is give the federal government the chance to adopt this approach at a national level, to make it a systemic issue. This would represent a massive step forward in ensuring the systematic affordability of publicly funded medical technologies.

As a champion of global access licensing, Canada can take a lead on the global stage in promising public benefits of federally funded health research.

From the development of insulin in 1922 all the way to the production of an Ebola vaccine in 2014, we've seen how Canadian laboratories and researchers have a long legacy of providing groundbreaking research. For them to contribute to this ever-growing body, we need to make sure the work of those scientists helps all of the people, not just the people who have the luxury to afford it.

These are our drugs, they're our labs, and ultimately they're our responsibility.

Thank you very much.

● (0915)

The Chair: Thank you.

Now we'll go to the Multiple Sclerosis Society. Welcome, Mr. Davis. You had a little travel connection problem.

Mr. Benjamin Davis (National Vice-President, Government Relations, Multiple Sclerosis Society of Canada): A boat would have been faster from Halifax, Mr. Chair, this morning.

Thank you.

Good morning. My name is Benjamin Davis, and I am the national vice-president of government relations for the Multiple Sclerosis Society of Canada. I am here with my colleague, Dr. Karen Lee, National Vice-President of Research.

We are pleased to speak to Motion No. 132 and the importance of investment in health research, the unique role health charities and patients play in the health research ecosystem and increasing access to medicines. All are key priorities for Canadians affected by MS.

I will give you a bit of context about MS in Canada.

Canada has one of the highest rates of MS in the world, with an estimated one in every 385 Canadians living with the disease. MS is a chronic, often disabling disease of the central nervous system. Since that includes the brain, spinal cord and optic nerve, MS can affect vision, memory, balance and mobility.

Women are three times more likely to be diagnosed with MS than men.

MS is the most common neurological disease affecting young adults in Canada.

Sixty per cent of adults diagnosed with MS are between the ages of 20 and 49 years.

On average, 11 Canadians are diagnosed with MS every day.

For Canadians living with MS and their families, research is key to new treatments, better quality of life and ultimately a cure.

Now I'll turn it over to Dr. Lee.

Dr. Karen Lee (National Vice-President, Research, Multiple Sclerosis Society of Canada): Canada remains at the forefront of MS research around the world. Through generous contributions from donors, corporate sponsors, and fervent fundraisers, the MS Society of Canada has invested over $170 million in research since its inception in 1948.

This investment has led to significant results for people affected by MS. More specifically, MS Society-funded studies have gone the distance in areas such as imaging, diagnosis, genetics, tissue repair and rehabilitation.

Let me share with you a story of a young woman diagnosed 20 years ago at the age of 20, at a time when there were very few treatment options available to her. She quickly progressed in her disability, becoming wheelchair-bound and unable to continue to work. Today, I'm happy to report that we witnessed her getting married, which included her walking down the aisle in heels, and she is back at work as a contributing member to Canada's economy. This story has a happy ending because the MS Society funded a stem cell clinical trial in the early 2000s, which she was a part of.

Although we have witnessed first-hand the real-life benefits of funding research for the person living with MS and their families, the MS Society continues to fund fundamental research, as we still don't know what causes MS or how we can prevent it in the future.

Most importantly, we need more treatments for progressive MS. This past year, we announced the funding of an international clinical trial in which the lead researcher is based here in Canada. The trial is focused on bringing immediate intervention to people living with the most debilitating form of MS—progressive MS.

We recognize that we are unable to do this on our own. Hence, the MS Society believes strongly in investing in research through collaboration and partnerships here in Canada and globally. However, we believe that there are important improvements that can be made to federally funded research to deliver better outcomes for Canadians.

We recommend that federally funded research include fundamental research, and include health charities as key partners of government, universities, and private industry.

Additionally, we recommend creating a framework for enhanced coordination among these four groups to better leverage health charity research investments with additional public and private investment dollars for research.

Finally, as part of the collective voice of the Health Charities Coalition of Canada, we recommend that national health charities do not provide funding for the indirect costs of research, such as the cost to the institutions of hosting research programs and laboratories. We believe that is the role of the government.

Canadians rely on advances in fundamental research to explore questions about how a disease develops, determine whether a new treatment may be effective, and help to identify optimal care. Investments made in research serve the dual purpose of not only impacting health outcomes and promoting innovation, but also of stimulating the economy through employment opportunities that lead to the commercialization of products and the development of intellectual property.

For the MS Society, turning research findings into life-saving outcomes for people living with MS is a top priority. This is why we recently partnered with the Brain Canada Foundation and Biogen Canada in a multi-million-dollar study to understand the MS population in Canada over time. It is only through these important innovative partnerships across different sectors that we can achieve a better understanding of what MS is and how treatments can impact Canadians living with MS in the community.

The Canadian MS progression cohort will provide research solutions that will provide hope not only for those living with MS here in Canada but around the world. To ensure that momentum in MS research continues, we must invest in the next generation of MS researchers. The MS Society of Canada annually invests in young researchers through grant funding in their graduate and postgraduate research. Funding researchers and providing them with educational opportunities across the academic and clinical spectrum enables training for the next generation of MS leaders while reinforcing their passion in the field.

● (0920)

Mr. Benjamin Davis: Not only is investing in health research critical and key to increasing benefits to the public, but we also recommend that federally funded research meaningfully engage patients in setting health research policy. We believe that federal research funding programs should be informed by the perspectives of patients, their caregivers and health care providers.

Health research is essential to addressing unmet patient needs by furthering our understanding of diseases and how to cure and care for those living with them. With their lived experiences, patients provide a unique perspective on the current state of clinical care that must shape the health research agenda moving forward. As such, the perspective of patients should be embedded within the health research agenda.

We recommend that the federal government implement research agenda priority-setting approaches that include patients and health charities across granting programs. Health charities are leaders in this area and have extensive experience in using a variety of mechanisms to help shape the agenda, including direct engagement with patients and international collaborations.

The MS Society has taken big steps to engage with diverse stakeholders in the MS community to develop a research priority agenda. This happened through a series of discussions that took place across the country with the intent of understanding their experiences and perspectives. This was instrumental in mapping out our research priorities, and we continue this ongoing engagement today.

At the same time, we are continually engaging the MS community directly in our research programs, including having them involved in the research decision-making process. It is through this forum that we have seen thoughtful discussion on the importance of research from someone with lived experience. For the scientist, it is a reminder that the work they are doing has a direct impact on those living with MS and their families. The discussions we have witnessed have brought a richness to our review process and have been invaluable for both the scientist and the person affected by MS.

As we mentioned earlier, Canadians affected by MS believe research is key to new treatments and ultimately a cure. Therefore, it is imperative that individuals have access to new and emerging therapies that can improve health outcomes or even cure diseases. Today there are 14 disease-modifying therapies approved in Canada for people with relapsing forms of MS. Ocrevus, a treatment for early primary progressive MS, was conditionally approved in Canada in February 2018. This is the first time that a treatment targeted at progressive MS has been made available to Canadians.

The MS Society believes strongly that a population health perspective may not reflect the needs of individual patients, especially as it relates to a unique disease like MS. In MS, no two people have the same course of the disease or respond in the same way to the same medication. We also know that early intervention is vital to avoid many of the long-term economic and personal costs that result from unnecessary irreversible disability. Literally, for brain health, time matters in MS.

We need to translate these advances in research into better outcomes for Canadians living with MS and their friends and family. We recommend that the federal government ensure timely and affordable access to all Health Canada-approved treatments for MS. Additionally, we believe that people living with MS and their unique perspective need to be proactively engaged throughout the drug review process, from Health Canada to the pan-Canadian Pharmaceutical Alliance.

In closing, we want to reiterate the importance of investing in federally funded research while recognizing the unique role health charities and patients have in the health research ecosystem. By all of us working together, we can achieve better outcomes for Canadians in accessing medicines.

Thank you for this opportunity to speak.

The Chair: Thanks to all of you for your presentations.

We're going to go to our seven-minute rounds. Our first questions will be from Mr. Ayoub.

You have seven minutes.

● (0925)

[*Translation*]

Mr. Ramez Ayoub (Thérèse-De Blainville, Lib.): Thank you, Mr. Chair.

I'd like to begin by thanking the witnesses for their presentations, especially Ms. Kyle, who shared her personal experience. That always gives the theoretical a whole other dimension. It's always important to hear what people have experienced personally.

My question is for Dr. Nickerson and Ms. Kiddell-Monroe.

Given your experience in countries other than Canada, would the models you described be applicable elsewhere? Would it be possible to replicate them? We'd rather not reinvent the wheel; we'd prefer to build on something that already exists.

Does the model you described exist elsewhere? How long would it take to set up? Ms. Kiddell-Monroe said it wouldn't take very long. The fate of this initiative ultimately depends on politicians. Where are we going with this?

The common thread in all of your proposals is money. All of you mentioned that, at the end of the day, nothing happens without money. The research funding is there, but it's the administration of that money that's being called into question, and we all know that money isn't limitless.

Is this type of model used in other countries? If so, how does it work?

[*English*]

Dr. Rachel Kiddell-Monroe: Yes.

[*Translation*]

Thank you for the question.

[*English*]

Mr. Ramez Ayoub: You can answer in English. That's okay with me.

[*Translation*]

Mrs. Rachel Kiddell-Monroe: I'm fine to answer in French.

Dr. Nickerson talked about the DNDi model in place at the international level. Under the model, partnerships with pharmaceutical companies like Sanofi have been established to carry out projects together.

The key to DNDi's success is that it's a virtual pharmaceutical company. That means it can leverage the expertise of scientists and people from all over the world. The initiative was the result of a six-way partnership, including the Malaysian and Indian governments, as well as other organizations. It's really a wonderful model, and it shows that, when all of these stakeholders come together, it's possible to create something at a much lower cost.

To answer your second question, I would say that it does exist elsewhere. For example, there is pricing competition. We come up with prices and people apply to get them. That's another way of going about it. Of course, it always takes money to do this kind of thing, so how does that money become available?

From a government standpoint, it's important to weigh the advantages against the drug costs. In Canada, a large chunk of the health care budget goes to medications. If we paid less for medications, we could do more in other health care areas. At the end of the day, it's about cost versus benefit.

What I've observed over the years is that investing in other models benefits the population because people gain access to drugs. Canada would also benefit. We have an excellent health care system, one that provides people with better support than is available in other parts of the world where people don't have that safety net. If we pay less for drugs in Canada, that would leave more money for other things, and that investment could be used to fund this other model, which also has the potential for a global impact.

[*English*]

Jason, would you like to add?

Dr. Jason Nickerson: Sure. We have all talked about a few things here. We've talked about the need to identify and set priorities. I think we can all agree that we need a process for identifying them. What are the tools that we are missing? What are the medicines, the diagnostics, the medical devices and so on that we need? Priority-setting is certainly one thing we need to do.

We've also heard, and we heard this on Tuesday as well, that we need a model that allows us to create this framework for collaboration among all of the different actors that are involved: universities, health charities, NGOs, patient groups, industry, and so on. That is really the missing piece that we just don't quite seem to have in Canada, this ability to set priorities, discover new things, and then develop them in a way that's affordable and accessible.

Canada is not alone in asking these questions. Other countries are thinking about this. We're seeing these discussions at the European Union. As Rachel mentioned, there is a UN High-Level Panel on Access to Medicines. Everyone is asking these questions and looking at this in very similar ways, trying to address similar problems.

What we see, and what UAEM has done a very good job of identifying, is that we have small pilots. We have universities that are taking action. We have DNDi that's delivering products. We have others that are actually experimenting with this and producing drugs and devices at a lower cost. What we need is to mainstream this. We need to integrate it into more funding streams.

● (0930)

Mr. Ramez Ayoub: If I may interrupt, I have one minute left.

As my last question, how is it that UBC took the challenge to have the global access licensing and the others haven't followed yet? Do you have an answer for that?

Dr. Rachel Kiddell-Monroe: I think that UBC was a real pioneer and it had a vision. It recognized that its social mission as a university was to serve society, and it saw that the model that was in place was not doing that. It actually decided to change that.

We also had a band of amazing students at the university who really pushed—

Mr. Ramez Ayoub: What about the others?

Dr. Rachel Kiddell-Monroe: The others? We've been working with them, and they're very slow.

Mr. Ramez Ayoub: Why?

Dr. Rachel Kiddell-Monroe: It's because people don't like to change the status quo. There's—

Mr. Ramez Ayoub: Is there any benefit to that? Why did they stop?

Dr. Rachel Kiddell-Monroe: I would love to have a president of McGill University here to answer that exact question.

We are making a lot of progress, but it's a slow progress, and universities have their interests as well. To be very honest, we sometimes feel that some universities lose sight of their social mission. What we found with some of the universities that we started this with in 2007 was that some of their concerns were whether they were going to lose revenue and whether there was a big cash cow that was going to come with massive royalty payments.

Actually what they found—and Yale publicly said this—was that introducing that kind of licensing had no impact on their bottom line, not one single bit of impact.

When I spoke to the technology transfer officer at Harvard University, they even said, “You know what has actually increased? Our abilities to license, because now there are different companies coming to us wanting to license. We have more openness to other companies.” It actually was a reverse.

We're very much hoping that in the coming weeks, there will be some major announcements here in Canada about universities as well, so please watch that space. I would like to make the report of UAEM available to you so that you can see these 81 alternative models that exist worldwide. It's a website, and I would be very happy to share that with the committee if that would be of interest.

Mr. Ramez Ayoub: Thank you very much.

The Chair: Thank you for the good questions and good answers.

Now we go to Mr. Lobb.

Mr. Ben Lobb (Huron—Bruce, CPC): Thank you very much. I'm glad for your candour because in my opinion—maybe I'm wrong—universities are very much takers when it comes to public dollars, but when there is an opportunity to license something or sell something, all of a sudden they become a private business.

I've always had a bit of an issue with universities taking federal money, provincial money, and then, when an idea becomes profitable, it becomes their idea, and all of a sudden they want the money. I agree with your concept. I just don't know how you're going to make the change.

While you were talking about it, I was thinking about different drug companies. In a way, they kind of do that global licensing anyway lots of times. I think—and I could be corrected—that if a pharmaceutical company is selling a drug in North America and then decides it doesn't want to sell it in Europe, it sells the European rights to a different drug company anyway.

I see that there is a lot of value in what you're saying, and it's not just in pharmaceuticals; it's in lots of technology companies as well.

If you go back 10 years, certainly on average, the funding line is trending upwards for the money that CIHR has to invest, so if you look at the last decade, it's pretty close to $10 billion. In the midst of all of that, there's also been tremendous money invested—probably hundreds of millions of dollars—in university campuses and college campuses, on labs and other upgrades. Is there a number annually that will achieve all that we're trying to do here, or is there enough money now, but it's just not being allocated appropriately?

Does anyone have any thoughts?

● (0935)

Dr. Rachel Kiddell-Monroe: I would love to have a number for you right here. I don't have that number. I think that could definitely be something for a further study, to find out what that number should be.

To go back to your earlier point about the concern about all of this funding going in and then the results of that funding not coming out for public benefit, I think what we're proposing is exactly where this mechanism would be important, because I think that when CIHR is deciding to fund a university or some research, if they have this global access licence included in that funding.... Actually, the NIH in the U.S. has been playing with this, and it has some of these clauses included in some of the funding that it gives.

If you do that, it ensures that the university has to make the product of that research available. They can still license it to a pharmaceutical company. There's no problem. It just won't be an exclusive licence, so if that research leads to a medicine that could have benefits for people that the company is not able to provide those medicines to, then the university has the ability to license that out to another company or institution.

Mr. Ben Lobb: Doesn't the federal government already do that with some vaccinations and immunizations that would seem to be on a pandemic level?

Dr. Rachel Kiddell-Monroe: Well, yes, but then we often do compulsory licensing as a government, to make sure that it's....

In the time of the anthrax scare—I can't remember the year now—ciprofloxacin was actually produced under a compulsory licence, but the Ebola vaccine, for instance, sat on a shelf in a university for 10 years, even while the Ebola crisis was raging. That's the other issue: that things will sit in a place and not go to market.

Mr. Ben Lobb: I agree with that too. In the past I talked to a few...I wouldn't want to call them "venture capitalists". That's some of their frustration as well. I'm not slighting a researcher or a scientist, but they get very comfortable sitting in the laboratory and coming up with this, this and this. Instead of taking it from the lab and marketing it, they are just so content to sit there. There has to be a mechanism down the road, not to force them, but to compel them to get out of the lab and do some public good with it.

I also want to talk about something else, and again it's with no disrespect.

Dr. Nickerson, you were talking about collaboration and the need to get the universities together and the NGOs together and this together and that. The federal government can do that. I guess they can do it, but when I look at all these organizations, I see that a lot of them have government relations people, strategic people. Do they need the government to get everybody together, or can they get themselves together? What do you think?

Dr. Jason Nickerson: I think we need the framework. That's what doesn't really exist, this partnership model to develop products. I think we have good push funding. CIHR and other funding agencies as well are granting agencies. You apply, and it's a competitive process. They evaluate the merits of your application and they push funding out to you. That works for initial discovery, but when you get into the subsequent stages of actual product development and as you move things out of a lab, you need that collaborative framework in order to do the phase I, II and III clinical trials.

Mr. Ben Lobb: I'm thinking back to 2009. You may remember this. When FedDev was first announced, they did a $20-million announcement on the Juvenile Diabetes Research Foundation and they partnered with McMaster and Western and different organizations to really put a massive investment. Is that more of what we should be looking at? Again, I was thinking about ALS. They partnered with Brain Canada to do a massive multi-year, multi-million-dollar investment to really try to push the dial. Is that more of what we should be looking at?

Dr. Jason Nickerson: I don't know the specifics of these funding proposals, but on this basic concept of bringing all of these actors together to work to solve a common problem, yes, but with the caveat that we need to think through the framework from start to finish, all of the steps that need to be in place, from the point of discovery through to the subsequent clinical trials to the marketing and access and affordability provisions. We can think of these things and build them into that product development pathway, and I think it's entirely possible for public funders to capture all of these things.

We have good clinical trial lists in Canadian public institutions. We have health charities and patient groups that are willing to work with collaborative models, but we need to create the framework that allows that collaboration to happen, not just at these punctuated intervals, but through a long-term perspective. Drug development is a long-term endeavour. If we don't have funding mechanisms and pathways that have thought through this and are there to provide that funding and that process and collaboration in a sustainable way, then we end up with a very fragmented system.

● (0940)

Mr. Ben Lobb: Do I have any time left? Did you say "Your five minutes are up"?

The Chair: Oh, sorry. Your time is up. You're going in a good direction.

Ms. Moore, you have seven minutes.

[*Translation*]

Ms. Christine Moore (Abitibi—Témiscamingue, NDP): Thank you very much.

My questions are for Dr. Nickerson and Ms. Kiddell-Monroe.

Three years ago, I went to South Africa, and I visited a hospital where they were treating people with multidrug-resistant and extremely drug-resistant tuberculosis. Right now, in Canada, are we prepared to deal with an outbreak of multidrug-resistant or extremely drug-resistant tuberculosis?

Mrs. Rachel Kiddell-Monroe: No actually. The treatment for multidrug-resistant tuberculosis is very new. Currently, thousands upon thousands of people around the world do not have access to the existing drug, bedaquiline, which is very expensive and isn't available. I work up north, in Nunavut, with indigenous populations. When I see how we are treating tuberculosis cases there, it's clear how inadequate it is. We could be doing much better.

In that sense, I would say Canada has a crucial role to play on the international stage: pushing for affordable access to adequate drugs. Canada should take that initiative in this era of globalization, with people travelling all over the planet and crossing borders. I completely agree that we need to be able to deal with these epidemics. In India, for instance, countless people have multidrug-resistant tuberculosis. It breaks your heart to see that.

I believe it is our role, as a country, to make sure drugs are available worldwide and to find a way to make that happen. Doing that requires another model. The DNDi organization is working on antibiotics right now. Access to antibiotics is a global problem. Antibiotics are used to treat tuberculosis, so we really have to find a way to ensure people have access to them.

[*English*]

Dr. Jason Nickerson: To add to that, we have a major problem with tuberculosis drug development. We are quite simply running out of viable options, and this is a global problem. The Canadian tuberculosis standards reflect global treatment options that are available to everyone, and the options are quite limited. This is a disease for which there is a growing resistance to the drugs that we have available.

In the last 40-plus years, two drugs have entered the market for a disease for which there are 10 million new cases and close to two million deaths per year—two drugs since 1971. Neither is registered in Canada.

In fact, registration of bedaquiline, which Rachel talked about, is also a global problem. We issued an open letter on September 17 of this year calling for broader registration of bedaquiline, because it is not registered in 18 high-burden countries around the world despite the fact that the development of the drug was a collaborative effort that involved health charities, pharmaceutical companies, public funds and so on.

[*Translation*]

Ms. Christine Moore: If I understand correctly, Canada has invested public money in drug development, in partnership with charities. A drug that could be useful was developed, but Canada has not ensured that it is available or that it is registered here, in Canada. It's a drug that could be used to treat patients here, if necessary. In other words, we are contributing to research, but we can't use the results. Is that correct?

● (0945)

[*English*]

Dr. Jason Nickerson: I don't believe that Canada contributed to bedaquiline. There were public funds, but I don't believe they were Canadian, to my knowledge. Canada certainly contributes to the development of other treatments, such as early-stage research and so on.

[*Translation*]

Ms. Christine Moore: Therefore, Canada can fund charities, which then contribute to clinical data and so forth. Canada doesn't contribute directly; rather, it supports the organizations involved. Nevertheless, Canada does commit funding to the effort.

I would also like to talk about the habits of travellers. A lot of people travel. Although they tend to take airfare and hotel costs into account, they completely overlook preventive drugs against diseases like malaria. Many don't buy health insurance. Some travellers could be described as a bit careless. For example, they might start to take the drug Malarone but then decide to stop taking it because they don't like it.

How are travellers contributing to growing drug resistance?

Mrs. Rachel Kiddell-Monroe: I have to admit I'm not an expert in that area, so I wouldn't venture to answer that directly.

However, I would say that, globally, resistance to antibiotics is a real problem because new antibiotics aren't being developed. I think that's the biggest and most significant global challenge right now. In my view, that's the reason why politicians around the world started to recognize that something had to change. Something has to be done about the fact that we don't have any new antibiotics, which we consider to be basic drugs, and the fact that people have become drug-resistant.

I can't answer your question directly, but I think that it can contribute to the situation, although it's not the number one problem. The issue is much broader than that.

[*English*]

The Chair: Thank you. Time's up.

We have to go to Dr. Eyolfson.

Mr. Doug Eyolfson (Charleswood—St. James—Assiniboia—Headingley, Lib.): Thank you, Mr. Chair.

Thanks to all of you for coming. I practised emergency medicine for 20 years, and I saw the associated problems when people did not have access to their medications. They would become my patients.

Ms. Kyle, you've been taking insulin for quite a while. I'm wondering if you know this: How long has it been since there has been any substantial reduction in the price of insulin?

Ms. Louise Kyle: Um...never? It's just been increasing exponentially. There have been consistent increases in the price of insulin since about 2013.

I'm not sure if folks are familiar with the history of insulin, but it's not really one drug: it's a family of different drugs. We started with pork insulin and then human insulin, and now we're into this analogue insulin period of time. The prices of these drugs are increasing in lockstep. Three big pharmaceutical companies control 90% of the insulin market, and there hasn't been a decrease in those prices at all. They control the market and are increasing the prices year over year, exponentially.

Mr. Doug Eyolfson: Essentially, yes, a drug that's a century old is just getting more and more expensive.

● (0950)

Ms. Louise Kyle: Exactly. Yes.

Mr. Doug Eyolfson: Okay.

It will take too long to ask for individual responses, so I'll just ask everyone to raise a hand if they respond “yes” to this: Is the cost of medication a barrier to access for patients?

I would say there was a unanimous raising of hands.

The reason I ask is that, as you know, we did a two-year study on national pharmacare. Many of us, including me, advocate for a universal system. I was at a meeting last week that was supposed to be a casual meet-and-greet with the new incoming head of our local chamber of commerce. I was more or less ambushed with some literature from a policy resolution meeting of the Canadian Chamber of Commerce. Among these resolutions was one on pharmacare, painting national universal pharmacare as something that was somehow going to have a number of negative effects on small business. It would take over an hour for me to describe the logic of this publication, so I won't go into that.

One of the things the publication they handed me said was that if we, in a national system, put the emphasis on cost rather than access, it would inhibit the development of new drugs and endanger the lives of Canadians.

Could we go down the line to get a response to that statement?

Dr. Rachel Kiddell-Monroe: There are some people who are extremely skilful at changing around discourses and narratives to serve their ends. That is how I would say it in very short terms. What we've seen and experienced over my now 20 years of working on the access to medicines issue is a shifting landscape in the pharmaceutical industry in terms of how to respond to the growing understanding that morally and ethically we are on the wrong path in terms of ensuring that people around the world are able to access the treatments they need.

I also want to recognize that pharmaceutical companies have made big steps in the right direction. They have. We have to acknowledge that. Also, we have to acknowledge that the role pharmaceutical companies can play is a very important role. We have to acknowledge that as well, but we are still unable to break down this barrier that pharmaceutical companies are there to make profits.

That's what a company does. They have stakeholders or shareholders. What we're talking about is a humanitarian goal of making sure that people are able to access the drugs they need. These two goals are in conflict with each other. We shouldn't expect a pharmaceutical company to be a humanitarian organization, just like I wouldn't like my organization to be a for-profit organization.

What we're talking about is, how do we find a way through? This question now—we shouldn't be talking about and starting to get obsessed about cost instead of access—is actually just another conflation of the same argument. Instead, we've seen that access has become the *terme du jour*. It's much more of a politically correct term these days.

Let's stop talking about the money. Let's talk about how we make this accessible to people. The problem is that a lot of that becomes window-dressing, because deep down it's never going to be accessible. Bedaquiline is a brilliant example.

We have this new treatment for hepatitis C, sofosbuvir, a name that I can never pronounce. These things are.... We can talk about access programs that pharmaceutical companies have, but this is not a systemic response to a crisis. What we're talking about here is how to get something that's systemic, that's really incorporated inside our system, to make sure these drugs are accessible.

I'm sorry to say that I think that's just another contortion of the narrative to serve the ends of profit.

Mr. Doug Eyolfson: Thank you.

Does anyone at the table have anything to add to that?

Ms. Louise Kyle: I'll add a quick comment.

I think it's important to note, especially with insulin but with every drug, that we're talking about two different things when we're talking about cost and price. A recent study that came out in the BMJ Global Health journal estimated that the cost to produce insulin sits at around $5 a vial, and current list prices in the United States are at around $300.

With regard to cost and access, ultimately I think that if you're looking at the cost, there's still an opportunity for pharmaceutical companies to make a profit when they're not charging the prices that they're charging today.

Mr. Benjamin Davis: If I may...?

Mr. Doug Eyolfson: Yes.

Mr. Benjamin Davis: Part of the submissions that the MS Society has made have been related to changes that are being proposed by the Patented Medicine Prices Review Board. I flag that here because the theme we have in our recommendations is certainly around patient-centred coordinated approaches and a priority-setting framework for these sorts of things.

At the end of the day, any changes that are made in the landscape should not result in a reduction in choice. That's critical. When we talk about access, certainly the financial piece of that is important, but outcomes are equally important. Some of the difficulties we hear about from our community and others in the health charities sector is that Health Canada-approved disease-modifying therapies are not consistently available across this country. There are stories of people moving from one province to another to get the treatment that works for them if they do not have private health insurance, and that's a concern.

● (0955)

Mr. Doug Eyolfson: Thank you very much. I think that's my time.

The Chair: That finishes our seven-minute rounds.

Now we'll go to five-minute rounds, starting with Mr. Webber.

Mr. Len Webber (Calgary Confederation, CPC): Thank you, Mr. Chair.

I want to go along the same lines as Dr. Eyolfson with regard to his questions on diabetes and insulin.

I'm a bit confused here. First of all, Sir Frederick Banting gifted his insulin to the world. I just don't understand why it's so expensive and why these pharmaceuticals are charging so much. They didn't have any R and D, or not much, and to charge what they are charging, they're obviously just trying to make a profit. Is there no pharmaceutical company out there that will have a kind heart and develop this insulin at a relatively reasonable price?

Ms. Louise Kyle: It's a really good question. I think it's something that folks in the insulin space have been grappling with quite a lot—trying to understand why this is going on, what the factors are, and where we can have an impact to see some relief.

There are a couple of issues going on here. The first is that globally, as you heard me mention, one in two people cannot access insulin. There are several different reasons for this, and only one of them is that the market is dominated by these three big companies. There are concerns about tariffs and concerns about physical access to the drug in different communities.

The second big issue going on in insulin is the price that's going up and up and up. We're seeing this really hit hard in the United States in particular right now. We've looked at emerging smaller companies that are trying to enter the insulin space. We think what's happening is that they're being bought by these big three insulin manufacturers. They're the subject of lawsuits for anti-competitive behaviour and a whole host of other things from different states in the United States right now—but I don't know; I wish there was a better answer, and I wish there was a pharmaceutical company that had a good heart.

Mr. Len Webber: Dr. Kiddell-Monroe, would you comment?

Dr. Rachel Kiddell-Monroe: I would just add that what happens with these things as well in terms of the intellectual property is that as you tweak and develop something, of course, you can get follow-on patents. Louise mentioned the move from the pork-based insulin to the human insulin and to the analogue. Well, as you go through all of these stages, you get different intellectual property and follow-on rights coming up that inhibit access for other companies that would wish to come in to compete.

Mr. Len Webber: I see. I guess there are other costs too, other than the insulin—the syringes and the monitoring devices and such.

Dr. Rachel Kiddell-Monroe: Yes, and these are extremely expensive objects. In many environments they often don't work. If your insulin pump breaks down and you're in the middle of Ecuador or somewhere, what do you do?

Ms. Louise Kyle: That's if you can even access an insulin pump in Ecuador.

Dr. Rachel Kiddell-Monroe: Precisely.

Dr. Jason Nickerson: As an organization that works predominantly in crisis-affected countries, generally in low- and middle-income countries, our experience in trying to access affordable medicines is that the way in which we get the price of these things down is through competition. This is really where we have seen the largest price reductions.

Look at the antiretroviral market for HIV treatments. For first-line antiretroviral therapies around the world where we now have really quite vibrant competition, we're probably approaching the lowest-sustainable price for these things. That's really what I think we need to be talking about: What is the sustainable price that ensures access, that is affordable for the patients and the health systems who need them, but is sustainable enough—in terms of manufacturing costs and a reasonable profit—to incentivize someone to be producing this and selling it?

Mr. Len Webber: That's interesting.

I'd like to move on to MS here. I'm quite a layman when it comes to knowledge of MS. Of course, we don't know what causes MS. You do mention that Canada is one of the highest population bases for MS in the world. I don't know if you can answer this, but is it because of the climate? Is it because of genetics?

● (1000)

Dr. Karen Lee: It's exactly those things that you just said. In fact, there are a lot of hypotheses looking at climate; that's vitamin D. Viruses like Epstein–Barr are heavily studied. For many of us that's known as the “kissing disease”, or mono. It's almost that what we're looking at is potentially a perfect storm that causes multiple sclerosis. Your genes may be primed, and when you are situated in the perfect environment, that might then cause multiple sclerosis. Therefore—and there are a lot of theories right now—being further away from the equator may actually be one of the reasons that we have one of the highest rates in the world.

Mr. Len Webber: That's interesting.

You talked a bit about this young woman who was married and who was on a clinical trial for a stem cell. I've heard stories of people being on clinical trials. The trials have been quite successful, but then, once they're over, the people are without the drugs.

The Chair: Please be very quick.

Mr. Len Webber: Okay.

To go back to the stem cell, is that a permanent fix?

Dr. Karen Lee: For this particular stem cell clinical trial that we funded, they saw in essentially a majority of the people a significant difference. They didn't have any more relapses. For this woman, who is actually situated here in Ottawa, she went from a wheelchair to now walking without any aids.

Mr. Len Webber: That's fantastic.

Dr. Karen Lee: It is a very aggressive treatment, but it does work for a very small population.

The Chair: Wow. That's exciting. Walking in heels, you said?

Dr. Karen Lee: Yes.

The Chair: Mr. McKinnon, you have five minutes.

Mr. Ron McKinnon (Coquitlam—Port Coquitlam, Lib.): Thank you, Chair, and thank you, witnesses, for your great testimony.

I'd like to ask you about priorities.

I'll start with you, Dr. Nickerson. You mentioned that your recommendation number one is to identify priorities. That sounds great, but then I started to think that it begs the question. When I think about it a bit further, I think that we already do establish priorities. There's limited funding and somebody makes choices about where that funding goes, whether it's government funding or an R and D fund in a corporation.

Here's my question to you, sir: How should we set those priorities? We can't necessarily do it on a population basis, because if you look at it in terms of the most people who have this disease, you leave the rare diseases orphaned. It's a tough nut to crack, I think. How would you suggest that we set those priorities?

Dr. Jason Nickerson: I agree completely with you. Really, this is about this idea of partnerships and multiple stakeholders. In order to set priorities, I think we need to be looking at what capacities we have and what kind of expertise we have domestically in different research and therapeutic areas. We need to be talking to patients, families and care providers who are on the ground every day and understanding what it is that they need. I think we also need to be looking at what are the public health priorities.

It's a real mix. I don't have a formula that I can easily hand to you. It's really about this idea of partnerships, but also about international coordination. We shouldn't be duplicating efforts and working in competition. We should be working in collaboration with what other countries are doing and working towards shared goals or different ones.

Just briefly, you mentioned that we do set priorities. I agree with you. In fact, CIHR has their research priorities that they've opened up various amounts of funding for—some of them small, some of them large. There's also an exercise that I believe was led by the Public Health Agency of Canada to identify vaccines that were priorities for research and development. I believe that's available on their website.

There are priorities that have been set that address public health needs. We should be allowing those to drive some of these experiments and alternative ways of actually developing products. It's about taking this priority that maybe has already been set and, as I said, thinking through it from start to finish and thinking about how we end up with a product that meets the needs of patients and health systems and is affordable and accessible. That's where we need to be talking about models and about the policies that we should have in place that commit us to access and affordability, so that public funding results in a return on public investment.

● (1005)

Mr. Ron McKinnon: Again, that sounds really good, but with respect, it sounds as though we're dancing around the problem here. There are a whole lot of different ways of setting those priorities and a whole lot of different people are doing it. It sounds to me as though you need—we need—a coherent mechanism for setting those priorities on a societal basis. Do you have any suggestions for what that might look like?

I invite anyone to participate.

Dr. Jason Nickerson: This ties into the broader question of innovation, right? We're talking about creating a Canada that innovates and is a leader in science and technology. That requires us—or government—to identify priorities that meet public health needs.

You're right: it's about choosing a few things and investing in them to deliver products that are needed, whether they are drugs, devices, diagnostics or other therapies. It certainly involves choices.

Mr. Ron McKinnon: Who should choose? Who should be making those choices?

Dr. Rachel Kiddell-Monroe: I think that maybe you can split the priorities into two sorts as well. You can talk about your national priorities, and then you can talk about your global priorities—our contribution, as Canada, to the broader world. If you're talking about global priorities we should be focusing on, we can look at the World Health Organization, which has very clear identification of some of the key issues, some of the key diseases, the key gaps, the key areas that desperately need new research and innovation around them. That's one area to look at.

I think you can also look at these international product development partnerships—like DNDi, for instance, which is identifying key priorities very much related to what's happening to patients on the ground in all of these countries, done very genuinely, without any sort of political or profit motivation behind their decisions on what they will do. They really go for the most neglected diseases.

For instance, they're now working on pediatric HIV. It's crazy, because we've been working on HIV/AIDS for years. The pediatric formulations have been extremely slow in coming, yet children are one of the largest affected parts of the population, so they said, "We have to work on this." It was the same with my example about Chagas disease. There weren't any pediatric formulations, and this was one of the key parts of the population affected, so DNDi went to make a pediatric version, which has completely transformed the lives of so many people. I think that on a global level we can look at those kinds of priorities.

Then, as Jason said, on a national level we just need to look at the main issues affecting our Canadian population. I work in the north, in Nunavut, and I think that tuberculosis should be something extremely high on the Canadian government's agenda. We have people in our country who are suffering and dying from tuberculosis, which is absolutely unacceptable for a country as wealthy as Canada.

I think that in looking at our population health here in Canada, we can make priorities. You talk about MS. You talk about insulin. I think there are some key areas that really are affecting our population here.

The Chair: We have to go to Mr. Lobb now.

Mr. Ben Lobb: Just to touch on pharmacare, because I know it's been touched on a few times, I think the public's view of pharmacare is being a medication for when you need it at any time. Maybe I'm wrong. I only bring it up because I know others have brought up pharmacare today. Is it rationalized medication to certain areas, or do you look at is as medication for everybody at any time?

Does anybody have any thoughts on that, or are we off topic here?

Dr. Rachel Kiddell-Monroe: I'm not a pharmacare expert, so I can't answer that question, I'm afraid.

Mr. Ben Lobb: Fair enough.

Mr. Davis, you made a comment about people moving around, and that's another reason I brought it up. I know that in some provinces maybe an insulin strip or a testing device is paid for, and in other provinces it's not paid for. What are we to do with that?

Mr. Benjamin Davis: I can address both your comments relative to pharmacare and access from a provincial perspective.

It's very fragmented, very confusing, and difficult for people to navigate. If you don't have private insurance, your options are very challenging. From the perspective of pharmacare, if indeed pharmacare is rolled out in such a way that choices are not reduced and people can get access to the medication that they need when they need it, that will be a success.

It is a patchwork across the country in terms of when a drug is approved and how it gets listed on a provincial formulary, and we think that problem should certainly be fixed. That problem should be eliminated. You should not ever have to move from one province or territory to another to receive the treatment you need.

● (1010)

Mr. Ben Lobb: There's another question I'll bring up. Maybe nobody wants to talk about it or address it, but in the recent negotiations with Mexico, the U.S., and Canada, there was an extension for intellectual property by two years. Do you have any comments on that? Is that an enhancement for companies or universities to make investments, or is that a negative? Maybe you don't want to comment on it.

Dr. Jason Nickerson: I can comment. The intention of a patent is to grant market exclusivity. As it was designed, it's supposed to be a reward for innovation. The intention behind it is to prevent competition. In our experience, the ways in which we have been able to access lower-cost medicines is through competition. Patent extensions will keep prices higher. I think that's clear, and I don't think that it incentivizes companies in the way that we think that it does.

Dr. Rachel Kiddell-Monroe: Just to underscore that point, patents have not been shown to be, as claimed, those drivers of innovation. We have innumerable scientific peer-reviewed reports showing that. Even The Economist on its front page has said that patents are actually a block to innovation, so any extension will—

Mr. Ben Lobb: But they're quite effective in the courtroom—

Dr. Rachel Kiddell-Monroe: Absolutely.

Mr. Ben Lobb: —and I think maybe in the laboratory.

I have one final question, if I have time. I know that the MS Society had a real challenge a number of years ago with the public and political pressures of the Zamboni treatment, or whatever they wanted to call it at that time. Millions of dollars had to be invested into proving that it didn't do anything, I guess. All of those are my words.

What do we do to prevent something like that from happening again? Do you think it's good for society to have a public debate about treatment like that, or the lack thereof?

Dr. Karen Lee: That's a really good question. We as an organization really struggled during that time to understand what to do. Our scientific community very much indicated that this probably wasn't going to work. However, at the end of the day, we really had to do the science, to do the good science, to show people that this wasn't going to work, so I don't want to say that millions of dollars were wasted in the sense that it didn't work. Unfortunately, quite a few drug trials become negative too. At times in science you do need to do that work to show that it doesn't work, versus always wanting to look for the positive.

Really, I think what we recognized as an organization, what we learned from it, was the education of the public about what science is, how people can be part of research, and the importance of research investment. What we learned from that Zamboni time frame, shall we say, was that we weren't really communicating the benefits of science and how people can be involved in research. That's really where we changed as an organization, to really involve patients in our research strategy. Prior to that, it was purely the scientific community.

I think that's the shift we're seeing through CIHR through the SPOR initiative. At the same time, like many of the health charities, we recognize now that it's not just the scientific community we have to engage when it comes to research; it's the entire population of stakeholders, including the patients, so they can have a complete understanding of the benefits of research. They can know what's coming down the pipeline, the benefits of clinical trials, what they can do for people, and the investments we need to make.

The Chair: Thank you very much.

Mr. Saini, you have five minutes.

Mr. Raj Saini (Kitchener Centre, Lib.): Thank you to all for coming here this morning.

Before I begin my questioning, I want to preface by referring to something Dr. Nickerson said in his opening comments that I think is very important. He mentioned that to develop a new chemical entity, it costs between $144 million and $216 million.

From some of the studies I have read, especially from Tufts University, which has kept an ongoing accounting, I guess, of the cost of new drugs right now, it can go from anywhere between $1.6 billion to $2.6 billion. However, that factors in the cost of failure. What you're giving is a more accurate price of what the development cost will be as opposed to factoring in the drugs that in many cases, 90% of them, don't make it past phase I clinical trials.

Mr. Lobb asked a good question about whether or not there's enough money and what the cost is. I think there is enough money. I just think it's the way we use that money. It's not resourced properly. Ms. Kiddell-Monroe mentioned TB, which, as a pharmacist, I know.... I mean, we're dispensing the same stuff I read about in pharmacy school. I'm not going to say when I graduated, but it's not a good sign when the drugs you read about when you were in pharmacy school are still continuing to be used.

Is there a way in which we can coordinate domestic and international research? Even from my own readings—I hadn't realized this—there's a lot of global philanthropy out there, a lot of money being poured in, but my feeling is that this money is being poured into individual silos or organizations that have been given a mandate that the money has to be used for a particular purpose. That's fine, but there is no conversation happening in between different organizations and universities or other members of the ecosystem.

To Dr. Nickerson and Ms. Kiddell-Monroe, is there a way we can coordinate domestically and internationally? One of the things I'm a big proponent of is open science and making sure there are collaborators. Is there a way?

● (1015)

Dr. Rachel Kiddell-Monroe: I absolutely think there's a way. I think you really hit the nail on the head in that one of the problems is that we see everything working in silos. We have a complete lack of transparency between different institutions.

I want to bring up the Neuro in Montreal. They have started an extremely interesting initiative. The head of the Neuro got so frustrated with the slow development that he said they were going to open it all up. They were going to open up all their data to everybody to see if they could speed things up. They saw really dramatic changes in the ability they had. We call it the "open science" approach. The open data has already made big transformations there in terms of the rate at which things are going.

Think about applying that on a larger scale. Just imagine what we could do. I keep going back to DNDi, but it really is one of the premium examples of how that openness and that sharing and that breaking down of the silos has resulted, in a very short space of time in pharmaceutical drug development terms, in incredibly important new drugs, whether they've been combinations of existing drugs in a new way, which was one of the first things they did for malaria with artemisinin and then the combination, or very new drugs, such as the one produced for sleeping sickness.

I think that collaboration requires openness. It requires sharing of data. It requires collaboration between academic institutions. Again, that's why I go back to universities and the importance of universities. Also, then, from the federal side, there's the importance of the public funding that's given by the federal government to these institutions. You can put conditions on that. You can say that we will give you the federal funding, but you have to have global access licensing and you have to make sure you're open and transparent with your data.

You all know how difficult it is to get data on research. If I go to a university and try to find out what they're researching, it's practically impossible for me to do it.

Therefore, I completely agree; I think there are opportunities for collaboration. I think we have to go out and look for them and also create them.

Dr. Karen Lee: Perhaps I could speak a bit about an international initiative that we have embarked on with five other MS societies worldwide. We recognized that there was a need to address the issue of progressive MS, which is the most debilitating form of MS. At the time, there were no drugs available. Five of the MS societies came together globally, and we formed an alliance. We each contribute at least one million euros. We now have a 30-million-euro initiative.

What's interesting here is that we also work with global industry players. They also are contributing at a global level. When we talk about open access, our aim is to make sure that the data being generated in this alliance globally is also available in open access. For instance, there's a researcher out of the MNI who is being funded. Interestingly, he's analyzing data from clinical trials from industry. They have let go of their industry data and have provided it to him to ensure that he can do the proper analysis. I think when we talk about manners of partnership and collaboration, that's a great example of how we're doing it at an international scale, using the resources within the Canadian community as well as partnering with industry. I know we've heard a lot of negativity around industry, but I think there are ways to partner to ensure that we reach our mandates of better access to treatments and developing new treatments.

● (1020)

The Chair: Thank you very much.

We'll now go to Ms. Moore for three minutes.

[*Translation*]

Ms. Christine Moore: I'd like to know what you think about this model: government corporations making generic drugs, mainly essential or basic medicines, that are widely used in their country?

Mrs. Rachel Kiddell-Monroe: One such example is Brazil, with Farmanguinhos, a nationally owned maker of generic drugs. The impact in Brazil has been unbelievable. Thanks to generic drugs developed in the country, Brazil has avoided the scourge of HIV-AIDS.

That's the case in India as well. India has always been considered a global pharmacy for generic drugs, and it's had a tremendous impact on the country's population.

I think it's a very promising approach.

Ms. Christine Moore: Under such a model, what criteria should be used in deciding which generic drugs to make or setting priorities?

Mrs. Rachel Kiddell-Monroe: I think that ties in with what Mr. McKinnon was asking about determining which drugs to prioritize.

A nationally owned company would likely support priorities that reflect the population in that country. In the world we live in, however, it's not a question that can be answered without looking at the broader issue, as we talked about earlier.

Ms. Christine Moore: I have one last question.

The scourge of fake drugs is a fairly widespread phenomenon. We know that people are fighting for access to affordable drugs. When you visit certain countries in Africa, for instance, you find street vendors who seem to have absolutely no qualifications to dispense drugs but sell just about anything. People try to find a way to buy medicines, online or otherwise.

Has the problem of fake drugs levelled off, or is it still growing?

Mrs. Rachel Kiddell-Monroe: As long as drugs aren't accessible, fake drugs will always be a problem. If people can't buy a drug, they will look for an alternative. That's always the way.

I think the problem of fake drugs is the result of medicines being too expensive for people to afford. If people could access a drug to combat malaria or HIV-AIDS, they wouldn't need to turn to the guy on the corner selling God knows what. I really think it has to do with drug prices.

[*English*]

The Chair: I think there's a lot of interest in our witnesses today. Our official time for questioning is up, but I'm going to propose that we do another first round at four minutes each. If everybody keeps their time to four minutes, we'll be able to get them all in. It's an incredible group of witnesses. You've provided us with an awful lot of information already—very succinctly, too, I would say.

We're going to start with, I believe, Dr. Eyolfson.

Mr. Doug Eyolfson: Yes. Thank you.

We were talking before about the cost of research. They are different costs from when I was a grad student. My research was basic medical science. I was basically a lab rat for three years—test tubes, centrifuges, years of plodding work to generate some numbers that may or may not mean something.

If I had come out with a molecule and said, “Hey, this could be really useful,” I would have done the cheapest part of the research. To take an interesting effect in an animal or a cell membrane model and turn it into a workable medication that's actually going to improve or save lives is of course the real big-ticket item. The gold standard is a randomized clinical trial of 10,000-plus patients. Those are very expensive.

We had a witness last meeting who said that we needed to be doing more population-based research. Although that's a little different from what I'm getting at, this is what we are leaving for private industry to do because it's so expensive. They have the resources to invest in this, and of course, again, they're a business. They're not a charity. They want to make up their investment, so they charge a lot of money, and they want extended patents for this.

Now, if we were investing more public money in universities and the universities were performing these large, 10,000-plus randomized clinical trials, would this lower prices and improve access to medications?

● (1025)

Dr. Jason Nickerson: This is, effectively, the experience that we've had with the drugs for neglected diseases initiative. DNDi is, effectively, a virtual not-for-profit pharmaceutical company. It coordinates. It runs randomized controlled trials under very difficult field circumstances. If you think it's difficult to do an RCT, a randomized controlled trial, in a well-functioning Canadian hospital, try doing it in the Democratic Republic of the Congo. It's complicated.

The difference there is that the DNDi model is transparent. We know what it costs. I have the figures in front of me. I've told you what they are. It's transparent. It relies on a partnership model that brings people together within a framework that says we are going to do this, and this is the way we're going to do it; and the end product is going to be accessible and affordable. It has brought the costs down through collaboration. Second, frankly, it's a transparent number.

The $1-billion figure was mentioned previously, but I think it's important to note that there's no transparency in that estimate. Nobody is actively quantifying the public investment that goes into individual drugs that are developed or the private investment, so we're left with this kind of black box figure that, frankly, doesn't align with the estimates that we're getting from our partners.

There's certainly at least a cheaper way of doing it, but I think that there's also a need for more transparency in this entire process. That is one of the things that public funders could be demanding. In the situation that you described, where a molecule is discovered in a public lab, at the point that it moves out of that lab, simply attach safeguards to it, and make that a requirement. Require that there be public reporting on the public and private R and D that goes into this in the subsequent stages, and require that at the point of licensing, there be safeguards attached that say, we're going to negotiate for this specific product what a reasonable final price, pricing strategy, or registration strategy going to be.

You described an exact moment at which there is actually quite a bit of leverage that could be exercised through basic policy changes. These are not legislative changes; these are policies that could be implemented to change that dynamic at a critical moment.

The Chair: Thank you very much.

We'll go to Mr. Van Kesteren.

Mr. Dave Van Kesteren (Chatham-Kent—Leamington, CPC): Thank you, Chair. Thank you all for being here.

I'm normally not a committee member here. I have sat on the heath committee for a short duration, so I'm coming in a little bit cold.

I want to go to you, Dr. Nickerson. I want to continue on with what Doug was talking about. I think that's essential as well.

What is the plan, then? Given that research is primarily being done at universities, are you suggesting that all that research would be offered to pharmaceuticals to produce the drugs, or would they contract for it? The fine details really make this thing difficult, as I see it. Maybe you could just elaborate on that.

Dr. Jason Nickerson: Yes, you're absolutely right. Right now, the pathway is effectively a licensing agreement. Someone discovers something, and then it's handed over through an exclusive licence. I'm simplifying things significantly here, but let's just work with that. From that point on, things are developed and bought up. There's a whole spectrum of things that happen, and as Dr. Eyolfson mentioned, it's complicated and expensive.

What our experience shows is that at that point, as opposed to issuing an exclusive licence that effectively grants a monopoly to develop and deliver something, partnerships that bring many of the same actors together within a program—if you want to call it that—still have the ability to develop and deliver these products. We have many of these capabilities that exist within publicly funded institutions anyhow, or industry brings certain things to the table. At a very early stage, we'll say that the universities or the health charities are able to coordinate the clinical trials and that industry is necessary for manufacturing capabilities and marketing capabilities, or whatever it may be. We define those things very early on, at the point of issuing that licence.

It is entirely possible to start setting these parameters. Canada can create that mechanism and create that framework to develop and deliver these things as opposed to stopping at the point of funding discoveries that are then commercialized, and saying, “Hope it works out.”

● (1030)

Mr. Dave Van Kesteren: How are you going to control the pricing?

Dr. Jason Nickerson: Well, that really depends on the kind of product we're talking about. On Tuesday we heard from a witness who said that as we move toward more precision medicine, everything will become a rare disease, right? Every version of diabetes, all the different genetic variations, and so on will require different products, so I think we need to be careful about assigning blanket strategies.

One thing UBC has done in their access licensing provisions is establish basic principles that make sense. These are publicly funded discoveries, and their principles essentially state that they should be accessible and affordable to people who need them. Individual products will still require specific strategies, and for some products there will be a competitive market, but perhaps for others there won't be. What we need to get right is that there should be, at the very least at the institutional level, a set of principles that says we are paying for this discovery, and it's incumbent on us, as an institution, to ensure that there is affordable access to it and it's available to the patients who need it.

Mr. Dave Van Kesteren: Do I have a few more seconds?

The Chair: You have 15 seconds.

Mr. Dave Van Kesteren: Once a pharmaceutical buys a licence, how are you going to stop them from what you might call “exploitation”, although they would just call “profitability”?

Dr. Jason Nickerson: I'm not a contract lawyer—I'm a clinician—but I think you insert some sort of clause that says these are the conditions under which the licence is being issued.

My colleagues from UAEM have put more thought into the particularities of this than I have.

Dr. Rachel Kiddell-Monroe: Basically, the difference would be that you wouldn't give an exclusive licence to that pharmaceutical company. You'd have a non-exclusive licence.

Mr. Dave Van Kesteren: But do you think they'd be interested?

Dr. Rachel Kiddell-Monroe: Yes, they'd still be interested. This was one of the things we were talking about.

To go back to Mr. Ayoub's question right at the beginning, one of the concerns was around why universities were not doing this, since it seemed so obvious. Well, one of the concerns they had was that they would lose income from royalties. In fact, though, the experience of Yale and Harvard, which their technology transfer offices have told me directly, is actually the opposite. It hasn't affected any bottom line.

As well, universities are not going to suddenly get this massive cash cow of hundreds of millions of dollars pouring in through the door because of the result of a discovery. That's just an urban myth. We can go into the story of how that happened, but it is an urban myth. This idea of technology transfer offices being this big, huge source of revenue for universities has absolutely not panned out. Now that we know that's not the case, there is no reason not to do it, but that is the key concern they have.

The Chair: Okay.

Now we will go to Ms. Moore.

[*Translation*]

Ms. Christine Moore: Thank you.

Do you think we are paying enough attention to other disease-related factors that aren't directly tied to medicines?

Think about the tuberculosis problem. Other factors can play a role, including overcrowded housing, substandard accommodations up north and a lack of access to quality food, which is often unaffordable. These things can affect a person's immune system.

For instance, diabetes can be treated with insulin, but people with diabetes also have to maintain a healthy lifestyle, which has a huge impact on their health.

Do you think we are paying enough attention to all that? Are we giving people the tools to address other factors so that they derive the maximum benefit from their treatment?

Mrs. Rachel Kiddell-Monroe: A disease like tuberculosis is considered a social disease. Tuberculosis still exists in Canada because indigenous populations live in appalling conditions. Up north, several families live together in the same house. Of course, the situation is ripe for the spread of tuberculosis. I live in Montreal, and that isn't an issue.

It is indeed a social disease. We need to focus more on that and address all of the factors involved. We can't overlook those who will become ill regardless, though. We can't focus exclusively on the recommendations of public health authorities. We need to pay more attention to the medical dimension and access to drugs because, even with ideal housing and the best living conditions, people will always get sick.

For example, I don't think Ms. Kyle takes insulin because of poor eating habits.

● (1035)

[*English*]

Ms. Louise Kyle: I think it's a really good point. It's important to know that when we look at social determinants, that's one of the biggest predictors of the health status of Canadians. You're absolutely right that there are other factors that influence a condition that someone is living with.

I have type 1, so I'm not taking insulin because of a poor diet. Type 2 diabetes has a lot of stigma around it, and it's not just a lifestyle disease; it is a condition that people are genetically predisposed to. When they're put in poor situations in which perhaps they don't have access to good-quality food or they don't have access to places to move and be outside and be active, those are contributing factors, but they are not the underlying causes of that disease. That's a really important distinction to make. There are a lot of factors.

Outside of this space, I talk a lot about preventive health care strategies for everyone in terms of ensuring that those other factors are met, but if someone doesn't have access to their diabetes treatment or their insulin, you end up with a lot of problems down the road that are more expensive for a health system than a bottle of insulin.

The Chair: You have a little bit more time.

[*Translation*]

Ms. Christine Moore: What should the federal government prioritize if it wants to make sure the results of health research are accessible to the public?

[*English*]

Dr. Jason Nickerson: I think it really comes back to this idea that we need to get the policies correct at the federal level.

The reality is that Canada contributes immensely to global health, to health research and to our understanding of population and public health. Our health researchers are productive and doing good things. However, we need the policies in place to say that we need to have a solid public return on this public investment. Universities and others who are recipients of public funds should have the policies in place to develop access plans and strategies for the products they develop and discover. This idea that you simply discover something that may be a cure for a disease and it's commercialized with no safeguards attached—I think we can do better than that.

The Chair: Thanks very much.

Now, quite appropriately, we go to Mr. Saini.

Mr. Raj Saini: Ms. Kiddell-Monroe, I want to pick up on something you said that I think is very important. You talked about exclusivity and non-exclusivity, and I think that really goes to the heart of what we're trying to discuss here.

Just so that it will be on the record, could you expand on your idea of global access licensing, the difference between exclusivity and non-exclusivity, and why you feel non-exclusivity would really make such a big difference in drug pricing?

Dr. Rachel Kiddell-Monroe: When you give an exclusive licence to one organization or institution or company, that gives them the sole rights to be able to exploit that licence. What happens then is that you get into a situation of monopoly. With the system we have now, that's usually with a patent attached to it. They last for 20 years, and then you get extensions, through what Mr. Lobb was talking about, and it can go on and on and on.

When we give a non-exclusive licence, that enables other companies to come in and be able to compete, or other institutions to come in and be able to compete, if there are found to be uses of the end product from that research that are very important for the Canadian population and for the international population. In fact, going to those 81 alternative models of R and D, they could also benefit.

For instance, let's say I'm a company and I get a non-exclusive licence for an end product of a hepatitis C drug that I want to sell for $1,000 a pill in the U.S. and Canada. However, they also need that drug in India and so on, and I don't want to produce it. Someone else can then come in and produce it at a price. They can use the information I have and they can fill it.

For me, then, it's something that could really benefit everyone. It's about making a jigsaw puzzle. This is where Jason's idea comes in around the collaboration and the way all these pieces fit together. For me, that's why non-exclusive licensing would absolutely open up the possibility of affordable and accessible medicines.

● (1040)

The Chair: You still have some time.

Mr. Raj Saini: Okay.

Dr. Nickerson, in your opening remarks you talked about prioritizing health research that responds to public health needs. Could you just expand on that?

Dr. Jason Nickerson: Yes, absolutely. I briefly mentioned our experience with sleeping sickness, or DNDi's experience with sleeping sickness.

Sleeping sickness is one of these diseases that was horribly neglected for years. The treatment that was available 13 years ago was effectively to dissolve an arsenic derivative into something similar to antifreeze and inject it into people. That was the treatment that was available for this disease that affected thousands of people. There was no interest by the private pharmaceutical industry in developing subsequent therapies, and this treatment killed one in 20 people who received it.

Now, flash forward to the DNDi experience, which is, again, able to draw interest from industry, academia and a variety of different places. They found a compound, fexinidazole, that had been sitting on a shelf, underdeveloped and abandoned, for whatever reason. They acquired the rights to it and developed it. Do you know what? It works.

DNDi, over a period of probably a decade or more, has managed to drastically transform the landscape of the treatment that's available by taking on fexinidazole, which was simply abandoned, doing the clinical trials and bringing in partners from civil society, academic, industry and so on. They did that within a framework that attached safeguards on this development process and said, “Okay, if this actually works, we need a commitment from everyone involved that the final product is going to be affordable and accessible for people.”

The results of the clinical trial were published sometime in the last year, I believe, in The Lancet. It works. We've now gone from a treatment that killed one in 20 people to an oral therapy that effectively cures the disease in 10 days.

These are models that build collaboration and attach safeguards to them, and they're developing and delivering treatments. There is no good reason why we couldn't be setting the same priorities through federal funding agencies to say that there is a need.... Granted, we've had a discussion about priority-setting. It's complicated, but there's no reason why we can't say that there is a need; we're going to invest the resources that are needed into that initial stage of discovery; we're going to manage the process from start to finish; and, everybody who is involved needs to agree to the parameters of it so that we develop and deliver treatments in a timely and affordable way.

It happens, it works, and it's time for us to simply try it in other disease areas. It's possible to do it within the existing frameworks, but we need new programs that bring everybody together through the subsequent stages of drug development and delivery.

The Chair: What a great way to finish the day.

On behalf of the committee, I want to thank all of you, because you've given us incredible information in a way that we can understand. Hopefully, our report will do it justice and we'll effect some change. On behalf of the committee, I give you our thanks.

I want to thank the committee, too, for doing their homework and following this subject so closely.

With that, I want to say that next Tuesday we are back on diabetes. We're going to do a report on the report; we're going to do the drafting instructions for diabetes. We'll talk about drafting instructions for motion M-132 as well. We won't do it, but we'll talk about it.

Again, thank you very much for coming. We appreciate it a lot.

The meeting is adjourned.