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Chair

Mr. Rob Merrifield

Standing Committee on Health

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● (1530)

[*English*]

The Chair (Mr. Rob Merrifield (Yellowhead, CPC)): I call the meeting to order. I want to thank the witnesses for coming forward, and we'll ask the members who are in the room to take their seats so we can get started.

First of all, this is the fourth meeting we've had on the CDR, the common drug review, with the beginning of our series on prescription drugs.

The witnesses today are from Cancer Care Ontario, the Cancer Advocacy Coalition of Canada, Princess Margaret Hospital, Canadian Breast Cancer Network, and the Colorectal Cancer Association of Canada. We'll start with Debbie Milliken from Cancer Care Ontario.

I want to thank the rest of the panel for being here. I'll introduce you as I yield you the floor, but we'll start the meeting with you, Ms. Milliken.

Ms. Debbie Milliken (Director, Provincial Drug Reimbursement Programs, Cancer Care Ontario): Thank you very much for the invitation to make a presentation to the Standing Committee on Health. I'm participating today as a representative from Cancer Care Ontario, and I currently hold the position of director of provincial drug reimbursement programs at Cancer Care Ontario.

Cancer Care Ontario is an independent government agency that's responsible for planning cancer services, developing and implementing quality standards and practise guidelines, as well as reporting on cancer system performance to the public and clinical and administrative leaders. We also act as the chief advisor to the minister in Ontario on all issues related to cancer.

In my presentation today I plan to describe the drug approval process for oncology drugs in Ontario, our experience to date with the CDR, and the challenges that we have with respect to evaluating cancer drugs for funding. In addition, I'll provide you with some information concerning the newly established joint oncology drug review, or JODR. Please keep in mind that the JODR is a provincial-territorial initiative being led by the Manitoba and Saskatchewan governments and that Cancer Care Ontario is a participant in that initiative.

The Chair: Excuse me.

[*Translation*]

Ms. Christiane Gagnon (Québec, BQ): Could the witness possibly speak more slowly, to give the interpreters a chance to keep pace?

[*English*]

The Chair: Perhaps you could speak a bit more slowly. The interpretation is having a difficult time keeping up.

Carry on, please.

Ms. Debbie Milliken: In Ontario, cancer drugs are funded through a variety of mechanisms. Drugs that are given in the hospital intravenously are primarily funded through our provincial IV cancer formulary, called the new drug funding program, a program that's administered by Cancer Care Ontario on behalf of the Ministry of Health and Long-Term Care.

Older medications given intravenously are paid for through hospital global budgets. Community-based medications are reimbursed, for eligible recipients, through our Ontario drug benefit program. As well, some people have private insurance or pay out of pocket for their cancer medications if given in the community or orally.

Ontario's oncology drug review process, which I'll refer to as the CED-CCO, or the committee to evaluate drugs-Cancer Care Ontario, process, was established in 2005 in response to a number of issues we had in the province. The first was the significant expenditure gross of over 30% that we were experiencing at a time when many new anti-cancer agents were in development and close to launch that we knew would cause increased pressure on our new drug funding program.

Traditionally, we didn't use health economic analysis in terms of trying to make decisions for formulary funding. We also saw there was an opportunity to improve the consistency in terms of policy decisions for the two publicly funded formularies in Ontario—the Ontario drug benefit program and the new drug funding program—and sought to bring together the process for approval of both programs.

This was a collaboration of the Ontario drug benefit program and Cancer Care Ontario, which was intended to create a single oncology drug review process that would build on the strengths of both of the current processes. From the Ontario drug benefit side, we built on their expertise of using pharmaco-economics in the review process, as well as their experience in handling manufacturers' submissions. From the Cancer Care Ontario side, we built on the expertise from our disease site groups on the clinical side and made use of our guideline development process through our program and evidence-based care that uses systematic review of the clinical literature in the evaluation.

The process allows for both pharmaceutical manufacturers and Cancer Care Ontario disease site experts to make a submission for reimbursement. There is a link to the common drug review process for community-based medications, but not for intravenous medications.

The joint CED-CCO oncology subcommittee first evaluates the clinical and economic evidence and makes a funding recommendation to our committee to evaluate drugs, and that committee is the committee that considers the broader context of oncology agents in the context of other therapeutic areas and makes the final recommendation to government. In Ontario, our executive officer makes the final funding decision.

Our subcommittee for oncology is made up of medical oncologists, internists, ethicists, pharmacists, and health economists. In the near future we'll be adding patient representatives as well.

The experience is limited to date with respect to the oncology drugs that have been evaluated since our joint CED-CCO process was implemented in 2005. Cancer Care Ontario has no direct experience with the CDR recommendations in informing the new drug funding program decisions, since the CDR does not currently evaluate intravenous drugs given in hospitals.

On the Ontario drug benefit side, we have experience with four orally administered cancer drugs that have been reviewed through the CDR and decisions made for the Ontario drug benefit formulary. In all four cases, the reimbursement decision of Ontario was consistent with the CDR recommendation.

The CDR reviews are considered a part of the CED-CCO process. They're one of a number of inputs that are considered by our subcommittee and, finally, by the committee to evaluate drugs.

A number of challenges face us in terms of being able to properly evaluate cancer drugs. Regardless of the process that's used, often clinical evidence required to make confident decisions regarding a drug's true value is not necessarily available. Ideally, we would like the level of evidence to come from multiple phase 3 trials, or randomized control trials. Often what we have is non-comparative data from what we call phase 2 trials. Often the relevant comparators we'd like to see aren't used in clinical trials, or the trial may not reflect our current practice patterns in Ontario or the rest of Canada.

It's unclear how unproven surrogate end points, such as response rate or tumour shrinkage or disease pre-survival, relate to the more important end points that decision-makers would like to see, such as survival and quality of life. And these are required for determining the true value for money of a new therapy.

● (1535)

Some trials also incorporate crossover designs, which may mean that decision-makers again never have the information they need to make a confident decision from a clinical perspective. If the clinical data isn't strong, the pharmaco-economics will likely be modelled around numerous assumptions, creating a large degree of uncertainty concerning its actual cost-effectiveness for a new therapy.

The key issue is not necessarily the process used for decision-making, but rather the question of what the decision-making threshold should be in assessing the new therapies where the data may be incomplete or unclear, to ensure that Canadians receive good value for money and that this is balanced with the needs of individual patients and our societal values.

In Ontario, we have a number of initiatives under way through our drug system secretariat to better inform decision-making and optimize access for oncology medications. These include our transparency initiatives and initiatives to improve public engagement in the process through the development of a citizens' council and participation of patients on our committees. We're trying to address these evidence gaps through conditional listing proposals and working with industry on partnership agreements. Cancer Care Ontario is also in the process of developing a pharmaco-economics unit to improve the quality of the economic data used in the decision-making process.

There are clearly a number of benefits to establishing a national oncology drug review process that would allow for all provinces to have local funding decisions informed by a single drug evaluation based on a rigorous review of both clinical and economic data. Certainly a single process creates the potential across the country for more consistent decision-making. It reduces duplication and maximizes resources and expertise across Canada. Certainly it provides a single review process for all oncology medications, regardless of how the drug is given, whether it's given orally or intravenously, or the location of treatment, whether it's in the hospital or in the community setting.

I want to talk a little about the joint oncology drug review. It is a provincial-territorial government initiative being led by Manitoba and Saskatchewan. Cancer Care Ontario is participating as part of the overall Ontario contribution to that effort. During the one-year interim JODR, submissions for all oncology products will be made to the Ontario CED-CCO process and considered as a submission to all participating jurisdictions. Each jurisdiction will continue through the JODR process to make the final funding decision.

There are four phases to the JODR initiative. The first was the memorandum of understanding phase, where all provinces signed on to the initiative, other than Quebec.

The second phase, which is the one we're in now, is the observation phase. All of the provinces will have the opportunity to review the Ontario process to learn from it and understand how it works.

In the third phase we hope to incorporate reviewers from other provinces and start to engage linkages with other national initiatives, such as the Canadian Partnership Against Cancer.

The fourth and final phase is the evaluation phase, where recommendations will be made to the provincial-territorial deputy ministers on the potential for a permanent process going forward. There's a governance structure, with a steering committee that includes an observer from the common drug review. There's also an advisory committee that will include membership from the cancer agencies. It hasn't been initiated quite yet.

Finally, from the perspective of the CDR, the Canadian Expert Drug Advisory Committee will not be deliberating or making funding recommendations during the interim process. However, the CDR will continue to provide clinical and pharmaco-economic reviews that will be used, as needed, as part of the JODR process for drugs that would normally meet the definition of a CDR review.

Thank you.

● (1540)

The Chair: Thank you very much.

Now we'll move to the Cancer Advocacy Coalition of Canada. We have William Hryniuk, the director and past chair. The floor is yours.

Dr. William Hryniuk (Director and Past Chair, Cancer Advocacy Coalition of Canada): Thank you very much, Mr. Chairperson, and thank you for inviting us.

First, we would congratulate the government for transferring the cancer drug portfolio from the CDR to the joint oncology drug review, JODR.

Let me place our credentials before you. The Cancer Advocacy Coalition of Canada is a non-profit organization comprised of cancer survivors, physicians, scientists, and cancer system administrators drawn from coast to coast across the ten public health care systems of Canada. Our board members have personally received cancer treatments and services, or have delivered the services to individual patients, or have administered cancer services on a regional basis, or have organized and conducted clinical research on a national basis, or have studied cancer prevention on an international basis. Not one of us is paid for our work on CACC. Board members are listed at the back of the presentation.

I am the immediate past chair and formerly a practising medical oncologist, a cancer researcher, and a director of university-based cancer centres in Canada and the United States.

The Cancer Advocacy Coalition is dedicated to ensuring that the spectrum of cancer control activities in Canada proceeds in an optimal fashion. Each year we investigate various aspects of cancer prevention, screening, treatment, supportive care, and research in Canada, and we publish the results in our annual report cards on cancer. You'll observe consistent differences in the amount of money provincial governments have allocated to cancer control, which we believe have resulted in the differences in cancer mortality in those provinces.

We have also shown how access to life-saving cancer drugs is very unequal and inconsistent among the provinces. We're therefore grateful for your attention to the process for cancer drug approval and to the Government of Canada for establishing the Canadian Partnership Against Cancer as a means of redressing these interprovincial differences.

Now to the point of the hearing: why was CDR unable to comprehensively evaluate oncology drugs and how can JODR do better? First of all, the committee of CDR, which was judging these drugs, was unable to deal with the complexity of oncology problems. Committee members were prevented from accessing the best knowledge about each new treatment and were therefore unable to judge data in context.

Let me explain. There are over 150 types of cancer. For each type of cancer there are several stages. For each stage there are several treatment options. These options constantly change as new trial data pours in almost daily. It is increasingly difficult to maintain the knowledge required to judge what is the state of our medicinal treatment in any given situation at any given time. This requisite knowledge is, arguably, best held by the investigators who actually do the clinical research establishing drug effectiveness. Yet the CDR committee was prohibited from hearing from those investigators.

As I understand it, the prohibition was based on the premise that the judgment and the advice of the investigators would be tainted by their affinity with the trial results or with their affiliation with the drug company sponsoring the drug application. By this reasoning, CDR committee members could not trust the testimony of trial investigators.

Granted, the various parties would have had different perspectives, but surely some knowledge exchange could have occurred and could have benefited the Canadian public. After all, these investigators are physicians who not only have the requisite knowledge to place the treatment results in proper context, but it is safe to assume they also have the interests of their patients at heart and a commitment to improve treatment for those patients. Otherwise, they wouldn't have done the study in the first place. We therefore strongly urge that the investigators who conduct the pivotal studies be allowed to contribute to the process of adjudication of drugs by JODR.

The JODR, as you've heard, is a process in which eight other provinces allow the Ontario committee to evaluate drugs, hereinafter called Ontario CED, to conduct all the oncology drug reviews on their behalf. The Ontario CED derives its oncology advice from a subcommittee comprised of oncology experts from Cancer Care Ontario and other representatives. There now arises a transparency problem as the responsibility for adjudicating cancer drugs is transferred to the CED because the identity of the members on its oncology subcommittee is shielded from the public. Among the reasons for this concern is that oncology subcomittee members may be subjected to undue pressure, or perhaps even bodily harm, if they render negative judgments about particular drugs. If that is the reason, it would be an entirely unique one in the annals of public service in Canada. I am sure you can judge the weight to be given to such a premise compared with the need to know the credentials and the competencies of the committee members. We therefore ask that the identities and credentials of JODR oncology subcommittee members be readily available to the public.

● (1545)

The third concern we have about the process followed by the CDR committee is the lack of transparency surrounding its judgments. We strongly suspect that the JODR, left to its own devices, will follow the same pattern of reporting. We therefore ask that you ensure that JODR make public the detailed explanations of why it renders particular judgments.

Central to the issue of lack of transparency is the lack of a robust economic model for judging cost-effectiveness. Regardless of whether it's CDR or JODR that is rendering the judgment, it is regarding the reference frame within which cost is addressed that we take issue. The new cancer drugs result from huge efforts in basic and clinical research and are therefore expensive. Cost-effectiveness must factor into their deployment.

Cost-effectiveness has usually been expressed in terms of the incremental cost for each quality-adjusted life year gained. Better methods of expression must be employed. To adequately judge the cost-effectiveness, additional factors must be taken into account. These include the cost of alternative, older, and less-effective but still expensive treatments; the cost of not treating the condition, which will result in more doctor visits, emergency room visits, and hospitalizations; the cost to society in the lost tax base and loss to the GDP from failure to adequately treat otherwise functioning cancer victims; the loss to the community from loss of its leaders; and above all the heavy emotional and economic cost to families from the loss of their loved ones.

We hasten to add that the entire western world is wrestling with the issue of cancer drug costs; however, somehow almost all other jurisdictions have come to very different conclusions compared to the CDR and have released many more drugs for general public use. On page 34 of our 2004 report card we give a detailed, broadly based, and comprehensive suggestion about how to approach this critical aspect.

We therefore strongly urge that the JODR embrace much more broadly based economic models when deciding whether or not a drug is cost-effective.

That immediately raises the next area of concern—the lack of representation by cancer patients. Individuals must participate to give strong voice to the millions of past, present, and future cancer victims in Canada. I have to remind the committee that for everyone in this room, the risk of developing cancer is now over 40%. Surely, patients are the stakeholders whose voice must be strongly heard.

My own experience with committees in 35 years of academic medicine and health care administration has taught me at least this: when well-informed patients are present, the tone, the content, the direction of discussion, and the final conclusions are very different from when patients are absent. We see this deficit in the CDR is now being redressed, but it still promises to be a major deficit in the JODR.

We therefore ask that you insist that well-informed and effective cancer patient representation be on the oncology subcommittee of JODR.

There arises the issue now of the type of evidence that guides the deliberations of both CDR and JODR. We strongly support the need for results from properly conducted studies. Randomized trials have been the driving force behind continued progress in cancer treatment. In fact, one of our own board members, Dr. Tony Miller, established the National Cancer Institute of Canada's Clinical Trials Group over three decades ago, and this group has since achieved international recognition.

However, you should be aware that in the case of adult cancers, randomized trials are conducted on a sample of only 3% of the patients, and the results are extrapolated to the remaining 97%. The effectiveness of the drug on the general population could be quite different from that predicted by the randomized trial results.

We therefore ask that community-based follow-up studies be routinely conducted after approval by a JODR to determine whether the results are those predicted from pre-approval studies.

We would like to raise one final issue. The CACC has investigated and published the fact that across Canada there are marked differences in the guidelines advising doctors in cancer treatment, even though the guidelines were developed by oncology experts analyzing ostensibly the same medical database.

There's a pressing need for national uniformity and guidelines for cancer treatment and for monitoring whether they're being adhered to and whether they are having an impact. The province with the most comprehensive approach to this aspect is British Columbia, which incidentally also has the best treatment outcomes and the lowest cancer mortality. Cancer mortality is dropping in British Columbia like in no other province in Canada. The rest of Canada would do well to follow B.C.'s lead.

● (1550)

Cancer treatment guidelines could be developed at the national level through the newly created Canadian Partnership Against Cancer, but it will require your attention and encouragement to ensure that the partnership proceeds strongly in this direction.

As it stands now, without such national guidelines, even when JODR approves a drug, the provinces don't have to pay for it based on their own biases. In such cases, as far as the cancer patients in that province are concerned, the JODR may as well not exist.

Thank you.

The Chair: Thank you very much for your contribution to the committee's deliberations here.

We'll now move on to Dr. Jennifer Knox, oncologist, University Health Network, Princess Margaret Hospital.

Thank you.

Dr. Jennifer Knox (Oncologist, University Health Network, Princess Margaret Hospital): Thank you very much, Mr. Chairman and members of the Standing Committee on Health, for letting me come today and talk about my concerns about drug funding. In particular, I'm going to talk about kidney cancer treatments and how recent CDR decisions are really going to get in the way of our Canadian patients being treated with what is now a global standard of care and how these decisions also impact on us as physicians, our primary obligation to provide care and benefit to our patients.

I'm a medical oncologist at Princess Margaret Hospital. I'm also a kidney cancer researcher and specialist, and I'm someone to whom many oncologists refer their patients for opinions, and I do a lot of research. But I can tell you today that I'm not speaking just for myself; I'm speaking for at least 30 kidney cancer specialists across the country who I met with on the weekend and who have signed a statement, which—I apologize for not having it translated—I'll get to you later. These are key thought leaders and kidney cancer specialists who really share my concern. For example, Dr. Martin Gleave, who's head of CUOG, the Canadian Urologic Oncology Group; Dr. Simon Tanguay, who works as a researcher in Montreal and McGill; Dr. Peter Venner, who runs the Cross Cancer Institute in Edmonton, and many others.

Basically, kidney cancer is not one of the big four. It's not breast or lung or colon or prostate cancer, so it doesn't get quite as much attention. It's also been a very difficult cancer to look after for many years because, essentially, nothing worked. It was a terrible disease.

If you have metastatic kidney cancer, which is essentially what most people who present end up having, your average survival is about a year. We did many clinical trials for years, and essentially chemotherapy, radiation, nothing really works. And along came this revolutionary new idea, this antiangiogenesis, which you probably heard about, which really means we've got these therapies now where we can't get at the cancer, but we can prevent the cancer from attracting blood vessels that feed it. It doesn't get rid of the cancer, but it stops it from spreading and metastasizing, which is essentially what kills the cancer.

This was science fiction 10 years ago and now we have real agents. Someone is going to get a Nobel Prize for this. Thankfully, some of the drugs that have come along first in their class, that are what we call these antiangiogenesis inhibitors, actually are pretty much home runs in kidney cancer.

The first drug that came along with evidence of survival was Nexavar, and then soon after that came the drug Sutent. Both of these drugs have recently been reviewed by CDR, and they advised that they not be funded in provinces, based on their understanding of the data and their cost-effectiveness analysis, which I think is very flawed.

I need to talk a little about how clinical trials are done. We strive hard to meet ethical standards, so it has to be reviewed through an ethics board, and patients give informed consent. Then usually, in the cases I'm talking about, the new treatment is compared to a standard of care. So the control arm is what would be your best and then the new drug.

In the case of the first example, Nexavar, what happened was kidney cancer patients who had already tried something and were progressing and in trouble were randomized to this trial. It was blinded, and they either got the Nexavar pill or a placebo. Then toward the end of the accrual of the patients, there's something called a data safety monitoring committee, which is independent, and this was also in dialogue with the FDA in the U.S.

One of the end points we look at is called progression-free survival, and you get information about this before you get information on overall survival. Progression-free survival says how long has this patient lived before their tumour has grown in a significant way, and that in itself is an important end point.

● (1555)

Basically the curves were so different at that point that we were advised to un-blind our patients. I hate to say this so bluntly, but anybody who was still alive on placebo could then have a chance to cross over and get the drug. Something like this doesn't happen very often in medical oncology. I remember when we got the message; the excitement was amazing.

I want to tell you about one of my patients, because it helps. Statistics don't tell the stories very well. I had this 46-year-old man with advanced kidney cancer. He was on the trial, but it turned out he was on the placebo and he was dying. We were setting up his hospice care. He came in to see me, which was probably going to be for the last time, and it just happened that the crossover logistics had worked out so that his wife had been delivered the bottle of the Nexavar pills that day—such irony. She asked, “What should I do?” I said, “Well, if he's well enough to swallow, what's the harm? Try to take it.”

He swallowed these pills and slowly started to get better. He came back to see me at about the eight-week mark, and I said, “You know, you're really looking better.” He said, “My pain is better and I'm feeling more hungry.”

We took a CAT scan, and lo and behold, he had a response, and it was shrinking. He went on probably to have another year, probably 10 months, under complete control by that drug, but then he progressed and died.

If you look at the clinical trial data, he's on the control arm and he's counted as control arm. You can actually see the point in time at which this crossover happened. The curves, which were further apart—so the difference was greater—start to come together. None of us would ever argue that that was the wrong thing to do; that was the ethical thing to do, and the whole world has embraced this as a positive trial.

When the CDR reviewed this data, they basically said we don't like this progression-free survival end point, and because the survival is not so great now, despite this crossover, we just don't have confidence that the drug is that different.

There's all kinds of different statistical analysis you can try to do to get the truth of what the true difference would have been, but there's nobody who treats kidney cancer, no expert in the world, who doesn't believe that drug had a meaningful impact on the survival of those patients. It's just that it's awfully hard to put a number on it. Then when you calculate cost-effectiveness and take the smallest number you can possibly get in terms of the benefit and put a big price tag on it, of course it doesn't look like it's that beneficial.

I have lots of other stories, but I want to mention that I came today for moral support with one of my patients, Mr. Clark, who had metastatic kidney cancer for three years. He knows the average survival is one year. He is looking very well. He got that drug through the mechanism of the clinical trial, and he wouldn't be here today, alive, if he hadn't gotten that drug. So the statistics don't tell all the stories.

The next drug that came along was Sutent. It has a similar mechanism of action, but we don't really know what the differences are between these drugs. It was tested in a slightly different patient population, patients who had never been treated before. Once again there was a remarkable separating of the curves, so much so that it went forward for licensing very quickly. The survival data had not matured yet. Then, of course, patients cross over; they move on to other therapies, and the survival curves come together.

Those are the two drugs that have been recently reviewed. In oncology circles, the way we think about these drugs is that they are home runs. We're not curing these patients with advanced disease, but this is the biggest thing that's happened in 30 years, and it has the potential to really build momentum to understand more and to make further progress.

One of my big concerns is not only with the CDR recommending they not be funded and provinces then following that. It's that, first of all, the patients are not going to get what the world considers to be a standard of care. Our patients are no longer getting good therapy. The second issue is that as investigators, how do we go forward—especially as Canadian investigators—in trying to ask the next questions? How do I build on that? All the next trials are going to be about what you do next.

● (1600)

Our patients won't be eligible for those trials because they didn't get the first line. Some patients are getting it paid through private insurance, but most Canadians don't have that kind of insurance, so many are not getting coverage. It's a very difficult thing as an oncologist to speak with your patient and say, not only do you have a bad disease, which is terminal, but we actually know about some new therapies that could prolong your life, but we're not going to be able to give them to you here in Canada. I'm going to fight for you, but I don't know how it's going to work out.

I'll end just by saying we're very unusual here in Canada in not embracing these drugs for funding very quickly. As far as I know, Nexavar, which is the first one that came along, is being reimbursed in Austria, France, Germany, Greece, Ireland, Italy, the Netherlands, Sweden, Spain, Switzerland, the United Kingdom, and the U.S.

I've always been so proud of our Canadian system and our health care system, and we've been real leaders in the world in clinical research, but if we allow this sort of thing to continue, we're really going to fall off very quickly, and our patients will be really woefully under-cared for.

I'll stop there.

The Chair: Thank you very much for that information.

We'll now move on to the Canadian Breast Cancer Network, and we have Diana Ermel, president, and Jackie Manthorne, executive director.

I don't know who will....

Ms. Diana Ermel (President, Canadian Breast Cancer Network): Thank you so much for having us here today. We appreciate it.

We have handed out a little blue folder with my notes. Sometimes I go off my notes, so you might want to be looking at them to follow along.

I really am privileged to be here.

The Canadian Breast Cancer Network is a network of survivors who represent all issues around breast cancer in Canada. We're made up of groups and individuals concerned about breast cancer, and we represent their concerns. We have 225 partner and member groups across Canada, and our board is composed of individuals who have been diagnosed with breast cancer. We know we are one of the top four, but we also know our issues apply to everybody diagnosed with cancer.

Right now, according to the Canadian Cancer Society's 2007 statistics, there are 162,600 people living in Canada who have been diagnosed with breast cancer in the last 15 years. That is a low number, because I know people who have been diagnosed more than 20 years ago. Over 22,000 women will be diagnosed with breast cancer this year and 5,000 women will die of breast cancer this year. It's the leading cause of cancer deaths in young women aged 20 to 49. It's second to lung cancer in older women, and once we get to be 70, it's the third leading cause of death. We're superseded by lung and colorectal cancer. We just want to live to be 70.

Our responses to your questions are really from the patient perspective. They're based on three values: equality, accountability, and inclusiveness. When we talk about equality, as I've said in my notes, we want timely and equal access to the best medications for all Canadians diagnosed with cancer. When we're talking about timely access, we mean that once a medication has been approved in Canada, a patient shouldn't have to be waiting and waiting to receive it, to have it funded. Equal access means that across Canada there cannot be differences. It should not depend on where we live in Canada or our social economic status whether or not we have access to medications. We want access to the best treatment, not just something that happens to be out there that maybe isn't as good as something else.

Accountability is about this whole decision-making process in terms of how drugs get funded, how they get put on the provincial formulary. It has to be just, it has to be fair, and it has to be transparent. We don't see it being any of those at this point in time. The accountability is in relation to not only the people on committees reviewing the drugs, but also to the provinces that follow up on those recommendations.

Inclusiveness, as other speakers have said, is about meaningful consultation and engagement of all stakeholders, including informed patients and health care providers such as oncologists and pharmacists, in the decision-making process. This has to be meaningful; it has to be real. We have to recognize that the decisions that are made about whether or not cancer drugs are funded most directly affect patients and their oncologists, and Dr. Knox spoke to that quite eloquently. When we're diagnosed with cancer we are in a partnership with our physicians. It is horrible to hear stories about frustrated people who can't have access to treatment and their physicians who can't help them.

In terms of your questions about the CDR and what we understand about it, we don't believe it has improved access to approved medications. There remains an unacceptable time lag from the time a drug is approved until it shows up on a provincial formulary. There is some transparency in that decision-making, but the actual criteria upon which decisions are based are not apparent to the average Canadian. Provincial reviews continue to follow the national reviews. That is obviously, in our minds, a duplication of effort and it delays decision.

There's absolutely no obligation on the part of provinces to follow through on recommendations from the CDR. We know they pretty much follow through on recommendations not to list a drug, but they definitely don't always follow through on listing one.

● (1605)

This whole process seems to be driven by economic considerations instead of health considerations. Fewer than half of the reviewed drugs were recommended, and also, we know this process isn't tailored to the new drugs, the targeted agents and the biologics.

Despite some improvements in terms of transparency and including patients, we know there are a growing number of Canadians, depending on where they live, who have to make a choice between quality of life, more years of life, or depletion of their financial resources and leaving their families bankrupt.

It's a terrible, terrible decision to make: “Shall we spend all our money to keep me alive for another 10 months, or shall I go quietly?” We don't want to go quietly. It's unacceptable in Canada that this is happening, and it is absolutely devastating that this disparity is increasing.

In terms of cancer medications and treatment for cancer, we have seen how this disparity is played out across the provinces. Bill Hryniuk's group has done a lot of work on that, and they have shown us the differences in what drugs are covered.

The idea of having one national strategy to look at oncology drugs seems to be a really wise one on the surface. The concept has potential and opportunity to eliminate regional disparity and to make sure that all patients receive the drugs they need.

Look at it. It will include all cancer medications now, not just the oral medications. It will include medications that patients take home, and it will include the intravenous medications. It will be a rigorous review, best use of expertise, no duplication of effort, decisions will be made based on evidence, it will shorten the wait time for funding, provinces will be collaborating, and it may actually improve the mechanism for pricing and negotiations with industry. So it sounds wonderful.

But when I look at my Saskatchewan government's press release about the JODR, my Minister of Health, Len Taylor, who is a wonderful man, says, in two quotes from him, that in Canada we require “a consistent”—yes, we do need something that's consistent —“rigorous review of the clinical effectiveness and cost-effectiveness” of new cancer drugs. That's fine, but what does that mean, and how does that translate? And who looks at that information, and what decisions do they make? If they make the best decisions for the citizens of Canada...oh, oh, the next quote says, “final coverage decisions will remain the responsibility of each jurisdiction”. So we do not see how there is going to be anything better than the bad stories we've heard about the CDR. The JODR will not achieve its potential if it's just merely a more complex iteration of the CDR process.

We at the Canadian Breast Cancer Network are very concerned that this process is going forward and may be entrenched in our decision-making for how drugs are funded in Canada. We don't have a lot of issues right now, as people with kidney cancers do, but we know there are going to be more and more new targeted, biologic, first-in-class medications coming out that will actually save our lives, and from what we can see, people with breast cancer will be denied access to them, or if they are allowed access, they will have to pay dearly for that access.

So our concern about the JODR is that the model on which the interim review process is based will not result in decisions that maximize the health of Canadians with cancer. We have read and heard from many sources, but the process doesn't value the recommendations of expert oncologists at this point in time.

Cost-effective analyses do not provide information that decision-makers need to make funding decisions that will maximize health gains from available resources. They just don't. That is not what is needed. It's too simple. There are many other factors that need to go into making these decisions.

It won't ensure access to needed medications for Canadians diagnosed with cancer, and it will just result in increased suffering and untimely deaths for some Canadians.

We are concerned so much that this is yet another cost-containment initiative, that that is the priority. They talk about a commitment to a consistent standard of care, but that does not translate into a commitment to a quality standard of care.

The cost of having cancer right now is horrendous, and on top of that, if you have to pay $35,000 for your course of treatment, it's completely unacceptable.

CBCN did a national survey back in 2004, looking at the financial costs of having breast cancer. In the package we handed out there's a little green booklet telling you about those results. On page 10, it says that 66% of respondents reported they had to pay for their drugs in some way or another. And these respondents are not the marginalized people in society. They're not the people who are poor and don't know how to go from one day to the next. So that's a huge number.

● (1610)

We don't understand, other than from a dollar-driven agenda, why the other provinces have agreed to follow a process that results in less access than their citizens now enjoy. The Ontario model has resulted in funding for very few drugs, as compared to other provinces. We don't understand why the model being adopted is not that of the province with the best record of providing access to drugs. The B.C. model funds the most drugs for patients. We are very concerned that patients are considered last, if at all.

Decisions are going to be made about the lives and quality of life of Canadians without any understanding of the perspective they have on these decisions or their involvement in making these decisions. Patients and families must be considered, and their physicians' opinions must be considered too.

Treatment options will be determined by where people live in Canada, not by evidence. Patients will be denied access to quality drugs. Patients who can afford drugs to continue living will access those drugs; patients who cannot afford such a luxury will die.

We don't know what the answer is to this problem. We know that it is not acceptable in Canada to have this going on. Patients must come first. Whatever system is in place for making these decisions, it must be one in which quality of life is prolonged and lives are saved. Equal access to cancer drugs requires federal funding to ensure equality, and it also requires a systemic change in thinking about the value of extending and saving human lives. All stakeholders must work together to ensure no Canadian receives less than the best possible care.

We want to see a transparent and just system where patients can move seamlessly from a clinical trial to ongoing access to needed medications, where patients are not denied access to needed drugs, and where no Canadian must choose between hope or bankruptcy or dying.

Thank you.

● (1615)

The Chair: Thank you very much.

We'll now move on to the Colorectal Cancer Association of Canada and Dr. Barry D. Stein, president.

Mr. Barry Stein (President, Colorectal Cancer Association of Canada): It's Barry. So I'm not a doctor; I'm a lawyer, actually, but close enough.

For those of you who don't know me, my name is Barry Stein. I'm the president of the Colorectal Cancer Association of Canada. For those of you who don't know me, you should be coming to our parliamentary colorectal cancer breakfast. Many of you have, so you should tell them how good the food is, actually. It's well worthwhile coming.

One thing about going last is that you're fed with the luxury of hearing all the other witnesses. I know you want to hear individual testimony. However, I find myself being in full agreement with the witnesses today, and in particular the very heartfelt and true and accurate story told by Dr. Knox. I didn't know that she was going to be testifying certainly on this story today, but I have to tell you that as it applies to renal cancer, it applies to colorectal cancer, and it will apply to all cancers. I can corroborate that in legal terms. That is a very true and accurate story that was represented.

The Colorectal Cancer Association of Canada is a national not-for-profit association dedicated to awareness and education of colorectal cancer. We deal with support of patients and their families, and we promote effective screening across the country, as well as timely access to effective treatment. Of course, it's the latter of those issues that I will deal with today.

In Canada, so that you understand the numbers...and if you haven't come to the parliamentary breakfast, you'll get your lesson now. I won't ask you if you've been scoped until the end, but we do that at our parliamentary breakfast. In 2007 an estimated 20,800 Canadians will be diagnosed with colorectal cancer, and unfortunately, 8,700 Canadians will die from it. It affects men and women almost equally. Overall, colorectal cancer is the second leading cause of cancer death in Canada. However, it is also highly preventable, treatable, and beatable, if caught early. And if we are to properly treat and effectively beat colorectal cancer, we urgently need access to the effective medications within the treatment guidelines.

This past March, the Colorectal Cancer Association of Canada organized a round table conference in Montreal on screening, as well as access to treatment, where about 150 individuals were in attendance. Some of the co-witnesses here were also in attendance at that round table, and I've marked in our notes the very broad spectrum of people—from government, cancer agencies, oncologists, and so forth, to patient organizations—who were present. These individuals, who came from across the country, came to express their views on access to cancer treatment, with a particular emphasis on colorectal cancer medications.

The broad base of participants at the round table, as well as our constituency of patients from across the country, has enabled me today to provide you with these comments.

Although the CDR, the common drug review, was set up with the intention of reducing duplication and providing equal access to expert advice for the Canadian public drug plans, the perception of patients is that there is a greater emphasis on cost containment rather than on ensuring patient access to important medications. This represents a difficult conflict for patients, who require timely and easy access to effective medications when they are in the most vulnerable of positions. Consequently, the CCAC believes that the accent on approval for cancer medications must be shifted from cost containment to providing patients with better access to effective treatments.

With the introduction of the joint oncology drug review, we have observed that there is a feeling of mistrust developing, largely generated by the seemingly non-transparent manner in the way it was set up. It was virtually sprung upon most of the population, and nobody actually heard about it...well, not everybody. I suppose some people heard about it, but the general population did not hear about it until it was a fait accompli.

There is an opportunity for the JODR to do it right, but we must be sure to capitalize on the lessons learned with the CDR. While we welcome the idea of a review group for oncology products, we're also concerned that this program will be another cost-containment process and this time aimed directly at cancer patients. That, of course, is not acceptable.

If the object is to bring equality to the approval of cancer drugs across the country, it must not be done at the expense of providing fewer medications to all patients. We should be looking to improve patient access to these new technologies that provide hope where none existed before.

● (1620)

Canadian cancer patients expect that they will receive the most effective medications, and in a timely manner, not simply based on the cost of these medications, but on the ability of these medications to extend their lives, improve the quality of their lives, and to produce better outcomes.

With respect to wait times, the Colorectal Cancer Association believes that a faster review process—not a less safe process, but a faster process—would result in fewer lives being lost to treatable diseases.

From the international perspective, we feel that the need to duplicate reviews already done in other countries is unnecessary and that an international joint review process would be more efficient. We feel there should be a harmonization of approval processes with other jurisdictions such as Europe and the United States. We could avoid delays and duplication by doing so.

In addition, we feel that all Canadians would benefit from having a unified drug approval process within Canada. That includes simultaneous approval of the processes of Health Canada and the provinces, to eliminate the consecutive wait times between Health Canada, whether it's the CDR or JODR, and the eventual provincial determination for eligibility for reimbursement. These delays, resulting from the different stages of approval, represent unnecessary roadblocks in the timeline of the treatment of cancer patients—needless to say, I reflect colorectal cancer patients today—where every day counts.

On a personal note, having had metastatic colorectal cancer since 1995, both to liver and to lungs, and having had to seek out-of-country health care to fight my disease at the same time as fighting in the Quebec courts for reimbursement, I know what it means to wait for treatment. I can tell you, it's no fun.

We believe we are at a crossroads in patient access to effective treatment in Canada. As newer biologics and small molecules and other expensive cancer treatments are used in the battle against cancer, provinces are struggling to determine whether they should cover these costs—whether or not they form part of the prescribed treatment guidelines.

At present the reality is that while patients in some provinces are already fortunate enough to have access to some of these new treatments, patients in other Canadian regions are forced to either pay the high costs of these medications—and you've heard some of those costs today, $35,000 and so forth—or they forego the treatment altogether. That, of course, is not acceptable.

We are saddened when we see patients across the country who are not receiving the optimal treatment for colorectal cancer in accordance with treatment guidelines because our governments are not reimbursing cancer treatments such as Avastin. As well, it is virtually impossible to get insurance in order to cover these types of medications. Just so we're in the same ballpark, when I refer to Avastin or bevacizumab, I'm talking about the same class of new antiangiogenics or tyrosine kinase inhibitors that Dr. Knox was talking about with Sutent.

We are just as saddened when we see the pharmaceutical companies that are not even launching effective treatments due to an inability to reach a price agreement with the Patented Medicine Prices Review Board, PMPRB. That was the exact case with Erbitux, and some of you may know it as the Martha Stewart drug. This drug was not launched in Canada because no price agreement could be reached.

Access to effective treatment should not be a matter of patients' financial resources. If the public purse cannot afford to provide treatment with existing resources, then alternate mechanisms must be found to ensure that Canadians are equally provided with the best possible treatments in a timely manner. However, access should not be equality at the lowest level. Canada must strive to achieve equal and timely access to effective treatments with the bar set as high as possible.

While patients may be prepared to accept the idea of setting limits on public funding of cancer medications, we feel that present limits are not acceptable and that it is not satisfactory to base approval purely on the costs of these medications. Broader social values must be incorporated.

Admittedly, it is difficult to find a consensus on setting limits to funding cancer drugs. However, the CCAC believes that any decision of funding must be evidence-based and benchmarked to other jurisdictions. It should be fair, transparent, and rational, and the review process must be simplified.

It is interesting to note that several participants at our round table conference felt that limits should not be set on cancer drugs, as they form a very small portion of the overall drug budget. As well, it was pointed out to me that in about two years, several of the major drugs that occupy a large part of the entire drug budget will soon come off patent, thereby adding the capacity to cover these new and expensive medications. In case you don't know what I'm referring to, some of the anti-cholesterol drugs and so forth that occupy about $1 billion of our drug money will be coming off patent, and we'll have an extra $500 million. You'll be able to say what a good job we all did because we have all this new money in cost containment. But the truth of the matter is, it won't necessarily have been from cost containment; it'll be from these drugs coming off patent.

● (1625)

Several groups at the round table conference also felt we had to get beyond the silo mentality of funding cancer drugs. The cost savings from other programs, such as prevention programs, etc., would make more money available for cancer drugs.

While opinions may vary on how limits for cancer drug funding should be set, as you've heard today, it was unanimous at our round table that there was an essential requirement for openness, fairness, transparency, and, perhaps most of all, accountability, as well as a greater public engagement at every level of the approval process, including the set-up of the process itself.

Patients cannot accept the refusal of the funding of medication if they do not understand the reasons for the refusal. This was one of the greatest criticisms of the CDR, and we hope this problem will not occur with the JODR.

If limits are set and certain medications are not to be covered, then patients must be provided with alternate mechanisms of funding for these medications. Failure to do so will mean Canadians will have to leave the country, as I did, to obtain standards of care for the treatment of colorectal cancer or other cancers in general.

There is an openness in Canada to discuss new and novel ways of funding to ensure that Canadian patients are not deprived of live-saving or life-prolonging medications. The round table produced some interesting and sometimes novel suggestions. For example, there could be shared costs of treatments for a period of time between pharmaceutical companies and provinces, whereby pharmaceutical companies would pay two cycles of treatment and, if the benefits were conclusive, the hospital or province would carry on with the rest of the payments.

Private insurance plans are seen as a major way in which access to medications could be increased. There is a growing consensus in this regard. For example, we could develop an expanded program based on what we have in Quebec. Employees are covered by private group plans, and when they don't have this coverage, the state then takes over.

Another possibility would be the setting up of a special federal cancer drug fund to assist provinces in the cost of these new and expensive technologies. This would encourage equality of access to all cancer medications across the country.

In conclusion, the common drug review or similar processes, such as the JODR, can only succeed in benefiting Canadians if they are committed to saving lives, improving the quality of patients' lives, and prolonging lives, rather than the emphasis being on cost containment.

Thank you.

● (1630)

The Chair: Thank you very much to all the witnesses.

We'll now move to the question and answer part of our meeting.

We'll start with Ms. Kadis. The floor is yours.

Mrs. Susan Kadis (Thornhill, Lib.): Thank you, Mr. Chair.

Thank you for your presentations today.

To your knowledge, has it always been that cost containment was the driving force in terms of what was covered and what was not covered previous to the JODR or CDR? Is this a new element?

Mr. Barry Stein: Is that question to me?

Mrs. Susan Kadis: It could be, yes.

Mr. Barry Stein: My understanding is that was actually the point of having a CDR. Of course, while we wanted expert advice and the best advice to be distributed through a panel such as that, as far as I understood it, the emphasis was on advising the drug plans when to make these financial decisions. In other words, it's cost containment.

Mrs. Susan Kadis: But is this a new element? Has it become more emphasized within the CDR and potentially the JODR?

Mr. Barry Stein: I think it started with the CDR. Well, it actually started in each individual province, with their individual plans. The provinces then got together and created the CDR.

Mrs. Susan Kadis: I'm particularly concerned here, listening today.

I think there was a reference by Dr. Knox. In comparison with other countries internationally, I think you laid it out pretty well in terms of new therapies, which are really a new frontier. We listened to Dr. Susan Love several years ago. It's really coming to the forefront that people will increasingly live with cancer as opposed to dying from cancer. I think it's what you were getting at.

My concern is that Canada will not be a leader in this area. I'm hearing here that it's not the direction we're going in.

Mr. Barry Stein: One of the things I have to point out is that we are entering into a new era in the treatment of cancer with targeted therapies. Of course, there's a very expensive price tag that goes along with that. If we want to have access to these drugs, we have to find ways of funding them. Needless to say, in situations where pharmaceutical companies are not able to manage a proper return on their money, they don't even launch them, and that's what's happened in one case, at least.

To make a long story short, I think what's happening right now is we're entering into a new era, and we're faced with these high costs. For example, when I was first diagnosed with colorectal cancer the treatment was 5-Fluorouracil, and they were deciding whether to add a couple of components—Levamisole or Leucovorin. We were talking $500 a patient to start off with. Now we could be talking $150,000 patient for the full course of treatment. That's probably what started the ball rolling, but at the end of the day, that doesn't mean we should deprive Canadians of this newest technology, which actually is making a difference.

I'll point out that one of the slides that Dr. Jean Maroun has raised at our parliamentary breakfast on numerous occasions is childhood leukemia. If we don't continue to make these advances and progress along the way, we'll never get the cure.

Mrs. Susan Kadis: Dr. Knox, can you comment on the issue of how we are comparatively throughout the world in terms of these new therapies?

Dr. Jennifer Knox: I think the point was made that up until very recently, as I said, we were doing very well. It's really just in the last couple of years...and the first really significant drug would be Avastin, which came along and prolonged life in colon cancer. It came at a big price tag, and that was the first decision that surprised us all a bit, that these weren't going to be covered. Four years ago we were doing just fine, relatively speaking, but in the last few years we've really been sliding off the curve.

I made this impassioned plea for kidney cancer basically because not only are these very good drugs, but they're the first. They're not "me too" drugs. They're not just adding a little something to what we already have for kidney cancer. We're going from nothing to these ones. I think we were all caught a little off guard that this was not found to be adequately cost-effective.

I know we're talking about a big picture here in terms of trying to find a way to sort out how we can afford these things and move forward as a first world country, but I think we also have to go back and fix these two recent problems. I would really hope that something could be done to get the provinces to fund those right now.

Sorry, I'm not answering your question, but yes, we are starting to be at real risk of not maintaining a first world standard of care in oncology—we really are.

● (1635)

Mrs. Susan Kadis: I think you did answer my question or my concern.

Another problem with the CDR that we were made aware of in previous testimony was that rare diseases were getting the short end of the stick in the drug review process, with the vast majority often not passing through the CDR, which caters to more widely used drugs. In terms of drugs that are used for rare forms of cancer per se, how has the JODR been dealing with those?

We've heard a bit about that today, but I'm particularly interested in this area of rare diseases.

Dr. William Hryniuk: I think I can answer that partially. We did an analysis this year of the number of cancer drugs made available to the patients of Ontario versus cancer drugs available to patients of other provinces. Ontario has the worst record of placing injunctions or restrictions or deletions or exceptions to access to these drugs. That's the same committee that's going to be the JODR. Our concern is that it will duplicate that for the country, and I think that's what you're hearing.

Mrs. Susan Kadis: I'm not hearing a lot of confidence here regarding the CDR, and I hear your overriding concern that the same will potentially occur with representatives in the JODR. I hear that you think it's a good concept that they are emphasizing the area of cancer, and there is a great need for that—with 150 cancers, the potential is great. But I'm not hearing a great deal of confidence.

Dr. William Hryniuk: That's correct. We have very little confidence that it's going to work. But we want something to work, and we have these suggestions for improvements.

I think the other part of it is there has to be some kind of federal-provincial initiative on a combined basis to deal with the cost of the drugs and introduce strategies that will make sure the drugs get to the right people. Just because the drug works in 5% or 10% or 15% in dramatic fashion, that doesn't mean you have to treat all 100 patients. You should be working on identifying those 5%, 10%, 15%, or 20%. There are ways to do this, but those efforts are not very strong.

Mr. Barry Stein: One of the things that isn't taken into account when the drug is approved is that at least 50% of the patients don't continue a full course of treatment. When they look at the cost analysis, they're basing it on a full course of treatment. Maybe they do two or three and it doesn't work, or maybe after two or three the patient doesn't survive. These financial considerations are not really looked into.

As well, they also look at a median survival as opposed to progression of disease as one end point, of course, but they're usually looking at the survival. I could tell you that in my own case, had I not gone with the new and novel therapies along the way, I never would have had the opportunity for the next thing that came down the pipeline.

Mrs. Susan Kadis: Thank you very much, Mr. Chair.

The Chair: Thank you very much.

We'll move on now to Madam Gagnon.

[*Translation*]

Ms. Christiane Gagnon: Good day and thank you for your presentations.

We heard that there are 150 different types of cancer. How many cancer-fighting drugs would have to be reviewed under the new JODR initiative in order for you to be satisfied? Some of you have doubts about whether this new approach will be effective, because not enough new drugs are being approved. Is the problem a lack of resources, reviews or experts?

Quebec carries out its own drug review. I can't say if its resources are comparable, but we are here to try and sort this all out and to ascertain if the JODR approach is indeed effective.

Can you tell us how many drugs you would like to see reviewed? In your opinion, will this new process be adequately funded? Will there be sufficient resources, in terms of reviewers and experts, to get the job done?

Mr. Barry Stein: Are your questions directed to anyone in particular?

Ms. Christiane Gagnon: They are directed to anyone who may wish to respond. I believe some of you broached these issues. If the Chair has no objections, several of you can wade it with a response.

[*English*]

The Chair: Go ahead.

Dr. William Hryniuk: Madam, I think the issue is not in our control. The drug companies decide which drugs have been proven to be effective in other jurisdictions. They bring them to Health Canada. Health Canada determines whether the drug is safe and effective and passes it on to other organizations, including CDR, and now JODR. So it's not a question of how many drugs we can handle. They come to us without our control. The issues here are the transparency, the expertise, the representation by the patients, the bases on which decisions are made. They're very narrowly defined bases, which have to change, and you have to take into account many more aspects of human living than just the cost of one year of life. I think we would all agree with that.

Some drugs, for example, are so powerful that they can make money for the economy if they're processed properly. They are so powerful and they cure patients so quickly that patients return to normal life, pay taxes, and contribute to the GDP. Those drugs, in fact, examples of which we've given in the past, have been stymied through this review process. So it's not a question of how many drugs we can handle. It's the process from CDR that we think is flawed, and those flaws will be translated into the new JODR. We have no confidence that they won't be, unless you intercede.

● (1640)

[*Translation*]

Mr. Barry Stein: It's not the system itself that gives us cause for concern. Of course Ontario has some very good oncologists. The problem is more that patients do not have access to new technologies because of the costs of some new drugs. Earlier, for instance, someone mentioned Avastin, or bevacizumab. This drug is used to treat colorectal cancer and down the road, it could be used to treat lung and breast cancers.

However, this drug costs approximately $35,000. Accordingly, when the drug was reviewed, it was noted that the survival time in this case was approximately 4.6 months. The cost of the drug is weighed against the survival time. You have heard testimony to the effect that giving a patient an additional 4.6 months does not justify the $35,000 cost of the drug.

Personally, I underwent surgery and received treatment in the United States. However, if I hadn't had access to this first category of drugs, I wouldn't have been able to receive the follow-up treatment. Treatment is what it is. However, some people survive much longer. In my case, I was given a 30% chance of surviving in 1995, and that was almost 12 years ago.

[*English*]

The Chair: Thank you very much.

I see no others.

Mr. Fletcher, you have five minutes.

[*Translation*]

Ms. Christiane Gagnon: Mr. Chairman, are my five minutes up?

[*English*]

The Chair: Yes. It was five minutes and twenty-seven seconds, actually.

Ms. Christiane Gagnon: Thank you for the twenty-seven seconds.

Mr. Steven Fletcher (Charleswood—St. James—Assiniboia, CPC): Thank you, Mr. Chair, and I'd like to thank all the witnesses for coming today.

As some of you may know, the Canadian Partnership Against Cancer is something this government has been very involved with. As health critic, I was humbled to have the opportunity to work with many of your organizations to bring that on to the agenda. I was further humbled to have had the opportunity to help the Minister of Health and the Prime Minister push that through.

Having said that, it's obviously an issue that is very close to I think everyone's hearts here, particularly in light of Dr. Knox's very personal and touching story, which is repeated millions of times throughout the world.

I have a couple of questions. First, how are you finding the interaction between the Canadian Partnership Against Cancer and the JODR? Is there a relationship there? And how is it between the JODR and the CDR? How are the three intermeshing, if there is any intermeshing? One of the points of the Canadian strategy against cancer, now the Canadian Partnership Against Cancer, is to ensure that there are best practices, and obviously drug therapy is part of that. So that's one question.

Second, in your opinion, how could the JODR process be merged with the common drug review process? And what changes, if any, would be required for the common drug review process to be merged? Or, if we accept your logic that the CDR is unable to deal with cancer and has to be taken out so that JODR can be dealt with, or that JODR is necessary to deal with the shortcomings of CDR, what confidence can this committee or Canadians have in the CDR dealing with the thousands of other diseases out there that are supposed to be covered by the CDR process?

So is CDR so far gone that it's impossible to fix, or is there a way of fixing it so they can deal with cancer and the thousands of other diseases out there?

So in twenty words or less....

● (1645)

The Chair: Go ahead, Debbie.

Ms. Debbie Milliken: I'll answer the first question on the relationship between the Canadian Partnership Against Cancer and the JODR. It's the intent of the JODR process in phase three, which started some time in the summer, to start to look for synergies and linkages with national initiatives such as the Canadian Partnership Against Cancer. We're looking at potentially doing that through the clinical guidelines action group, which might be a mechanism to bring together national panels of experts, for example. There are other national initiatives under way, such as the National Cancer Institute of Canada economic working group, which we also might want to tap into in terms of national initiatives.

On the relationship with the JODR and the CDR, there is a linkage in terms of the governance. The CDR participates in the steering committee as an observer, so they're linked in that manner as well. Although the CPAC committee will not be deliberating during the interim one-year process, we will have the benefit of having some of the reviews that come out of the CDR for drugs that are within the scope of CDR, or normally would have been within the scope of the CDR.

Mr. Barry Stein: I have to thank Mr. Fletcher for all his efforts in the past. He really has made a difference. I actually say that about both sides of the bench—we dealt with Carolyn Bennett as well.

To answer your question more specifically, when we called the round table conference in Montreal this past March we specifically reached out to the JODR chairmen, because one of the chairs on the access side was the chair of the clinical practice guidelines of CPAC. So we thought we would take the initiative, take the bull by the horns, and try to see if we could actually create some sort of discussion between the individuals, more so than the bodies per se.

When I talked to you before about it being off to a bad start because the patients should have been involved in the initial setting up of the program, I think that would have made a difference. Nobody from JODR showed up. Admittedly the process had just started, but there has been very little interaction, as far as I know—certainly with our group and with CPAC. I stand corrected if something has changed, but until March nothing had happened.

So I think what we're missing is this interaction between bodies such as JODR and CDR and CPAC on the one hand, but really the patient groups or advocacy groups, to provide input. CPAC is not an advocacy group; it's more of a resource.

● (1650)

The Chair: We'll go with one more answer.

Dr. William Hryniuk: Thank you for your work in establishing CPAC.

On your first question about JODR–CPAC interactions, one of the difficulties is that the membership of the oncology subcommittee of this JODR is kept secret. That's why there are difficulties in interaction. That's why they weren't at the meeting. Are we not going to know the credentials and membership of a group that's deciding the lives of thousands of Canadians? I think that's ridiculous. That's the first issue. Second, I think you need to encourage interaction at that level. There are other reasons for their not interacting, which I think you can break though. But I would encourage you to keep an eye on that.

As far as JODR versus CDR, the lesions of CDR could be replicated in either condition. You have to correct the lesions of transparency of membership, credentials, patient representation, what the decisions are really about, and the cost-effectiveness model. Those lesions exist no matter which way you go, and they have to be fixed.

Finally, I think those lesions apply to CDR in other diseases. If you fix them for JODR you can fix them for CDR. Get adequate representation. Get experts on the diseases who did the trials to testify to the committee and explain carefully—as we heard from Dr. Knox—why this drug is so important. Nobody on that committee must have realized that this was a breakthrough drug. They purposely excluded the investigators who proved that this was a breakthrough drug because somehow their testimony would be tainted or not believed. I think that speaks to the lack of competency and knowledge, and you have to repair that defect in CDR.

With JODR we don't have so much worry. It's well staffed by expert oncologists. But they should still hear from the investigators who proved that the drug was effective.

The Chair: Thank you very much.

Time has gone, so we will go to Ms. Priddy, and perhaps you'll have a chance to answer later. Go ahead.

Ms. Penny Priddy (Surrey North, NDP): Thank you, Mr. Chair.

I have to say I speak with some bias. I'm from British Columbia, and I was the health minister. I am a woman from B.C. surviving after breast cancer, so I appreciate that. I was in the very fortunate position to be in that province during that time.

It wasn't a question I was going to ask, but now I'm really puzzled. I'll probably ask it another time, but I didn't realize the names of committees were not public. I cannot think, other than of one particular example of medical treatment in our country, where anybody's life has ever been put at risk because their names were published. I think we all know what that one was, but I'm somewhat startled by that. I don't need that explanation today, but I will pursue that because I'm a little bit...well, a lot astounded by it.

I would like to know, if we were to rely on the information gathered by other jurisdictions without then redoing that information, would there have to be some—and somebody said harmonization, but I don't think they meant around this—kind of trust and harmonization in the way that information is gathered? People gather information in a variety of ways. Is it possible to do it so jurisdictions would gather information in ways in which different jurisdictions would have confidence?

Could someone comment on that, please? I have two more questions, so not a long answer, please.

Mr. Barry Stein: Certainly, getting this done on a regular basis, informally at this point, I think we rely on a lot of the information from the FDA, for example. I think there's unquestionably a possibility of working together with the other groups, such as the FDA, to consolidate the information. Many of these trials, of course, are done internationally in any event, so I don't think it would be a problem.

Ms. Penny Priddy: All right. Thank you.

Around cost-effectiveness, and again, it's probably a debate for another day, but was there debate at the table you had in Montreal around...? I understand doing cost-effectiveness for a variety of reasons in a variety of ways. It seems to me somewhat more difficult to do cost-effectiveness either around rare disorders or around oncology drugs, because no matter what, it's going to be expensive. So it's not going to be cost-effective from a money perspective.

I don't know if at the tables you sit at cost-effectiveness has been explored in a broader way, in a more socialistic, cultural, dynamic way, as well as just the money part. Has anybody been part of that kind of discussion?

● (1655)

Dr. William Hryniuk: The answer is no, they haven't.

Ms. Penny Priddy: Okay, thank you.

The JODR is separate. There's certainly a suggestion that disorders be separate. Do you think that weakens, in any way, the CDR? Do you think that's simply a compatible partnership? If you had a magic wand—not a big one, a little one—would there be ways in which CDR could make changes?

They've acknowledged there are changes they can make as well, particularly around transparency, which you spoke about as well. The transparency patients have looked for, I know, is not there, other than people are planning on printing or putting out information about why the drug wasn't approved. I don't know what you can put, other than that it wasn't safe, without breaking intellectual property if the drug is not registered.

Could you just speak quickly to the transparency one? Given that CDR is prepared to say they need to do things differently as well, is that possible?

Then I'm done—I know I am; that's why I'm not looking at the chair.

Mr. Barry Stein: Any panel can improve itself, there's no question about it, if they change enough.

Transparency helps, perhaps, in the carefulness of the decision and in the acceptability of the decision.

Ms. Penny Priddy: So trust of the decision.

Mr. Barry Stein: Needless to say, transparency in and of itself is not the answer. What we're looking for, of course, is easier access. So cost-effectiveness certainly has to be taken into account; we know that from experience. However, one of the experts who was speaking at the round table conference pointed out that with all the formulas, whether it's quality or whatever, largely at the end result it's disregarded.

In any event, the levels that are set are very artificial. If you set a $50,000 quality, where did that $50,000 come from? It came from 10 years ago, and perhaps the number should be $100,000 today. So these are artificially set values in any event.

At the end of the day, what we have to look at...we have to look at ourselves in the mirror and ask if we're taking these new technologies to Canadians who will best benefit from them, or are we depriving them?

Ms. Penny Priddy: I understand that.

Diana, you look like you want to say something.

I know I'm done, Mr. Chair, without looking at you.

Ms. Diana Ermel: I really agree with Bill and Barry about this. I guess what we can see—and you said this common drug review is too far gone to be helped. It's the process or the—

Ms. Penny Priddy: Yes, Steven asked that, not me, though.

Ms. Diana Ermel: Yes.

What we see is that with this cost-effectiveness comparison versus how much longer you are going to live, it just doesn't give the answers to help make decisions. If the drug isn't too expensive and it's going to let you live two months, well, great, there's no problem. So it really is about how much money.

So somehow or other this system—and the way we work and the way we make these decisions in Canada—is what needs to be fixed. Somebody said drilling down and looking at the process. I put in my notes a systemic re-look at what are our values, what are we valuing, and what is the value of life. I don't know the answer to it. These people have suggested some.

Sorry, I've finished.

The Chair: Thank you very much.

Ms. Priddy is very perceptive. She was actually finished a while ago, but I don't want to cut off Ms. Knox twice in a row, so I'll allow her to answer.

Dr. Jennifer Knox: That's okay.

Very quickly, on a much less sophisticated level, Canadians have a publicly funded health care system and they understand that the money is not endless. But I honestly think everybody is saying that if you could involve them in the decision-making and the debate, we might actually come up with something productive about what we all agree should be paid for and not.

It's the secrecy about how the decision is made. I can't even explain to my patients sometimes why that decision was made and about the way the patients weren't at the table. I think there needs to be this dialogue, and that's not happening.

● (1700)

The Chair: Thank you very much.

Ms. Davidson, you have five minutes.

Mrs. Patricia Davidson (Sarnia—Lambton, CPC): Thank you, Mr. Chair.

Thanks very much to all of the presenters.

I have a couple of questions, and my first one is just a brief question to Dr. Knox.

You referred to a couple of the drugs for kidney cancer treatment that were withdrawn and were not available, but they were available in many other countries.

Dr. Jennifer Knox: Yes.

Mrs. Patricia Davidson: Now, could these drugs have been approved by the provinces? If the CDR does not approve them for the formulary, could the provinces have approved them?

Dr. Jennifer Knox: Yes, they can.

Mrs. Patricia Davidson: Have they ever?

Dr. Jennifer Knox: British Columbia does. Correct me if I'm wrong, but so far Ontario has decided not to fund Nexavar, based on the CDR recommendation. Is that correct?

Ms. Debbie Milliken: Nexavar is currently under reconsideration through the Ontario process.

Mrs. Patricia Davidson: So there's no consistency then. Each province can act independently.

Dr. Jennifer Knox: Yes, but I think in general they don't, and that's why you see such differences. Quebec gets them. British Columbia gets them. Ontario often doesn't. The Maritimes do worse. That's upsetting.

Mr. Barry Stein: I think there's a general perception that if the CDR says no, then it's no, and if they say yes, then it's maybe.

Dr. Jennifer Knox: Yes, that is correct.

Mrs. Patricia Davidson: My next question is for Mr. Hryniuk.

I have a quote in front of me by Dr. Terrence Sullivan, president and CEO of Cancer Care Ontario. It says:

> This is an attempt to say let's put all the information on the table, let's bring the best people, let's bring the highest standards of evidence. And let's bring transparency to the process, including patient participation.

So could you explain to me how the JODR compares to and differs from the CDR in terms of process, expertise, and standards of evidence, and how they're going to bring transparency to the drug review process? How will the new process differ from what CDR does? Does the JODR have a timeframe they have to act within? Is there a spot for both of the bodies?

Dr. William Hryniuk: On the last question, one or the other but not both. The differences are that CDR has published the names and credentials of their membership that adjudicates the subcommittee of CED, the Ontario.... The new JODR does not. We don't know who they are.

CDR has published some information on why they made their decisions; the JODR successor doesn't. We don't have any reports from them publicly, of what led to their considerations. CDR was very poor in having expertise from oncology. JODR promises to have much more expertise, but perhaps not all the expertise they need. Neither committee looks at post-marketing surveillance of the drugs or at whether their decisions were actually, when they approved the drug, accurate and true, that they really did work.

So I would say that in the balance it's equipoise. The JODR is presently constituted. Notwithstanding what Dr. Sullivan said, those are promises; at the moment they're just promises. I think we need to make sure they turn into reality.

Mrs. Patricia Davidson: Does the rest of the panel agree with Mr. Hryniuk's statement that there's room for one but not both of these bodies?

Mr. Barry Stein: I don't think anybody could judge that at this particular stage. We're very early on in the process. No decisions have been rendered. No submissions have been made.

In fairness to the JODR and to Dr. Sullivan, I think there's an opportunity that shouldn't be missed. Assuming that this process is going to go forward, what we have to ensure is that the lessons from CDR are learned and that we mitigate the experiences of CDR.

Bottom line? We have to see if it'll provide further access.

Dr. William Hryniuk: But Barry, you can't have two committees now looking at oncology drugs. We're just talking about oncology drugs.

I'm not saying we should get rid of CDR for the other drugs, just oncology drugs.

Mrs. Patricia Davidson: Okay.

Mr. Barry Stein: My understanding is that the JODR would have the exclusive domain over oncology.

Dr. William Hryniuk: Yes. I'm just saying one committee, but please, not two.

Mrs. Patricia Davidson: Thank you.

The Chair: Thank you very much.

We'll now move on to Dr. Bennett.

Hon. Carolyn Bennett (St. Paul's, Lib.): Thank you very much for this.

Is the JODR for all drugs that oncologists might want to use? When there's a new drug, how do you decide which committee it goes to?

● (1705)

Dr. William Hryniuk: All of the oncology drugs would be judged by—

Hon. Carolyn Bennett: But there are lots of immune drugs. There are lots of drugs that oncologists use. Do you guys get to decide which group you want to see it, whether you want it...?

Dr. William Hryniuk: If the provinces are asked to fund an old drug for a new indication, it would come to JODR.

For example, there are 400 drugs in the pipeline. Not all of them are unique. But there are 400 potential applications for about 60 new drugs. So Nexavar, which we've talked about for kidney cancer, could be considered next for another indication. That would also come—

A voice: Liver cancer.

Dr. William Hryniuk: For liver cancer. It may be highly effective there. But in order to fund it for that indication, it would have to go to JODR.

The Chair: One more answer.

Ms. Debbie Milliken: Just as a clarification, in terms of what JODR is looking at within its scope, it's essentially drugs for active treatment of cancer, both oral and intravenous drugs, for new chemical entities and new indications for the older drugs. The—

Hon. Carolyn Bennett: But say if there was an interferon, or something that would be used for lots of things, if oncologists wanted to use it, you could choose to have it go through JODR?

Ms. Debbie Milliken: For the oncology indication, it would go through JODR if it was for cancer treatment.

Hon. Carolyn Bennett: And would it go through CDR for the other indications?

Ms. Debbie Milliken: It may.

Hon. Carolyn Bennett: Come on.

Who asked for JODR? You guys were obviously very frustrated with CDR. How did we get this extra thing so that, obviously, any given drug might have to go through both places? And if you were going to design a system, wouldn't you fix the other one rather than create another one?

The Chair: Does anybody want to try that one?

Dr. William Hryniuk: First of all, a particular drug can have many indications in many diseases. If it was for diabetes, it would go through the CDR, but if it's for cancer, let's say cancer of the left ear, it would go to JODR. The funding for each individual indication is the responsibility of the province, right? So they may pay for drug X for disease Y but not drug X for disease Z. They base the evidence proving the drug is effective—

Hon. Carolyn Bennett: If you were going to design a perfect system—I mean, you guys meet all the time and want citizens, patients, and providers to have a say on what gets the green light, what we need and what we don't—how would you do this?

Around the world, the biggest nightmare for any health minister I've ever met is what drug goes on a formulary. There are some places like Israel, where they have a different formulary every year, and all the health minister does all year is receive petitions and lobbies.

So with Herceptin, with all of these things, when something goes politically ballistic, the minister has to make a different decision. This doesn't seem like a good system.

Dr. William Hryniuk: The reason with CDR and the reason I think the portfolio was lifted was because of the goof with the kidney cancer drugs. They really made the wrong decision there.

Hon. Carolyn Bennett: So because of one goof we set up a whole new bureaucracy.

Dr. William Hryniuk: I think it was symptomatic of other goofs, but this was the most egregious one.

Hon. Carolyn Bennett: Were there not enough people on CDR who knew enough about cancer?

Dr. William Hryniuk: Yes, that's correct, or where this drug fitted in the armamentarium, or what it really meant. They didn't appreciate that.

Hon. Carolyn Bennett: I know you guys care about cancer, but you must have friends who care equally about diabetes, heart disease, and all the others. Haven't you sort of abandoned it by now, thanking people nicely for this JODR, instead of actually saying we need this thing fixed for all Canadians, not only the ones with cancer?

Dr. William Hryniuk: Our mission is cancer and I don't make any apologies for that. If you fix these things for cancer on JODR and you fix them for CDR, it'll work much better than it does right now. In any case, transparency, competency, embracing a broad perspective, looking to post-marketing, getting patients on those committees—those are the lesions in CDR.

Hon. Carolyn Bennett: I think, Bill, this is absolutely true, and having some secret black box where nobody knows if it comes out yes, no, or white smoke goes up the chimney as to whether—

Dr. William Hryniuk: That's what you have for JODR now.

Hon. Carolyn Bennett: So how much further along are we on post-market surveillance?

● (1710)

Dr. William Hryniuk: We haven't done anything except receive data. As I understand it, Health Canada receives data on adverse reactions but doesn't do anything with it. It doesn't receive any information on the efficacy of drugs, and of course it doesn't do anything with it.

The Chair: The time is gone.

Go ahead.

Hon. Carolyn Bennett: Do you see, in a best possible world, that something like JODR or CDR would have almost a research capacity that could track this stuff forever in terms of post-market surveillance so that you would always be evaluating what's working and what's not working?

Dr. William Hryniuk: Yes, but get it to work in the first instance. Then, as an afterthought, work to see whether it really is correct or not.

Hon. Carolyn Bennett: Lifting the curtain and finding out what wizard is behind there would be good, yes.

Dr. William Hryniuk: That's the first step, finding out who's there and what—

Hon. Carolyn Bennett: Okay.

The Chair: Thank you very much.

Simply for the committee's information, JODR is a 100% provincial body, is that right?

Dr. William Hryniuk: Yes, but the CDR has observers there.

The Chair: But there's no federal funding for JODR, is there?

Ms. Debbie Milliken: It's a provincial-territorial initiative.

The Chair: Exactly. That's for the information of the committee.

Go ahead, Mr. Brown.

Mr. Patrick Brown (Barrie, CPC): Thank you, Mr. Chairman.

I'm glad to have the perspective of cancer groups and agencies here today. I've asked questions previously as we've had testimony and opinions brought before us. One of my questions is related to a constituent's concern I had brought to my office, and it was very heartfelt. I'll ask it again today because it falls into an area you'd have greater familiarity with.

A daughter came in about her mother who was sick with cancer. Her mother had spoken to their physician and the physician mentioned that because of what he called government bureaucracy, the drugs he thought would be useful for her mother weren't available. One he mentioned was Iressa and another was Tarceva. They were very concerned and felt the CDR was holding that up. Not knowing very much about the CDR, I said I'd certainly look into it.

It concerned me, because I think the guidelines we should be worried and always concerned about in the Government of Canada are patient access and safety. What I'm interested in knowing about the CDR is whether, in your opinion, it has improved patient access to cancer drugs. Has it enhanced safety, in the sense that if it has reduced access, has it made up for it in increased safety? My concern is that I haven't seen evidence that it's doing that.

Perhaps you could comment on those two drugs and what happened with the CDR there. I understand it was approved in some provincial jurisdictions but not approved by the CDR. What are your general opinions about how this enhances or limits patient access?

Mr. Barry Stein: I think we first have to clarify the existing situation, which is that safety concerns are generally evaluated at the federal level by TPD or by BGTD at Health Canada; then the funding decisions are made on the provincial basis, and that's likely what the JODR is going to look at in terms of oncology products.

In my presentation I was referring to the harmonization or unification of this type of process. One of the things that I think would be very important to take away is that when it comes at least to the oncology products, an earlier review could be started at the time that Health Canada is evaluating the safety of the product, so as not to lose time and have an additional delay down the track.

I think in at least one case or so, CDR has attempted to do that in order not to add to the eventual delays. This becomes of paramount importance when we're talking about cancer medications, because this is life or death, as opposed to the situation with other medications, which may not necessarily be life or death. I think you actually alluded, maybe unwittingly, to the whole connection between the shortening of the delays between the decisions being made for reimbursement and the safety concerns. I think that opportunity should be looked into.

Mr. Patrick Brown: Are there any other comments on the case of—

● (1715)

Dr. William Hryniuk: Yes. Health Canada judges safety and efficacy; CDR judges on cost-effectiveness. They also go back over the effectiveness, which is not their job. The answer to your question on whether they enhance access to the drugs is no. It is quite the contrary. They turn down two-thirds of the drugs for funding.

Mr. Patrick Brown: In terms of this situation brought before me by this constituent, are you concerned that there are cases in which CDR is turning down a drug that a provincial body is approving? Doesn't there seem to be a waste of evaluation there?

Dr. William Hryniuk: I'm grateful that the provinces see more clearly than CDR has in the past.

Mr. Patrick Brown: In terms of cancer drugs, do you think this double evaluation is wasting time and resources?

Dr. William Hryniuk: To a large extent it is, yes.

Mr. Patrick Brown: Okay. Thank you.

The Chair: Mr. Fletcher, you have the floor.

Mr. Steven Fletcher: I have one really quick question.

CDR includes—

The Chair: Excuse me. I didn't have the name down, but Madame Gagnon wanted to speak, so we'll let her go. Then we'll go back to you, if that's all right. I'm sorry about that.

[*Translation*]

Ms. Christiane Gagnon: Could you clarify something for me? Is the correct acronym in French PEMO or PECMO? In her submission, Ms. Diana Ermel refers to the PEMO, whereas the acronym used in the Library of Parliament briefing notes is PECMO, or JODR, the Joint Oncology Drug Review. Are you talking about the same thing?

[*English*]

Ms. Jackie Manthorne (Executive Director, Canadian Breast Cancer Network): I apologize that we gave away all our copies of our submission, so I don't have the French-language document. If there is an error, we will correct it before it's distributed further.

Thank you.

[*Translation*]

Ms. Christiane Gagnon: JODR is a joint process, whereas in your submissions, you refer to the PEMO, or Oncology Drug Review.

[*English*]

I thought that was not the same thing.

Ms. Jackie Manthorne: Yes, that's an omission on our part. I apologize.

Ms. Christiane Gagnon: It's okay. I just wanted to understand if it was the same.

Ms. Jackie Manthorne: I apologize that we created that confusion. We'll correct the translation before it goes any further.

Thank you.

Ms. Christiane Gagnon: Thank you.

[*Translation*]

I have a question for Ms. Ermel.

You stated that you would like to see the joint drug review process centralized so that all provinces and territories as well as the federal government adopt a common approach when reviewing the efficacy and cost of drugs.

What process would be the most appropriate to ensure that more drugs, whether it be new oncology drugs or existing drugs, are reviewed and become more widely available to the public, to patients?

[*English*]

Ms. Diana Ermel: So what we have said in consulting with women across the country is that it just makes sense to do this once rather than having each province and territory make their own decisions.

In terms of the structure, we don't have a lot of expertise with that. Dr. Hryniuk has said, again, that it's the process and the way the decisions are made, the people involved. I guess for us breast cancer survivors, we feel the priorities on which the decisions are made have to be about what is best for the patients, what are the best drugs for the patient.

I don't know that I'm answering your question very well. Bill wants to say something.

Go ahead.

Dr. William Hryniuk: You're asking about the nexus of the issue. The provinces have to be the final payers, but the provinces have different guidelines for cancer treatment. So they look at their guidelines and say, yes, this is an effective drug for this disease, so we will treat it. Another province will say, our guidelines say this is not an effective drug, so we won't treat it.

What we need are guidelines that cover cancers across the country, so we get rid of that part. If we had national guidelines for cancer treatment, then when CDR or JODR says this drug is effective, all the provinces will say, all our guidelines are the same, we agree, we'll all fund it.

That's what I meant in my presentation. If we don't close the loop and have national guidelines, each province will continue to do its own thing, regardless of what JODR decides, but if we have national guidelines and JODR decides the drug is effective, then with all the provinces having the same guidelines, it would be difficult for one to say, we have the same guidelines, but we don't agree, so we won't use the drug.

You have to close the loop. You have to have the same treatment guidelines, and then you have to have the same adjudicatory process. Right now, we have different guidelines in each province, so each province decides to fund or not fund on its own, regardless of what JODR or CDR says.

● (1720)

The Chair: Thank you.

Mr. Fletcher.

Mr. Steven Fletcher: Thank you.

I just want to make a comment on the national guidelines. I assume you're wanting the highest common denominator, not the lowest common denominator.

I wonder if you could comment on CDR in comparison to Quebec, because of course CDR includes all the provinces save Quebec. And could you, from your perspective in oncology, comment on Quebec and their coverage versus the rest of the country, and why there is the difference?

Dr. William Hryniuk: In the 2005 and 2006 report cards, we analyzed the access to the 24 new cancer drugs, province by province. When we came to Quebec, it was very difficult to determine the true access, because although the provincial government will approve a drug, not every hospital is given the money to use the drug. So there's intra-hospital variation in access to the drugs. For the some of the drugs, if you go to hospital A, you'll get them, and if you go to hospital B, you won't get them, even though the province has approved the use of the drug throughout the province. We don't have the resources to drill down on just how much of that is —

Mr. Steven Fletcher: What about doctor to doctor? If you go to doctor A at a family clinic, is it different from...?

Dr. William Hryniuk: I'll let Dr. Knox speak to that. I don't think there's that much variation doctor to doctor.

Dr. Jennifer Knox: In my institution or in Quebec?

Mr. Steven Fletcher: In Quebec, in this case.

Dr. Jennifer Knox: In Quebec. I can only speak to what I've heard. A good colleague of mine, Dr. Jeremy Sturgeon, has moved to Montreal to try to help deal with this problem. What he has said is that this happens. A patient will come into a hospital, and Avastin, for instance, won't be funded, so they'll get an appointment with a doctor in the hospital across town, or something.

Although on paper I think Quebec sounds like they might be behaving a bit like British Columbia, which we're holding up so highly, I think there's still a lot of unfair disparities there.

Dr. William Hryniuk: But that's not an issue of the doctor; that's an issue of the hospital at which the doctor works. So he or she may realize, I can't give this drug to this patient referred to me, so don't send the patient to me.

Mr. Steven Fletcher: What about outside? I assume that outside of Quebec a family physician can prescribe a drug and there's no discrepancy from family doctor to family doctor within that province.

Are you suggesting that there is a difference, even outside the hospitals, when prescribing drugs?

Dr. William Hryniuk: I think almost all the drugs are prescribed by oncologists, and I would think there's much greater uniformity by oncologists in the prescription of cancer drugs.

Mr. Steven Fletcher: Oh, it's cancer drugs, okay.

Mr. Barry Stein: I can give you a specific answer with respect to Quebec by way of the example of one medication, Avastin. We know that Avastin has federal approval, so the safety requirements have been met and it is available. Two provinces fund it: British Columbia and Newfoundland. In Quebec, although it forms part of the treatment guidelines for colorectal cancer, and those were set in Quebec, unfortunately, only one hospital is paying for this drug out of its hospital budget.

So having something within the treatment guidelines is not necessarily a guarantee that it will be offered to the public, and that's something, of course, that we're addressing in Quebec. Guidelines are very important, but they don't necessarily guarantee that it will be reimbursed.

Mr. Steven Fletcher: Okay. Thank you.

The Chair: Ms. Brown, go ahead.

● (1725)

Ms. Bonnie Brown (Oakville, Lib.): I have a couple of questions. One is for Mr. Stein, who self-disclosed that he had tried some out-of-country treatments that were not approved here yet. I'm wondering, first of all, if I may ask, whether you had to pay for those out of your own pocket.

Mr. Barry Stein: In my case, going back to 1996, it was really types of surgery and surgical delays. And there was what we call hepatic arterial infusion, a process for infusing chemo directly to the liver, that wasn't offered in Canada. So the delays were a big issue, perhaps, more so than the actual medications.

The principle is still the same, and that applies, for example, in Ontario, where patients are leaving Ontario to go to Buffalo, to Roswell Park, to receive Erbitux. Then they're reimbursed through OHIP, yet they can't get it in their own province. These anomalies seem to go on throughout the country, particularly....

Let's get down to the point. When we talk about cost-effectiveness, we're talking about cost. It is also about the effect, but really, if the cost were very little, we wouldn't be worrying so much about it. So what we need to do to have equalization of these types of treatments is to have perhaps a new and novel method of reimbursement.

This is an example—I always throw out examples to make people think. What if we had a system, an insurance plan, like we have in Quebec? What if the federal government created a special drug fund for expensive cancer treatments? And what if the pharmaceutical companies would lower their prices, knowing there would be greater access to the availability of the product? Perhaps we need new and novel solutions.

When I left the country, it was life and death. I could stay in Canada and accept my fate or go and get these—accepted, by the way—treatments. You can't just leave the country and expect to be reimbursed. We understand. We have a process for that. In my case, I spent $250,000, and ultimately, through the Quebec Superior Court, RAMQ was ordered to reimburse. The same principles apply, though, today.

Ms. Bonnie Brown: Those treatments you got elsewhere and paid for and then were later reimbursed for, are they common procedure now in Montreal?

Mr. Barry Stein: As I said, some of it had to do with the timeliness, being available to have surgery at that time. This was at a time when—

Ms. Bonnie Brown: So it was more a wait time issue.

Mr. Barry Stein: It was a wait time issue, for sure. And it was also an issue of treatments, which are still not available in Canada but are readily available in every major cancer centre in the United States.

Dr. Knox talked about fearing what would happen in Canada when drugs such as Sutent or Avastin are not readily available. We fear that because they are readily available elsewhere as part of the normal course of treatment within the treatment guidelines, patients will have to leave the country for the very same reasons.

Ms. Bonnie Brown: Thank you.

We all know that in the past, Health Canada checked for safety, and the provinces and territories did their own reviews for efficacy and cost-effectiveness, and then they listed or did not list it on their formulary. They made that decision.

Now we have the CDR and the JODR in the middle of that process giving recommendations, which the provinces may or may not follow but tend to follow. Would any of you rather go back to the earlier system, when each province made the efficacy and cost-effectiveness decision? Would you rather go back to the system you had than the one you don't seem very happy with today?

Ms. Diana Ermel: The problem with the system we have in terms of cancer drugs is this inequality across the country. We joke around that we don't know whether or not we're going to develop metastatic disease, but maybe we'd all better move to British Columbia in case we do. It's unacceptable.

Ms. Bonnie Brown: Ms. Ermel, what you're talking about is actually based on our Constitution.

Ms. Diana Ermel: I know it is.

Ms. Bonnie Brown: The provinces have the right to deliver health care, and they have the right to decide which drugs they will pay for.

On the part of your speech that you gave about equal access and equal reimbursement, how do you think it's going to happen?

Ms. Diana Ermel: I don't know, but I believe it should happen. I have actually said we may have to go back and change the BNA Act, but I don't know. It is not right that this is happening across the country. It is just not right.

These gentlemen have thought of more ways around this. I think people who have really put their minds to looking at fair and just solutions need to be listened to.

It's almost like it's a cop-out. Well, it isn't almost like a cop-out; it is a cop-out that federally we can't do anything because it's the job of the provinces, and the provinces say they don't have enough money. Everybody has to work together to do something.

One of my board members e-mailed me and said the system is broken, tell them to figure out how to fix it. There are plenty of people with expertise and ideas on how this can be fixed.

● (1730)

Ms. Bonnie Brown: Dr. Hryniuk, at one point, you or some people on the panel were talking about national guidelines. Have the oncologists come up with agreed upon national treatment guidelines?

Dr. William Hryniuk: Some have and some haven't. All of the United States operates under one set of guidelines, the NCCN guidelines. For all of us in this room, we would do well to put that down in our books. NCCN.org tells you how each cancer should be treated.

Ms. Bonnie Brown: But have the Canadian oncologists as a society come up with guidelines?

Dr. William Hryniuk: No.

Dr. Jennifer Knox: We have in some areas. We wrote a consensus statement on the treatment of colorectal cancer. The west coast met and the east coast met, and we independently came up with almost identical documents. It's out there and it's been published. I'm leading a group now in which we are going to have a national consensus on kidney cancer.

We haven't always had to do that because we haven't been challenged with the problems of the cost until recently. I think it behooves us to try to do it more.

I think it's quite possible and easy for us to get consensus on it. We do it in the hope that it's going to lead to funding. That being said, all the other issues really need to be addressed so something can come of it.

Dr. William Hryniuk: You can write guidelines all you want. But if you don't monitor to see whether or not they're being adhered to and, if not, why they're not adhered to, there's no sense in writing national guidelines.

In B.C., they write guidelines, and they watch the monitoring. They see where there's no adherence and close that loop.

The Chair: Very good. Thank you.

Ms. Bonnie Brown: But would it not be easier to get public will behind national funding standards for these drugs, if there were in fact national practice guidelines the practitioners agreed to?

Let's face it, if there were guidelines, patients would demand that doctors in their jurisdictions use those guidelines and that provincial governments pay for the drugs those guidelines implied.

Dr. William Hryniuk: Amen.

Ms. Bonnie Brown: In some ways, the ball is then in your court, is it not?

Mr. Barry Stein: I don't think it's within the court of patient advocates to decide public policy.

Ms. Bonnie Brown: No, I didn't say that. I'm talking about oncologists coming to some level of agreement.

Dr. William Hryniuk: Yes.

Mr. Barry Stein: Yes.

Ms. Bonnie Brown: It would carry a tremendous amount of weight with patients, governments, and voters.

Dr. William Hryniuk: If you encouraged us to do it through the mechanism of CPAC, it would work.

Mr. Barry Stein: The truth of the matter is we've had guidelines. I alluded to some in Quebec by way of example. It's no different from any other province, and the drug is still not funded. It's not a guarantee.

Ms. Bonnie Brown: You have to pressure one province against the other.

Mr. Barry Stein: We're trying.

The Chair: Thank you, Ms. Brown.

Thank you to the witnesses.

It's been very interesting, and the questions equally so. We want to extend our thanks to you for coming to testify before the committee. We consider this to be an important subject.

With that, I'll call the meeting adjourned until next time.

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