

Regional Ethics Program

IDEA:

Ethical Decision-Making Framework Guide

The Regional Ethics Program is an ethics service based on a hub and spoke model. The hub is Trillium Health Partners and spokes include organizations in the region that contract services from the Regional Ethics Program.

The IDEA: Ethical Decision-Making Framework was modified by the Regional Ethics Program and builds upon the Toronto Central Community Care Access Centre Community Ethics Toolkit (2008), which was based on the work of Jonsen, Seigler, & Winslade (2002); the work of the Core Curriculum Working Group at the University of Toronto Joint Centre for Bioethics; and incorporates aspects of the accountability for reasonableness framework developed by Daniels and Sabin (2002) and adapted by Gibson, Martin, & Singer (2005).

Introduction

Ethics is about making "right" or "good" choices and the reasons that we give for our choices and actions. Ethics promotes reflective practice in the delivery of health care. Ethics addresses the question "What should we do and why?"

Another way to describe ethics is as follows. It is about:

- Deciding what we should do what decisions are morally right or acceptable;
- Explaining why we should do it justifying our decision using language of values and principles; and
- Describing how we should do it outlining an appropriate process for enacting the decision.¹

Ethical issues arise every day in health care (See Appendix A). Everyone has a role to play in ensuring the ethical delivery of care, from the point of care to the boardroom. Ethical principles and values are incorporated into the way that decisions are made and care is delivered every day. Accreditation Canada expects that healthcare organizations will have in place a framework for guiding ethical behavior that is publicly accessible and consistent with the law.

As healthcare organizations seek to provide quality care in the face of significant financial constraints, they face difficult decisions. Both technical (e.g., cost-effectiveness analyses) and principle-based solutions (e.g., distributive justice) alone are limited in their ability to resolve priority-setting challenges (Gibson, Martin, & Singer, 2005). Given that there may be competing goals and values, ensuring procedural fairness may be the best way to ensure that decisions are socially accepted and demonstrate public accountability (Gibson et al., 2005).

The purpose of the IDEA: Ethical Decision-Making Framework (see Figure 1) is to provide a step-by-step, fair process to help guide healthcare providers and administrators in working through ethical issues encountered in the delivery of healthcare. The Framework can be used to guide decision-making and actions about ethical issues that arise from the point of care to the boardroom. The framework addresses two general types of ethical decisions that lie across a continuum: clinical and organizational.

Clinical ethical decisions are typically those that involve and impact specific individuals or staff members and focus on individual values (e.g., Should Mr. B's life-sustaining treatment be discontinued?). Organizational ethical decisions are generally those that involve and impact groups of patients/residents or staff members, units, systems, or the organization as a whole and center on the values of the organization (e.g., Should the maternal-child program be expanded, reduced, or remain unchanged?). Some ethical decisions may be predominantly clinical in nature; others will be largely organizationally focused. A number of ethical decisions will have both clinical and organizational aspects. There may also be ethical decisions related to the conduct of research.

Use of the framework can help an individual, team or community to work through an ethical issue. It can help a team or community work together by introducing a shared systematic process, facilitating effective communication, developing a shared language and building a common understanding of how to approach difficult ethical issues.

It is important for every individual to be attentive to their own personal values, biases and triggers when they identify an ethical issue and work towards its resolution. Attention should also be paid to addressing systemic considerations such as equity, diversity, inclusion and anti-racism.

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¹ Definition adapted from Dr. Barbara Secker, Joint Centre for Bioethics, University of Toronto.

The IDEA: Ethical Decision-Making Framework is comprised of four steps and five conditions. The four steps guide the substantive decision-making process and the five conditions ensure procedural fairness. The conditions were first described in the accountability for reasonableness framework developed by Daniels and Sabin (2002) and further adapted by Gibson, Martin, and Singer (2005).

The first letter of each step in this framework forms the acronym "IDEA." In the centre of the framework there is a light-bulb (a further reference to the framework's acronym, IDEA). The light-bulb contains a set of questions to assist healthcare providers/administrators in the identification of ethical issues to which the framework can be applied. The framework is depicted as circular, suggesting that decisions need to be revisited as new facts emerge.

The four steps are:

- 1. Identify the facts.
- 2. Determine the relevant ethical principles.
- 3. Explore the options.
- 4. Act.

The five conditions are:

Empowerment: There should be efforts to minimize power differences in the decision-making context and to optimize effective opportunities for participation (Gibson et al., 2005).

Publicity: The framework (process), decisions and their rationales should be transparent and accessible to the relevant public/stakeholders (Daniels & Sabin, 2002).

Relevance: Decisions should be made on the basis of reasons (i.e., evidence, values/principles, arguments) that "fair-minded" people can agree are relevant under the circumstances (Daniels & Sabin, 2002).

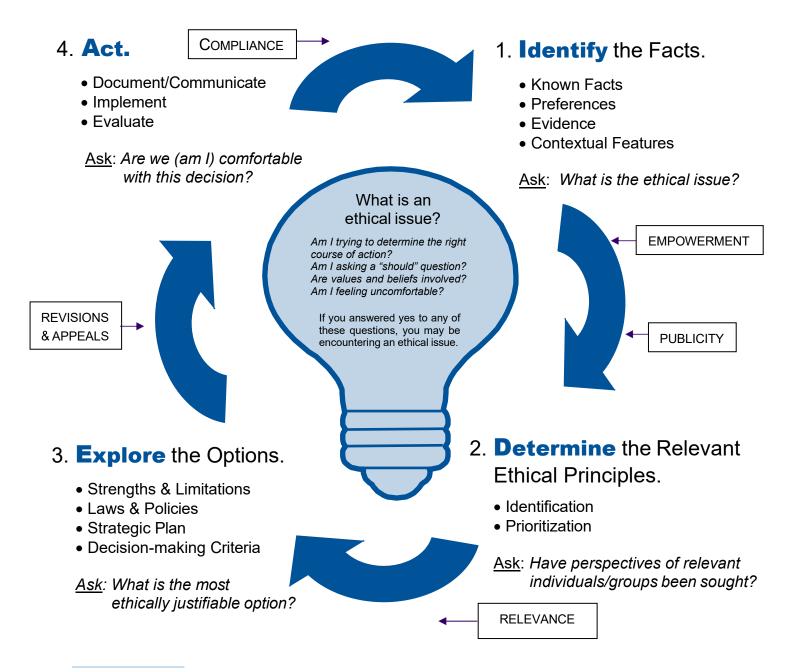
Revisions and Appeals: There should be opportunities to revisit and revise decisions in light of further evidence or arguments. There should be a mechanism for challenge and dispute resolution (Daniels & Sabin, 2002).

Compliance (Enforcement): There should be either voluntary or public regulation of the process to ensure that the other four conditions are met (Daniels & Sabin, 2002).

Figure 1

IDEA:

Ethical Decision-Making Framework



The IDEA: Ethical Decision-Making Framework builds upon the Toronto Central Community Care Access Centre *Community Ethics Toolkit* (2008), which was based on the work of Jonsen, Seigler, & Winslade (2002); the work of the Core Curriculum Working Group at the University of Toronto Joint Centre for Bioethics; and incorporates aspects of the accountability for reasonableness framework developed by Daniels and Sabin (2002) and adapted by Gibson, Martin, & Singer (2005).

Using the Ethics Worksheet

The Ethics Worksheet (see Appendix B) has been developed to facilitate the use of the IDEA: Ethical Decision-Making Framework. Each step in the IDEA Framework is identified and key questions to address are outlined. These questions are intended to guide your fact finding process and are not exhaustive; not every question will be applicable to a given situation. In addition, the conditions that should be met during each step of the process are described.

At any point in the process, you can seek the assistance of an ethicist, ethics facilitator, ethics forum, or other professionals to help work through the process and resolve any areas of uncertainty or disagreement.

Step 1: Identify the Facts

Given that ethical issues often arise because of a lack of sufficient information or evidence, as well as disagreements about the facts, the first step in the ethical decision-making process is an explicit call for identification of the facts. This may help to resolve some conflicts and sets the stage for an effective process in others. Begin by briefly describing *the ethical concern*.

a. Known Facts of the Situation

Clinical Ethics:

- What is the individual's diagnosis, prognosis?
- Is the problem acute, chronic, critical, emergent, reversible?
- What are the goals of treatment?
 - o What are the probabilities of achieving these goals?
 - What are the plans in case these goals are not achieved?
- What are the benefits of the treatment? How can these be maximized?
- What are the harms of the treatment? How can these be minimized?
- Are there non-traditional approaches to health that are important to the individual?

Organizational Ethics

- Which groups/communities are impacted by this situation?
- How many persons are affected?
- What are the cost implications?
- What are the potential harms and benefits?

b. Preferences of the Relevant Parties (values and beliefs, prior expressed wishes)

- What are the preferences of the relevant parties?
- What are the person's expressed needs? How do they want the healthcare team to help?
- If the person is currently incapable, have they expressed any wishes in the past that are applicable to the current situation (in writing, verbally or in any other manner)?

c. Contextual & Societal Features

Law and Policy Considerations:

- Is there any relevant legislation?
- What organizational policies are relevant to the decision?
- Is the organization's strategic plan relevant to the decision?
- If the individual isn't capable of making the decision, who is substitute decision maker (SDM)? Is SDM following principles governing substitute decision-making?

- If the individual is incapable, have we included them to the greatest extent possible and sought their assent?
- Is the individual's right to choose being respected to the greatest extent possible in ethics and law? (i.e., have we maximized their capacity to consent)

Positionality/Intersectionality² (see definitions in footnote below):

- Does the person have family/friends to support them?
- What does the person wish us to know about how they identify that is relevant to this situation (e.g., culture, religion, race, gender, disability)?
- Has the person shared any history of trauma that is relevant to this situation?
- What are the socioeconomic considerations associated with the decision?
- Are they accessibility considerations?
- Are there any power differentials that need to be acknowledged and addressed?

Potential conflicts of interest and personal biases:

- Do relevant parties have any perceived, potential or actual conflicts of interest?
- Do relevant parties have any biases that might influence decision making, including judgments about quality of life?
- Have unconscious biases been considered (e.g., race, gender, age, culture)?
- Have parties reflected on their personal emotions, feelings, values and biases regarding this case/issue?
- How might the above influence one's professional role? Are parties able to respond professionally (as opposed to personally)? What steps can be taken to address any concerns?

d. Evidence to inform decision:

Lived Experience:

- What is the person's lived experience?
- How can the person's lived experience inform decision?

Research:

- What data to inform decision is available locally, regionally, provincially, etc.?
- What research findings/literature are available to inform decision?

Standards of Practice:

- What is the local standard of practice?
- Are there professional bodies that have issued relevant position statements or guidelines?

Conditions:

Empowerment - Strategies to minimize power differentials and optimize effective opportunities for participation should be implemented at the outset and incorporated throughout the process. This may include provision of interpretation services, accessible educational materials (e.g., different languages, lay language) and communication devices. Remove barriers that impede inclusiveness (e.g., provide a senior friendly environment, promote cultural sensitivity, create welcoming and accessible spaces). Depending on the nature of the situation, community engagement, encouraging expression of divergent views, democratic voting procedures, secret ballots, ample preparatory time, and capacity building are additional strategies that can be used to achieve this condition (Gibson et al, 2005).

² "Positionality refers to how differences in social position and power shape identities and access in society. Intersectionality refers to particular forms of intersecting oppressions, for example, intersections of race and gender, or of sexuality and nation." (University of British Columbia, CTLT Indigenous Initiatives Document, Accessed 09/08/22, indigenous initiatives.ctlt.ubc.ca)

Publicity - Similarly, the condition of "publicity" should be evident at each step of the process. This requires establishing and maintaining open channels of communication between relevant parties and transparency about the process.

Overarching Question:

Before proceeding to Step 2, revisit the question: "What is the ethical issue(s)?" Sometimes after the collection of relevant facts, the framing of the ethical issue requires modification.

Step 2: Determine the Relevant Ethical Principles

In the second step, open discussion about the values and principles of the relevant parties (individuals and/or groups, as well as those of the organization) is necessary to further clarify the ethical issue(s) at hand. This step requires an exploration of the nature and scope of the identified ethical principles (see Appendix C for a list of ethical principles). The agreed upon set of prioritized principles will be used to evaluate the options.

- What principles do relevant parties consider most applicable to this issue?
- Which principles do the relevant parties agree are most important?
- Are there any additional factors that ought to be considered?

To elicit values, one might ask questions such as:

- What is most important to your well-being?
- What are your concerns/worries related to the decision at hand?
- What are you hoping for?
- How has your upbringing shaped your life?

Condition:

Relevance - Completion of Step 2 of the process helps to satisfy the condition of relevance, that is, decisions should be made on the basis of reasons (principles and values) that "fair-minded" reasonable people can agree are pertinent and important given the current context.

Overarching Question:

Before proceeding to Step 3, the question: "Have perspectives of relevant individuals been sought?" should be considered.

Step 3: Explore the Options

The third step encourages brainstorming and reflection on a range of alternative courses of action. In any given situation, an attempt to identify at least three options should be made. For each option, determine whether it is consistent with: relevant laws and policies and the organization's strategic plan (see Appendix D). Strengths and limitations of each option are explored including how they may or may not support the decision-making criteria (i.e., the agreed upon principles identified in Step 2). For each option, any additional resources required for implementation should be identified.

Condition:

Revisions and Appeals - Before a decision is acted upon, a mechanism for revisions and appeals is established, if not already in place. The decision may be revisited and revised in light of new or additional evidence. These procedures are necessary to satisfy the condition of "revisions and appeals."

Overarching Question:

What is the most ethically justifiable option?

Step 4: Act.

Finally, the fourth step focuses on action. The most ethically justifiable option as identified in Step 3 is recommended for implementation. The decision(s) and the process used to arrive at the decision(s) is documented and communicated to relevant parties. An implementation plan is articulated. A process for evaluating the decision is outlined. Where applicable, indicators and outcomes are identified and monitored. Identify key learnings that can be applied to future practice.

Condition:

Compliance (Enforcement) - Lastly, to satisfy the condition of "compliance (enforcement)" the decision-making process should be reviewed to ensure that all of the conditions have been satisfactorily met. Although this review can be carried out by those directly involved in the decision-making process, validation by an individual or group that has not been directly involved is preferable as it is likely to be perceived as less biased.

Overarching Question:

Lastly, it is important to the ask the question: "Are we (am I) comfortable with this decision?"

The decision arrived upon might not be the one that would be most preferred by particular individuals or groups. However, those involved in the decision-making process should feel comfortable with the decision and the process that was used to reach the decision. If decision-makers are not feeling comfortable with the decision, further exploration of the reasons for the discomfort is warranted prior to implementation. Another way to think about this question is to consider: "If this decision and the reasons for it were published in the paper tomorrow, would I be able to adequately defend the decision and the process?"

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Appendix A: What is an Ethical Issue?

Ethics is about:

- Deciding what we should do (what decisions are morally right or acceptable);
- Explaining why we should do it (justifying our decision in moral terms); and
- Describing how we should do it (the way we respond).

Ethical issues are often framed as "should" questions. For example:

- How should the organization make decisions about how much funding to provide to each of its programs?
- If there is a shortage of critical care beds, how *should* decisions about who to admit (and who not to admit) be made?
- Should life-sustaining treatment be continued for an individual for whom the treatment is burdensome with minimal benefit?
- Should a colleague's alcohol abuse be reported?
- Should an individual be informed of a "near miss" in their care?

Ethical issues may involve one or more of the following:

- <u>Ethical Violation</u> when an action that appears to be unethical is being proposed or carried out (e.g., an individual is being given a treatment without providing a valid consent)
- <u>Ethical Dilemma</u> when there are competing courses of action both of which may be ethically defensible (e.g., conflicting values) and there is a difference of opinion as to how to proceed
- <u>Ethical Uncertainty</u> when it is unclear what ethical principles are at play or whether or not the situation represents an ethical problem
- <u>Ethical (Moral) Distress</u> when one finds themselves in a situation of discomfort, if one has failed to live up to their own ethical expectations, or if one is unable to carry out what they believe is the right course of action due to organizational or other constraints

Appendix B: Ethics Worksheet – IDEA Framework

Date:
Participants:
Cton 4. Identify the Foote
Step 1: Identify the Facts.
Brief Description of the Ethical Concern
Known Facts of the Situation
Preferences of the Relevant Parties (values and beliefs, prior expressed wishes)

Contextual & Societal Features
Law and Policy Considerations
Positionality/Intersectionality
Potential Conflicts of Interest and Personal Biases
Evidence to Inform Decision
Lived Experience
Research
Standards of Practice
Standards of Fractice
What is the ethical issue?

Step 2: Determine the R	elevant Ethical Principles	S.
Who are the relevant parties?	What principles do relevant parties believe are applicable to the issue?	Which principles do relevant parties agree are most important?
Are there any other factors to	be considered?	
Have perspectives of relevant	parties been sought?	

Step 3: Explore	th:	e C	pti								
Option 1:				Option 2:			Option 3:				
Consistent with:	Yes	No	?	Consistent with:	Yes	No	?	Consistent with:	Yes	No	?
Laws and policies				Laws and policies				Laws and policies			
Strategic plan				Strategic plan				Strategic plan			
Strengths:		ı		Strengths:				Strengths:			
Limitations:				Limitations:				Limitations:			
Additional Resources Required:		ed:	Additional Resources Required:			ed:	Additional Resources Required:				
Decision-Making Criteria: List from Step 2 Yes No ?			Decision-Making Criteria: List from Step 2 Yes No ?			2	Decision-Making Criteria: List from Step 2 Yes No ?				
List Horri Step 2			·	List from Step 2			·	List iroin Step 2			<u>·</u>
					\boxtimes						
What is the most e	thica	ally	just	ifiable option?							

Step 4: Act.	
	on of Decision (who, what, where, how):
Implementation Plan (who, wi	hat where how):
Implementation Francisco, wi	nat, where, nowy.
Evaluation Plan (outcomes ar	nd indicators):
Are we (am I) comfortable with	h this decision?
Kay Loornings	
Key Learnings	
Process Met Conditions:	Evidence:
☐ Relevance	
☐ Publicity	
☐ Revisions and Appeals	
☐ Empowerment	

Appendix C: Ethical Values/Principles

Below you will find list of ethical values (things that may be deemed important in health care) and principles (how to enact those values in practice). This is not an exhaustive list and is subject to iteration. There may be other ethical values/principles at play in a particular situation. Each value is listed in bold capital letters followed by the principle in bold lowercase letters.

AUTONOMY: Respect for autonomy – respect people's right to self-determination or self-governance such that their views, decisions and actions are based on their personal values and beliefs; e.g., in health care, this principle is the foundation of the informed consent process.

ACCOUNTABILITY: Take ownership of actions and inactions – clear governance structures in place that identify who is responsible for what decisions.

BENEFICENCE: Act beneficently toward others – contribute to the welfare of others, which may include preventing harm, removing harm and promoting well-being.

COMMON GOOD: Work towards a common good – Understand the shared and beneficial goals of a given community and support their achievement.

CONFIDENTIALITY: Keep private information confidential – personal information should not be disclosed unless consent to disclose this information is given by the person to whom it belongs or disclosure is permitted by law.

CONFLICT OF INTEREST: Address conflicts of interest – identify perceived, potential and actual conflicts of interest (i.e., situations where one has competing obligations, duties or goals) and take steps to mitigate.

DIGNITY: Respect the dignity of persons – treat persons in a way that honours their inherent value or worth.

DISCLOSURE: Disclose information that people or groups have a right to – provide information in an accessible and compassionate manner; e.g., diagnosis/prognosis, errors/adverse events in treatment or research.

DIVERSITY: Respect diversity – ensure that people are valued and have equitable access to all opportunities whatever their differences (e.g., race, religion, culture, gender, disability).

HONESTY: Be truthful – act in a way that promotes open communication and avoids deception (e.g., lying, withholding of information).

INCLUSIVITY: Ensure proportionate and equitable representation of relevant individuals and groups – Promote a culture that fosters safety and a sense of belonging for all. Ensure steps are taken to promote patient's voice is heard, e.g., interpreter/translation. Remove barriers that are impeding inclusiveness.

INTEGRITY: Act with integrity – Conduct oneself in a way that is consistent with one's personal values and principles.

JUSTICE: Promote justice and fairness – treat people and groups fairly by treating morally relevant cases alike, by promoting fair relations among individuals and groups, and by ensuring fair and equitable access to resources and opportunities, including fair distribution of benefits and burdens, work towards elimination of racism and other forms of discrimination.

NON-ABANDONMENT: Fulfill duty to provide care – professional and ethical obligation to provide standard of care to those in need and to ensure no one is left behind; facilitate transfer of care to colleagues when appropriate.

NON-MALEFICENCE: Act so as to do no harm – take actions to promote safety, avoid harm and minimize risks of harm to individuals or groups.

PERSON-CENTRED: Provide person-centred care – engage persons as active participants in their care in ways that respect and respond to their values, preferences and decisions.

PROPORTIONALITY: Distribute benefits and burdens commensurately – act in a way that corresponds to the gravity and urgency of the situation; consider the least restrictive actions required to achieve the desired outcome.

RECIPROCITY: Minimize disproportionate burden – provide support and resources to individuals so they can more readily fulfil obligations.

RELATIONSHIPS: Foster connections with others – acknowledge our relational way of being and importance of considering self in relation to others.

SOLIDARITY: Stand together to support a cause or collective purpose – listen, learn, collaborate and advocate.

STEWARDSHIP: Manage resources entrusted to one's care – carefully and responsibly utilize assets (e.g., public healthcare dollars).

TRANSPARENCY: Ensure decision-making processes are transparent – communicate decisions and their rationales in an accessible manner to all relevant parties. Transparency helps to promote trust.

TRUST: Act reliably – consider how cultural/historical/social/personal factors may be contributing to a lack of trust.

UBUNTU: Recognize the humanity in all persons – acknowledge that we are mutually related and interdependent ³

UTILITY: Maximize utility – Act in ways that bring about the greatest good for the greatest number.

Regional Ethics Program – June 2023

³ Ubuntu is an ethical principle that students from Africa who studied at the Joint Centre for Bioethics shared with professors and fellow students that we think captures an important philosophical concept.

Appendix D: Strategic Plan

