# Making an Informed Decision

A guide for healthcare providers to support families in making health-related decisions for a child







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by/par health nexus santé

# **About This Resource**

The purpose of this resource is to equip healthcare providers with information and tools that support parents, guardians, caregivers, and families when making health-related decisions for a child in their care. Informed decisions may relate to screening, testing, treatment, or medical care.

Throughout this resource, the term "decision-maker" refers to a parent, guardian, caregiver, or family member that is responsible for making a health-related decision for a child. The content in this resource can be applied to a variety of health-related decisions that parents, guardians, caregivers, or family members may face.

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# Making an Informed Decision

### About informed decisions

An informed decision is the selection of an option after reviewing enough information about the different choices available to recognize and understand the facts, implications, and consequences of the decision.

Specific to health-related decisions, making an informed decision is especially valuable when:

- There is more than one care and treatment option available.
- There are several benefits and risks for each care and treatment option.
- The available care and treatment options can impact patients differently.
- There are multiple healthcare providers involved.
- · There are cultural considerations.

(National Learning Consortium, 2013).

# Supporting an informed decision

An informed decision requires two-way communication between a healthcare provider and a decision-maker, based on the following elements:

- An accurate understanding of the health risk/condition.
- The availability of different care and treatment options.
- The clinical evidence regarding the benefits and risks of different care and treatment options.
- The values, preferences and cultural context of the decision-maker.
- Literacy skills and English as a second language.

(Gao, Waddell & Wilson, 2018; Légaré & Witteman, 2013; National Learning Consortium, 2013; Queensland Health, 2017).

# Benefits of making an informed decision

The outcomes associated with informed decisions include:

- Increased knowledge, satisfaction, self-efficacy, decision quality, quality of care, and treatment adherence.
- Decreased decisional conflict, anxiety, and perceived communication barriers.
- · More effective use of healthcare resources.

(Aarthun & Akerjordet, 2014; Boland, Kryworuchko, Saarimaki & Lawson, 2017; Gao, Waddell & Wilson, 2018; Légaré & Witteman, 2013).



# Roles and responsibilities in making an informed decision

When supporting families and caregivers to make an informed decision, the role of the healthcare provider shifts away from the paternalistic model that views the healthcare provider as the sole decision-maker. Instead, the healthcare provider is positioned as a partner in the decision-making process who:

- Provides information about the health risk/condition.
- · Presents the care and treatment options available.
- · Describes the risks and benefits of each option.
- Ensures the decision-maker understands the information that has been shared.
- · Supports the decision-maker in selecting care and treatment options.

(Coulter, 2018; Joseph-Williams, Elwyn & Edwards, 2014; Stiggelbout, Pieterse & De Haes, 2015).

To make an informed decision, the decision-maker is responsible for evaluating the information given by a healthcare provider to determine if they:

- · Understand the health risk/condition.
- · Understand the available care and treatment options.
- Understand the outcomes associated with different options.
- · Have assessed how personal/family values and beliefs are reflected in the options.
- · Have enough information to make a decision.

(Joseph-Williams, Elwyn & Edwards, 2014; Légaré & Witteman, 2013; National Learning Consortium, 2013; Stiggelbout, Pieterse & De Haes, 2015).

# Steps to making an informed decision

This resource outlines a five-step process that healthcare providers can use to support decision-makers in making an informed decision. Each step is based on evidence-informed strategies related to patient education, patient-centered care, decision coaching, and shared decision making.

- · Step 1: Discuss the available options
- · Step 2: Ensure understanding
- · Step 3: Clarify values and preferences
- · Step 4: Determine additional needs and resources
- Step 5: Identify next steps

Each step includes tips, strategies, and conversation prompts that healthcare providers can use to support decision-makers in making an informed decision.

Supporting tools have also been created:

- Tool 1: Steps to Making an Informed Decision
- · Tool 2: Supporting an Informed Decision: Checklist for Healthcare Providers
- Tool 3: Making an Informed Decision: Checklist for Families and Caregivers
- Tool 4: Considerations for Indigenous Populations

# Step 1: Discuss the available options

Decision-makers need to understand the health risk/condition and the available care and treatment options. Healthcare providers can use the strategies below to highlight the choices available.

# **Emphasize** participation

- · Highlight that the decision-maker's participation is critical, and that their decision will be respected.
- · Ask open-ended questions to promote discussion.
- Convey empathy to encourage the decision-maker to express themselves without being judged.

"I would like to know your thoughts on ..."

"Your point of view is important to the conversation."

"I'd like to hear more about ..."

## Build on existing knowledge

- Begin by sharing information that is relevant to the decision-maker's situation-unnecessary information can be overwhelming.
- Find out what the decision-maker already knows about the health risk/condition and the available care options.
- Tailor the information provided based on existing knowledge.

"What have you heard about ...?"

"What are the treatment options you are familiar with?"

"Based on what you've said, here is some additional information ..."

### Share necessary information

- · Discuss options, including benefits and potential for success.
- · Review risks, including potential complications and side effects.
- Recognize that no treatment may be a consideration for the decision-maker.

(As a healthcare provider, be aware of your duty to report a child in need of protection due to refusal of medical treatment. This information can be found in your provincial Child and Family Services legislation).

"Here are some options to consider ..."

"The possible positive outcomes for this option include ..."

"The possible negative outcomes for this option include ..."

"No treatment is also an option, which may result in the following outcomes ..."

# Ensure information is evidence-based and unbiased

- Provide information that is evidence-based, credible, comprehensive, up-to-date, and neutral.
- Engage in self-reflection to identify and address any personal biases you may have.
- Share all available options, including those that are not in line with your personal values or cultural
  context, and avoid passing judgment.

"Here are your options based on the best available evidence ..."

"Research demonstrates that ..."

"The most recent information suggests that..."



# **Step 2: Ensure understanding**

It is important that decision-makers understand the information being presented to them. Healthcare providers can use the strategies below to increase understanding.

# Use easy-to-understand language

- · Speak slowly and clearly.
- Use plain language and avoid technical jargon.
- Present information in small segments to allow decision-makers time to digest information.

"Please let me know if I'm speaking too quickly."

"Are you ready for me to continue?"

"Is anything I've said confusing or unclear?"

# Consider language barriers

- Use printed materials that are at a grade 8 or lower reading level, and summarize key information with visuals.
- · Seek out materials in the first language of the decision-maker.
- · Offer to engage a medical interpreter or cultural expert. Do not use a child as an interpreter.

"Here's a diagram that summarizes what we've talked about."

"Let me see if I can find materials in your language that will help you understand."

"Would you like to talk with a medical interpreter or a person with cultural expertise?"



# Confirm comprehension

- Ensure the decision-maker understands the options available, their risks, and their benefits.
- Have the decision-maker repeat back the information provided in their own words.
- Ask questions about the information provided to the decision-maker.
  - "Based on what we've discussed, what can you tell me about your options for care and treatment?"
  - "How would you summarize our conversation?"
  - "Is there something you would like to discuss further?"

## Provide clarification

- Offer the decision-maker the opportunity to ask questions.
- Use visual aids, such as diagrams, illustrations, and charts, to emphasize key information.
- Consider different approaches, including discussion, printed materials, and videos, to appeal to individual learning preferences.
  - "Do you have any questions?"
  - "Can I clarify any of the information I've shared with you?"
  - "Here's a different way to look at the information I've shared..."

# Step 3: Clarify values and preferences

Decision-makers will have thoughts and opinions that will influence their decision. These may be rooted in culturally diverse experiences. Healthcare providers can use the strategies below to help decision-makers identify their values and preferences.

# Discuss goals and expectations

- Find out what is most important to the decision-maker.
- · Discuss concerns that the decision-maker may have.
- · Have the decision-maker identify reasons to choose and not choose the available options.
  - "What are your goals and expectations for care and treatment?"
  - "What are some reasons to choose [option X]?
  - "What are some reasons to avoid [option X]?"
  - "How do you feel about what I've shared with you?"



# Support the decision-maker

- · Display interest in the situation the decision-maker is facing.
- Acknowledge and affirm the feelings of the decision-maker.
- Use active listening skills and reflect key information back to the decision-maker to demonstrate your understanding.

"That sounds really [identify emotion decision-maker is displaying]."

"It sounds like ... is really important to you."

"I'm interested in hearing your thoughts."



## Ensure cultural competence

- Recognize that culture is more than ethnicity, and can include many factors such as sexual orientation, gender identity, and class.
- Avoid making cultural assumptions, and recognize that diversity results in a variety of perspectives, attitudes, beliefs, and behaviours.
- Consider cultural supports, such as community-based programs and services that are available to assist decision-makers.

"Are there family or cultural traditions that would impact your decision?"

"Please tell me about any values that are important to you that we have not yet discussed."

"Are you familiar with services in your community that would support your values or traditions?"

# Include values and preferences of others

- Invite other family members to engage in values-based conversations to support the decision-maker.
- Recognize that depending on developmental maturity, a child's preferences might be considered.

"Are there others you would like to involve in the discussion?"

"Talking with someone close to you may help clarify your feelings."

"Would you like to involve [child's name] in the discussion?"



# Step 4: Determine additional needs

Decision-makers may not be ready to make a decision right away. Healthcare providers can use the strategies below to determine if decision-makers have additional needs.

# Emphasize taking more time to decide

- If appropriate, let the decision-maker know they can take some time to think about the information presented.
- If the decision is time sensitive, let the decision-maker know how much time is available to select an option.

"This is a big decision - take the time you need to consider all the options."

"Let's schedule another time to meet once you've thought things through."

"Ideally, a decision will need to be made by ..." (if decision is time sensitive)

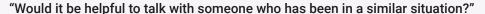


# Ask what the decision-maker still needs and provide additional support where appropriate

- · Discuss what the decision-maker still needs to make an informed decision.
- Direct the decision-maker to credible sources of information if they still have questions.
- Facilitate connections with others, such as other families that have made a similar decision, medical specialists, or community supports.

"Do you feel ready to make a decision?"

"What do you still need to know?"





### Consider the use of a decision aid

- Introduce a decision aid to clarify and understand the options available.
- A decision aid should include the following content:
  - Description of the condition that requires a decision.
  - Information on the care and treatment options, including potential outcomes, harms, and benefits.
  - Information to help clarify and express personal values.
  - A step-by-step process to follow to help make the decision.
- A comprehensive inventory of pediatric decision aids can be found on the Children's Hospital of Eastern Ontario (CHEO) website: <a href="http://www.cheo.on.ca/en/decisionaids">http://www.cheo.on.ca/en/decisionaids</a>

"Can I provide you with a tool that will assist in clarifying your thoughts and feelings?"

"Here is a decision aid."

"This support may help you in making a decision."



# **Step 5: Identify next steps**

Decision-makers need to be clear on what happens following the initial discussion with a healthcare provider. Healthcare providers can use the strategies below to identify next steps for decision-makers.

## Provide an overview of the discussion

- · Summarize what was discussed, including:
  - Recapping all the options available.
  - Highlighting the benefits and risks of each option.
  - Reviewing the decision-maker's values and preferences.

"Here are the options we've discussed ..."

"Regarding treatment, the benefits are ... and the risks are ..."

"Based on our conversation, you've highlighted that ... is important to you."

# Clarify action items

- · Establish what happens next, including:
  - Reflecting on the information provided.
  - Consulting with other family members, community/religious/spiritual leaders, or cultural experts.
  - Seeking answers to additional questions.
  - Returning for an additional consultation.

"These are the next steps ..."

"This is what needs to happen over the next little bit ..."

"Let's reassess after ... has happened."

## Address potential barriers to following through with the decision

- · Assist the decision-maker in implementing the decision, including:
  - Identifying community-based resources that can support the decision-maker.
  - Discussing potential challenges the decision-maker could face.
  - Arranging ongoing follow-up.

"Do you think you'll encounter any challenges with making your decision?"

"Who can support you in overcoming the challenges you are facing?"

"Do you need help accessing support services?"



# **Tool 1: Steps to Making an Informed Decision**

# Step 1: Discuss the available options

- · Emphasize participation.
- · Build on existing knowledge.
- · Share necessary information.
- · Ensure information is evidence-based and unbiased.

# Step 2: Ensure understanding

- Use easy-to-understand language.
- Consider language barriers.
- · Confirm comprehension.
- · Provide clarification.

# 2

# Step 3: Clarify values and preferences

- · Discuss goals and expectations.
- Support the decision-maker.
- Ensure cultural competence.
- Include values and preferences of others.

# 3

# Step 4: Determine additional needs

- · Emphasize taking more time to decide, if possible.
- · Ask what the decision-maker still needs.
- Provide additional support where appropriate.
- · Consider the use of a decision aid.

# 4

# Step 5: Identify next steps

- · Provide an overview of the discussion.
- Clarify action items.
- Address potential barriers to following through with the decision.

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# Tool 2: Supporting an Informed Decision: Checklist for Healthcare Providers

Step	1: Discuss the available options
	I engaged in two-way conversation by asking open-ended questions.
	I found out what the decision-maker already knew, and used this as a starting point for our discussions.
	I shared the benefits and risks for all available options, including no treatment.
	I provided information that is unbiased.
Step	2: Ensure understanding
	I used plain language without jargon.
	I used visuals to emphasize key points.
	I encouraged questions.
	I asked the decision-maker to repeat the information back to me.
	I offered to engage a medical interpreter or cultural expert.
Step	3: Clarify values and preferences
	I helped the decision-maker identify what is important to them with respect to care and treatment outcomes.
	I supported the decision-maker by displaying empathy.
	I avoided cultural assumptions.
	I invited other family members to participate in the discussion.
Step	4: Determine additional needs
	I let the decision-maker know they can take more time to decide.
	I asked the decision-maker if they felt ready to choose an option.
	I supported the decision-maker by providing additional sources of information, and any necessary referrals.
	I shared a decision aid that is relevant to the decision-maker's situation.
Step	5: Identify next steps
	I summarized our discussion.
	I clarified action items.
	I offered supports to overcome potential challenges.
	I set a time to check in.

# Tool 3: Making an Informed Decision: Checklist for Families and Caregivers

Step	1: Discuss the available options	
	I was invited to participate in the conversation.	
	I shared what I already knew about the situation.	
	I was provided with more than one option, including no treatment.	
	I felt the information shared was accurate, reliable, and unbiased.	
Step	2: Ensure understanding	
	I understood the language used by the healthcare provider.	
	I am aware of the care and treatment options available, and their benefits and risks.	
	I asked questions about the information provided.	
	I reviewed printed visuals to help me understand the information.	
	I knew I could ask for a medical interpreter or cultural expert.	
Step	3: Clarify values and preferences	
	I reviewed reasons to choose and not choose the options available.	
	I discussed any concerns I have with the healthcare provider.	
	I felt that my values and preferences were supported and respected.	
	I was able to include other family members in the conversation.	
Step	4: Determine additional needs	
	I felt comfortable taking more time to decide.	
	I identified what I still need to make a decision.	
	I know where to find credible information.	
	I was given a decision aid to help with my choice.	
Step	5: Identify next steps	
	I understand what needs to happen next.	
	I identified any potential challenges with making my decision.	
	I know how to find supports to help me overcome potential challenges.	
	I have plans to connect with the healthcare provider again.	

# **Tool 4: Considerations for Indigenous Populations**

While the five step process for making an informed decision is still relevant with Indigenous populations, there are additional cultural considerations that should be acknowledged to best serve decision-makers.

# Develop a solid foundation for discussion

 Ensure discussions are rooted in trust, respect, compassion, understanding, equity, and empowerment

(Best Start Resource Centre, 2013; Best Start Resource Centre, 2016).

 Develop trust by being honest with information that is shared, and do not make promises that cannot be kept.

(Best Start Resource Centre, 2012).

 Be mindful of the physical environment: limit distractions, ensure adequate lighting and comfortable room temperature, and plan an effective seating arrangement. If possible, sit at a round table to create a circle formation.

(Best Start Resource Centre, 2015; Best Start Resource Centre, 2016).

 Engage in self-reflection, and acknowledge that healthcare providers can learn and grow from their experiences with Indigenous populations.

(Best Start Resource Centre, 2013; Best Start Resource Centre, 2017; Health Council of Canada, 2012).



- Cultural humility: understanding any preconceptions you may have about a culture. (Best Start Resource Centre, 2017).
- Cultural sensitivity: being respectful of the differences between cultural groups, (Best Start Resource Centre, 2013).
- Cultural competence: having the skills, knowledge, and attitudes to meet the needs of a specific cultural group.

(Best Start Resource Centre, 2013).

 Cultural safety: analyzing power imbalances, institutional discrimination, colonization, and colonial relationships as they apply to healthcare and health education.

(Best Start Resource Centre, 2017).

# Respect diversity

· Recognize First Nations, Métis and Inuit as distinct Peoples.



 Appreciate that language, culture, beliefs, customs, traditions, and practices will differ across groups and communities.

(Best Start Resource Centre, 2013; Best Start Resource Centre, 2017).

 Understand that individuals may have traditional beliefs, mainstream beliefs, or a combination of beliefs.

(Best Start Resource Centre, 2016). These may be based on where an individual resides (e.g., urban, reserve, Northern).

 It is important to not make assumptions or perpetuate stereotypes.

(Best Start Resource Centre, 2016; Best Start Resource Centre, 2017; de la Ronde et al., 2013; Health Council of Canada, 2012; The Indigenous Physicians Association of Canada and the Royal College of Physicians and Surgeons of Canada, 2009).



# Acknowledge cultural values and beliefs

• Understand that cultural supports may be important in the decision-making process. These may include Elders, healers, extended family, children, and local Indigenous organizations, programs, and services.

(Best Start Resource Centre, 2012; Best Start Resource Centre, 2013; Best Start Resource Centre, 2017; Ministry of Health and Long-Term Care, 2018).

• Be willing to use a collaborative approach with cultural resources that are important to the decision-maker. This may include the use of traditional medicines, Indigenous-based healthcare providers, and a holistic approach to wellbeing that recognizes the spiritual, physical, mental, and emotional aspects of self.

(Best Start Resource Centre, 2012; de la Ronde et al., 2013; The Indigenous Physicians Association of Canada and the Royal College of Physicians and Surgeons of Canada, 2009).

# Consider trauma-informed practice

 Be aware that individuals with intergenerational trauma related to colonization and marginalization may become overwhelmed or triggered during your discussion as a result of their experiences. Recognizing, accepting, and talking about trauma can help move away from stigma, guilt, and shame, and towards improved self-esteem, empowerment, and self-reliance.

(Best Start Resource Centre, 2015).

- Use the following approaches to reflect trauma-informed practice:
  - Emphasize safety.
  - Build trustworthiness.
  - Maximize choice and control.
  - Offer collaboration and power sharing.
  - Create empowerment.
  - Focus on strengths.

(Best Start Resource Centre, 2016).

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