



HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

43rd PARLIAMENT, 2nd SESSION

Special Joint Committee on Medical Assistance in Dying

EVIDENCE

NUMBER 002

PUBLIC PART ONLY - PARTIE PUBLIQUE SEULEMENT

Monday, June 7, 2021

Co-Chairs: The Honourable Hedy FryThe Honourable Yonah Martin



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• (1925)

[English]

The Joint Chair (Hon. Hedy Fry (Vancouver Centre, Lib.)): I will be chairing the meeting because the two joint chairs decided amongst ourselves that we're going to do alternate meetings. This is my meeting today.

[Translation]

Good evening, everyone.

Welcome to the public portion of this meeting of the Special Joint Committee on Medical Assistance in Dying.

Welcome to the members of the committee, to the witnesses and to everyone watching us online.

[English]

My name is Hedy Fry. I am the joint House of Commons chair of this committee between the House of Commons and the Senate.

Today, we're starting our examination of the statutory review of the provisions of the Criminal Code relating to medical assistance in dying and their application.

Before we begin, I would remind members and witnesses to keep their microphones muted at all times unless recognized by name by the chair.

With that, I welcome our witnesses from the Department of Health and the Department of Justice.

From the Department of Health, we have Ms. Abby Hoffman.

Abby, it's so good to see you again. I haven't seen you for ages.

Also from the Department of Health, we have Jacque Lemaire, senior policy adviser for the strategic policy branch. From the Department of Justice, we have Joanne Klineberg, acting general counsel in the criminal law policy section, policy sector; and Caroline Quesnel, counsel, also in the criminal law policy section.

We will now begin with opening remarks of five minutes. To the witnesses, I just want to ensure that you know you have five minutes, and I'm going to have to cut you off brutally at five minutes. Following that, we will have questions and answers by the committee.

Thank you for joining us. We will start with opening remarks by Ms. Hoffman, and then Ms. Klineberg.

Ms. Hoffman, please begin.

Ms. Abby Hoffman (Senior Executive Advisor to the Deputy Minister, Department of Health): Thank you, Madam Chair. Good evening, everyone.

The picture of MAID in Canada, in 2020, that I am presenting this evening will be published in the next few weeks. That's the medical assistance in dying in Canada report. We will provide a copy to the committee as soon as the final report is available.

The data maps directly to Canada's legal framework for MAID, which embodies two elements: eligibility criteria persons must meet, particularly related to the nature of the suffering they experience; and the safeguards that must be administered by medical providers in the course of assessing eligibility and before undertaking a MAID procedure.

Every MAID decision requires the active participation of two independent health care providers whose responsibilities are set out in the relevant sections of the Criminal Code.

Behind the statistics, of course, there are real persons whose suffering is a result of one or possibly several serious health conditions that causes them to consider a medically assisted death. With this in mind, let me go to some of the numbers.

In 2020, 7,595 cases of MAID were reported, representing 2.5% of all deaths in Canada. This is up slightly from 2% in 2019. By contrast, in countries that permit some form of assisted dying, the percentage of deaths attributed to MAID ranges from 4.3% in the U.S., where patients must be at the end of life and only self-administration is permitted, to 4.1% in the Benelux countries, where eligibility is based on suffering rather than proximity to death and clinician-administered MAID is permitted.

An increased awareness and greater acceptance by Canadians of MAID as an end-of-life option has resulted in a steady growth in MAID since 2016. There is a variation in the rate of MAID deaths across the country, but distribution among males and females, and across rural-urban settings, is consistent and reflects population distributions. Quebec and British Columbia, at 3.1% and 4%, have the highest rates respectively. Newfoundland and Labrador and Saskatchewan have the lowest.

A slightly greater proportion of men than women received MAID. Males were slightly younger, but less than 6% of all MAID deaths involved individuals under the age 65. Cancer is the most commonly cited illness, representing 69% of MAID cases. This is followed by cardiovascular conditions, chronic respiratory conditions and neurological conditions.

MAID assessors provide a clinical judgment about an applicant's eligibility to ensure alignment with the legal framework, but they also report on how individuals considering MAID characterize their suffering and its impact on their lives. The most commonly cited manifestations of suffering among persons seeking MAID are their loss of ability to engage in meaningful activities and the loss of ability to perform activities of daily living.

The majority of MAID applicants have received palliative care, or have had palliative services available to them. By their own accounts, their suffering cannot be sufficiently relieved through these measures or through other medical interventions.

Who provides MAID in Canada? The legal framework allows physicians, nurse practitioners and pharmacists to play specific roles. There's a small community of practitioners who deliver MAID in Canada. In 2020, 1,345 providers were involved in MAID. The overwhelming majority were physicians, and 5% were nurse practitioners. Only 40% were involved in just a single case, and only 15% were involved in more than 10 cases. Many other specialists are often consulted by the lead practitioner to assess the nature and likely course of the applicant's condition, as well as treatments or interventions that might be considered.

What happens to MAID requests? About 80% of the 9,300 written requests resulted in MAID in 2020. Of the remaining 20%, applicants either died prior to receiving MAID, were deemed ineligible or withdrew their request. Of the 2.5% of applicants who withdrew, about 50 did so immediately prior to the planned procedure. There are various reasons for ineligibility, and I'd be happy to respond to those in questions.

By way of conclusion, I want to note that in the written document we provided to the committee, we touched on a couple of things. First is the fact that some aspects of the MAID framework have not materialized as expected, notably self-administration of the substance causing death. Second, there has been a very consistent approach taken across Canada. This goes back to the inception of the discussions about MAID and a real effort made by providers, the provinces and territories. Finally, with respect to oversight, we just note that this is a shared responsibility.

As a result of the amendments made to Bill C-7, there will be a significant enhancement to the data that we will collect and what we are able to report on in the future.

- (1930)

Thank you very much. I'm happy to respond to any questions.

The Joint Chair (Hon. Hedy Fry): Thank you. You were bang on. That was very nicely done.

Ms. Klineberg.

[*Translation*]

Mr. Luc Thériault (Montcalm, BQ): A point of order, Madam Chair.

Perhaps the witness did stay within the speaking time she was given, but it did not turn out very well for me. At times, I thought I was at the Formula One Grand Prix.

At certain points, her words were not even intelligible. Just because we hear sentences, in English or in French, does not mean that our brain grasps their meaning.

The witness was speaking far too quickly. If we are to understand what is being said, things are going to have to slow down.

[*English*]

The Joint Chair (Hon. Hedy Fry): Thank you very much.

Ms. Klineberg.

Ms. Joanne Klineberg (Acting General Counsel, Criminal Law Policy Section, Policy Sector, Department of Justice): Thank you, Madam Joint Chair.

We will provide a brief overview of the chronology of medical assistance in dying law in Canada and where Canada is now situated in comparison with other jurisdictions that permit MAID.

The Supreme Court of Canada's 2015 Carter decision struck down the prohibition on MAID for adults with decision-making capacity who suffer intolerably from a grievous and irremediable medical condition. In response, the federal government introduced former Bill C-14, which was enacted in June 2016, amending the Criminal Code to exempt practitioners from otherwise applicable criminal offences.

One of the eligibility requirements was that natural death had become reasonably foreseeable, a criterion that required a temporal but flexible connection to a person's death. Canada's initial [*Technical difficulty—Editor*] regime similar to the approaches that existed at the time in several U.S. states and the regimes that have since been adopted in the Australian states of Victoria, Western Australia and Tasmania, and in New Zealand.

In enacting Bill C-14, Parliament also directed the government to commission independent studies of some of the issues this committee is now examining. We encourage the committee to consider the three reports of the Council of Canadian Academies on MAID for mental illness, for minors and by advance request.

Following the 2019 Superior Court of Quebec decision in Truchon and Gladu, Parliament enacted Bill C-7. It repealed the reasonably foreseeable natural death eligibility criterion, but retained the concept as a way to determine which of two sets of safeguards applies. Persons whose sole condition is a mental illness are excluded until March 2023. MAID can now be provided to a person who is no longer able to consent at that moment, if their death is foreseeable and if, while they had capacity, they were approved for MAID, scheduled the procedure and agreed with a practitioner to receive MAID on the scheduled day even if they lost capacity. This is distinct from the more complex issue of advance requests, where a person wants to direct in writing that they should receive MAID at some future point if certain conditions arise that they expect would cause them unbearable suffering.

As MAID is now available as a response to intolerable suffering regardless of proximity to natural death, Canada's MAID regime is now more similar to those of Belgium, the Netherlands and Luxembourg, and possibly also Spain, which recently enacted a law.

In terms of advance requests, we note that relatively few jurisdictions permit this. Belgium and Luxembourg only allow MAID by advance request for irreversibly unconscious persons. Colombia allows MAID to be provided to a conscious but incapable person who is dying in the short term. Only the Netherlands allows MAID by advance request for incapable but conscious persons who are not dying in the short term.

In addition to ethical and practical complexities around advance requests, as set out in the Council of Canadian Academies' report, legislative challenges also arise from the fact that advance requests may be prepared long in advance of when MAID would be provided. Safeguards are required for both the request, such as voluntariness and decision-making capacity, and the much later provision of MAID, such as who triggers the request and what to do if the person appears happy or refuses the procedure. Mature minors are eligible for MAID in Belgium and the Netherlands, whose laws highlight some of the policy questions in this area, such as whether eligibility should be the same for minors as for adults and whether additional safeguards are desired.

With this brief background set out, we will be happy to answer the committee's questions.

• (1935)

The Joint Chair (Hon. Hedy Fry): Thank you very much, Ms. Klineberg.

We will now begin our round of questions, starting with members of the House of Commons.

Clerk, who is the first person from the Conservative Party?

The Joint Clerk of the Committee (Mr. Marc-Olivier Girard): If you follow the routine motion that was passed, it's the Liberals first with Mr. Arseneault. Then we go to the Conservatives.

The Joint Chair (Hon. Hedy Fry): Yes, thank you.

[*Translation*]

Mr. René Arseneault (Madawaska—Restigouche, Lib.): Thank you, Madam Chair.

I have the honour of getting the ball rolling.

It is a great honour for me to sit on this committee, for the second time. I actually sat on the first committee with my colleague Michael Cooper. He is on Parliament Hill at the moment.

My first question goes to Ms. Hoffman.

I read the statistics for 2020 with great interest. They are interesting and they tell us a lot. However, I would really like to have all the statistics from the beginning.

Here is my question.

At the first Joint Committee on Medical Assistance in Dying, we heard testimony by officials from the Canadian Medical Association. They told us that some physicians were reluctant to provide medical assistance in dying, for reasons of conscience. They also told us that it was not a problem because, if I recall correctly, Canada has about 80,000 physicians. It was five years ago now that we were told that.

What can you tell us about the statistics of physicians refusing to provide medical assistance in dying, because of their personal conscience?

• (1940)

[*English*]

Ms. Abby Hoffman: Thank you for the question, Mr. Arseneault.

We don't have statistics on the specific number of health care providers who might often be authorized to play a role in some aspect of MAID, as an assessor, a consultant or somebody who actually administers the procedure. We can tell you about the providers who received requests and actually moved forward with them to conduct the assessment and potentially administer the procedure.

Our impression is that, generally speaking... This is partly because, in a number of jurisdictions, there are what we call care coordination and patient navigation networks. Someone who is interested in pursuing MAID can actually go into a kind of regional or province-wide network to have their case and their potential application moved forward.

We're not aware that the exercise of conscience rights is specifically impeding access at the moment. We are aware, however, that there are some institutional impediments. Some of you, I am sure, will have read about these in the media where in certain institutions—whether it's long-term care homes, palliative care centres or whatever it might be—there is an institutional objection, religious or otherwise. Often these are faith-based, but not necessarily always, where there is an objection to MAID and, therefore, someone seeking access is not referred to someone who actually can assist them. There have been a number of high-profile cases of that nature, and needless to say those are a matter of concern.

I would say that, at the present time, the issue is more an institutional objection rather than the behaviour of certain specific individual providers.

[Translation]

Mr. René Arseneault: That is very interesting.

Do we know whether those who have not been able to receive medical assistance in dying, at facilities that are reluctant to provide that assistance, have been able to find the assistance elsewhere?

[English]

Ms. Abby Hoffman: I would have to respond in generalities to that question. There certainly are cases where there is significant tension in the interaction between the provincial government, which is providing funding to certain of the institutions in question and objects strongly to the outright refusal and the failure to refer. That certainly is a concern.

We also know that in cases where, for example, someone is in some sort of residential setting, organizations like Dying with Dignity have a list of potential witnesses and support personnel who, if they are contacted, can assist a person even if they are residing in a setting with resistance to MAID.

[Translation]

Mr. René Arseneault: Thank you.

Ms. Klineberg, do you believe that, in some cases, removing the foreseeable death criterion will have an effect on the demand, the requests, for medical assistance in dying?

Ms. Joanne Klineberg: I feel that the evidence is quite clear that there will be an increase in requests. But it will probably not be a huge one, if you look at the statistics from Belgium and the Netherlands where medical assistance in dying is permitted. In comparison to others, the number is always low.

• (1945)

[English]

The Joint Chair (Hon. Hedy Fry): Thank you, Ms. Klineberg. Maybe when you get a question from someone else they will allow you to expand on that.

Now I am going to the next questioner, who is a Conservative.

Ms. Findlay, you have five minutes.

Hon. Kerry-Lynne Findlay (South Surrey—White Rock, CPC): Thank you, Madam Chair.

This is for the Department of Health, for either Ms. Hoffman or Ms. Lemaire.

I certainly thank you all for being here today on rather short notice. We don't have a lot of time, but I do want to say that this review is long overdue. Bill C-14 called for a statutory review in June of 2020, and in the interim we have, instead, had an expanded MAID regime. The state of palliative care was supposed to be examined in the Bill C-14 review, so I'd like to start there.

The first annual report on MAID in Canada said that while many recipients of MAID had received some sort of palliative care, "it does not speak to the adequacy of the services offered. This may be an area for future study."

I think that's part of what we're doing here.

Where are we on reviewing the quality of palliative care MAID recipients were offered or experienced? Also, do we have any way of knowing if any Canadians have chosen to end their lives through MAID because of a lack of quality palliative care or resources more generally?

Ms. Abby Hoffman: Maybe, Ms. Findlay, I'll start and my colleague Ms. Lemaire may want to jump in here.

I think we will freely admit that just as we wrote in last year's report, there is only so much information we are able to gather through these reports that come from providers, which basically ask whether a person accessed palliative care and, if they didn't, whether they would have had access to it if they so wished.

We do know that some of the providers reported that for people who had palliative care and who chose to proceed with their assisted death in any event, the palliative care was not sufficient for them to get relief from their suffering or from the decline in capability and capacity that they were facing.

To be perfectly candid, I don't think we are in a position to really and truly say that we know, qualitatively speaking, what the nature of that palliative care is in each particular case. We are relying on the reports from those providing commentary to us about access to palliative care.

I think the work this committee will do, frankly, will be very welcome, but we are not aware of cases in which someone has said, "I don't have access to palliative care," or "The palliative care realistically could be better and the consequence of that is that I am proceeding with my decision to end my life through a MAID procedure."

Hon. Kerry-Lynne Findlay: Would you agree with me that there are differences and discrepancies across the provinces and territories in terms of the availability and quality of care? From the reports you're getting, they are not all offering exactly the same amount or in the same areas.

Ms. Abby Hoffman: I think one could go further to say that even within the same community, different institutions and different hospitals may offer different levels of palliative care. We know that some institutions have well-established palliative care and end-of-life services and are well known because of these, while others may be better known for other things.

I would say it's not even a question of pan-Canadian variability. It could be within any given jurisdiction or within any given community for that matter.

This is one of the things we're trying to address through the funding to provinces and territories for an array of home care, palliative care and end-of-life care services, but we all acknowledge that there is a long way to go.

Hon. Kerry-Lynne Findlay: Ms. Lemaire, do you have a comment on this?

Ms. Jackie Lemaire (Senior Policy Advisor, Strategic Policy Branch, Department of Health): Yes. Thank you.

The only other thing I would add to what Abby said is that there was some initial research done. What comes to mind is research by Dr. James Downar, who's a palliative care physician and also a MAID provider, using administrative data in Ontario. It compared the socio-economic characteristics of decedents who received MAID to all decedents in Ontario, and from that initial research, in terms of comparing their use of palliative care services, between the two, there wasn't any difference.

Their initial findings were that there is not a difference in terms of access to palliative care services for people who receive MAID versus those who don't. Of course, that's just some research, and certainly more is required.

• (1950)

The Joint Chair (Hon. Hedy Fry): Thank you.

You have 14 seconds, Ms. Findlay.

Hon. Kerry-Lynne Findlay: I'm not going to ask a very quick question.

Thank you very much.

The Joint Chair (Hon. Hedy Fry): Thank you.

The next person is Monsieur Thériault, for five minutes.

[*Translation*]

Mr. Luc Thériault: Thank you very much, Madam Chair.

My first question goes to the officials from the Department of Justice. I'd like clarification on one point.

In the second paragraph of the first page of the report, you say:

Canada's initial MAID regime was an "end of life" regime similar to the approaches that existed at the time in several US States...

Can you clarify what you understand by "end of life regime"? Are you referring to what was also Quebec's end of life regime in the Act Respecting End-of-Life Care?

Ms. Joanne Klineberg: Yes, absolutely.

Mr. Luc Thériault: If I understand correctly, you are saying that the regime deals with the end-of-life phase, from the moment when death has an irreversible hold. In a way, it excluded people whose disease was in the terminal phase, but who were not at the end of life and were not necessarily going to die, even though they were dealing with intolerable pain. Is that correct?

Ms. Joanne Klineberg: I think so. The criterion was reasonably foreseeable death. The intention was to be flexible in terms of the

end-of-life criterion as defined in Quebec's legislation. So the scope may be broader but, in principle, yes. Eligibility depends on the foreseeability of a person's death in the near future.

Mr. Luc Thériault: My second question goes to the officials from the Department of Justice. I will leave it up to them as to who answers.

On page 4 of the report, you say:

The majority of written requests (78.8%) result in MAID. In 2020, the remaining (21.2%) resulted in an outcome other than MAID: most (12.7%) of these patients died prior to receiving MAID...

Do you have an idea of the reasons? Is it caused by the safeguard measure, the 10-day period that has to go by between the time of the request and the second check? Is that documented?

[*English*]

Ms. Abby Hoffman: Monsieur Thériault, was this question directed to me or directed to health...?

[*Translation*]

Mr. Luc Thériault: When I started my question, I clearly indicated that I was asking either one of the officials from the Department of Health.

Madam Chair, I hope that will not be taken off my time.

[*English*]

Ms. Abby Hoffman: I'm sorry. I might have misunderstood.

Specifically with respect then to the question of people who died and for that reason.... Even though their application was accepted and they were deemed eligible, they died before the MAID procedure could be provided. It is the case, under the current regime, that a significant portion of the people who died before a MAID procedure could be delivered had died within 10 days.

In fact, it was one of the reasons the government recommended the abandonment of the 10-day period of reflection.

• (1955)

[*Translation*]

Mr. Luc Thériault: We know that 2.5% of the patients withdrew their request.

Are the reasons for those withdrawals documented? Do you have any data on that?

[*English*]

Ms. Abby Hoffman: Yes, we do have data on that. In some cases, a very small proportion of that number of people who withdrew their request actually withdrew at the time—literally moments before—the MAID procedure was to be provided. There were about 50 people in that category.

Many of the others said, “I’ve had palliative care. I have had other interventions, and I think I can carry on without proceeding with my MAID procedure.” There is a mix of reasons why individuals who were declared eligible decided not to proceed in the end.

The Joint Chair (Hon. Hedy Fry): Thank you, Ms. Hoffman.

Thank you, Monsieur Thériault.

I go to Mr...

Mr. Alistair MacGregor (Cowichan—Malahat—Langford, NDP): It would be me, Madam Chair.

The Joint Chair (Hon. Hedy Fry): I’m sorry, Alistair. I couldn’t see you there.

Mr. MacGregor, you have five minutes.

Mr. Alistair MacGregor: Thank you so much.

Thank you to our witnesses for helping us launch this very important study.

I believe that maybe my first question would be best suited to the Department of Justice. I was present in the previous Parliament when we were debating Bill C-14, and I know that there were some legitimate concerns raised about the safeguards that we were placing in the legislation.

Is there any information about how those safeguards have acted over the years? What about compliance? Have there ever been any kinds of investigations, or is there just general satisfaction that they’ve been adequate and that they’ve been followed? Anything you can do to inform us on that, please....

Ms. Joanne Klineberg: Thank you.

I think that is probably a question better answered by our colleagues from Health Canada, who will have collected data through the monitoring regime.

Mr. Alistair MacGregor: Sure. I’ll turn it over to Ms. Hoffman then.

Thank you.

Ms. Abby Hoffman: Thank you. I’m happy to respond to that question.

I’ll just tell you that when I mentioned at the beginning of my remarks the monitoring that we do and that the monitoring report maps to the legislation, I actually meant that in a very literal manner.

Each provider who fills in the information that they are legally obligated to provide.... That starts with the very first safeguards, which are things like whether this person is eligible for health services in the province or territory where they reside, whether they are capable of making decisions about their health, whether they are of the right age, etc. There are questions related to each of the eligibility criteria and each of the safeguards, and in every case, the provider must respond and provide the information about all of that.

We do, in fact, have that information, and we do report on it very specifically. When you have the opportunity, hopefully, to see the report in a couple of weeks, you’ll see how that is documented.

Mr. Alistair MacGregor: Thank you.

For those of us who represent ridings with fairly large indigenous populations.... My riding is home to many Coast Salish nations, including the Nuu-chah-nulth. There has been a general distrust—very warranted—over the decades by indigenous people toward health care providers.

Is there any information that you can provide from Health Canada’s perspective on that sort of ownership of the data, any information that would help us with our study as it relates to indigenous peoples?

Ms. Abby Hoffman: I think that we need to do better in terms of data on indigenous. We certainly know that there is a huge range of attitudes and views, some of which clearly do not see MAID as a viable form of end-of-life care. However, at the same time, we do know that there are MAID providers who are indigenous and that there are indigenous people who have accessed MAID, and we know that there are many challenges in doing that.

In a big urban centre, obviously, you have all kinds of choices around providers, timing, the witnesses that have been required in the past, and so on. Those are very difficult arrangements to make in a remote, indigenous community. Also, I will just say that I mentioned at the end of my remarks the new kinds of data that we are required to collect and are looking forward to collecting, in fact, for our monitoring reports. Some of that will be specifically with respect to indigenous communities.

The last thing I would say is that it’s not a monolithic world out there in terms of either attitudes or [*Technical difficulty—Editor*].

• (2000)

Mr. Alistair MacGregor: You made mention of the fact that, yes, many indigenous communities are remote and certainly other non-indigenous communities are remote. Can you elaborate a little bit more just on how the provinces are doing in collecting the information for people who live in remote communities and who have a desire to access this service?

How well are they doing in meeting those demands?

Ms. Abby Hoffman: I’ll have to speak, I’m afraid, in generalities here.

I mentioned the care coordination and patient navigation networks. Those certainly help. We do know—although I have to say for me I find these statistics sometimes a bit counterintuitive—that apparently the number of MAID applications and services is actually proportional to the geographic distribution of the population. However, that’s an issue we need to dig into a bit more to really see whether there’s truly comparable access across the country in all settings.

The Joint Chair (Hon. Hedy Fry): Thank you, Ms. Hoffman and Mr. MacGregor.

We move on to the senators now.

I have Senator Mégie.

[*Translation*]

Hon. Marie-Françoise Mégie: Thank you, Madam Chair.

My thanks to the witnesses for joining us.

I would like to ask the question that Mr. MacGregor has just put to the officials from the Department of Health, but in a different way.

In your notes, you say that your data show that the distribution of MAID deaths in urban and rural settings in each province is roughly representative of the general pattern of population distribution. You provide figures to support all the other statements you make. How did you determine that the situation is similar in urban and rural settings?

When you answered Mr. MacGregor's question, you talked about Indigenous populations. We don't know how you come to that conclusion.

Let me add a supplementary question. Did you do a gender-based analysis plus, a GBA+?

[English]

Ms. Abby Hoffman: Gender-based analysis... This is at the level of the relative numbers of males and females, and the distribution by age. Not surprisingly, for example, we know that there are slightly more males than females who access assisted dying. We know that the males are slightly younger. Females are slightly older. The older the age cohorts, the larger the numbers in relative terms of females. This is not surprising. This is very similar to the pattern of morbidity and mortality among males and females in that post-65 age group, the individual five-year cohorts, which is where the bulk of MAID requests occur.

[Translation]

Hon. Marie-Françoise Mégie: Allow me to interrupt.

In your GBA+, you could have included groups of people like Indigenous and non-Indigenous people in remote regions. Those are the groups I was thinking of when I asked the question. Did you think about those groups, yes or no?

[English]

Ms. Abby Hoffman: We have absolutely thought about it. You won't find it in the report. This is work we need to do and we need to get at it through other ways than simply asking providers for one-off information about individual cases. We need a parallel line of research activity to really understand better which groups of people are accessing MAID and which ones aren't, why they are or why they are not, and what the rest of their social circumstances are.

Bill C-7 has provisions on data collection that will authorize us to collect a whole lot of new information that we have not been collecting in the past, but we still need parallel studies using linked data with Statistics Canada information and so on. This is a big field that is ahead of us. I cannot tell you that we have done that work yet.

[Translation]

Hon. Marie-Françoise Mégie: Thank you.

I will move to another topic.

How much time do I have left, Madam Chair?

[English]

The Joint Chair (Hon. Hedy Fry): You have about 40 seconds, unfortunately.

[Translation]

Hon. Marie-Françoise Mégie: Okay. In that case, I will ask a quick question.

Budget 2021 provides for \$2.6 million per year to make sure that medical assistance in dying is provided in a uniform way, through things like orientation and training. What is your organizational strategy to make all those expenditures efficiently?

• (2005)

[English]

The Joint Chair (Hon. Hedy Fry): You have 20 seconds, Ms. Hoffman.

Ms. Abby Hoffman: I was going to pass this to Jacquie Lemaire, who's been working on this.

Ms. Jacquie Lemaire: What we are doing is using the terminology in the budget to look at ways that we can work with the provinces and territories and their regulatory bodies to develop guidance that will help uniform an application of the new legislation, as well as look at increased sensitivity and culturally safe application of the new legislation by those practitioners.

The Joint Chair (Hon. Hedy Fry): Thank you.

I go to Senator Kutcher for three minutes.

Hon. Stanley Kutcher (Senator, Nova Scotia, ISG): Thank you very much.

Before I start the question, would it be possible for Ms. Lemaire to provide us with the study that she referenced in her earlier testimony?

To the Health Canada representatives, I have one very specific question and a larger question. Let me start with the larger, and I'll say them together.

Is robust, high-quality, mixed methods data collection and analysis really necessary? How do you think the current MAID dataset can be improved to allow for a more nuanced understanding of MAID practice across Canada? Is the Canadian MAID dataset open and accessible to bona fide independent researchers?

On the more specific question, thank you very much for your answer on that small number or percentage of people who withdrew their MAID request and for their characteristics. Out of curiosity, were there any of those individuals who again asked for MAID following the period after they withdrew their request?

Ms. Abby Hoffman: I can start with some response to that.

On the issue of withdrawals, the data deals principally with people who have withdrawn their request and do not proceed with a procedure under that same request. There may be some who file another request. I'm not sure I can answer that question positively, Senator Kutcher. We may have to provide you with that data after this meeting.

If I could go to the issue of data, one thing that we need to remember about data is that our system of data collection under the original Bill C-14, and now enhanced through Bill C-7, imposes obligations on those individuals who are exempted from certain prohibitions in the Criminal Code.

These are health care providers. They're not sociologists or cultural specialists. I think we certainly can and will ask them for more information, but we need more linked data studies. We need more research along the lines of what my colleague Jacquie Lemaire told you about, James Downar's study of palliative care.

I don't think it's reasonable for us to think that we're going to collect everything we need through individual case files provided by providers, among other reasons because I think it's safe to assume that there will be some applicants for MAID, some recipients of MAID, who will resent mightily a deeper probing of their reasoning, their personal circumstances and so on.

We need to find other ways to get at this more robust understanding of the dynamics of what motivates MAID. This is a combination of data collection, reporting, research and so on.

Hon. Stanley Kutcher: Thank you very much for that.

I have a question on the palliative care.

You mentioned that there were great discrepancies across some centres on how palliative care is delivered. In your experience and to your knowledge of Canada's health care system, is that discrepancy similar to or vastly different from other types of health care interventions that are available across the country?

Ms. Abby Hoffman: Briefly, inasmuch as palliative care is relatively newer, it might be somewhat dissimilar. On the other hand, if you think about our health care institutions, many of them specialize in certain aspects of health and disease, chronic or acute disease. I think there may be wider discrepancies now, but they are, over time, narrowing as palliative care takes on a much more legitimate and fulsome place in the array of health care services in Canada.

The Joint Chair (Hon. Hedy Fry): Thank you, Ms. Hoffman.

I go to Senator Wallin.

• (2010)

Hon. Pamela Wallin (Senator, Saskatchewan, CSG): Thank you very much.

To our legal expert from the justice department, I want to read back what you presented to us.

You said:

MAID can now be provided to a person who is no longer able to consent at that moment, if their death is foreseeable and if, while they had capacity, they were approved for MAID, scheduled the procedure and agreed with a practitioner to receive MAID on the scheduled day even if they lost capacity.

You go on to say:

This is distinct from the more complex issue of advance requests, where a person wants to direct in writing that they should receive MAID at some future point if certain conditions arise that they expect would cause them unbearable suffering.

I would like to know why the latter is always seen as so much more complicated than the former.

Ms. Joanne Klineberg: It's a bit of a complicated question, and there are several dimensions to it. One of the things I could recommend to you would be the report of the Council of Canadian Academies—

Hon. Pamela Wallin: I've read that, yes. Thank you.

Ms. Joanne Klineberg: —that talks about the three uncertainties. One of the uncertainties relates to the clarity with which the person expressed their desire for MAID to be provided in the future if certain conditions arose. In the case of what's permitted under Bill C-7, the conditions are already there, the conditions that render the person eligible under the current law. They are already unbearably suffering, and they have already made the request with a view to having it shortly, but in the case of advance requests, it is their belief that circumstances might arise in the future that would cause them to be suffering unbearably that leads to their desire to create the advance request.

One of the things that research tells us is that people sometimes poorly estimate their ability to deal with situations before they have arisen, so one of the complexities is that, when the future circumstance arises one or two years down the road, the person might cope with it better. However, if they no longer have the capacity to withdraw a MAID request, the concern suddenly arises. At least the possibility of MAID being provided—

Hon. Pamela Wallin: As some of you will know, my issue specifically relates to those with dementia or different forms of dementia and Alzheimer's. It seems to me that, if you did that in one-two order, it wouldn't be that complicated at all.

Ms. Joanne Klineberg: I'm not sure I understand the one-two order.

Hon. Pamela Wallin: If you engaged in the first action that I read to you, someone who's been in touch with a MAID provider who has scheduled an event, etc., then I don't see the leap, particularly for people with dementia who do not have the ability to consent, although they may be conscious at a later point, which is, of course, precisely why they're seeking an advance request.

The Joint Chair (Hon. Hedy Fry): Thank you. I think that time is up. I'm going to have to ask Ms. Klineberg to try to fit that answer in her next round of questioning.

We now have Senator Martin.

The Joint Chair (Hon. Yonah Martin (Senator, British Columbia, C)): I'm sorry. Senator Dalphond should be first.

Hon. Pierre Dalphond (Senator, Quebec (De Lorimier), PSG): Thank you, Madam Joint Chair.

My question is for Ms. Hoffman. In the report on page 3, you state, “The majority of MAID applicants have received palliative care or have had palliative services available to them.” On page 2 it is reported that about 48% would be receiving MAID in private residences, 28% in hospital and about 17% in palliative care facilities.

Does that mean that some people are receiving palliative care and, finally, when they want to receive MAID, they go back home to receive MAID?

Ms. Abby Hoffman: I think there are a couple of things here. One is that there is palliative care services that could be made available in one's own home, a retirement home or whatever constitutes a private residence, so it doesn't have to be institution-based palliative care. I think that maybe is one important factor to take into account.

• (2015)

Hon. Pierre Dalphond: My next question is about the reliability of the information you gather, especially when they see the cause of why MAID was provided, when people are suffering from comorbidity or many causes.

Is it up to the provider to decide what she should put there in the box?

Ms. Abby Hoffman: Yes, there has been considerable discussion and guidance provided to providers about how to respond to the questions, but it is true. I think I'll just maybe repeat a point that I made in my remarks and also in our submission, which is that, yes, people are suffering pain and they're suffering grievously, and they worry about that pain becoming more and more acute and less sustainable for them, but a lot of what they worry about is capacity. They can't do the things that they used to do. They cannot take care of themselves in terms of the normal activities of daily living.

I think this explains why many of these providers on behalf of these patients say that, yes, palliative care was available, but palliative care doesn't fully address the decline in capacity for vital individuals who are used to being self-sustaining and relatively independent. In a way, it's not the right solution for the perception of capacity that individuals in these circumstances often have.

The Joint Chair (Hon. Hedy Fry): You have one minute, Senator Dalphond.

Hon. Pierre Dalphond: I'll leave it for Senator Martin in order for her to get close to three minutes.

The Joint Chair (Hon. Yonah Martin): Thank you, Senator.

Thank you, Madam Chair.

My first question is related to the data you've been talking about, which will be in your report but which doesn't seem to give us the kind of detail that we were trying to understand: the demographic profiles, especially with the indigenous communities. We heard from the study of Bill C-7 that they really didn't feel they were consulted, and they're really grappling with this.

In regard to the small group of MAID practitioners, do you have some information about their demographics? Are there indigenous practitioners? Obviously we are in a very diverse country. Would you speak about this small group as well?

Ms. Abby Hoffman: I'm happy to respond to that.

One thing I should mention is that there is an organization called the Canadian Association of MAiD Assessors and Providers. I think some of you may have been at committees where you've had representatives from this organization address you. This organization is quite likely going to be the recipient of some of the funding we mentioned that's available through budget 2021.

One of the tasks we expect they will take on is doing more work with a broader array of providers and with all providers to make sure the MAID they provide is done with the appropriate sensitivity and, in fact, is widely available across the country.

On your specific point, Senator Martin, about indigenous MAID assessors and providers, there are some, but only some and the needs are not necessarily the same thing, of course.

The Joint Chair (Hon. Yonah Martin): This is what we're hearing from them, that they just need to really grapple with this and have more consultation.

Having said that, in terms of the stop mechanism in the system, I've asked this question of many different witnesses and no one seems to be able to confirm if, along the way, once something is triggered, there is every opportunity for people to withdraw.

Would you speak about the specific stop mechanisms that are in place?

Ms. Abby Hoffman: Sure.

The ultimate stop mechanism is that, at the time of a procedure, the person must give final consent. Therefore, there's no procedure, even if the person has.... Through every action and every word up to that point, the person is absolutely given the opportunity to change their mind. In fact, it's reported that one of the reasons for withdrawing is simply people changing their minds. They may be influenced by family. It may just be their own decision.

I think we know—I think we can speak with confidence—that the MAID provider community is extremely diligent and extremely compassionate. They are not in the business of “come hell or high water, we're going to proceed with this MAID process”. That is just not the prevailing mentality at all. I think this constantly checking in with the person who has expressed interest to make sure that remains their resolve is the hallmark of how MAID is actually delivered in Canada.

• (2020)

The Joint Chair (Hon. Hedy Fry): Thank you, Ms. Hoffman.

I now go to the second round for the House of Commons.

We have Ms. Koutrakis for three minutes, please.

Ms. Annie Koutrakis (Vimy, Lib.): Thank you, Madam Chair.

Welcome to—

The Joint Chair (Hon. Hedy Fry): By the way—just for a quarter of a second—I need the questioner and the responder to know that the three minutes include both of you, so let's be tight, please.

Ms. Annie Koutrakis: Thank you, Madam Chair, and thank you to our witnesses this afternoon.

A lot has been heard this afternoon on palliative care. I will continue in that vein.

As we all know, an important safeguard in Canada's administration of MAID is the assurance that a patient must be made aware of all treatment options available, including palliative care, in order to provide informed consent. Can you comment on the steps that are taken to ensure patients are aware of and have truly considered all other available options?

Also, how often do patients actually accept alternative treatments when given the option?

Ms. Abby Hoffman: I'll try to answer quickly.

I don't think we can answer your last question. We don't have definitive data on that. What we can tell you is that every provider involved with a patient seeking MAID must ask and must advise a patient about the treatments and services, including palliative care, and they report on that. In each case file where they respond, they indicate what they have offered to the patient.

Is there someone sitting on either the MAID applicant's or the provider's shoulder directly overseeing what it is they have said to the individual and how the individual has responded? No, there isn't. We are relying on the providers' accounts of those conversations, but as I said in response to a previous question, these providers are interested first and foremost in the well-being of these individuals who come to them, so—

Ms. Annie Koutrakis: I'm sorry to interrupt. My time is limited.

On the flip side of that, can you provide some clarity on the measures that are currently in place to ensure that a request for MAID has been made freely and without undue influence? What steps are taken, then, when a practitioner determines that influence has occurred?

Ms. Abby Hoffman: Again, it's the provider's testimony. If the provider has reason to believe that the patient or applicant is being coerced in any way, that provider should not be proceeding further because that is one of the initial screening eligibility criteria, I would call them, that the request is voluntary.

As in everything else in health care, we have to rely on providers, who are subject to their regulatory professional bodies, behaving in a way that their own bodies and the law requires.

The Joint Chair (Hon. Hedy Fry): Thank you very much.

We go to the Conservatives for their round. It's for three minutes, please.

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

I will direct my questions to the Department of Health officials.

The question I have relates to the federal monitoring regulations within the context of sharing monitoring data with law enforcement

in instances where the Criminal Code safeguards are not followed. More specifically, it's my understanding that right now there are two streams of monitoring data. In about a half of the provinces and territories, MAID practitioners are expected to report to the federal government through a designated provincial or territorial body, in which those governments would have access to such data. However, in the other half of the provinces and territories, MAID practitioners report directly to the federal government.

Can you speak to that issue of sharing federally collected monitoring data with local enforcement agencies?

● (2025)

Ms. Abby Hoffman: Sure, and I'll keep this fairly brief.

First of all, I'll say that the federal government is not in the business of enforcing the Criminal Code. This does fall to provinces, and it falls to a combination of public authorities and self-regulating professions.

I will say, though, that the jurisdictions where the reporting is through a provincial so-called designated recipient—in other words, we receive the reports in bulk from those provinces—represent the overwhelming majority of the population and MAID cases in the country.

That's only to say that, with the adequacy of the reports from a Criminal Code-MAID legal framework perspective, it's not difficult at all for provinces to examine that data and make their own assessments about compliance with the Criminal Code.

Mr. Michael Cooper: How can Canadians be confident that the criteria and safeguards are respected in each province and territory on a consistent basis?

Ms. Abby Hoffman: I mentioned this before. When we report, we're reporting on what the providers are saying about each and every eligibility criteria and each and every safeguard that's spelled out in the legal framework.

If you're asking if we have monitors out there or if provinces, for that matter, have on-the-ground monitors who are validating that data, the answer to that question is no. This is very similar to how things work in the health care system generally. People who feel aggrieved or wronged can complain. There are medical oversight bodies in Ontario. The coroner's office investigates and so on—

The Joint Chair (Hon. Hedy Fry): Thank you, Ms. Hoffman. I'm sorry. We're running very tightly here with time.

We go to Mr. Thériault now for two minutes, please, for the question and the answer.

[Translation]

Mr. Luc Thériault: Earlier, we read that 6% of the requests were deemed ineligible. I wonder, because we know that practitioners must justify the act of providing medical assistance in dying and that they can be investigated for certain practices.

[English]

Ms. Abby Hoffman: It certainly could be investigated but not by the federal government. Investigation of inappropriate practice is absolutely a provincial responsibility.

[Translation]

Mr. Luc Thériault: I haven't finished my question.

Requests that are deemed ineligible [*Technical difficulty*] are also investigated.

Does the data that you have collected show whether requests deemed ineligible are also investigated, not just the requests for medical assistance in dying?

[English]

Ms. Abby Hoffman: We don't have data on that, but presumably a person who is refused could pursue some further reconsideration of their case.

The Joint Chair (Hon. Hedy Fry): You have 41 seconds, Monsieur Thériault. It's not a lot, but you can have one quick question and one quick answer.

[Translation]

Mr. Luc Thériault: You indicated that 82.8% of the recipients had palliative care services. You said that they could be provided in a unit, at home, in a hospital, in a palliative care facility, and so on. Really, that's quite vague and quite broad.

Is getting pain medication in a hospital corridor considered palliative care?

[English]

The Joint Chair (Hon. Hedy Fry): I'm afraid you have three seconds, Ms. Hoffman, to answer that question.

Ms. Abby Hoffman: What's counted is what providers consider to be palliative care. I think they know what that is.

The Joint Chair (Hon. Hedy Fry): Thank you.

I will move to Mr. MacGregor for two minutes for the question and the answer.

Mr. Alistair MacGregor: Thank you.

Maybe what I'll do in the interest of my two minutes here is to front-load two questions.

First, and I'm sorry if you've covered this already, but out of the written requests, you said 12.7% of patients died prior to receiving medical assistance in dying. Is that primarily because they were so advanced in their state, or were there some unnecessary delays? Could you just illuminate that a bit?

My second question is how Canada's model is holding up in international discourse on the subject of medical assistance in dying. Are other countries seeking our official feedback when developing their own systems? Can you talk about whether other countries are looking to Canada as a model or anything like that?

Thank you.

• (2030)

Ms. Abby Hoffman: Very quickly on the first point, 56% of the people who died before their request was actioned died within 10 days, so clearly they were very close to the end of their life.

With respect to other countries, we know that New Zealand, for example, is in the process right now of developing its own regime. There has not, that I am aware, been direct outreach to the Government of Canada with regard to insight about the Canadian system. There may be all kinds of interactions going on within the provider community, researchers and so on, but I cannot comment on those specifically.

Mr. Alistair MacGregor: I'll leave it there, Chair.

The Joint Chair (Hon. Hedy Fry): Thank you very much. That fit nicely.

I want to thank our witnesses for coming and answering some fairly complex questions.

I would entertain a motion to adjourn the meeting. Thank you, Mr. Arseneault.

We will see you again next week, same time, same place.

The committee is adjourned.

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