

# Knowing Your Rights Toolkit: Sexual and Reproductive Health



Native Women's Association of Canada

L'Association des femmes autochtones du Canada

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**Disclaimer:** Content in this toolkit contains information and discussions on the common causes of trauma, such as forced or coerced sterilization and traumatic health care experiences, which may trigger trauma. If you need support at any time, please call the Hope for Wellness Help Line at 1-855-242-3310.

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# **About this Toolkit**

As of April 2019, over 100 Indigenous women from across Canada have come forward to say that they were forced or coerced to undergo a sterilization procedure. Of these women, most had not been offered other forms of birth control and were only given inadequate information about sterilization. Some of these women recall feeling pressured, if not threatened, by health care providers to consent to a sterilization procedure — without fully understanding the procedure's risks or permanency. In some cases, sterilization procedures were conducted despite the women expressly refusing to provide consent and/or sign a consent form.

In response to the forced or coerced sterilization of Indigenous women, advocates, experts, and leaders have since called for systemic, sweeping changes to the health care system. Their recommendations include making changes to accountability standards and to legislation and policy; providing education and training on cultural safety, informed consent, and anti-racism to health care providers; and offering Indigenous-specific services and supports, including education on patient rights and responsibilities and informed consent.

With funding from the First Nations and Inuit Health Branch of Indigenous Services Canada, the Native Women's Association of Canada (NWAC) was able to hold engagement sessions with Indigenous women to explore sexual and reproductive health needs and priorities. In these sessions, participants highlighted a gap in sexual health education and a need to empower and raise awareness among Indigenous women on their rights within the health care system; their understanding of their options when it comes to sexual and reproductive health; and the need for information on what to do when those rights are abused. The participants stressed there is a lack of trust between Indigenous community members and mainstream health services, which leads to hesitancy on the part of Indigenous community members to use these services — and, ultimately, to poorer health outcomes.



From these engagement sessions, NWAC developed this toolkit. This resource aims to provide education that empowers First Nations, Inuit, and Métis women, girls, and gender-diverse people to "know their rights" in the context of sexual and reproductive health. The toolkit includes resources on:

- **Informed Consent:** Explore the meaning of free, prior, and informed consent, its application in health care, and what to do when it is not followed.
- **Patient Rights:** Gain a deeper understanding of your rights within the health care system to better protect and advocate for yourself.
- **Birth Control Options:** Delve into birth control options including their permanency, efficacy and side effects, so you can make an informed choice about what is best for you.
- **Informed Choice:** Learn how to make an informed choice based on your personal knowledge, preferences and values using the informed choice decision-making tool.
- Filing a Complaint: If you feel that you have not given informed consent for a procedure, follow our step-by-step guide on how to file a complaint with health care governing bodies, appeal a decision and seek legal action.



# Knowing Your Rights: Informed Consent

# Free, Prior, and Informed Consent

Consent in the context of health care must be free, prior, and informed. Informed consent originates from a person's right to direct what happens to their body and is an ethical and legal obligation of health care providers.

# What is meant by free?

The individual must have "decision-making capacity" to consent. It must be a voluntary decision that is **freely** given without undue pressure or coercion.

# What is meant by prior?

The individual must be given the opportunity to consent well **before** the medical intervention and **after** the health care provider has educated them about the details, risks, benefits, alternatives, and expected outcomes of said intervention.

The health care provider is responsible for providing accurate information that is not misleading and must ensure that the consenting individual understands this information. The provider must ensure that the consenting individual is aware that they are the main voice in the decisionmaking process, and ultimately determine their own medical course of action.



# What is meant by informed?

For consent to be "informed," a health care provider must provide and document the following:

- 1. The nature and description of the intervention
- 2. The benefits and risks of the intervention
- **3.** Outcomes of the intervention (how the intervention will affect the individual)
- **4.** Reasonable alternatives to the intervention and their respective risks and benefits
- **5.** Consequences of abstaining or refusing the intervention (what will happen if the person chooses not to have the intervention)

### What are the pillars of consent?

- 1. Consent must be informed: it is the patient's right to have adequate information before either agreeing to or rejecting a given medical course of action.
- 2. Consent must relate to the proposed intervention: consent for one intervention does not necessarily simply consent for another.
- **3.** Consent must be provided independently and voluntarily: the consenting individual should not feel pressured or forced into making a decision.
- 4. Consent must not be obtained through misrepresentation or fraud: the information given must be accurate and unbiased.



# What is "capacity to consent"?

Capacity to consent is the ability to understand information and make a decision based on that information. It is presumed that all adults have sufficient capacity to decide on their medical course of action, unless evidence suggests otherwise. There are various situations where an individual can lack capacity to make a decision at the time. For example:

- **1.** Physical or mental conditions that cause loss of consciousness or drowsiness
- **2.** Intoxication due to alcohol or drugs (recreational or medicinal), including anesthesia
- 3. Severe learning disabilities
- 4. Brain damage due to injury or stroke
- 5. Mental health conditions, including schizophrenia or bipolar disorder
- 6. Dementia

An individual **cannot** provide informed consent if they **cannot** understand the information provided to them, **cannot** remember said information, or **cannot** make a decision based on the information. If the health care provider questions the individual's capacity to make decisions, they may request a competency evaluation by a psychiatrist. This step should only be executed for the individual's safety and not when an individual disagrees with their physician's course of action.

# When is informed consent not required?

Exceptions for the requirement of informed consent include:

- 1. *Emergencies:* Informed consent may be waived during emergency situations. A health care provider may not be able to obtain informed consent due to time constraints and may make decisions to save their patient's life.
- 2. Incapacitation: If an individual does not have the capacity to consent and a surrogate decision-maker is unavailable, a health care provider may proceed with medical treatment without informed consent.





#### **Reproductive rights**

According to the United Nations Population Fund (2014), reproductive rights are a component of human rights. You have the right to:

- 1. Decide the number of children you have or do not have;
- 2. Decide the spacing and timing of your children; and
- 3. Have access to safe and dignified health services.

# What if informed consent protocols aren't followed?

Medical interventions conducted without your free, prior, and informed consent is a **violation** of your human rights, medical ethics, and reproductive rights. It is the physician's obligation to ensure that you have accurate, up-to-date information on the details, risks, benefits, alternatives, and expected outcomes of any intervention. You are the main voice in the decision-making process and as such have the last say over your medical course of action. If this is not done, you have the right to complain and seek restitution. Please see the "How to file a complaint" section in this toolkit.



# Scenario

# Not Free, Prior, and Informed Consent

A young woman in university goes to the clinic requesting birth control. The physician says, "You people have too many kids, at such young ages. You don't take the medications a doctor prescribes and aren't responsible. It is best for you to have an IUD; that way you won't have any accidents that result in pregnancy." The doctor then proceeds to book an appointment for the woman to have an IUD.

### Free, Prior, and Informed Consent

The doctor takes the time to explain all methods of birth control with the woman without making any assumptions. She goes through all the contraception methods from least to most invasive while outlining the efficacy, risks, and benefits of each method. The doctor ensures that all the information she is providing the woman is accurate, up-to-date, and clear. The doctor frequently stops to ask the woman if she has any questions or needs anything clarified. The doctor then asks the woman to decide which option is the best for her and clearly documents how the woman would like to proceed.

A young woman goes to the hospital explaining that she missed her period. She is anxious and mentions that she may be pregnant. The doctor orders some tests that verify that she is, in fact, pregnant. The nurse asks her to sign some forms and tells her to come back in 10 days. At that time, she is put under anesthesia and when she wakes up, she is advised that she is no longer pregnant; the doctor informs her that they performed an abortion. Puzzled, she asks why. The doctor informs her that she is much too young to have a baby and she seemed anxious when she first came into the hospital, so the doctor thought they were doing the right thing.

After confirmation of the pregnancy, the physician sits down with the woman and asks her what she would like to do next. The doctor outlines all of her options and goes through the risks and benefits of each. The doctor does not expect the woman to make a decision right then, instead recommending that she take a few days to think about it. The doctor advises her to speak to people she trusts like family, Elders, or counsellors. The woman returns to the clinic the next day and advises the doctor that she would like to continue with the pregnancy. The doctor offers her a warm congratulations and reviews the next steps with her.

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# Scenario

# Not Free, Prior, and Informed Consent

A woman goes to the hospital to deliver her sixth child. Three of her previous children are living with foster families and her other two live with her mother.

The woman's labour becomes complicated and the baby's heart rate starts to drop. The doctor informs her that she will need a C-section, or her baby will die. The doctor tells her that she will also be tying her tubes during the C-section. The woman consents to the C-section but not the tubal ligation. The doctor is frustrated and tells her that she must consent: if she doesn't. the doctor will contact Child Protective Services and they will take her baby away. The doctor tells her that she has too many children in care and that she cannot take good care of her children. She says the woman is putting a burden on the system and must be stopped from conceiving. She then goes on to tell the woman that tubal ligation is a temporary, effective form of birth control and once the woman gets her life in order, she can get the procedure reversed. The doctor informs her that the longer she puts off signing the forms, the longer it will take to get her to an operating room and the longer her baby will be in distress. She is provided with consent forms, which she signs out of fear for her unborn child.

One month before the woman's due date, her doctor schedules an appointment where birth control following delivery are discussed. The doctor goes through all the contraception methods from least to most invasive while outlining the efficacy, risks, and benefits of each method. The doctor ensures that all the information she is providing the woman is accurate, up-to-date, and clear. The doctor frequently stops to ask the woman if she has any questions or needs anything clarified. The doctor then asks the woman to decide which option is the best for her and clearly documents how she would like to proceed. On the day of delivery, when the unborn child starts to show signs of distress, the doctor approaches the woman and has a clear, concise conversation with her about needing a C-section. A description of the procedure, the risks, benefits, and alternatives are all laid out clearly. The woman consents to a C-section and because the doctor already knows which method of birth control the woman prefers, they did not have a conversation about tubal ligation.

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# Scenario

# Not Free, Prior, and Informed Consent

A woman has been in labour with her second child for about 16 hours. She is finally dilated enough to start pushing. Ten minutes into pushing, she hears her doctor say, "I'm going to perform an episiotomy now." Confused, the woman asks for clarification. The doctor replies in an annoyed tone "an episiotomy. I am going to cut the skin of your perineum to make delivery easier." The woman pleads with the doctor not to cut her, to which he replies, "It's already done. Calm down and focus on pushing."

## Free, Prior, and Informed Consent

One month before the woman's due date, her doctor schedules an appointment with her to discuss labour and delivery. The doctor walks the woman through various options on what might happen when she goes into labour. The doctor is comprehensive about all the potential options, including the use of medication to speed up labour, the use of an episiotomy, the use of tools including forceps and vacuum, and the potential for a C-section. The doctor clearly outlines the risks, benefits, and alternatives for each option and clearly documents how the woman feels about each option. Instead of medical jargon. the doctor uses illustrations and photos to ensure the woman understands every option. When the woman is in labour, the doctor determines that an episiotomy may be a good next step. He walks over to the head of the bed and explains to the woman once again what an episiotomy is, why he needs to do it, the risks and benefits of the procedure, the expected outcomes, the alternatives, and the consequences of foregoing the procedure. Understanding her options, the woman consents.

A woman pregnant with her first child underwent standard screening tests at 12 weeks of pregnancy. They revealed that her unborn child may have Down's syndrome. The doctor told her that the only next step was to have a procedure called an amniocentesis to find out for sure. The doctor explains what the procedure is, has the woman sign a consent form, and schedules an appointment. After the procedure, the woman started to experience cramps and had a miscarriage a few days later. What the doctor neglected to tell her was that the procedure posed a risk of miscarriage. Upon reviewing the results of her screening, the doctor lays out all the woman's options, including amniocentesis. The doctor explains the risks, benefits, and alternatives to the procedure while ensuring the woman understands all the information that is being provided, including the risk of miscarriage.

# Knowing Your Rights: How to File a Complaint

I suspect a health care provider violated my rights. What can I do?

Step 1: Seek culturally safe supports
Step 2: Explore what has happened
Step 3: File a complaint
Step 4: What to do after a complaint is filed
Step 5: What happens when your complaint(s) are unsuccessful?
Step 6: Consider pursuing legal action



### Step 1: Seek culturally safe supports

Concerns that your rights may have been violated can negatively impact your mental health and take a toll on your well-being. Consider reaching out to a neutral third party — someone with whom you feel safe to open up and discuss your feelings. Elders, family members, friends, social workers, or counsellors may be an excellent place to start. Additionally, some hospitals and health care centres have Indigenous patient navigators or patient liaison officers who can provide support, help you navigate the health system, and sort out what has happened. Some Indigenous friendship centres can also provide additional supports.

Finally, if you prefer to remain anonymous or don't feel comfortable reaching out to an individual in person, you can call the Hope for Wellness Help Line at **1-855-242-3310**. This line provides anonymous, free counselling, and crisis intervention in English, French, Cree, Ojibway, and Inuktitut. It is available 24 hours a day, seven days a week. You can also connect to the online chat option at <u>www.hopeforwellness.ca</u>.

### Step 2: Explore what has happened

This is an important step and can happen at the same time as the first step. Consider whether you would like to react to the event that occurred by filing a complaint. Think back to when the incident occurred. It is important to document the event; be as precise and specific as possible. Include details such as times, dates, places, and names. Think about who else may have first-hand information of the event, such as nurses, allied health professionals, or other individuals who may have been present at the time. You can record this information by writing it down, tape recording your voice, or even through a video. You can also ask your support person to help you write things down while you share the details.

Consider the questions below:

- Why are you thinking of filing a complaint? What happened? For example, were you treated inadequately? Were you provided with substandard care? Did the health care provider have an inappropriate attitude or unprofessional conduct? Do you feel that you did not give informed consent for a procedure?
- What was the outcome of the event? What has happened to you mentally, physically, emotionally, and spiritually as a result of this event?
- Would you like to file a complaint and if so, what do you want to happen to resolve your complaint? For example, does a policy need to change? Do you want an apology? Do you want disciplinary action directed at the health care provider?

#### Step 3: File a complaint

Complaints can be filed at any time. There are no time limits, statute of limitations, or expiration dates. Complaints can be filed with hospitals, clinics, long-term care homes, and home and community care services, all of which have their own internal process for handling complaints. You can also file your complaint with a provincial/territorial health care professional regulating body, such as the College of Physicians and Surgeons, College of Nurses, College of Physiotherapists, and College of Psychologists.

Typically, to file a complaint you must: (1) complete and sign a complaint form; (2) complete and sign a release of information form; and (3) mail or fax it to the body you are submitting it to.

There is no cost to filing complaints. You may reach out to an Indigenous patient liaison officer or navigator at your local hospital or your provincial/territorial patient ombudsperson to help you fill out the form and navigate the system. Ensure you collect all the necessary paperwork and background documents and attach/ include it with your complaint form.

Regulating bodies are mandated by the provincial/territorial Health Professions Act to ensure that patients are safe, protected, and receive quality care when treated by licensed health care providers. Each College manages patient complaints and concerns and ensures they are resolved by taking appropriate action. For further assistance or to access the necessary forms, you can call or visit the website of your provincial/territorial College of Physicians and Surgeons.

COMPLAINT

Alberta	College of Physicians and Surgeons of Alberta: 1-800-661-4689 or <u>complaints@cpsa.ab.ca</u> . Web portal to begin process: <u>http://www.cpsa.ca/complaints/file-a-complaint/</u>				
British Columbia	College of Physicians and Surgeons of British Columbia: 1-800-461-3008 or email option through the web portal at: <u>https://www.cpsbc.ca/contact-us</u> . The complaint form can be found at: <u>https://www.cpsbc.ca/for-public/file-complaint</u>				
Manitoba	College of Physicians and Surgeons of Manitoba: 1-877-774-4344 or: <u>cpsm@cpsm.mb.ca</u> . Instructions can be found at: <u>http://www.cpsm.mb.ca/complaints/complaint-process/</u> <u>submitting-a-complaint</u> .				
New Brunswick	College of Physicians and Surgeons of New Brunswick: 1-800-667-4641 or for instructions on filing a complaint, email <u>INFO@CPSNB.ORG</u> . Instructions can also be found at: <u>https://cpsnb.org/en/complaints/filing-a-complaint</u>				
Newfoundland and Labrador	College of Physicians and Surgeons of Newfoundland and Labrador: 709-726-8546 or <u>complaints@cpsnl.ca</u> . Instructions and form for filing a complaint can be found at: <u>https://www.cpsnl.ca/WEB/CPSNL/Complaints/Making_a_Complaint/CPSNL/Complaints/</u> <u>Making_a_Complaint.aspx?hkey=57f3895d-b7d9-4218-9652-851b57bcc40f</u>				
Northwest Territories (NWT)	NWT Health and Social Services: Contact Dr. Michael Caffaro, Complaints Officer: 1-800-561-3899 ext. 4971 or <u>Michael.Caffaro@cpsa.ab.ca</u> . The process for a complaint can be found at: <u>https://www.hss.gov.nt.ca/sites/hss/files/complaint-procedure-doctors.pdf</u>				
Nova Scotia	College of Physicians and Surgeons of Nova Scotia: 902-421-2201 or instructions and form for filing a complaint can be found at: <u>https://cpsns.ns.ca/complaints-investigations/</u> <u>filing-a-complaint/</u>				



Nunavut	Nunavut Patient Relations: 1-855-438-3003 or email for instructions at: <u>patientrelations@</u> <u>gov.nu.ca</u> . The complaint form and instructions can be found at: <u>https://www.gov.nu.ca/</u> <u>sites/default/files/opr_ecomplaint_form_eng.pdf</u>
Ontario	College of Physicians and Surgeons of Ontario: 1-800-268-7096 ext. 603 or email <u>feedback@cpso.on.ca</u> for instructions. Instructions and form for filing a complaint can be found at: <u>https://www.cpso.on.ca/Public/Services/Complaints</u>
Prince Edward Island	College of Physicians and Surgeons of Prince Edward Island: 902-566-3861 or email for instructions/support at <u>mmacdonald@cpspei.ca</u> . The complaints process is outlined at: <u>https://cpspei.ca/wp-content/uploads/2014/06/Complaint-Process-Brochure-update-April-2014.pdf</u>
Québec	Collège des médecins du Québec: 1-888-633-3246 or email for <u>instructions at info@cmq.org</u> . Complaints form can be found at: <u>http://www.cmq.org/hub/en/porter-plainte.aspx</u>
Saskatchewan	College of Physicians and Surgeons of Saskatchewan: 1-800-667-1668 or email <u>complaints@cps.sk.ca</u> . The complaint form and complaints process can be found at: <u>http://www.cps.sk.ca/imis/CPSS/Complaints/complaints.aspx?ComplaintsCCO=The%20</u> <u>Complaints%20Process%20Overview</u>
Yukon	Yukon Medical Council: 1-867-667-3774 or email for instructions at: <u>ymc@gov.yk.ca</u> . Instructions for filing a complaint can be found at: <u>http://www.yukonmedicalcouncil.ca/</u> <u>complaint_process.html</u>

#### Step 4: What to do after a complaint is filed

Once the regulating body receives your complaint, they will send a letter to you to confirm receipt. This typically takes several weeks. They may contact you by phone or request a meeting to discuss your complaint further. They will also contact the health care provider(s) involved in the complaint and ask them to respond. You will receive a copy of this response and be given an opportunity to provide your own feedback. Once all the relevant information from you, the health care provider, and the hospital/clinic have been received, the complaint is forwarded to a review committee. This unbiased group of health care providers and members of the public review the entire file and decide on next steps.

Filing a complaint is an exhaustive, often difficult, lengthy task. You may require health support during this time. You are advised to rely on your social support system and attempt to seek care from another health care provider (if possible). Most regulating bodies advise that you avoid contact with your health care provider during the course of the investigation.

Once the investigation is completed, you and the health care provider will receive a written response from the regulating body. The response may state that the regulating body deemed the health care provider's actions to be appropriate and will take no action. However, if the regulating body has confirmed that the health care provider did violate your rights, the response can include the following:

- · Advice on where the health care provider erred and a reminder to them on the expected standards of care
- Advice to the health care provider on how to improve their practice; this can include a recommendation to attend education courses/training
- · Official warning or caution to the health care provider, which goes into their file
- · General review of the health care provider's practice
- Limitations, monitoring, or conditions on a health care provider's practice
- Removal of the health care provider from practice

Regardless of the outcome of the investigation, your complaint will remain in the health care provider's file.

#### Step 5: What happens when your complaint(s) are unsuccessful?

If you are dissatisfied with the outcome of your complaint, you have a right to appeal to the Health Professions Review Board (HPRB). Every province and territory has an HPRB, which is an independent tribunal that reviews the appropriateness of the investigation and its outcome.



#### Step 6: Consider pursuing legal action

It is important to understand that health care regulating bodies do not offer or influence financial reparations nor can they commence legal proceedings on your behalf. If you decide to go down the legal route, you should decide if you want to start a civil lawsuit or criminal proceedings. With a civil lawsuit, the outcome you are seeking is financial compensation from the health care provider. On the other hand, the outcome of criminal proceedings would be that the health care provider is either found guilty or not guilty of committing a crime against you. You should seek legal advice from a lawyer in order to decide if you want to pursue legal action, and what legal route you would like to follow.

- a. If you choose to pursue a civil case against the health care provider, your first step should be to get a lawyer to represent you. If you do not know how to find a lawyer, visit a legal clinic or friendship centre where you will be given advice on the available legal resources.
- b. If you prefer to pursue criminal proceedings, the first step you should take is to file a complaint with the police. The police will take a statement (your version of what happened) from you. Next, the police will have your complaint investigated by an investigator. If the investigator finds enough evidence, your file will be transferred to the Crown Prosecutor of the region where the incident occurred. The prosecutor will then formally charge the health care provider with an offence. The criminal process has begun. Throughout the process, you will have support from a worker in the Victim Witness Assistance Program.

Keep in mind that regardless of what route you choose to take either civil or criminal, the whole process might be stressful and will involve substantial time and possibly financial commitments.









# Knowing Your Rights: Informed Choice

Care providers and advocates are encouraging the adoption of an Informed choice model rather than just informed consent. Informed choice is when an individual is given options for several interventions, educated about the details, risks, benefits, and outcomes of each option, and asked to choose the one that best fits their needs. This model promotes an individual's right to direct what happens to their body, giving control back to the individual in the care setting.<sup>1</sup> This allows them to only undergo interventions that align with their needs, values, and preferences.

Studies show that having a lot of information doesn't always mean that the information is used to help make choices.<sup>2</sup> Further, without a holistic understanding of the choices and their consequences, individuals can feel frustrated and disempowered.<sup>2</sup> You are encouraged to seek out your support system, including Elders, family, friends, health care providers, or your hospital's Indigenous patient liaison officer, to guide you through the choices, upon which you can ultimately decide on the best option for you.

Another useful instrument can be the Informed Choice Decision-Making Tool (see next page). This tool structures the decisionmaking process around your knowledge, preferences, and values, and highlights next steps. This tool was adapted from the Ottawa Personal Decision Guide.<sup>3</sup>

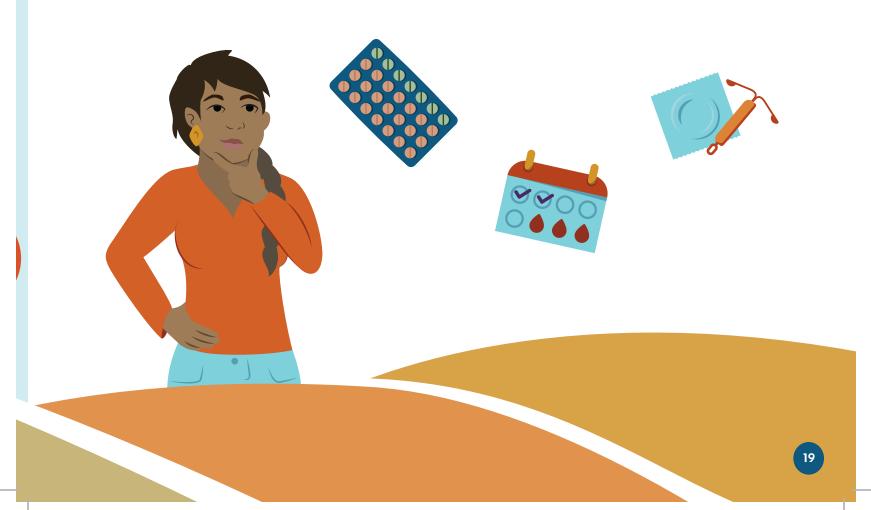
# Informed Choice Decision-Making Tool

# **Step 1: Define your decision**

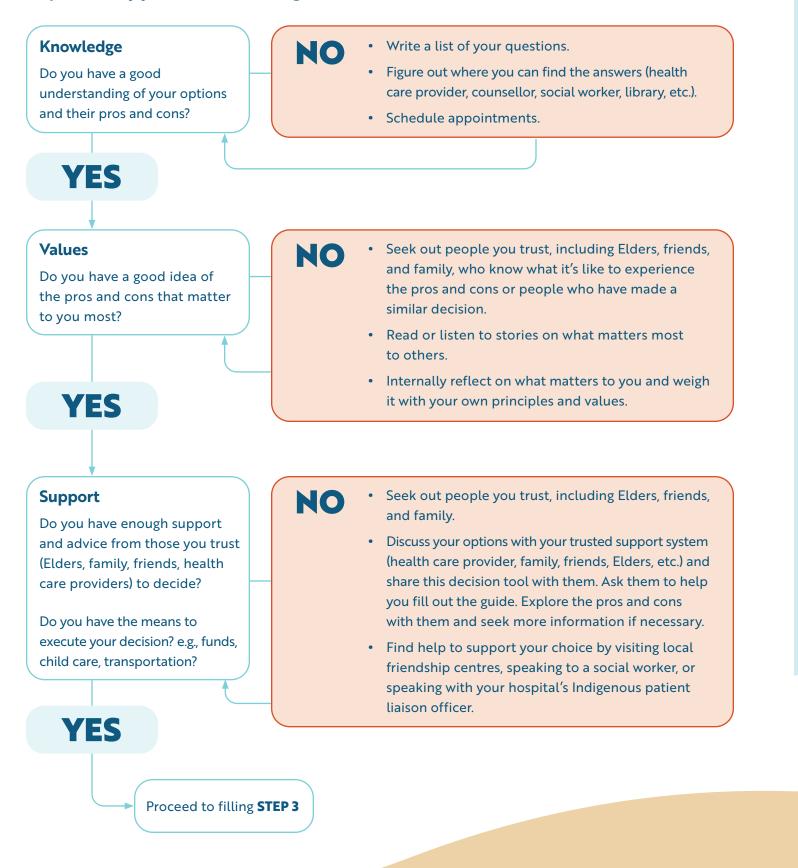
a. What is the decision? e.g., which method of birth control should I use?

b. Think about your reasons behind making the decision. e.g., family planning, new relationship

c. Is there a time you need to make your decision by? e.g., next appointment, next month

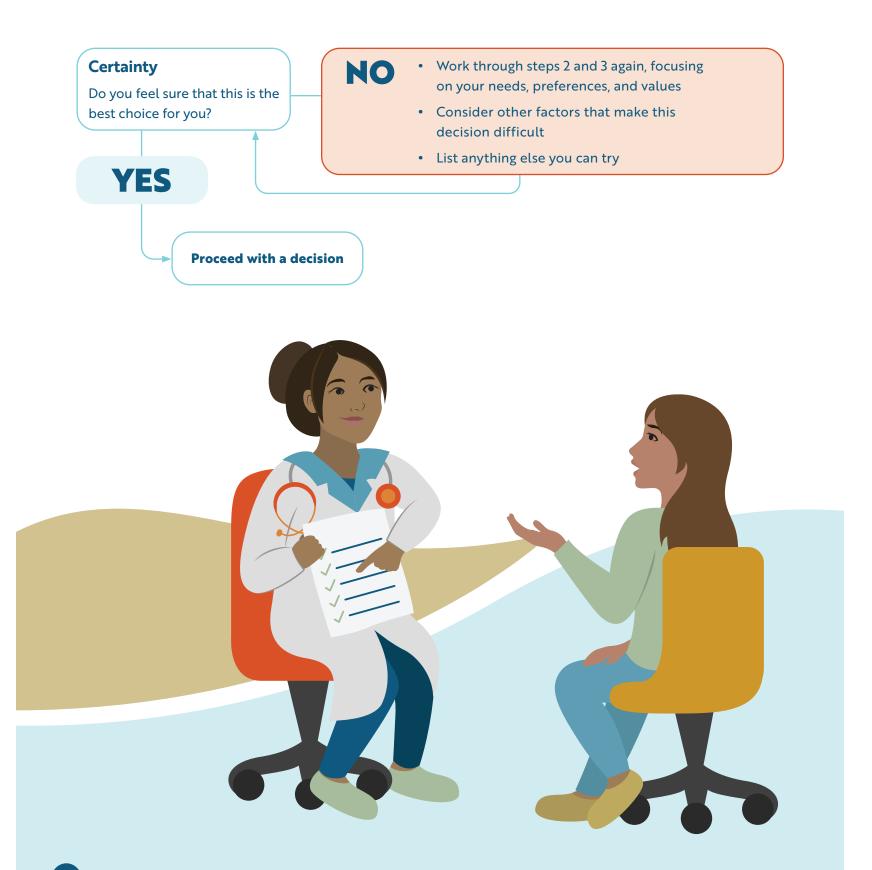


### Step 2: Identify your decision-making needs



	Pros (reasons to choos	se)	Cons (reasons to av	oid)	Overall Ratin
Option 1:					
Option 2:					
Option 3:					
Option 4:					
Step 4: Based	on your knowledge, pre	eferences, and v	values, which opt	ion will you	choose?
□ Option 1	□ Option 2	□ Option 3	□ Option 4		

# Step 3: Use your knowledge and personal values to explore your choices



# References

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# Native Women's Association of Canada

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L'Association des femmes autochtones du Canada

