WHAT WE HEARD REPORT
A Public Consultation on Medical Assistance in Dying (MAID)
March 2020

What We Heard

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What We Heard

Introduction

In early 2020, the Government of Canada consulted with people about the medical assistance in dying (MAID) law. Medical assistance in dying is when doctors help people to die when they are very sick and suffering a lot.

The Government did an online survey that the public could fill out. The survey was open for two weeks in January 2020.

The Government also consulted with other people. This included experts and stakeholders. Stakeholders are people who are very concerned about the issue. These consultations took place in January and February 2020.

This report is a summary of the information that was collected. It is called *What We Heard*.

Background

MAID became legal in Canada in June 2016. The *Criminal Code* of Canada was changed so that people who provide MAID can do it without breaking the law. Doctors and nurse practitioners can provide or help to provide MAID.

There are two ways that MAID can happen.

- A doctor or nurse practitioner can use medication to cause a person's death. This can only happen at the request of the person.
- A person can get medication or a prescription from a doctor or nurse practitioner. This can only happen at the request of the person. The person can then use the medication to cause their own death.

Canada's MAID law has conditions that people have to meet to be able to get to have it. There are also safeguards in the law. Safeguards are protections in the law to make sure it is used properly. Doctors and nurse practitioners must follow the safeguards before providing MAID. They must make sure the person requesting MAID understands what it means. They must also make sure the person has given their consent freely. Consent is when a person agrees and gives permission for something to happen.

There is more information on medical assistance in dying on the Government of Canada's website. The following topics are covered.

- Eligibility criteria (who is allowed to get MAID)
- Process for obtaining MAID
- Roles of the provinces and territories
- How Health Canada monitors and reports on MAID
- Independent reviews
- How Health Canada supports palliative and end-of-life care. Palliative care means providing medication and special care to limit a person's suffering while they are dying.

How MAID developed in Canada

Before it became law, the MAID legislation was called Bill C-14. It became law in 2016. The MAID law gave a choice to Canadians who were suffering extremely during the dying process. It allowed them to have a medically assisted death.

After MAID was law, the Government of Canada asked for some study on these three complex issues:

- The issue of requests for MAID that are made by mature minors. Mature minors are people who are under 18 years old who can fully understand the treatment they are asking for and the other treatments offered to them.
- The issue of advance requests for people who do not want MAID right now but may want it later.
- The issue of requests for people who have mental illness as their only health condition.

The Government asked the Council of Canadian Academies (CCA) to look at these issues. The reports on these issues are available on their website (CCA's website).

The 2016 MAID law said there had to be a way to monitor the system to make sure it is working properly. There are rules around what information needs to be shared about a MAID request, and when MAID is given to a patient. Doctors and nurses who provide MAID would have to report this information. These rules came into effect in November 2018.

The federal government will use this information to report to the public on MAID in Canada. The first report from the federal government is expected in spring 2020. For now, Health Canada has four shorter reports on their website (Health Canada's website). These reports are based on information the provinces and territories give.

The 2016 MAID law also requires a review by Parliament. The review is supposed to happen five years after the law was passed. The review should start in 2020. This review will give Canadians another opportunity to tell the government what they think about MAID. They can let the government know if any changes should be made.

Since MAID became law, there have been four court challenges in Canada. In British Columbia there was the *Lamb* case. In Quebec, there was the *Truchon* case. Both of these cases challenged the MAID law based on the eligibility conditions. The eligibility conditions are the rules around who is allowed to get MAID. The persons who brought the case to the court said the MAID law went against the *Canadian Charter of Rights and Freedoms* because it was too limiting.

In Ontario, there was the *Foley* case. In Saskatchewan, there was the *Katzenback* case. Both these cases also said the MAID law went against the *Charter*. But they said that the safeguards were not enough to protect people. They said people might be offered MAID instead of getting enough support services or other ways to reduce their suffering.

Background and purpose of the consultations

In the *Truchon* case, the Superior Court of Quebec ruled on September 11, 2019. The court found that it was against the *Charter* to limit access to MAID to only people who are expected to die.

This case was brought by two people living with disabilities. One was Mr. Truchon. He has lived with cerebral palsy since he was born. The other was Ms. Gladu. She lives with paralysis and severe scoliosis caused by poliomyelitis. The practitioners who assessed them said they met all the conditions for MAID except for one: they were not expected to die.

The court found that a condition in the *Criminal Code* was against the *Charter* and so was invalid. Quebec also has a provincial law on MAID. The court also found the same thing for a similar condition in Quebec's provincial law on medical assistance in dying. It was also against the *Charter*. Both the conditions are about the fact that the person is expected to die.

The *Truchon* ruling only applies in the province of Quebec. But the Government of Canada has accepted the ruling. And it has committed to changing the MAID law so it is the same for the whole country. The law was meant to help people who are suffering and dying to die more peacefully. The Government wants to change the law so that it would also help people who are suffering and who are not expected to die. This will mean that MAID can be used by people who are not expected to die, if that is what they choose.

Because of the changes it wants to make to MAID, the government wanted to know what Canadians think. The consultations asked their views on additional safeguards needed with the change. They also wanted to know what Canadians thought about circumstances where people say they want to use MAID after they lose the ability to give their consent for it. The Government made a survey available online from January 13 to 27, 2020. The Government also held meetings across the country.

Results from the Online Survey

In total, there were 300,140 responses to the online survey. Members of the public could do the survey directly online. They could also download a form to fill out. They could then send the completed survey by email or through regular mail. The survey was open for two weeks.

The online survey was monitored. This was to make sure that real people were filling it out and not 'bots.' There were some responses that were rejected. For example, one set of automated responses was rejected. This was about 1,000 responses.

There were also cases where the same set of responses was submitted more than once. They were sent by a person from four times up to 63 times. These surveys were not included in the total. Any response that was received after the deadline was not included.

The results are presented below. They follow the questions that were in the survey.

Demographics

Section A of the survey asked people where they live and what language they speak (what are called demographics). The sections below show the demographics of the people who filled out the survey.

Province or territory

The table below shows the number of people in each province or territory that responded to the survey. It also shows the percentage of people from each province or territory, compared to all people in Canada who answered the survey.

Ontario had the most responses at about 35% of everyone who responded. British Columbia had the second most responses at about 23%. And Alberta had the third most responses at about 12%.

Table 1: Province or Territory

Province or Territory	Number of Responses	Percentage of Total
Newfoundland and Labrador	5,021	1.7%
Nova Scotia	19,097	6.4%
Prince Edward Island	2,204	0.7%
New Brunswick	7,984	2.7%
Quebec	27,580	9.2%
Ontario	105,460	35.1%
Manitoba	10,563	3.5%
Saskatchewan	10,826	3.6%
Alberta	35,988	12.0%
British Columbia	68,410	22.8%
Yukon	856	0.3%
Northwest Territories	474	0.2%
Nunavut	113	0.0%
No Response	5,564	1.9%
TOTAL	**300,140**	**100%**

Urban or rural

The table below shows what type of place people who filled out the survey lived in. People were asked if they lived in a city (urban) or in a rural location. About 70% of the people lived in a city. About 27% said they lived in a rural area.

Table 2: Urban or Rural Location

Urban or Rural Location	Number of Responses	Percentage of Total
Urban	212,117	70.7%
Rural	82,000	27.3%
No response	6,022	2.0%
TOTAL	**300,140**	**100%**

Language of submission

The table below shows the language used by the people who filled out the survey. The language used was based on the version of the survey that was completed. Most of the people responded in English. About 92% responded in English and 8% responded in French.

There were also 153 surveys submitted in Chinese. An organization translated the original survey and made paper copies for a group of Chinese speakers. After these were reviewed and checked for accuracy of the translation, they were included.

There were also 26 responses received in sign language. This includes American Sign Language (ASL) and *la langue des signes québécoise* (LSQ).

Table 3: Language of Submission – All of Canada

Language	Number of Responses	Percentage of Total
English	275,741	91.9%
French	24,220	8.1%
Chinese (Traditional)	153	<0.1%
LSQ/ASL	26	<0.1%
TOTAL	**300,140**	**100%**

The table below shows the language used in the responses from people in Quebec. Most of the responses were in French at about 81%. About 19% of responses were in English.

Table 4: Language of Submission - Quebec

Language	Number of Responses	Percentage of Total
English	5.269	19.1%
French	22,285	80.8%
LSQ/ASL	26	<0.1%
TOTAL	**27,580**	**100%**

Eligibility for medical assistance in dying

Section B of the survey gave some background information about the MAID eligibility conditions. It was there to inform people who filled out the survey. This information is on the Government of Canada's website.

Safeguards to protect against misuse or abuse of MAID

Section C of the survey was about safeguards. The first question asked people about the current safeguards. It asked if these would be enough to stop abuse or misuse of MAID if the conditions to be eligible are opened up to people who are not expected to die.

The table below shows the responses to the first question. About 73% of people said that the current safeguards are enough. About 25% did not think they were enough.

Table 5: Safeguards to protect against misuse or abuse of MAID

Response	Number of Responses	Percentage of Total
Yes	219,281	73.1%
No	74,781	24.9%
No Response	6,108	2.0%
TOTAL	**300,140**	**100%**

The second question in Section C provided a list of possible safeguards. Some were suggested changes to safeguards that are already in place in Canada. Some are not currently in place in Canada. These safeguards are similar to the safeguards that other countries have around MAID.

The question was about using these safeguards for people who were not expected to die but who want to access MAID. In the question, the people all meet the rest of the conditions that allow them to use MAID. The question asked people to rate how important the safeguards in the list would be for people who are not expected to die. The ratings use a scale from 'not important at all' to 'very important.'

The table below shows the list of safeguards and how they were rated in the survey.

Table 6: Additional Safeguards

Safeguard	Not important at all	Slightly important	Important	Fairly important	Very important	No opinion	No Response
A. A different amount of time between the written request for MAID and having MAID. The current time is 10 days to reflect.	20.9%	13.6%	16.3%	16.3%	34.4%	4.1%	1.4%
B. MAID should only be available if all other treatments have been tried and did not work. Both the MAID practitioner and the patient have to agree on this.	16.1%	15.2%	17.5%	8.9%	38.5%	2.1%	1.7%
C. A psychologist or psychiatrist has to say that the person is able to consent to receiving MAID.	17.5%	16.0%	17.3%	8.9%	37.2%	1.7%	1.4%
D. Making sure the person asking for MAID is aware of all the ways that might relieve their suffering. This includes health and social support services. It can include counselling, disability support, or palliative care.	3.6%	6.0%	19.4%	7.2%	61.9%	0.6%	1.3%

Table 6: Additional Safeguards							
Safeguard	Not important at all	Slightly important	Important	Fairly important	Very important	No opinion	No Response
E. An expert in the person's medical condition would have to say the person is eligible. This is in addition to the two medical assessments already required.	27.8%	16.7%	13.7%	8.9%	29.7%	1.8%	1.4%
F. Past MAID cases would be reviewed by a committee. The committee would see if the eligibility conditions were met and the safeguards followed.	18.9%	15.9%	19.8%	9.2%	32.0%	2.8%	1.5%
G. Special training and tools to help MAID practitioners to see if there was any worry about a person who is asking for MAID. These could be mental health issues or outside pressures to take MAID.	3.5%	7.3%	20.3%	10.4%	55.9%	1.1%	1.4%
H. MAID practitioners would have to offer to discuss the patient's situation with family or loved ones. This would be done with the patient's consent.	12.0%	12.1%	20.2%	12.3%	40.1%	1.9%	1.5%

The third question in Section C was a place where people could fill in their own comments. The question asked if there were any other comments about possible safeguards for people who are eligible for MAID but who are not expected to die.

The table below shows the number of people who gave comments. Almost 32% of the people who answered the survey gave comments for this question.

Table 7: Number of Respondents Providing Comments in C.3.		
	Number of Responses	Percentage of Total
Comments added	95,473	31.8%
No Response	204,667	68.2%
TOTAL	**300,140**	**100%**

In this report, the section **Summary of Comments** has the contents of the responses. They are discussed by theme. This section is coming later in the document.

Advance requests for MAID

Section D of the survey was about what some people call "advance requests". In the question, people were given situations and asked if they agree or not.

The situation for question 1 was as follows.

> Imagine that a person makes a request for MAID. They are found to meet the eligibility conditions. They are waiting for the procedure. But something happens to the person a few days before they are scheduled for MAID. They lose their ability to understand their situation and make decisions about their health care. They cannot provide the final consent needed just before the procedure. In your opinion, should a doctor or nurse practitioner be allowed to provide MAID to a person in this situation?

The table below shows the responses to this question. About 78% of people said 'yes' to this question.

Table 8: Advance Request for MAID, Question D.1.

Response	Number of Responses	Percentage of Total
Yes	235,852	78.6%
No	59,174	19.7%
No Response	5,114	1.7%
TOTAL	**300,140**	**100%**

The situation for question 2 was as follows.

> Imagine that a person is diagnosed with an illness that will affect their mind over time. It will take away their ability to understand their situation and make decisions about their health care. Alzheimer's disease is an example. The person prepares a document that says they might want to receive MAID at some point in the future. In the future they might be sick and suffering a lot. At that time they might not have the ability to ask for MAID. They say in the document that they want MAID at that time even if they can't ask for it. In your opinion, should a doctor or nurse practitioner be allowed to provide MAID to this person in this situation if they no longer have the ability to give consent for it?

The table below shows the responses to this question. About 79% of people said 'yes' to this question.

Table 9: Advance Request for MAID, Question D.2.

Response	Number of Responses	Percentage of Total
Yes	238,431	79.4%
No	57,350	19.1%
No Response	4,359	1.5%
TOTAL	**300,140**	**100%**

The third question in Section D was another place where people could fill in their own comments about these situations.

The table below shows the number of people who gave comments. Almost 32% of those who submitted the survey gave comments for this question.

Table 10: Number of Respondents Providing Comments in D.3.		
	Number of Responses	**Percentage of Total**
Comments added	95,608	31.9%
No Response	204,532	68.1%
TOTAL	**300,140**	**100%**

In this report, the section **Summary of Comments** has the contents of the responses. They are discussed by theme. This section is coming later in the document.

Additional comments

Section E of the survey provided a final place for people to give any additional comments. The table below shows the number of people who gave final comments. About 21% of people left additional comments. These responses are discussed in the next section.

Table 11: Number of Respondents Providing Additional Comments in E.3.		
	Number of Responses	**Percentage of Total**
Response	63,492	21.2%
No Response	236,648	78.8%
TOTAL	**300,140**	**100%**

Summary of comments

Overall, there were more than 254,000 comments. These were made over 136,144 responses. A comment had to have more than five letters to be counted.

There were so many comments that they had to be sorted by a computer. They were sorted by the theme or topic of the comment. This was done by searching for certain key words and phrases. Then researchers read the comments and analysed them.

The researchers found eight themes. The themes are described below.

1. Safeguards
2. Advance requests for MAID
3. The right to die
4. Concerns about mental illness and mature minors
5. Opposition to MAID
6. Personal experiences
7. The role of the family in MAID
8. Specific concerns about MAID

There is a summary of the comments for each theme in the next section.

Theme 1 – Safeguards

Most comments about this theme did not support more assessments by doctors and nurse practitioners when a person asks for MAID. There were many concerns that this would increase delays and people would suffer more. There were concerns that people who lived in rural or remote areas would have even more delays.

There were also concerns that assessments would not be available in rural or remote areas, so people wanting MAID would have to travel to a city to be assessed. This would cost money and some people would be unable to pay. It would also be hard for people to travel when they are already suffering.

Some people suggested that we need accessible and quick consultations with medical practitioners. There were suggestions to use video conferencing. There were also suggestions to use computers and mobile devices to access health care services in rural and remote areas. There were also suggestions to have medical practitioners travel to the rural and remote areas. Some people suggested that the expert assessment should be required to be done in the 10-day period to reflect or the same kind of short period.

There were different views on the length of the period to reflect. Some felt that 10 days was long enough. Others wanted to see it be made shorter or removed in certain situations. This would be when a person is going to die very soon. It could also be done when a person is in distress with no chance they will improve. They wanted this done to reduce the amount of suffering.

But other people wanted to see the period to reflect made longer. They felt this should be done for people who request MAID but who are not expected to die. It could also be done for people who are not getting worse very quickly.

Theme 2 – MAID through advance requests

There was a clear majority of people that supported advance requests for MAID as an option. The two questions in Section D that were about advance requests show the support of about 78% and 79% of the people who responded.

Some suggested safeguards for advance requests. There could be regular reviews and renewals of the request. There could be regular follow up by medical practitioners. This would show if there are new questions, concerns or decisions to be made. This could confirm whether the person still wants to make an advance request.

Some felt that patients should not have to give consent for MAID just before they get it. They felt this was especially true for people with diseases that affect the brain or people who have conditions that will not get better. Many people pointed out that the reason a person makes an advance request is because their health is getting worse and they want to avoid suffering at a time when they can no longer request MAID.

In the comments, people stressed the right to withdraw consent at any time for those who can give consent just before they get MAID. Some people pointed out that if a person is no longer able to say yes, then they are also no longer able to change their mind. They think the request that was made when they were of sound mind should stand.

There were some concerns that people may choose to get MAID earlier than they want. They do this because they are afraid they might lose their ability to consent at the time of the procedure. Some people said that an advance request is like a will, a Do Not Resuscitate (DNR) order or agreeing to organ donation. They felt it was not right to disregard a request made earlier. They think it will mean that patients will have to suffer more.

Some people suggested a process could be required for these cases. This could include the person naming someone who can make the decision for them if they lose their ability to consent.

In the comments, there were some personal stories told by family members. They had loved ones with illnesses like dementia, Alzheimer's, ALS (Lou Gehrig's disease), Huntington's, and Parkinson's diseases. There were some concerns about the role of family members. This included whether or not family members could ask for MAID for their loved one. It also included whether or not they should be allowed to change what the patient asked for.

Many felt that it was important for people to have the option to make an advance request for MAID. They also felt that advance requests should be followed. They felt that if the person went through all the steps for their advance request that they should get it even if they lose the ability to consent at the last minute. They felt that the person should have MAID unless they show fear or they resist just before the procedure.

Theme 3 – The right to die

Most of the responses were focused on the person's right to choose when to die, no matter what the situation. Many people referred to how we treat our pets. It was said that we give them more compassion than our fellow human beings. There were calls for less 'red tape.' People also said the process should be as simple and easy to get as possible. Many argued that it is important to honour the wishes of the patient and grant them dignity in dying.

Theme 4 – Concerns about expanding the eligibility for MAID

The comments under this theme included worries about letting more people have MAID. This would be for those who suffer from mental illness and mature minors.

Most of the comments were not in favour of expanding MAID to people who suffer from mental illness. They had concerns that people who had an illness such as depression may feel that MAID is their only option. But there may be effective treatments that could help them to feel better.

Instead of letting more people have MAID, many felt there should be a different focus. They felt that more should be done to help people. This included more options and tools for people with mental health issues. It also included more resources for people with physical disabilities.

Some people said there was a danger that people with different kinds of disabilities could be influenced or pushed by other people. They may also feel like they are a burden to their family and friends. They may also feel like a burden to the health care system. Some people suggested that there should be different, specific conditions for these groups to have MAID.

But others felt that people with mental illness should be eligible for MAID in certain situations. This would include where the mental illness is really affecting the person and where treatment does not work. Some noted that mental health conditions can cause as much suffering and pain as physical conditions. Mental health conditions may not respond to treatment. Sometimes this can make people attempt suicide in dangerous ways rather than ending their life in a safe way.

Most people did not support MAID being expanded to minors. They said minors are still growing and changing. They could make a decision that cannot be reversed and die before their time. Other people agree with minors being able to have MAID. This would be where the young person is expected to die. The proper safeguards would have to be in place.

Theme 5 – Opposition to MAID

This theme was about being against MAID in general.

Some of the surveys were 'form responses.' These were surveys that had the exact same response for each question. They were submitted individually. There were thousands of surveys like these. They all said the same thing. They were opposed to the idea of MAID in general.

In these form responses, comments included the following: people who are sick must be encouraged to embrace life and not seek out suicide; advance requests would make it impossible for a person to change their mind; and MAID is just another word for murder.

Other form responses made it clear that governments should be putting more money into palliative care instead of offering MAID. Some were concerned that there is not enough supervision of the MAID law.

Some responses said that the end-of-life condition to receive MAID protects vulnerable people with disabilities and mental illness. Others felt that this condition limits a person's access to MAID and may trap them in unbearable suffering.

There were also concerns that MAID would be cheaper than treating people with chronic illnesses and disabilities.

Some said that they were disappointed with the consultation questions. They said it forced them to agree with MAID in order to argue about giving more people the ability to have it.

There were other responses, than the "form responses" that were opposed to MAID.

The focus of the comments on this theme was on the importance of human life and the value it has to offer. Many said that life has a value all of its own. They said that MAID violates the sacred nature of life. One person wrote that "life is a gift of God, and God is the giver and taker of life." Many other people agreed with that person.

In addition, many said that MAID is a way for the government to reduce its financial costs. They said this would happen by government using MAID to speed up the deaths of elderly, disabled or sick people who are seen as costing society a lot of money.

Many people also thought MAID was a 'slippery slope.' They said it opened the door to government helping people die when that would be good for the government in some way.

Along the same lines, many comments made note of the practitioners who could be asked to provide MAID. They said it was immoral for the government to force health care professionals to perform MAID. It would put them in a situation where they are forced to end someone's life.

Overall, the responses about this theme stress that life is precious. They say that it is not the government or medical professionals who should control when life ends.

Some said that there was no place for religious objections to MAID in our society. These religious objections should not be pushed on those who do not have the same beliefs.

Theme 6 – Personal experiences

This theme included personal stories from thousands of Canadians who shared their first-hand experiences with MAID.

In many of the stories, the person's loved ones did not have access to MAID. In some cases, this was because their illness happened before the MAID laws. In other cases, it was because their loved one was unable to give consent. Many made comments about the poor quality of life for those who are suffering or who have a lot of pain for a long time.

Some commented on how they had witnessed MAID. They said people were surrounded by friends and family. They said it gave the person receiving MAID compassion and dignity.

There were also many comments about people who stop their pain medication so they can keep the ability to give consent at the last minute. Most of these comments said that the MAID law needs to let people have MAID even if they can't give consent at the last minute.

Theme 7 – The role of the family, caregivers and loved ones

Comments on this theme were about the role of family members, caregivers and loved ones. In Part D, many people left comments about the role of those who are close to the patient or involved in their care and support. For example, many people commented that family members must be involved in decisions about MAID.

Another view was that the person's decision must be respected. This is regardless of what the family members might want or believe. There were many suggestions of ways to make MAID easier for people who are not able to consent. This included having legally binding documents. It also included having video recording requests. There was a suggestion to have a panel of experts for this type of MAID request. It was also suggested that people could be allowed to choose a person they trust to make decisions about MAID for them.

Theme 8 – Specific concerns about MAID

The comments showed a clear demand for more money for different kinds of services. This was for better long-term, palliative, and mental health care. People also felt that better support would reduce the need for MAID. This included better social support, counselling, and disability support. This would improve the quality of life for people.

There were also many comments that showed concern for the mental health of people who have to provide MAID. They said that health care professionals need to have their cultural, religious, and personal values respected. Some people commented that forcing doctors and nurses to take part in

MAID violates their rights. Other people commented that publicly funded hospitals should not refuse to provide the services the public needs.

Perspectives from the Roundtables

Along with the online survey, there were also roundtable meetings held across the country. The meetings took place between January 13 and February 3, 2020.

The roundtable meetings were hosted by three ministers. The Minister of Justice, the Minister of Health, and the Minister of Employment, Workforce Development and Disability Inclusion hosted 10 in-person roundtable meetings.

The meetings were held in the following cities across the country.

- Halifax, Nova Scotia
- Montreal, Quebec
- Toronto, Ontario
- Vancouver, British Columbia (2 meetings)
- Calgary, Alberta
- Winnipeg, Manitoba
- Ottawa, Ontario (2 meetings)
- Quebec City, Quebec

These meetings allowed the three ministers to hear from over 125 experts and stakeholders on key issues. The experts and stakeholders included people from the following groups.

- Doctors and nurse practitioners
- Organizations that make rules about health care
- Key health stakeholders
- Legal experts
- Disability community
- Civil organizations

In addition, the ministers hosted a separate roundtable for Indigenous practitioners and community leaders. The meeting was focused on getting specific feedback from this group.

People in all the roundtables had a wide range of views on all the MAID issues. There is a summary of those views in the next section.

Eligibility conditions

A clear MAID law

In the roundtable meetings, some people said the main terms of the MAID law must be clear. This is very important with respect to criminal law. There are serious consequences if a person breaks the law.

Some people noted that there were differences in the way certain terms and words are understood. These terms are in the eligibility conditions. This includes the following terms.

- Reasonably foreseeable natural death
- Grievous and irremediable
- Incurable
- Advance state of irreversible decline

Some noted that if the term 'reasonably foreseeable natural death' was removed it could make other parts of the law more important. For example, the condition that the person must be in an 'advanced state of irreversible decline' in their capacity would be more important.

Some stakeholders said that the rest of the eligibility conditions would be clear enough to determine if a person was eligible for MAID. They said it would not be necessary to pass more laws on eligibility conditions.

Many noted that the law should not be too strict or inflexible. This would allow each MAID request to be assessed on a case-by-case basis.

Access to MAID and having enough practitioners to provide MAID

In the roundtable meetings, some people said it was important that everybody had access to MAID. Certain people warned that if the law was not clear, it could reduce the number of practitioners who are willing to provide MAID. If doctors and nurse practitioners felt that parts of the MAID law were not morally right, this could also reduce the number of those who are willing to provide MAID.

Some people thought that the *Truchon* decision might lead to more MAID requests. This could depend on how the law was changed in response to the decision.

People noted that the amount of people asking for MAID could have an impact on access. They also noted that the amount of MAID practitioners could have an impact on access as well. These things could make it harder for some people to actually get MAID. All levels of government would need to deal with this.

Scope of eligibility

There were discussions about letting people who are not expected to die have MAID. Some people asked questions about how this would change things.

Most people at the roundtables had concerns about people with mental illness having MAID. They said it would be very hard to tell if a person was able to make health care decisions if they have a mental illness. They said it is hard to know if a mental illness will get better. They said it would be a challenge to put a safe system in place for people with mental illness. This is especially true because of the eligibility condition that an illness needs to be 'incurable.' This term is not used in the mental health field. It is also hard to know enough about the person's suffering in the case of a mental illness.

Even though they had these concerns, some people noted that stopping people with mental illness from having access to MAID would be discrimination. Some felt it was too early to let people with only a mental illness use MAID. They also felt that evaluating MAID request from these patients would take a lot of resources. These resources may not be available. Doing this may also take away resources from patients who want to get treatment for their mental illness.

Other people had concerns about providing MAID to people who had recently had a traumatic injury or became disabled. They said there needs to be a period of time when people are not allowed to apply for MAID after their injury. This would give the person time to adjust to their new situation.

Some people who represented disability rights organizations said they were disappointed that the Government of Canada decided not to appeal the *Truchon* decision. They thought the MAID law was already careful and balanced. It allows for people who are expected to die to access it but prevents anyone else from using it. They said the role of the "reasonably foreseeable death" condition is to protect against the harm to society that might happen if disability was a reason to end life. They felt that removing this condition would make disability or illness a reason to end someone's life, which is not the case for any other personal feature.

Some disability organizations said that a law that compares disability with the eligibility to die would be subject to a *Charter* challenge. They said this could violate section 15 of the *Canadian Charter of Rights and Freedoms*. This section has to do with equality rights. They noted that this had not been considered by the courts in any real way.

Indigenous individuals and practitioners noted unique challenges for MAID in their communities. This is a result of a history of trauma for many generations of Indigenous people. Many spoke about the harmful experiences that Indigenous individuals have had with the health care system.

This includes having procedures against their will. There are also ongoing challenges in getting culturally safe care. There is limited access to the health care system and discrimination in the way health care is provided. There were concerns about expanding the MAID system outside of the end of life. Some were worried that Indigenous patients may choose MAID because they don't have access to adequate health care services. This includes palliative care programs. It also includes options to help people who have a lot of pain and who have mental health issues. Some also worried that Indigenous patients could choose MAID because of outside pressures like a lack of housing.

It was noted a number of times that access to MAID in general is more limited in remote and northern communities. Some questioned how a broader and more complex MAID regime could be put into place in these communities.

Safeguards

Existing safeguards

The people who took part in the roundtable discussions strongly supported getting rid of two safeguards. The first is the need for two independent people to witness the signature on the written request. The second is the 10-day period to reflect. They said that these two safeguards can cause unnecessary suffering or keep people from accessing MAID.

Some practitioners noted that in most cases the patient has already thought about MAID for a long time before they ask for it. It is also likely that they spoke to their family and their health care team.

Others noted that having two witnesses does not give any more protection. They said people who cannot find two independent witnesses will simply get strangers to witness their request.

Some noted that it can be hard for some people to find two independent witnesses. This is especially true for people who live in long-term care facilities.

Possible new safeguards

Many people at the roundtable meetings noted that a number of the possible new safeguards are already in place in standard medical practice. This includes having additional consultations. This also includes telling the patient about all of the ways available to relieve their suffering. It includes involving their family members in the discussions.

People said that directives on MAID need to be developed. They said the delivery of MAID needs to be more consistent across Canada. This should not get in the way of access to MAID.

There were mixed views on the idea of a safeguard that required an agreement between the practitioner and patient that all options have been tried. They said this was not in line with a patient-centered approach to health care. They also said that requiring treatment might impact a person's autonomy to make their own health care decisions. But there were others who thought this was a necessary safeguard. They thought it would protect people who are at risk, especially people with mental illness.

A number of people at the roundtable meetings noted that they did not believe a psychiatric assessment would be necessary for all MAID requests. They also felt it could decrease access in some areas. This is especially true in rural, remote, and Indigenous communities. Access to mental health professionals is already very limited in these areas.

Many people suggested that a two-track system of safeguards be introduced. This would depend on the person's situation, such as whether they are expected to die or not, and whether they have a physical illness or a mental illness.

Some disability rights organizations felt like this system would be a good way to protect vulnerable people, and would not place more burdens on people who are expected to die. But some people thought that making extra safeguards for certain medical conditions might not be good. They thought this might add shame or stigma to certain medical conditions. But this would depend on how this system was approached if it were to be used.

Some Indigenous people at the roundtable said that the best safeguards for Indigenous people would be more services. They said that appropriate medical care needs to be provided. And that health services and mental health care need to be available.

Many said that cultural safety was a key safeguard needed for Indigenous people in relation to MAID. They said it would be important to train health care providers to deliver culturally safe care.

Some Indigenous people at the roundtable highlighted the differences in how Indigenous people view death and dying. They stated that there is a need for guidance from Elders and spiritual leaders. This would help to make sure MAID is done in a way that is culturally safe and appropriate. Some stakeholders said it was difficult to talk about MAID and advance requests in the North. Many patients speak a different language. Certain words and terms in the MAID law do not exist in their language. This makes communication about MAID difficult.

Waiver of final consent and advance requests

A waiver of final consent means that the need to give consent for MAID immediately before it is provided, also called “final consent”, does not apply and does not have to be given.

Many people at the roundtable meetings were comfortable with the idea of allowing advance requests for certain persons. This would apply to those who have been approved for MAID but are at risk of losing their capacity before MAID is provided. Some argued that these situations result in less uncertainty for the practitioner as to what the patient wants. They said this could avoid situations where a person suffers because they have reduced their pain medication in order to keep their capacity. Some noted that Quebec’s Expert Group on Incapacity and Medial Aid in Dying supports advance requests for MAID in these situations.

Many people said that advance requests are more complex when they are done after the diagnosis of a condition that limits the person’s capacity, but before the person is found eligible for MAID. They thought this situation needed more reflection, consultation and study. This was similar to the findings in the report by the expert panel on advance requests by the Council of Canadian Academies.

Several people who represented disability rights organizations had strong concerns about removing the need for final consent by allowing advance consent for MAID. They also had concerns with any form of advance request. They recommended that these issues be addressed during the Parliamentary Review process.

They said there was not enough time to review this topic. They said there were many concerns about allowing ‘proxy consent’ or substitute decision making for MAID, which means that the decision is made by someone else. They had concerns that substitute decision making might be allowed in broader situations in the future if it was first allowed in the case of a person who is approved for MAID.

There were others outside the disability rights area that were also concerned about the idea of a substitute decision maker for MAID. They noted the challenges for people at risk who do not have close family or friends that could act as a substitute decision maker in their best interests.

Some people noted that the general idea of advance requests is not in keeping with the objective of MAID to ensure a person’s autonomy until the end of their life. They said people often have trouble saying how they will react in the future in certain situations. For example, a person with dementia may not be unhappy like they thought they would be as a result of their illness. A patient’s anxiety may decrease as their disease progresses. Sometimes, an effective treatment may become possible for a patient.

Some doctors and nurse practitioners stressed that they would hesitate to provide MAID to persons who have lost the ability to consent before the procedure, even if the person has already been approved. They argued that an advance consent should only be valid for thirty days. They said they would be uncomfortable providing MAID based on consent given more than 30 days ago.

Practitioners indicated wanting to think about the ethical issues related to advance requests. They said it would be hard to provide MAID to a person who has an advance request but who now seems content or even happy. The same was felt about someone who is resisting the MAID procedure through words or gestures.

Miscellaneous

Access to alternative treatments, supports and services

Many people at the roundtables stressed the need for improved health care and social system supports. These are needed for palliative and disability services. They would help to protect people by preventing them to choose MAID because there are not enough supports. The same applies to mental health and suicide prevention services. Some disability groups were concerned that some people may choose MAID because they cannot access the supports to relieve their suffering.

Some people warned that any changes to the MAID law should not put people at an advantage for services because they requested MAID. It should not disadvantage people in other situations who do not want MAID, but who want to have access to the same services in order to receive help and have a better quality of life.

It was noted by some people that individuals make decisions based on their real world situation. They should not be denied access to MAID because of a lack of resources for other services.

Oversight

The comments relate to how the MAID system in Canada is monitored.

Some people at the roundtables said that the Canadian oversight system could be improved. Some noted that the federal monitoring system does not perform a true oversight function. They noted that the process should be more transparent and understandable. They referred to practices in the Netherlands. In that country the work of the MAID review committee is available to the public.

A number of practitioners thought that the review of past cases is important. They said high-level information that combines many cases is not detailed enough. It is not much help to medical professionals. It is also not much help to groups that make rules around health care.

Some people gave examples of good models to follow. One example was Quebec's *Commission sur les soins de fin de vie*. Another example was Alberta's MAID review committee.