



Bioethics 101

Reasoning and Justification

Grades 7-12 | First Edition

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Credits

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Table of Contents

1	Credits
5	Curriculum Overview
9	Correlation to National Learning Standards
13	LESSON 1: Introduction to Bioethics
19	STUDENT HANDOUT 1.1 — Pandemic Flu!
21	LESSON 2: Principles of Bioethics
27	TEACHER RESOURCE 2.1 — Skit Improvisation List
28	STUDENT HANDOUT 2.1 — The Principles of Bioethics—Background
29	STUDENT HANDOUT 2.2 — Focus on the Principles
31	LESSON 3: Finding the Stakeholders
35	STUDENT HANDOUT 3.1 — Dennis’s Decision
36	STUDENT HANDOUT 3.2 — Values Definition Table
37	STUDENT HANDOUT 3.3 — Facts, Values, and Stakeholders
38	Possible Answers for STUDENT HANDOUT 3.3 — Facts, Values, and Stakeholders
39	LESSON 4: Making a Strong Justification
45	TEACHER RESOURCE 4.1 — Take This! Take That! Silent Debate
46	STUDENT HANDOUT 4.1 — A Decision for Dennis
47	STUDENT HANDOUT 4.2 — Elements of a Strong Justification
48	Possible Answers for STUDENT HANDOUT 4.2 — Elements of a Strong Justification
49	STUDENT HANDOUT 4.3 — Your Decision and Justification
51	LESSON 5: Putting it all Together
55	STUDENT HANDOUT 5.1 — Case Study: The Time and the Place?
56	STUDENT HANDOUT 5.2 — Ethical Decision-Making Framework
58	Possible Answers for STUDENT HANDOUT 5.2 — Ethical Decision-Making
60	STUDENT HANDOUT 5.1 — Elements of a Strong Justification

61	APPENDIX
63	Creating Discussion Ground Rules
64	STUDENT HANDOUT — Elements of a Strong Justification
65	Ashley’s Case Overview
66	STUDENT HANDOUT — Assessment Questions
69	Scoring Rubric
71	Teacher Support Materials



Bioethics 101

CURRICULUM OVERVIEW

Most of the secondary science teachers who shy away from incorporating ethics into their curricula are quite clear about the reasons they do so. First, they are uncomfortable with teaching ethics, a subject that science teachers often have very little experience with. Ethics as a discipline is full of unfamiliar terms and its own jargon. Secondly, teachers fear classroom discussions “getting out of control,” degenerating into a battle of opinions, or having parents and administrators confuse teaching about values and morals with teaching **particular** values and morals. Lastly, something as seemingly subjective as ethics can be perceived as somewhat out of place in a science classroom, where the focus is ostensibly on objectivity: “Why are we studying values in science class?” Ethics seems like just one more element in already crowded programs. The *Bioethics 101* curriculum focuses on tools and strategies for overcoming these barriers.

Bioethics 101 provides a systematic, week-long introductory course for the teacher who would like to incorporate ethics into the classroom through the use of sequential, day-to-day lesson plans. This curriculum is designed to help science teachers guide their students to analyze issues in light of the scholarly discipline of ethics.

Teachers who have incorporated ethics into their science classrooms have reported a number of gains. Students have become more engaged with the science content, have become better discussion participants, and have shown a better understanding of the way science impacts everyday life. In addition, students have gained valuable critical thinking skills as they learn to “think through” complex problems and justify their position on an issue.

The *Bioethics 101* curriculum is based on *An Ethics Primer*, NWABR’s resource guide of lesson ideas and ethics background. Teachers in the NWABR educational community have been using *An Ethics Primer* for a number of years as a flexible, wide-ranging, mix-and-match teaching resource. Teachers familiar with the *Primer* were asked for their “all time favorite” introductory lessons that would be compiled and rewritten to create a focused, week-long introductory unit. This “best of” compilation of introductory lessons and activities is this curriculum: *Bioethics 101*.

CURRICULUM FRAMEWORK

This unit builds sequentially from *Lesson 1* to *Lesson 5*. **Concepts** are introduced early in the unit and students are given the opportunity to practice those concepts using a variety of **techniques**. Please refer to the *Concept Introduction and Reinforcement* section of this *Curriculum Overview*.

Concepts: Students are first introduced to **ethics** as a discipline, what constitutes an **ethical question**, and the idea that **values** serve as a basis for behavior and contribute to decision-making. The **Principles of Bioethics** are then introduced, followed by the concept of **stakeholders**. Students learn how to generate **options** to resolve an ethical dilemma and learn how to write a strong **justification** for their position. New concepts are layered on in each lesson; students practice known concepts while being introduced to new ones. In the last lesson, students synthesize all the concepts and apply them to a new case study.

Techniques: The curriculum employs case studies throughout. By reading and analyzing different cases, students practice the concepts they have learned in concrete scenarios. Students are asked to think about concerns related to the case from the perspective of different stakeholders. The curriculum also makes use of structured Decision-Making Frameworks and graphic organizers to help students “reason through” complex issues.

INSTRUCTIONAL COMPONENTS

The Curriculum: The *Bioethics 101* curriculum consists of five sequential lessons plus a pre/post-test option.

Time Requirement: Each lesson requires at least one 55 minute class period. The entire curriculum module should take between five to seven class periods.

Target Audience: The target audience is 10th grade Biology class, although the curriculum could be modified for other age and content groups.

Pre-/Post-Test: The impact of the curriculum on students is assessed through a pre- and a post-test. The pre- and post-tests consist of a case study with accompanying questions. The case study, questions, grading rubric, and additional teacher resources can be found in the *Appendix*. Teachers should allow 15–30 minutes for the test.

Discussion Norms: Teachers should review or create classroom discussion ground rules (norms) before beginning the unit. Instructions for doing this can be found in the *Appendix*.

ESSENTIAL UNDERSTANDINGS

There are several “essential understandings,” or core concepts, that are important for communicating with students about ethics. We hope to foster among students an understanding of the **importance of well-reasoned judgments**, combined with a **respect and empathy for other approaches**.

Intellectual Rigor: The Importance of Well-Reasoned Judgments

Students need to learn to differentiate between opinions based on emotions and those supported by evidence and logical argument. A key misconception among students is that ethics is a matter of opinion (the issue of moral relativism), and that therefore ethical issues are not worth discussing or cannot be resolved. The discipline of ethics stresses an analytical approach to evaluating issues. Successful arguments are both well-reasoned and clearly articulated. A **solid understanding of science content** provides the foundation from which students can develop their positions. What matters most is not which position students take, but how thoroughly they have analyzed the ethical dilemma and how well-justified and supported their arguments are.

Citizenship in a Democratic, Pluralistic Society: Respect for Alternate Approaches and Viewpoints

Ethics allows students to gain greater understanding and respect for other positions and approaches, even if they do not agree with them. It enhances their ability to understand the issues and values informing different points of view, and thus makes them better citizens of our democratic and pluralistic society.

Students should also be aware that in certain contexts, well-reasoned judgments can sometimes be used to support morally unacceptable practices. The ethical perspectives of some stakeholders may be morally reprehensible to others. It is important to stress that at the community and societal levels not all values are deemed equally defensible.

UNIT OBJECTIVES

Students will be able to:

1. Identify the characteristics of an ethical question and recognize an ethical question embedded in a case study.
2. Distinguish different types of questions (subjective, objective, and those of reasoned judgment) and understand that each requires a different type of answer.
3. Describe major bioethical principles and accurately apply those principles when evaluating a case study.
4. Recognize stakeholder individuals or groups and articulate their concerns and values.
5. Apply their understanding of the elements of a strong justification when creating a strong justification for their own position.
6. Reason through a case study using a decision-making framework.

SOURCE MATERIAL

The source material for many of the lessons, activities, student handouts, and teacher resources is *An Ethics Primer: Lesson Ideas and Ethics Background* by Jeanne Ting Chowning and Paula Fraser, produced through the Northwest Association for Biomedical Research. The complete *Ethics Primer* is available free for download from <http://www.NWABR.org>.

The *Ethics Primer* provides engaging, interactive, and classroom-friendly lesson ideas for integrating ethical issues into a science classroom. It also provides basic background on ethics as a discipline, with straightforward descriptions of major ethical theories. Several decision-making frameworks are included to help students apply reasoned analysis to ethical issues.

Although the *Ethics Primer* is designed for secondary school science classrooms, it has been used by teachers in a variety of classes and grade levels. It is particularly suited to social studies and integrated/interdisciplinary classrooms. It has also been used with adults. The *Ethics Primer* is not designed to be used cover to cover. Teachers should review materials and select lessons that fit their needs. The *Ethics Primer* is also intended to be used as a general resource, with a wide variety of topics.

LESSON OVERVIEW

Lesson One: Introduction to Bioethics

In this lesson, students are introduced to the characteristics of an ethical question and learn to distinguish ethical questions from other types of questions, such as legal or scientific questions. Students then identify an ethical question and participate in an ethical dilemma involving the distribution of a scarce resource—a flu vaccine—during a flu outbreak. Students are asked to determine the best course of action in the face of conflicting choices, while examining the underlying themes that serve as a basis for their reasoning. Lastly, students experience how relevant facts influence decision-making.

Lesson Two: Principles of Bioethics

Students consider questions with answers based on fact, preference, or reasoned judgment, and determine where those questions fall along the range of purely subjective to purely objective. Students then improvise short skits to illustrate familiar concepts such as fairness, respect, and “doing good.” This sets the foundation for the **Principles of Bioethics: Respect for Persons, Maximize Benefits/Minimize Harms, and Justice**. Students then apply these bioethical principles to the pandemic flu ethical dilemma they were introduced to in *Lesson One*.

Lesson Three: Finding the Stakeholders

Students read a case study about Dennis, a 14-year-old boy who has been diagnosed with leukemia. The doctors treat the leukemia with chemotherapy, which dramatically reduces the number of Dennis’s blood cells; Dennis, however, refuses life-saving blood transfusions because they conflict with his faith. Students identify an ethical question to explore, and consider how the **Principles of Bioethics (Respect for Persons, Maximizing Benefits/Minimizing Harms, and Justice)** relate to the case. Students then identify the stakeholders—the people or institutions that are affected by the outcome—and work in small groups to clarify stakeholder values, interests, and concerns. After stakeholder groups present their positions to the class, the class generates options for possible resolutions to the case.

Lesson Four: Making a Strong Justification

In this lesson, students learn the characteristics of a strong justification and apply them to a decision about an ethical question. Students brainstorm what makes a **weak** justification, and are then primed to identify what makes a **strong** justification through their participation in a silent debate. Students refer to the *Case Study: Dennis’s Decision* from *Lesson Three*, and evaluate a number of pre-written justifications for that case. For each justification, students consider whether: a decision has been made, scientific facts have been included, stakeholder views are represented, there is reference to bioethical principles, and alternate solutions are considered. Once students understand the elements of a well-crafted justification, they come to their own decision about Dennis and write their own justification.

Lesson Five: Putting it all Together

In this lesson, students consider the case of a young doctor hired by a U.S. pharmaceutical company to test a new antibiotic in Nigeria during a meningitis epidemic. Students work through a **Decision-Making Framework** in small groups, in which they identify the ethical question, determine which facts are known or unknown, consider the values of different stakeholder groups, generate possible solutions, and then make and justify a decision about the case. This is a jigsaw exercise, in which students first meet in “like” stakeholder groups to become experts in the values and concerns of that group. Teams are then rearranged so that each new group has students from different stakeholder viewpoints. After sharing the views and values of each stakeholder group with their peers, groups work together to generate options for solutions to the case study. Lastly, students come to individual decisions about the case and write a thorough justification.

CONCEPT INTRODUCTION AND REINFORCEMENT

	<i>Students are introduced to:</i>	<i>Students practice:</i>
Lesson 1	Ethics and bioethics by discussing a scenario containing an ethical dilemma. Identification of an ethical question .	
Lesson 2	Subjective and objective questions. Bioethical principles.	Application of bioethical principles to a specific ethical dilemma in a story.
Lesson 3	Stakeholders and their values and concerns. Generation of options for resolving an ethical dilemma.	Identification of an ethical question rooted in a story/scenario. Application of bioethical principles to a specific ethical dilemma in a story.
Lesson 4	Justification of the resolution to an ethical dilemma.	Identification of an ethical question rooted in a story/scenario. Application of bioethical principles to a specific ethical dilemma in a story. Identification of stakeholders and their values and concerns. Generation of options for resolving the ethical dilemma.
Lesson 5		Identification of an ethical question rooted in a story/scenario. Application of bioethical principles to a specific ethical dilemma in a story. Identification of stakeholders and their values and concerns. Generation of options for resolving the ethical dilemma. Justification of the resolution to an ethical dilemma.

CORRELATION TO NATIONAL LEARNING STANDARDS

National Standards Alignment: Science (Grades 5-12)

	Lesson One: Introduction to Bioethics	Lesson Two: Principles of Bioethics	Lesson Three: Finding the Stakeholders	Lesson Four: Making a Strong Justification	Lesson Five: Putting it All Together
A. Science as Inquiry					
Abilities necessary to do scientific inquiry.					
Understandings about scientific inquiry.		•			•
E. Science and Technology					
Abilities of technological design.		•	•	•	•
Understandings about science and technology.		•	•	•	•
F. Science in Personal and Social Perspectives					
Personal and community health.	•	•	•	•	•
Science and technology in local, national, and global challenges.	•	•	•	•	•
G. History and Nature of Science					
Science as human endeavor.	•	•	•	•	•
Nature of scientific knowledge.	•	•	•	•	•
Historical perspectives		•		•	•

National Research Council. (1996). *National Science Education Standards*. Washington D.C.: National Academies Press.

Common Core State Standards

For English Language Arts & Literacy in History/Social Studies, Science, and Technical Subjects

	Lesson One: Introduction to Bioethics	Lesson Two: Principles of Bioethics	Lesson Three: Finding the Stakeholders	Lesson Four: Making a Strong Justification	Lesson Five: Putting it All Together
Comprehension and Collaboration, Grades 9-10					
1. Initiate and participate effectively in a range of collaborative discussions (one-on-one, in groups, and teacher-led) with diverse partners on topics, texts, and issues, building on others' ideas and expressing their own clearly and persuasively.	•	•	•	•	•
a. Come to discussions prepared, having read and researched material under study; explicitly draw on that preparation by referring to evidence from texts and other research on the topic or issue to stimulate a thoughtful, well-reasoned exchange of ideas.			•	•	•
b. Work with peers to set rules for collegial discussions and decision-making (e.g., informal consensus, taking votes on key issues, presentation of alternate views), clear goals and deadlines, and individual roles as needed.	•	•	•	•	•
c. Propel conversations by posing and responding to questions that relate the current discussion to broader themes or larger ideas; actively incorporate others into the discussion; and clarify, verify, or challenge ideas and conclusions.	•	•	•	•	•
d. Respond thoughtfully to diverse perspectives, summarize points of agreement and disagreement, and, when warranted, qualify or justify their own views and understanding and make new connections in light of the evidence and reasoning presented.	•	•	•	•	•

National Governors Association Center for Best Practices, Council of Chief State School Officers. (2010). *Common Core State Standards for English Language Arts & Literacy in History/Social Studies, Science, and Technical Subjects*. Washington D.C.: National Governors Association Center for Best Practices, Council of Chief State School Officers.

Framework for K-12 Science Education

	Lesson One: Introduction to Bioethics	Lesson Two: Principles of Bioethics	Lesson Three: Finding the Stakeholders	Lesson Four: Making a Strong Justification	Lesson Five: Putting it All Together
Scientific Practices					
Asking questions.	•	•	•	•	•
Developing and using models.		•	•	•	•
Analyzing and interpreting data.				•	•
Constructing explanations.	•	•	•	•	•
Engaging in argument from evidence.	•	•	•	•	•
Obtaining, evaluating, and communicating information.	•	•	•	•	•
Crosscutting Concepts					
Systems and system models.		•	•	•	•
Stability and change.				•	•
Core Ideas: Life Sciences					
LS 1: From molecules to organisms: Structures and processes.			•		
LS 2: Ecosystems: Interactions, energy, and dynamics. D: Social interactions and group behaviors.			•	•	•

Committee on Conceptual Framework for the New K-12 Science Education Standards, National Research Council. (2011). *A Framework for K-12 Science Education: Practices, Crosscutting Concepts, and Core Ideas*. Washington D.C.: National Academies Press.



LESSON 1:

Introduction to Bioethics

INTRODUCTION

Students are introduced to the characteristics of an ethical question and learn to distinguish ethical questions from other types of questions, such as legal or scientific questions. Students then identify an ethical question and participate in an ethical dilemma involving the distribution of a scarce resource—a flu vaccine—during a flu outbreak. Students are asked to determine the best course of action in the face of conflicting choices, while examining the underlying themes that serve as a basis for their reasoning. Lastly, students experience how relevant facts influence decision-making.

KEY CONCEPTS

- Ethical questions are characterized by the following:
 - They often involve the words “ought” or “should,” implying a difficult decision must be made.
 - There are several alternate solutions, none of which is without some challenging or problematic aspect.
 - They contain conflicting moral choices and dilemmas, and the underlying values of the people involved may clash.
 - They have no right or wrong answer that satisfies all parties, but better or worse answers based on well-reasoned justifications.
- It is important to gather as many facts as possible when making decisions about ethical questions.
- Ethical questions arise because of our **social responsibilities** to others in our community and because our behavior is capable of influencing the welfare of others.

Values signify what is important and worthwhile. They serve as a basis for moral codes and ethical reflection.

Morals are codes of conduct governing behavior. They are values “put into practice” as actions.

Ethics provide a systematic, rational way to work through dilemmas and to determine the best course of action in the face of conflicting choices.

LEARNING OBJECTIVES

Students will be able to:

- Identify the characteristics of an ethical question, and distinguish an ethical question from other types of questions.
- Recognize that reasoned judgment is valuable when making difficult decisions.
- Understand how facts contribute to decision-making.
- Reason through a difficult ethical scenario.

CLASS TIME

One class period of 55 minutes.

MATERIALS

Materials	Quantity
Student Handout 1.1— <i>Pandemic Flu!</i>	1 per student
Computer with projector (<i>optional</i>)	1

TEACHER PREPARATION

Make copies of Student Handout 1.1—*Pandemic Flu!*, one per student.

NOTE TO THE TEACHER

It is especially important to foster a safe classroom atmosphere when discussing ethical issues that may involve conflicting moral choices. Please review or create classroom discussion ground rules (“norms”) before proceeding. Instructions for doing this can be found in the *Appendix*.

PROCEDURE

Part I: What is Bioethics?

Activity Time: 5 minutes

1. Tell students that the class is embarking on a week-long study of bioethics. Define both **ethics** and **bioethics** for students, as follows:

Ethics is a field of study that looks at the moral basis of human behavior (“*Why do we act as we do?*”) and attempts to determine the best course of action in the face of conflicting choices (“*How do we decide what to do when people disagree about a complex issue?*”). It is a key component of living within a society in a civilized way.

Bioethics is a subfield of ethics applied to the life sciences. The discipline of bioethics helps us, as a society, make decisions about how best to use new scientific knowledge, how to make policy decisions regarding medicines or treatments, and how we should behave with each other. It explores ethical questions such as:

“How should we decide who receives organ transplants?” or, “Should a terminally ill patient be allowed to end his/her life with physician-prescribed medication?”

2. Tell students that they will begin the unit by delving into an ethical discussion, after defining what constitutes an ethical question.

Part II: What is an Ethical Question?

Activity Time: 15 minutes

3. Tell students that, in the study of bioethics, the first step is often to recognize and define what the **ethical question** is. Students will need to refer back to this definition; teachers may either project the definition or ask students to take notes.

Ethical questions have the following components:

- Ethical questions often involve the words “ought” or “should,” implying a difficult decision must be made.

- There are several alternate solutions, none of that is without some challenging or problematic aspect.
- They contain conflicting moral choices and dilemmas, and the underlying values of the people involved may clash.
- They have no right or wrong answer which satisfies all parties, but better or worse answers based on well-reasoned justifications.

Reminds student that not all questions with the word “should” are ethical questions. For example, *“Should I bring my umbrella today?”* does not meet the other criteria.

4. Tell students that there are different types of questions, each having different characteristics. In addition to ethical questions defined above, there are questions pertaining to law, to science, to personal preference, to one’s culture or religion. [Note: These additional types of questions are further defined in **Step #7**.]
5. Ask students to pick out the ethical questions from the following list of questions. It may be helpful to project the questions for all to see.
 - a) Is it legal to sell human kidneys in the United States?
 - b) How does a kidney function inside the body?
 - c) What does my religion say about whether or not it is acceptable to donate a kidney?
 - d) Should individuals who donate a kidney choose who their organ should go to?
 - e) What type of diet allows for the best athletic performance?
 - f) Is killing someone always illegal?
 - g) Should people select the sex of their child in advance?
 - h) Are same-sex marriages constitutional?
 - i) What is the most appropriate way to worship?
 - j) Do kidneys taste good?

Questions **d** and **g** are ethical questions, as they fulfill the criteria listed in **Step #3**.

6. Further define other types of questions based on the definitions below.

7. Revisit the list of questions, a- j, and have students identify which type of question they represent.

Legal questions ask what the law says about a particular issue. Questions **a**, **f**, and **h** are legal questions.

Scientific questions can be explored through scientific inquiry and observation. They rely on empirical and measurable evidence. Questions **b** and **e** are scientific questions.

Religious/Cultural questions ask what would be in line with a particular belief or practice, or the common practices of a particular culture. Questions **c** and **i** are religious/cultural questions.

Personal preference questions relate directly to the speaker and are often modified by cultural bias. Question **j** is one of personal preference.

[**Note:** Questions may be of more than one type, and other types of questions also exist.]

A good complementary activity can be found in the National Institutes of Health Curriculum Supplement Series *Exploring Bioethics*. Activities in Module 1 support students in distinguishing types of questions. The curriculum can be found at: <http://science.education.nih.gov/customers.nsf/HSBioethics.htm>.

Part III: Ethical Group Discussion—Pandemic Flu

Activity Time: 20 minutes

8. Ask students what type of question the following is:
“Who should be saved during a flu outbreak when there is not enough life-saving vaccine available for everybody?”
9. Review the criteria for an ethical question to see that it is, indeed, an ethical question.
10. Pass out Student Handout 1.1—*Pandemic Flu!* Allow about 5 minutes for students to read the scenario and individually make their choices about the distribution of the vaccine. Ask students to pay close attention to **how** they are making their decisions.

11. On the board, draw the following table. Students will record their answers on the *Student Handout*.

Who should receive the vaccine?	How do you decide?

The purpose of this exercise is to allow students to practice “reasoning through” a difficult situation that cannot be solved easily, rather than exercising omnipotent powers.

“Who should receive the flu vaccine?” is a question that asks us to decide how best to share a scarce resource. This type of question can be applied to many topics, from organ donation allocation to natural resources.

12. Some students may be blocked to the point of inaction by the lack of facts given in the case. In this case, a decision **must** be made immediately. (“What if the vaccine was expiring right away?”) **Not** making a decision will also have consequences.
13. In small groups, have students spend about 5 minutes discussing their answers, filling out their tables as they proceed. They do not need to come to consensus, but need to understand where there are differences in viewpoints and opinions.
14. Begin debriefing the exercise by reading through the list of characters one by one and having students raise their hands if they chose to give that character the vaccine. Ask questions such as: “Who chose to give the vaccine to the doctor?” Go through the list with minimal discussion.
15. Next, choose characters to discuss in more detail. Ask students **how** (on what basis) they made the decision to give the vaccine to a particular character. For example, “For those of you who chose to vaccinate the doctor, how did you decide?” You may also choose to ask, “Did anybody choose **not** to vaccinate the teacher? How did you decide?”

16. In the interest of time, make sure to discuss the doctor, the orphaned two-year old, and the mother refusing treatment. These three individuals highlight concepts behind bioethical principles that will be introduced to the students in *Lesson Two*. Continue with other characters from the exercise as time permits.

17. Point out some common approaches that may appear during the student discussion and write the italicized words on the board. By a show of hands, have students show whether they considered that approach when making their decisions.

Approach 1: *Save the Youngest*. In choosing this, students are maximizing the life span for the greatest number of people.

Approach 2: *Draw Straws* (or any randomization technique). This option values fairness.

Approach 3: *Save the Weakest*. This option considers the special needs of vulnerable populations.

Approach 4: *Save the Most Useful*. Saving someone who has special knowledge and/or may be able to save others benefits a larger number of people.

Approach 5: *Respect Relationships*. Honoring the dignity of human beings includes acknowledging their relationships.

18. Tell students that these approaches reflect ***societal standards*** or ***codes of conduct*** that we often rely on when faced with difficult decisions or ethical questions. We will be exploring these in greater detail throughout the unit.

Part IV: The Need for Facts

Activity Time: 10 minutes

19. Underscore for students that in considering any ethical question, it is important to ***examine the facts*** available, and ***assess what additional information*** is needed. In the pandemic flu scenario, students had very little information from which to make difficult decisions. In most cases, more information may be gained through research or study.

20. Ask students, “What are the facts of this case?” and discuss what is known.

21. It is also helpful to define the “unknowns” in a case, as very few real-life situations will supply all the facts for all of the people involved. Eventually, a decision must be reached in the absence of a complete set of facts.

22. To illustrate how additional facts influence decision-making, present the following facts to add to the pandemic flu scenario.

What if...?

a) The senior citizen is primary caretaker for eight of her grandchildren.

b) The mother refusing treatment is in her 60s. The son is in his 40s.

c) The doctor is a podiatrist.

d) The woman who thinks she is pregnant has been married to the orderly for about a year. They have no children.

23. Discuss with students how, or if, these additional facts changed their decisions.

24. Refer to the approaches written on the board. If students changed their minds about who should receive the vaccine, did the decision still fit one of the approaches? Are there other approaches that should be added to the list?

CLOSURE

25. Tell students that ethical questions arise whenever **individuals**, with their own values and moral codes, interact within a larger **community** and a decision must be made about conflicting choices.
26. Share with students that science is a human enterprise that is conducted in a social context—science clearly has ethical implications. Offer the following examples of ethical questions (not for discussion, merely as illustration):
- Should we allow embryos left over from in vitro fertilization clinics to be destroyed for stem cell research, if they would otherwise be discarded?
 - Should human clinical trials be conducted in populations that may not be able to afford the final medication, even if that population benefits from the trial?
27. Tell students that these are real-world, complex, engaging ethical questions. By learning how to **recognize** an ethical question, **assess** the facts, **listen** to different viewpoints, and make a **reasoned judgment** about a course of action, students gain experience in critical thinking, and grow in their understanding and respect for other points of view. In their lifetimes, students will be confronted with many ethical issues related to science—an understanding of bioethics and decision-making will help them make well-reasoned and informed choices.

HOMEWORK

- Ask students to find a news article that highlights the larger societal and ethical implications of science. Students should **identify and write down an ethical question** pertaining to that news topic or issue, and be prepared to share it with the class.
- Alternately, students may write down an ethical question they have faced in their own lives. Students should not be expected to share these with the class.

ADDITIONAL RESOURCES FROM AN ETHICS PRIMER

From the *Lesson Strategies* section:

- **General Discussion Background:** Suggestions for Conducting Classroom Discussions
- **Awareness:** Ethical Questions



STUDENT HANDOUT 1.1

Pandemic Flu!

Name_____ Date_____ Period_____

Read the scenario and come to a decision on your own. When you and your group are finished, discuss your answers in a group. **Be prepared to explain how you reached your decision.** The purpose of this exercise is to practice using reasoning skills in a difficult, hypothetical situation in which there is no clear answer.

Scenario

A severe worldwide outbreak of a flu caused by a respiratory virus has occurred. It threatens everybody in your community—healthy young people as well as the very old and very young. You cannot count on receiving federal assistance during this pandemic. This deadly flu has already killed people in your community and exposure to the flu is expected. Anybody who has not been vaccinated will succumb to the flu and most likely die. Effective vaccines exist in limited supply. There are enough vaccines to treat more than half of the community members during the first wave of the pandemic.

There are ten people who require the vaccine at this time and you can only treat six.
The four individuals who do not receive the vaccine will most likely die.

Which six should receive the flu vaccine?

- Woman who thinks she is six weeks pregnant
- Recently orphaned two-year old
- Nurses' aide who works at a nursing home
- Senior citizen who has 15 grandchildren
- Thirteen-year-old twins
- Doctor
- Elementary school teacher
- Mother and son; the mother is refusing treatment so her son will be treated

Who Should Receive the Vaccine?	How Did You Decide?

LESSON 2:

Principles of Bioethics

INTRODUCTION

Students consider questions with answers based on fact, preference, or reasoned judgment, and determine where those questions fall along the range of purely subjective to purely objective. Students then improvise short skits to illustrate familiar concepts such as fairness, respect, and “doing good.” This sets the foundation for the **Principles of Bioethics: Respect for Persons, Maximize Benefits/Minimize Harms, and Justice**. Students then apply these bioethical principles to the pandemic flu ethical dilemma they were introduced to in *Lesson One*.

KEY CONCEPTS

- Ethical discussions are not “my opinion vs. your opinion” but require reasoned judgment and logical thought.
- Students already have an awareness of ethical principles, though they may not have the vocabulary to explain them as such.
- Bioethical dilemmas can be evaluated using various ethical perspectives.
- The Principles of Bioethics introduced are:
 - **Respect for Persons** (Respecting the inherent worth of an individual and their autonomy)
 - **Maximize Benefits/Minimize Harms** (Beneficence/Nonmaleficence)
 - **Justice** (Being Fair)
- Exposure to ethical perspectives provides students with the language to give shape to their thoughts, and supports them in justifying their reasoning.

LEARNING OBJECTIVES

Students will be able to:

- Understand that different types of questions require different types of answers.
- Describe major bioethical principles.
- Understand the relationship between stating a position, or claim, and the use of principles to support that position.

CLASS TIME

One class period of 55 minutes.

MATERIALS

Materials	Quantity
Teacher Resource 2.1— <i>Skit Improvisation List</i> (cut into strips)	1
Student Handout 2.1— <i>Principles of Bioethics—Background</i>	1 per student
Student Handout 2.2— <i>Focus on the Principles</i>	1 per student
Student Handout 3.1— <i>Dennis’s Decision</i> , as homework (found in <i>Lesson Three</i>)	1 per student
Sticky notes in two different colors	2 sticky notes per student
Poster paper for <i>Principles Poster</i>	1
Colored markers	Assorted

TEACHER PREPARATION

- Make copies of Student Handout 2.1, 2.2, and 2.3, one per student.
- Make one copy of Teacher Resource 2.1—*Skit Improvisation List*. Cut into strips. You will need one strip for each small group.

FRAMING THE LESSON

In *Lesson One*, students discussed a difficult ethical question and explored the reasoning behind making a difficult decision. Briefly elicit some ethical questions that students wrote down for homework. Today, they will build on this by looking at questions that draw on objectivity, subjectivity or reasoned judgment. Students are introduced to the Principles of Bioethics by considering how they are rooted in common, respected values. **By the end of the lesson, students should be able to name and describe the three Principles of Bioethics.**

PROCEDURE

Part I: Subjective and Objective Questions

Activity Time: 20 minutes

1. Tell students that they will be considering subjective and objective questions. On the board or on a banner stretched across the room (the bigger the better) make a continuum like the one below. Mark the line at intervals and label them 1–10. Have students draw the continuum in their notes.



Subjective Questions:

2. As a class discussion, ask students for examples of questions that would be purely **subjective**, such as, "What is your favorite ice cream flavor?" or, "Do you like to wear sneakers?"
3. Write these at the "Purely Subjective" end of the continuum.
4. Have students choose one representative subjective question from the class discussion to record in their notes.
5. Tell students that subjective questions usually relate directly to the speaker, often have an emotional component, and are modified by cultural bias.

Objective Questions:

6. As a class discussion, ask students to give examples of questions that are purely **objective**, such as, "What is the capitol of California?" or, "How many legs does an arachnid have?"
7. Write these at the "Purely Objective" end of the continuum.
8. Have students choose one representative objective question from the class discussion to record in their notes.
9. Tell students that objective questions require facts and evidence to answer and are often yes/no or right/wrong answers.

Science:

10. Ask students to work individually to locate the point on the continuum where they think **Science** falls and draw it in their notebook.

Ethics:

11. Working individually, ask students to locate the point where they think **Ethics** falls on the line in their notebook and draw it in.
12. Give each student two sticky notes of different colors. Assign one color for **Science** and the other for **Ethics**.
13. Have students approach the class continuum and attach their sticky notes at the point they think is most accurate.
14. Ask students why **Science** is not purely "objective." It may be helpful to ask a student who has put his or her sticky note furthest away from the "Purely Objective" end of the continuum. Guide the discussion toward the following ideas:
 - o While the "facts" of science tend to be objective, the "process of science" is done by humans, and happens in a social context.
 - o For example, values enter into questions about what science to fund, how to conduct science responsibly, and how to apply new scientific discoveries and technologies and use them appropriately.
15. Ask students why **Ethics** is not purely "subjective." It may be helpful to ask a student who has put his or her sticky note furthest from the "Purely Subjective" end of the continuum. Guide the discussion toward the following ideas:
 - o Ethical questions require critical thinking and tools of **reasoned judgment**. This type of question requires a thoughtful balance on the subjective-objective scale.
 - o Emphasize that, contrary to what many people think, ethics is not purely subjective ("my opinion vs. your opinion") but has many elements from the objective end of the spectrum. Answering questions involving reasoned judgment requires evidence and logic as well as bioethical analysis.
16. Tell students that in answering questions of reasoned judgment, bioethicists rely on a number of ethical perspectives and theories to structure their thinking. These bioethical principles are introduced to students in the next part of the activity.
17. Give students a chance to revisit the continuum in their notebooks and reflect on their original choices.

Part II: Introduction to the Principles of Bioethics through Skits

Activity Time: 20 minutes

In this activity, students first perform skits, and then derive the ideas underlying the Principles of Bioethics taught in this unit during a teacher-led discussion. The skits provide a way for students to show their awareness of concepts supporting the Principles of Bioethics though they may not have the precise vocabulary to explain them as such. The teacher will know which bioethical principle is being introduced (in parentheses after a – f, below) but the students will not. **After** each set of skits and class discussion, the teacher should name the principle and write it down for the class to see. Do not say the principle by name **before** the students create their skits.

18. Divide the class into six groups.
19. Give each group of students one of the scenarios a – f, found below in Step #20, and in Teacher Resource 2.1—*Skits Improvisation List*. Two to three students from each group will come to the front of the class to improvise 30-second role-plays of interactions between a parent and child.
20. Give the students about 2 minutes to prepare to simulate the following interactions between a parent and child. Tell students that it is helpful for them to “give voice” to the ideas inside a person’s head by saying them out loud. The skits (also found in Teacher Resource 2.1—*Skits Improvisation List*) are:
 - a) Parent respecting the child’s career choice.
(Respect for Persons and their autonomy)
 - b) Parent **not** respecting the child’s career choice.
(Respect for Persons and their autonomy)
 - c) Parent helping child with her homework.
(Maximizing Benefits/Minimizing Harms)
 - d) Parent **not** helping child with her homework.
(Maximizing Benefits/Minimizing Harms)
 - e) Parent being fair between siblings.
(Justice)
 - f) Parent **not** being fair between siblings.
(Justice)
21. Have students from groups ‘a’ and ‘b’ present their skits.
22. Ask students, “What code or standard is being honored (or not)?” Students may say “respect” or “right to choose for him/herself.”
23. Tell students that one of the bioethical principles is called **Respect for Persons**.

24. Write the principle on poster paper for all to see using information from the box below or Student Handout 2.1—*Principles of Bioethics—Background*. This is your class *Principles Poster*.

Respect for Persons emphasizes the inherent worth and dignity of each individual, and acknowledges a person’s right to make his or her own choices. It means not treating people as a means to an end.

25. Have students from groups ‘c’ and ‘d’ present their skits.
26. Ask students, “What code or standard is being honored (or not)?” Students responses may include “helping” or “being good.”
27. Tell students that another of the bioethical principles relates to **Maximizing Benefits and Minimizing Harms**.
28. Add this principle to the poster:

Maximizing Benefits and Minimizing Harms asks how we can do the most good and the least amount of harm. It considers how one would directly help others and act in their best interests, while “doing no harm.”

29. Have students from groups ‘e’ and ‘f’ present their skits.
30. Ask students, “What code or standard is being honored (or not)?” Student responses may include “fairness” or “equality.”
31. Tell students that the third bioethical principle is called **Justice**.
32. Add this principle to the poster:

Justice considers how we can treat people fairly and equitably. It involves the sharing of resources, risks, and costs according to what is “due” to each person.

33. Leave the *Principles Poster* with the three bioethical principles posted in the classroom for the remainder of the unit.
34. Distribute Student Handout 2.1 – *The Principles of Bioethics—Background*. Give students 3-5 minutes to read through the principles individually.

In addition to the Principles of Bioethics introduced here, ethicists use a number of different ethical perspectives and theories to defend their positions, including:

- Moral Rules and Duties
- Virtues
- Outcomes
- Care

Part III: Application of the Principles of Bioethics

Activity Time: 10 minutes

35. Have students think about how they made their decisions about whom to give the vaccine during pandemic flu scenario in *Lesson One*.
36. Tell students that these principles are built upon familiar values respected by many different cultures. They are the result of a long history of humans grappling with how to treat each other in a humane and ethical manner. They provide support for reasoned judgments and help the field of bioethics incorporate more objectivity and rely less on subjectivity.
37. Divide the class into three groups, and assign each group a principle: Respect for Persons, Maximize Benefits/Minimize Harms, and Justice. Larger classes can be divided into six groups, with more than one group being assigned the same principle.
38. Revisit the pandemic flu scenario from *Lesson One*. Based on the bioethical principle the group has just been assigned, ask students which one or two people they would save. Provide them 3-5 minutes to discuss their ideas.
39. Debrief by asking one person from each group to share how their principle can be used to make decisions about who should receive the medication. For example:
 - **Respect for Persons:** By respecting the mother's choice to forgo medication, we are respecting her autonomy and right to self-determination.
 - **Maximizing Benefits/Minimizing Harms:** If we want the highest number of people to benefit, we might choose to save the doctor in hopes that she could, in turn, help to save more lives.
 - **Justice:** Drawing straws (distributing the medicine without regard to social status, age, or profession) would be a "fair" way to make the decision.
40. Revisit the approaches that arose from the discussion of the flu scenario:

Approach 1: Save the Youngest. In choosing this, students are maximizing the life span for the most number of people. This relates to the principle **Maximize Benefits and Minimize Harms**.

Approach 2: Draw Straws (or any randomization technique). This option values fairness. It relates to the principle **Justice**.

Approach 3: Save the Weakest. This option considers the special needs of vulnerable populations. It relates to the principle **Respect for Persons**.

Approach 4: Save the Most Useful. Saving someone who may be able to save others benefits a larger number of people. This relates to the principle **Maximizing Benefits and Minimizing Harms**.

Approach 5: Respect Relationships. Honoring the dignity of human beings includes acknowledging their relationships. This relates the principle **Respect for Persons**. This approach also relates to **Care**, an additional principle which can be used alongside the other principles mentioned.

CLOSURE

41. Wrap up the lesson by reviewing the Principles Poster and Student Handout 2.1 – *The Principles of Bioethics—Background*.
42. Tell students that the Principles of Bioethics are used to add structure when reasoning through an ethical question. Used as an analytical tool, the Principles of Bioethics help to move **Ethics** toward the "objective" end of the subjective-objective continuum.
43. Distribute copies of Student Handout 2.2—*Focus on the Principles*, one per student. Assign students to use the handout as an organizer for that night's homework, as well as future ethical analysis.

HOMEWORK

- Distribute copies of the case study for Lesson Three (Student Handout 3.1—*Dennis's Decision*), one per student. Assign the reading as homework. In addition, students should fill out Student Handout 2.2—*Focus on the Principles* as they read the case study.

EXTENSION

- Ask students to read the article “In Pandemic, Should Shots Go to the Old or the Young?” and fill out Student Handout 2.2—*Focus on the Principles*.

“In Pandemic, Should Shots Go to the Old or the Young?” Connolly, Ceci. *The Washington Post*. May 2006. http://seattletimes.nwsources.com/html/nationworld/2002988710_flu12.html

- Expand the discussion about “Subjective and Objective Questions” in *Part I* of the lesson by asking students to assess where different components of science would fall on the continuum from “Purely Subjective” to “Purely Objective.”

Where would each of these fall?

- o Physics
- o Chemistry
- o Psychology
- o Math
- o Biology
- o Deciding which research grants get funded
- o Using human subjects to test a medicine for effectiveness and safety

Emphasize that different disciplines are open to different degrees of interpretation. For example, in a math problem there is more of a sense of a “correct” answer than in the interpretation of social phenomena.

- Revisit students’ homework from *Lesson One*, in which students found a news article highlighting the larger societal and ethical implications of science. Have students identify how the bioethical principles might apply to their stories.

ADDITIONAL RESOURCES FROM AN ETHICS PRIMER

The *Ethics Background* section has additional background information on principle-based ethics, as well as information on different ethical perspectives such as Moral Rules and Duties Ethics, Virtues Ethics, Outcome-based Ethics, as well as the process of ethical inquiry.

CREDIT

The “Along the Line” activity is modified from an activity developed by Bruce Fuchs, PhD, and is used with permission.



TEACHER RESOURCE 2.1

Skit Improvisation List

Cut out the following phrases indicating interactions between a parent and child. Student groups (a – f) will create and improvise 30-second role-plays. Give the students about 2 minutes to prepare their scenes. Do not tell the students the name of the principle they will be illustrating.

- Skits 'a' and 'b' relate to **Respect for Persons** (autonomy).
- Skits 'c' and 'd' relate to **Maximizing Benefits/Minimizing Harms**.
- Skits 'e' and 'f' relate to **Justice**.

a. Parent respecting a child's career choice.

b. Parent not respecting the child's career choice.

c. Parent helping child with her homework.

d. Parent not helping child with her homework.

e. Parent being fair between siblings.

f. Parent not being fair between siblings.

STUDENT HANDOUT 2.1

The Principles of Bioethics—Background

Name _____ Date _____ Period _____

Principle

Respect for Persons

This principle values the inherent dignity and worth of each person, as well as respecting individuals and their **autonomy**. It means not treating people as a means to an end.

Autonomy emphasizes the right to self-determination and acknowledges a person's right to make choices, to hold views, and to take actions based on personal values and beliefs. It emphasizes the responsibility individuals have for their own lives. The rules for informed consent in medicine are derived from the principle of respect for individuals and their autonomy. In medicine, there is also a special emphasis on privacy, confidentiality, truthfulness, and protecting individuals from vulnerable populations.

Maximizing Benefits/Minimizing Harms

This principle stresses “doing good” and “doing no harm.” To **Maximize Benefits** one would directly help others and act in their best interests. It requires positive action. **Minimizing Harms** obligates others to avoid inflicting harm intentionally. It relates to one of the most traditional medical guidelines, the Hippocratic Oath, which requires that physicians “do no harm”—even if they cannot help their patients. “Doing good” is also referred to as **Beneficence**, and “do no harm” is also referred to as **Nonmaleficence**.

Justice

This principle relates to “Giving to each that which is his due” (Aristotle) or **Fairness**. It dictates that persons who are equals should qualify for equal treatment, and that resources, risks, and costs should be distributed equitably.

Other Considerations

Some ethicists also add **Care**, which focuses on the maintenance of healthy, caring relationships between individuals and within a community. The principle of care adds context to the traditional principles and can be used alongside them.

Additional considerations include **Duties & Responsibilities** or taking actions that reflect personal **Virtues**.

Historical Context

The historical basis for these principles goes back thousands of years. We find references to fairness and justice in Aristotle's writings. The Hippocratic Oath entreats physicians to “First, do no harm.” The Nuremberg Code was created in response to World War II atrocities in which prisoners were used for experimentation without their consent. The Code helped to define “Respect for Persons” and created guidelines for conducting ethical human clinical trials. The principles were further refined in the 1970s in a document outlining guidelines for research called the *Belmont Report*. The advent of new life-saving technologies such as the first dialysis machines and organ transplants created a need to establish policy regarding the fair distribution of scarce resources, and to understand how to balance the benefits and burdens of this new research.

STUDENT HANDOUT 2.2

Focus on the Principles

Name_____ Date_____ Period_____

Consider how the principles apply to the ethical question.
Some principles may apply more than others to a particular situation.

RESPECT for PERSONS <ul style="list-style-type: none">• What would be respectful to the people (or other stakeholders) involved?• How can we respect people and their right to make their own choices (autonomy)?	MAXIMIZE BENEFITS/ MINIMIZE HARMS <ul style="list-style-type: none">• How can we do the most good (beneficence) and the least harm (nonmaleficence)?• What kinds of harms and benefits might arise from different solutions?
JUSTICE <ul style="list-style-type: none">• What would be fair?• How can we treat others equitably?• How can we distribute resources so that each person gets what is due him or her?	OTHER <ul style="list-style-type: none">• Are there any other ethical considerations?

ETHICAL QUESTION

LESSON 3:

Finding the Stakeholders

INTRODUCTION

Students read a case study about Dennis, a 14-year-old boy who has been diagnosed with leukemia. The doctors treat the leukemia with chemotherapy, which dramatically reduces the number of Dennis's blood cells. Dennis, however, refuses life-saving blood transfusions because they conflict with his faith. Students identify an ethical question to explore, and consider how the **Principles of Bioethics (Respect for Persons, Maximizing Benefits/Minimizing Harms, and Justice)** relate to the case. Students then identify the stakeholders—the people or institutions that are affected by the outcome—and work in small groups to clarify stakeholder values, interests, and concerns. Stakeholder groups then present their positions to the class as a group.

KEY CONCEPTS

- Personal values contribute to decision-making.
- A stakeholder is any person, institution, or entity that is interested in, invested in, or will be affected by the outcome of the ethical decision.
- Consideration of different stakeholder values and concerns entails viewing dilemmas from different perspectives—"stepping into someone else's shoes."
- An answer that satisfies one stakeholder group may conflict with the values of another group or individual; this conflict is often at the heart of an ethical dilemma.
- Not all of the Principles of Bioethics will be equally relevant to any one situation.

LEARNING OBJECTIVES

Students will be able to:

- Identify an ethical question embedded in a case study.
- Characterize stakeholders and their values.
- Apply biomedical ethical principles to a specific ethical question.

CLASS TIME

One class period of 55 minutes.

MATERIALS

Materials	Quantity
Student Handout 2.1— <i>Principles of Bioethics</i> (handed out in <i>Lesson Two</i>)	1 per student
Student Handout 3.1— <i>Dennis's Decision</i>	1 per student
Student Handout 3.2— <i>Values Definition Table</i>	1 per student
Student Handout 3.3— <i>Facts, Values, and Stakeholders</i>	1 per student
Possible Answers for Student Handout 3.3— <i>Facts, Values, and Stakeholders</i>	1 per student

Student Handout 3.3—*Facts, Values, and Stakeholders* is a type of decision-making framework, or conceptual model. This can serve as a tool to help students think about, and make sense of, their own experience.

TEACHER PREPARATION

Make copies of *Student Handouts*, one per student.

NOTE TO THE TEACHER

In discussing the case, students may focus on Dennis's religious position and either vilify or support the religion itself. Please be clear that the purpose of analyzing the case is not to evaluate the religion in any way. The underlying matter is one of **autonomy**, not religion. Does Dennis have the right to make independent choices regarding his own life, including which religion to practice?

FRAMING THE LESSON

In *Lesson One*, students learned to identify an ethical question and see how relevant facts can influence decision-making. In *Lesson Two*, students learned the Principles of Bioethics. Today, students will **practice** those skills by identifying an ethical question embedded in a case study, and considering how the Principles of Bioethics relate to the case study. Students are also **introduced** to stakeholder groups—the people or institutions that are affected by an outcome—and look more closely at the values within those groups.

PROCEDURE

Part I: Considering the Principles and Identifying the Ethical Question

Activity Time: 15 minutes

1. If students have not already read the case study for homework after Lesson Two, have students read Student Handout 3.1—*Dennis's Decision*.
2. As a class, refer to the *Principles Poster* (and Student Handout 2.1 from *Lesson Two*) to identify the Principles of Bioethics that are most prominent in the case. Student Handout 2.2—*Focus on the Principles*, which was assigned as homework in *Lesson Two*, will also be useful.
3. Briefly address the main ethical considerations for this case. This case highlights a conflict between **Respect for Persons**, specifically the issue of autonomy (whether Dennis has the right to make choices and take actions based on his personal values and beliefs) and **Maximizing Benefits/Minimizing Harms** (the doctors are in a position to “do good” by providing medical treatment).
4. Consider different ethical questions that could be asked regarding the case. Present (or arrive at through discussion) the following ethical question: “Should Dennis be allowed to reject life-saving medical treatments?”
5. Distribute copies of Student Handout 3.3—*Facts, Values, and Stakeholders*. Have students write down the ethical question on the handout.

Part II: Facts and Questions

Activity Time: 10 minutes

6. Divide the class into groups of 4. In these groups, have students write down the relevant facts from the case, and any questions that remain.

7. As a class, list the **facts** on the board. Have each group share their additions to the whole class list. Allow students to add to *Part II* of Student Handout 3.3—*Facts, Values, and Stakeholders*, if needed.
8. As a class, make a list on the board of the **questions** that remain. Have each group share (or add to) the whole class list. Allow students to add to *Part II* of Student Handout 3.3—*Facts, Values, and Stakeholders*, if needed.

Part III: Stakeholder Values and Principles

Activity Time: 25 minutes

9. Ask the students, “Which individuals and/or institutions have a stake in the outcome? Who has a vested interest and will be affected by the solution to the ethical question?” Tell students these are the **stakeholders** in the case.
10. In small groups, have students brainstorm a list of stakeholders. Tell students not to write on their handouts yet, since there is space for only four stakeholders and more than four exist. How many stakeholder groups can they think of?
11. As a class, list the stakeholders on the board.
12. Have each group share their additions to the whole class list. The list of stakeholders could include:
 - Dennis
 - His aunt
 - His parents
 - The doctors
 - Their religious community
 - Other relatives of Dennis
 - Social services (since Dennis is a minor)
 - The hospital in which this takes place
 - The ethics committee involved in the decision
13. Choose the 4 stakeholders that are most affected by the decision and have students list these on their handout. Those most affected by the decision are probably:
 - Dennis
 - His biological parents
 - His aunt
 - The doctors

14. Assign one stakeholder to each small group (more than one group can represent the same stakeholder, if needed).
15. Distribute copies of Student Handout 3.2—*Values Definition Table*, one per student. Have students consider the values that a stakeholder might bring to the case. What does that stakeholder value? What are his concerns? What does she care about? Encourage students to imagine that they are the stakeholder.
16. Ask students, “If your stakeholder group alone were to make the decision, what would you choose? Why?” and “Do any of the Principles of Bioethics support your position?” Students can refer to Student Handout 2.1—*Principles of Bioethics* to determine which principle(s) best support(s) their stakeholder group’s argument.
17. Have each group prepare a one-minute statement to make to the class from the perspective of their stakeholder.
18. Allow time for each stakeholder group to share their testimony. Other groups should take notes in *Part III* of Student Handout 3.3—*Facts, Values, and Stakeholders*.
19. After the stakeholder statements, ask students if they found it difficult to imagine being a stakeholder with a view different from their own. Acknowledge that it may be difficult to listen and try to understand what others are saying, especially if your personal views are at odds with the stakeholder views.
20. Tell students, “It takes courage to listen and try to understand what others are saying. You respect and honor both yourself and others when you do so.”

Part IV: Values and Principles—What’s the Difference?

Activity Time: 5 minutes

21. Tell students that individual values signify what is important and worthwhile to a person. Individuals have their own values based on many factors, including family, religion, peers, culture, race, social background, and gender.
22. Have students refer to the subjective/objective continuum they worked with in *Lesson Two*. Where would **values** go on the continuum?
23. Tell students that, though many values are highly respected across cultures, values are shaped by personal experience and individual background. This tips “values” toward the subjective end of the continuum.
24. Remind students that the Bioethical Principles are built upon values, but provide unified standards that have

been collectively agreed-upon in a process that has been honed over thousands of years (see the *Historical Context* section of Student Handout 2.1—*Principles of Bioethics*.) The Bioethical Principles, when used in conjunction with the facts of a case and consideration of stakeholder viewpoints, help provide a systematic, rational way of working through an ethical question. This tips “bioethical principles” toward the objective end of the continuum, relative to “values.”

25. Ask students, “What if decisions on difficult ethical questions were **only** based on values?” A conflict in stakeholder values is often at the heart of an ethical dilemma. Should the resolution be left to personal preferences—or the person with the loudest voice?

CLOSURE

26. Note that identifying the stakeholders and their concerns and values is a powerful step in analyzing an ethical issue. An answer that satisfies one stakeholder group may conflict with the values of another group or individual; this conflict is often at the heart of an ethical dilemma.
27. Not only can students use the concept of stakeholders to “step outside themselves” and think about the perspectives of others, they can use this information to form solutions that consciously consider those perspectives.
28. Share with students that the Principles of Bioethics are also helpful in analyzing an issue because they help us think about different ethical concerns. Not all of the Principles of Bioethics will be equally relevant to any one situation.

HOMEWORK

Ask students to choose a combination of two values from the list below (or choose your own from Student Handout 3.2—*Values Definition Table*) and write a short (1-2 paragraph), imaginary scenario in which those values conflict and a decision must be made.

- o Honesty vs. Friendship
- o Compassion vs. Utility
- o Generosity vs. Financial Security
- o Sacrifice vs. Personal Happiness
- o Cooperation vs. Independence
- o Status vs. Justice

Example: Cooperation vs. Independence

Daniela liked to work alone; she was good at reading information, understanding things, and pacing herself. One of her teachers was giving extra credit for working on a project in pairs. Daniela's friend, Mary, wanted to work with her. Mary was fun to work with and put in a lot of effort but didn't get the same high grades as Daniela. Mary would benefit from Daniela's help, but Daniela might have to sacrifice some of her high standards. Should she pair up with Mary for the project?

EXTENSION

Ask students to prioritize their 5 top values on Student Handout 3.2—*Values Definition Table*. Ask students what they learned from the activity. Was it difficult? What was challenging about it? Did they learn anything new about themselves and their own priorities?

ADDITIONAL RESOURCES FROM AN ETHICS PRIMER

The *Lesson Strategies* section has additional information on identifying stakeholders and their values. Specifically, see the section: *Values Prioritization: What is a Value?*

CREDIT

The following sources were used to develop the case study, *Dennis's Decision*.

"Judge Allowed 14-Year-Old Jehovah's Witness to Refuse Potentially Lifesaving Care." *ABC News*, November 29, 2007.

"Judge: Teen can reject treatment on religious grounds." Ostrom, Carol. *The Seattle Times*, November 28, 2007. http://seattletimes.nwsources.com/html/nationworld/2004040925_webtransfusion28m.html.

"Boy dies of leukemia after refusing treatment for religious reasons." Black, Cherie. *The Seattle Post Intelligencer*, November 29, 2007. http://seattlepi.nwsources.com/local/341458_leukemia29.html.

Diekema, Doug. Professor of Pediatrics, University of Washington School of Medicine. NWABR Ethics reunion. Seattle, May 17, 2008.

STUDENT HANDOUT 3.1

Dennis's Decision

Name_____ Date_____ Period_____

Dennis Lindberg had already survived more than most young people by the time he reached the age of 14. Born to drug-addicted parents, Dennis tried to ignore the needles in the toilet and his mom's pale skin and strangely constricted pupils. He was too scared to ask her if she did drugs. Throughout his childhood, Dennis moved constantly and rarely attended school, often being left with neighbors while his parents were getting high.

He had the chance to make a fresh start, however, after his dad was jailed for drug possession. In an effort to save him from suffering while they got their lives back on track, Dennis's parents sent Dennis to live with his aunt and gave her guardianship of the boy. Over the next four years, Dennis flourished in his aunt's home. He began attending school regularly, made friends, and found comfort in regular meetings of the religious community to which his aunt belonged. Dennis soon expressed interest in joining the congregation and did so. He participated fully in the life of the congregation, and spent many Saturdays witnessing door-to-door about the evils of drugs—the effects of which had touched him personally.

Then, at the age of 14, Dennis received grim news. He had leukemia and would need immediate treatment to survive. Dennis was diagnosed with acute lymphocytic leukemia (ALL), a type of cancer that affects blood or bone marrow. ALL is the most common type of leukemia in children under age 15, and doctors gave Dennis a 70% chance of full recovery if he underwent chemotherapy and repeated blood transfusions over the course of three years. In chemotherapy, patients are treated with drugs to kill the affected cells. Because bone marrow produces blood cells, chemotherapy causes a dramatic decrease in the number of blood cells the patient has. To make up for the lost blood cells, the patient is given blood transfusions. Without the transfusions, the patient will die. Dennis was prepared to begin chemotherapy immediately, but recognized that blood transfusions conflicted with his faith.

Dennis's religious faith teaches that blood is sacred in God's eyes, that the soul or life is in the blood. Because of this, members of Dennis's faith believe it is wrong to eat blood or to eat any animal that has not been properly bled. Likewise, they believe blood transfusions are wrong and that if they receive blood they are breaking God's laws. Although blood transfusions are prohibited, the faith is not anti-medicine.

Dennis was clear with his doctors when they began chemotherapy that he would refuse blood transfusions. He even threatened to pull out the IV if they attempted to give him blood, which meant that physical force would be required, not once, but repeatedly, as Dennis received ongoing treatment. His aunt agreed with his decision, as did members of his congregation. When his biological parents found out, however, they were stunned—not members of that religion themselves, they wanted doctors to do everything possible to save their son. Since giving up custody of Dennis, his parents had completed drug treatment and were now sober. They felt they should have a say in this life or death decision. As Dennis's blood count dipped dangerously low, his doctors struggled with what they should do, and an ethics board from the hospital was engaged.

Based on a factual story. Please see the Teacher Resource section for source information.

Contributed by Jodie Spitze, Kent-Meridian High School

STUDENT HANDOUT 3.2

Values Definition Table

Name_____ Date_____ Period_____

Value	Definition
Altruism	Caring for others without regard to yourself.
Assertiveness	Being confident and knowing you deserve respect.
Autonomy	Being free to guide and control yourself, and make your own choices.
Caring	Feeling and showing concern for others.
Compassion	Being deeply aware of and wanting to lessen the suffering of others.
Cooperation	Working willingly with others to accomplish something.
Courage	Ability to face danger, fear, and obstacles with confidence.
Diversity	Respecting and wanting difference and variety.
Equality	Believing that everyone deserves the same treatment.
Fairness	Strictly following what you believe is fair and just.
Financial Security	Having enough money to lead a secure and comfortable life.
Friendship	Having a relationship based on mutual respect and good will.
Generosity	Willingness and desire to give.
Helping others	“Doing good” by directly helping others and acting in their best interest.
Honesty	Acting in a straightforward and fair manner.
Humility	Feeling that you are no better than other people.
Independence	Being able to do things for yourself and be self-reliant.
Individual Potential	Ability to contribute or make an impact in the future.
Lawfulness	Following the rules of what is required in a given situation.
Love	Feeling a deep, tender affection or attachment.
Loyalty	Feeling devotion, attachment, and affection toward a person or idea.
Perseverance	Being continuously steady in effort or belief.
Personal Happiness	Feeling pleasure, satisfaction, or joy.
Personal Safety	Being free from danger, risk, or injury.
Power	Being capable of exerting force or authority to act effectively.
Practicality	Being efficient, level-headed, and useful.
Resourcefulness	Ability to act effectively and creatively, especially in tough situations.
Respect	Valuing individual worth and dignity.
Responsibility	Being accountable and answerable for something.
Sacrifice	Willingness to give up a thing for something else more important.
Self-Control	Being able to control your emotions, desire, or actions.
Stability	Being free from variation or change.
Status	Having high standing or prestige.
Tolerance	Recognizing and respecting the beliefs and practices of others.
Usefulness	Being of practical use and able to provide service.
Wisdom	Ability to make good decisions based on experience and learning.

List adapted from the Ethics Resource Center (ERC), <http://www.ethics.org/resource/definitions-values>.

STUDENT HANDOUT 3.3

Facts, Values, and Stakeholders

Name_____ Date_____ Period_____

Part I: Ethical Question

Part II: Facts and Questions

Relevant facts (known)

Questions that remain (unknown, need to know)

Part III: Stakeholder Values

Stakeholders (people/entities affected by the decision)

Values/concerns of each stakeholder

Bioethical Principle(s) given priority

_____	▶ _____	▶ _____
_____	▶ _____	▶ _____
_____	▶ _____	▶ _____
_____	▶ _____	▶ _____

If your stakeholder group alone were to make the decision, what would you choose? Why?

HANDOUT

Possible Answers for STUDENT HANDOUT 3.3

Facts, Values, and Stakeholders

Answers can vary widely. Possible answers are below.

Part I: Ethical Question		
<p><i>"Should Dennis be allowed to reject medical treatments that would save his life?"</i></p>		
Part II: Facts and Questions		
<p>Relevant facts (known)</p> <ul style="list-style-type: none"> Dennis is 14 years old—still a minor. His aunt has legal custody of him. To treat leukemia, patients undergo chemotherapy. This kills the diseased cells, but also kills off "good" blood cells made in the bone marrow. Patients undergoing treatment for leukemia will die without transfusions of healthy blood cells. Dennis would need transfusions for about three years. Dennis's parents gave custody to his aunt because they were unable to care for him while in jail and/or addicted to drugs. Dennis has a 70% chance of survival with treatment. 	<p>Questions that remain (unknown, need to know)</p> <ul style="list-style-type: none"> Are there any other treatments for leukemia that don't require blood transfusions? Why did the doctors begin chemotherapy if they knew Dennis would refuse blood transfusions? What is the relationship like between Dennis and his aunt? Dennis and his biological parents? Does the hospital have a policy on blood transfusions and minors? 	
Part III: Stakeholder Values		
Stakeholders (people/entities affected by the decision)	Values/concerns of each stakeholder	Bioethical Principle(s) given priority
Dennis	Dennis is being loyal to his beliefs, even if it means sacrificing his life for something he feels is greater than himself.	Respect for Persons (autonomy)
The doctors	They want to provide service to their patient (value of usefulness) and preserve Dennis's life. As doctors, they would also be concerned about the wishes of their patient.	Maximizing Benefits/ Minimizing Harms
Dennis's biological parents	They value the life of their son over his belief system. They care for and love their son.	Maximizing Benefits/ Minimizing Harms Some Justice issues (Is it fair if they have no voice?)
Dennis's aunt	Dennis's aunt is supporting Dennis's independence (autonomy) and remaining loyal, or obedient, to their beliefs. She undoubtedly cares for and loves him, too.	Respect for Persons (autonomy)
<p>If your stakeholder group alone were to make the decision, what would you choose? Why?</p>		

LESSON 4:

Making a Strong Justification

INTRODUCTION

In this lesson, students learn the characteristics of a strong justification and apply them to a decision about an ethical question. Students brainstorm the characteristics of a **weak** justification, and are then primed to identify what makes a **strong** justification through their participation in a silent debate. Students refer to the case study from *Lesson Three*, *Dennis's Decision*, and evaluate a number of pre-written justifications for that case. For each justification, students consider whether: a decision has been made, scientific facts have been included, stakeholder views are represented, there is reference to bioethical principles, and alternative options are considered. Once students understand the elements of a well-crafted justification, they come to their own decision about Dennis and write their own justification.

KEY CONCEPTS

- Students need to consider a wide range of viewpoints when generating options for resolving an ethical dilemma.
- An excellent justification has the following components:
 - o Clearly-stated position (claim) that relates directly to the ethical question.
 - o Reference to important facts and science content of the case.
 - o Consideration of how stakeholders will be impacted by the decision.
 - o Reference to one or more Bioethical Principles.
 - o Consideration of the strengths and weaknesses of alternative options.
- "Pro" and "con" positions can often be equally well defended by a reasoned, thoughtful answer rooted in critical thinking.
- For the purpose of evaluation, the student's ability to put forth a reasoned, thoughtful answer is more important than the student's position on the issue.

LEARNING OBJECTIVES

Students will be able to:

- Understand the elements of a strong justification.
- Distinguish between a strong justification and a weak justification.
- Provide a strong justification for a position, one that shows a connection between the claim and evidence.

CLASS TIME

2 class periods of 55 minutes each. This time could be reduced by assigning Student Handout 4.3—*Your Decision and Justification* as homework.

MATERIALS

Materials	Quantity
Student Handout 2.1— <i>The Principles of Bioethics</i> (handed out in <i>Lesson Two</i>)	1 per student
Student Handout 3.3— <i>Facts, Values, and Stakeholders</i> (from <i>Lesson Three</i>)	1 per student
Teacher Resource 4.1— <i>Take This! Take That! Silent Debate</i>	1
Blank paper for Silent Debate	2–3 per pair of students
Student Handout 4.1— <i>A Decision for Dennis</i>	1 per student
Student Handout 4.2— <i>Elements of a Strong Justification</i>	1 per student
Possible Answers for Student Handout 4.2— <i>Elements of a Strong Justification</i>	1
Student Handout 4.3— <i>Your Decision and Justification</i>	1 per student
Optional: Projector or document camera	1

TEACHER PREPARATION

Make copies of the *Student Handouts*, one per student.

NOTE TO THE TEACHER ABOUT ARGUMENTATION

As students write their own well-reasoned justifications in the next two lessons, they are honing their argumentation skills by using evidence to support their claim to a position relating to a bioethical case study. This is an important practice in science, and students are often encouraged to show how data support the claim. The types of data used to support one's claim when analyzing a case study may be different from the types of data collected through conventional scientific inquiry, however. When using a socio-scientific case study, **data** may refer to the scientific facts of the case, the bioethical principles that apply to the case, or even the social context of the case. Student argumentation skills will also be supported when considering the perspectives, views, and interests of various stakeholder groups to help identify possible weaknesses in their own (or others') arguments.

FRAMING THE LESSON

The previous days' lessons have led students to this point: A decision must be made for Dennis, and strong reasoning must be provided for that decision. Because writing a thorough justification for an ethical decision can be difficult, students are **introduced** to the concept by reading six pre-written justifications and using a decision chart to judge the relative strengths and weaknesses of each justification. **By the end of this lesson, students should be able to build on the justifications provided and write their own, well-reasoned justification.**

PROCEDURE

Part I: More About Dennis...

Activity Time: 10 minutes

1. Re-engage students with the case study *Dennis's Decision* by reminding them of the different stakeholder views presented in *Lesson Three*.
2. Introduce additional information about the case:
 - Doctors diagnosed Dennis's leukemia a month before he needed his blood transfusion. He agreed to and started chemotherapy but immediately refused the blood transfusions. The hospital's experience in similar situations was that patients who initially refused blood transfusions would eventually agree to them after becoming very ill.
 - Dennis's hospital room became a place for members of his religion to congregate, with up to 20 friends and family members staying with him around the clock.
 - The hospital policy is to inform parents/guardians that while the hospital will do everything it can to avoid transfusions, it will not let a child die because he or she needs blood. This policy is most often used for one-time transfusions in emergency surgical cases, such as after a car accident.
 - The hospital policy would be difficult to enact in Dennis's case. The treatment would require his full and on-going cooperation; in addition to complying with the repeated blood transfusions, he would need to take medications at home, come to follow-up visits, and undergo frequent blood counts.

Part II: What Makes a Strong Justification?—Introduction

Activity Time: 20 minutes

3. Ask students, "By a show of hands, how many of you think you already have an answer to the ethical question, 'Should Dennis be allowed to reject medical treatments that would save his life?'" Do not ask students what their individual answers would be.
4. Tell students to put their answers "on hold" for the rest of the class. The decision they come to is only as strong as the reasons they give for supporting their decision. Assure students who do not have an answer that they will get practice working this out today.

5. The reasons given to support a position, or claim, are called the **justification**. Students may have experience with writing thesis statements in Social Studies or English papers; a justification is similar to a thesis, where evidence is marshaled to support a position or claim.
6. Tell students that when presented with an ethical dilemma, many people quickly jump to their decision/position, without a sense of their justification, or they may say that their position is “simply what I believe” or what intuitively “feels right.”
7. Tell students that they will look at what makes a good justification soon, but sometimes it is easier to recognize a **weak** justification.
8. Ask students whether “I don’t like it,” “That’s not the way it should be done,” or “I just don’t think it is right” are good justifications, and prompt them to explain why or why not.
9. List the characteristics of weak justifications for all students to see.

Weak justifications:

- Are based purely on subjective opinion.
 - Rely on an undefined “feeling.”
 - Can’t be substantiated with facts or science.
 - Are based on a cultural bias that is not universal.
 - Are not relevant or logically linked to the facts of the case.
10. Ask students to offer other examples of weak justifications.
 11. Tell students that they will be debating what should be done in the case of *Dennis’s Decision* with a partner, and that they should keep in mind the characteristics of weak justifications so that they can avoid them in their own arguments.

Part III: Take This! Take That! Silent Debate

Activity Time: 15 minutes

In this portion of the lesson, students take sides on *Dennis’s Decision* and participate in a silent debate to practice their use of reasoning. Because the debate is in written (silent) form, conversation cannot deteriorate into a shouting match. At the end of the debate, students identify the strongest arguments and justifications made, and analyze what makes them so.

12. Project a copy of Teacher Resource 4.1—*Take This! Take That! Silent Debate* for all students to view.

13. Ask students to form pairs and decide who will represent the “For” and “Against” positions. The positions can be assigned to students if needed.
14. Use Teacher Resource 4.1—*Take This! Take That! Silent Debate* to describe the debate format to students. A pair of students can read the school uniform example aloud for the class, or students (or the teacher) can model the practice debate using a PowerPoint presentation found at: <http://www.nwabr.org>. Clarify any questions about the debate.
15. Begin the debate. During the exercise, students pass a blank piece of paper back and forth. One student makes one argument, and the other person can rebut it. Students take turns presenting new arguments.
16. Allow this silent exchange to occur for a few minutes. Have more paper available, as the debate may go on for several pages.
17. After 5 or 6 minutes, stop the debate.
18. Have students look over the written debate and find the strongest arguments the **other** person made.
19. Have students discuss with their partner what, specifically, made the argument strong. Did it rely on facts from the case? Take the concerns of the stakeholders into consideration?
20. Elicit some responses from the whole class.
21. Have students refer to the *Principles Poster* created in *Lesson Two*. Was their partner’s argument strengthened by giving voice to an ethical principle?
22. Ask, “What makes a strong justification?” As a class, develop the criteria for a strong justification.
23. List the characteristics of strong justifications for all students to see.

Strong justifications may include:

- A clearly-stated position (claim) that relates directly to the ethical question.
- Reference to important facts and science content of the case.
- Reference to one or more Principles of Bioethics or other ethical considerations.
- Consideration of how other people will be impacted by the decision.
- Consideration of the strengths and weaknesses of alternative options.

Part IV: What are the Options?

Activity Time: 15 minutes

24. Tell students that, before coming to a decision about a case, an important step is to generate all the options for possible solutions to that case.
25. As a class (or individually first, if time permits) have the students generate a list of alternative options for possible solutions. This is a brainstorming step, to generate a wide range of ideas.
26. If options are scarce, two strategies to help with this step are:
 - Think about the solutions different stakeholders would propose.
 - Consider extreme positions from both ends of the spectrum, and work to find middle options.
27. As a class, write on the board some key words distilled from the different options provided below. Some options for possible solutions include:
 - Dennis's wishes could be honored and he receives no blood transfusions. He is allowed to die.
 - The doctors are allowed to treat their patient as they see fit, in his best interests. Dennis receives blood transfusions against his wishes, even if that means the medical staff must restrain him during transfusions.
 - Dennis is given sedatives to incapacitate him during blood transfusions. This allows him to **not** give his consent to receive transfusions (thereby honoring his beliefs), yet allows the doctors to "do good" and treat their patient.
 - The parental rights of the biological parents are legally reinstated, thereby giving them the authority to override the wishes of Dennis and his aunt and receive blood transfusions.
 - Dennis is not given chemotherapy in the first place, allowing his disease to take its natural course without the need for blood transfusions.
 - Dennis is encouraged to spend time with his biological parents to build that relationship; they convince him to receive the transfusion.

Part V: What Makes a Strong Justification? – Justify the Answer

Activity Time: 20 minutes

28. Remind students that an ethical question is a type of **reasoned judgment** question that relies on evidence, critical reasoning, and thoughtful balancing of opposing values and viewpoints.
29. Distribute copies of Student Handout 4.1—*A Decision for Dennis* and Student Handout 4.2—*Elements of a Strong Justification*, one per student.
30. As a class, read through the pre-written justifications (A-E) from Student Handout 4.1—*A Decision for Dennis*. Tell students that they will be evaluating each justification using the decision chart found on Student Handout 4.2—*Elements of a Strong Justification*.
31. As a class, fill out the decision chart together for justification "A." Ask students, "Has a decision been made?" Since a decision is clearly stated, put a "Y" in the first box of column A. Ask students, "Are facts from the case included in the justification?" Since scientific facts concerning chemotherapy, blood cells, and transfusions are addressed, put a "Y" in the second box of column A. Continue asking questions about stakeholder views, ethical considerations (students can refer to Student Handout 2.1—*The Principles of Bioethics*) and alternative options. Students fill out the decision chart for justification "A" as a class.
32. Teachers can refer to Possible Answers for Student Handout 4.2—*Elements of a Strong Justification*, if needed.
33. Instruct students to evaluate justifications B – E (and fill out columns B – E) on their own or in pairs. Teachers could also assign a different justification to small groups of students.
34. When the students are finished, go over Student Handout 4.2—*Elements of a Strong Justification* as a class. Because there may be some variation in the Y/N answers due to student interpretation, **pose higher-level questions** such as, "Is one justification particularly strong? Why?" or "Is one justification particularly weak? Why?" Ask students what they would add to make a strong justification even stronger.
35. Point out to students that a well-reasoned justification can be made to support either side of the argument; there are strong justifications for both treating and not treating Dennis. For the purposes of this class, the **justification** for the decision is more important than the decision itself.

Part VI: Student-Written Justification

Activity Time: 20 minutes in class, or given as homework

36. Pass out Student Handout 4.3—*Your Decision and Justification*. Have students begin writing their own decision and justification for *Dennis's Decision* following the prompts on the Student Handout.
37. The decision and justification should be completed as homework.

Part VII: Variations on the Story (Optional)

38. Once students have come to a decision about the case and have justified their decision, have them consider the following variations to the story. Would any of these change their decision? Why or why not? Have students discuss the following variations in pairs or small groups.

What if...

- Dennis were younger than he is in this case? What if he were 12? 10? 8 years old?
- Dennis were older than he is in the case? What if he were almost 18, but not yet legally an adult?
- Dennis was not religious at all, but simply wanted his illness to "run its natural course" because that is how life, in its most organic and raw form, works?
- Dennis were still under the legal care of his biological parents?

The Rest of the Story

[**Note:** Share "The rest of the story" **only if** the students have finished writing their own decision and justification.]

After spending time with this case, students will understandably be curious about what happened to Dennis. After students write their own decision and justification, share with them the rest of the story:

Through the court system, the state and Dennis Lindberg's biological parents attempted to force Dennis to receive blood transfusions. After hearing from Dennis's parents, aunt, doctors, and social workers, the judge ruled that Dennis was a "mature minor" saying, "I don't believe that Dennis's decision is the result of any coercion. He is mature and understands the consequences of his decision."

The judge called the decision the most difficult of his career. Before the court decision was made, Dennis fell into a coma. He died soon after. This took place at Children's Hospital & Regional Medical Center in Seattle, Washington in November, 2007.

CLOSURE

39. Emphasize the importance of providing reasons for taking a certain position, as well as making sure those reasons are strong.
40. Review the elements of a strong justification and stress the need for students to consider those elements when they defend a position.
41. Tell students that Student Handout 4.2—*Elements of a Strong Justification* is a conceptual model that can be applied to other sorts of difficult or ethical decisions, not just *Dennis's Decision*.

HOMEWORK

Ask students to finish writing their own justification using Student Handout 4.3—*Your Decision and Justification*.

SOURCES

Take This! Take That! Silent Debate contributed by Rosetta Eun Ryong Lee, Seattle Girls' School. Original idea shared by teacher Aimee Trapp.



TEACHER RESOURCE 4.1

Take This! Take That! Silent Debate

The Issue: *Should Dennis be allowed to reject life-saving medical treatments?*

Students should form pairs and decide who will represent the FOR (YES) position and who will represent the AGAINST (NO) position.

Silent Debate Instructions:

1. There is no talking once the silent debate starts.
2. Note whether you are making an argument FOR or AGAINST the issue.
3. If you change the type of argument you are making, you may draw a line to separate your ideas. For example, the first argument about school uniforms (below) is about individuality, and the second argument is about money.
4. Add additional sheets of paper as necessary.

Silent Debate Example on School Uniforms

- **Student 1:** There should not be a school uniform because it does not allow students to express their individual personality.
 - **Student 2:** Students are in school to learn, not to express their personality.
 - **S1:** Part of school is to figure out who you are, and lack of ability to express personality does not help that process.
 - **S2:** Students learn to be like everyone else when it comes to fashion. There should be lessons that help students figure that stuff out, not clothing choices.
-
- **S2:** There should be a school uniform because it makes less obvious the differences in how much money students have.
 - **S1:** Students know those differences anyway – they compare shoes, accessories, cars, homes, electronics, etc. Uniforms just become an additional expense for families that are already struggling.
 - **S2:** It still decreases the biggest comparison factor – name brands and variety of clothing. Uniforms could be provided free to families that cannot afford them.
 - **S1:** Avoiding the problem won't help students learn how to deal with real-life problems like how to deal with people of different economic

STUDENT HANDOUT 4.1

A Decision for Dennis

Name_____ Date_____ Period_____

Read justifications A – E, which address the following ethical question:

“Should Dennis be allowed to reject life-saving medical treatments?”

Evaluate each justification using the decision chart found on Student Handout 4.2—*Elements of a Strong Justification*. If the necessary part of the justification is present (A DECISION, FACTS or STAKEHOLDER VIEWS, for example) put a “Y” for yes in the box. If not, put an “N” for no in the box. You will go through example “A” as a class, then complete B – E individually.

A. “No. The blood products he needs are medically necessary. Since his leukemia was treated with chemotherapy, most of his blood cells have been destroyed. He needs blood transfusions to survive. In following the principle ‘Maximize Benefits’ for Dennis (to ‘do no harm’) the doctors are required to save his life.”

B. “Yes. The doctors probably don’t know what they’re doing, and he’ll probably die anyway. People get sick in hospitals all the time from diseases they didn’t come in with. In his weakened state, he could easily get sick from something else and die.”

C. “Yes. The principle ‘Respect for Persons’ includes the idea of autonomy which allows a person to make decisions about his or her own fate. Dennis is 14 years old, old enough to fully understand what it means to refuse blood transfusions. He should make this decision and his wishes should be respected.”

D. “The doctors should ‘Maximize Benefits’ and ‘do good’ by not allowing him to die. On the other hand, they should respect his autonomy and his wishes. His parents gave guardianship over to the aunt, so their opinion shouldn’t matter. The aunt and the doctors should make the decision together.”

E. “No. It will be too emotionally difficult on his biological parents. They are now sober and just because they made mistakes in the past, that doesn’t mean that they should have to watch their son die. They probably thought that giving custody to the aunt was temporary, and that they would get him back.”

STUDENT HANDOUT 4.2

Elements of a Strong Justification

Name_____ Date_____ Period_____

What Makes a Strong Justification for a Decision on an Ethical Question?

Read through possible justifications for *Dennis's Decision* found on Student Handout 4.1. Evaluate each justification (A – E) using the following decision chart. If a justification contains the needed element, write "Y" for Yes in the box. If not, write "N" for No.

A good justification includes:	Which means...	A Decision for Dennis Justifications				
		A	B	C	D	E
A DECISION	A position (claim) has been clearly stated. The decision relates directly to the ethical question.					
FACTS	The facts and science content can be confirmed or refuted regardless of personal or cultural views. This can be used as evidence to support the claim.					
ETHICAL CONSIDERATIONS	Ethical considerations may include Respect for Persons, Maximize Benefits/Minimize Harm, and Justice, in addition to others. This can be used as evidence to support the claim.					
STAKEHOLDER VIEWS	There are a variety of views and interests in the decision and more than one individual or group will be affected by the outcome.					
ALTERNATIVE OPTIONS and REBUTTALS	No one decision will satisfy all parties. A thorough justification considers strengths and weaknesses of various options.					
REASONING and LOGIC	A logical explanation that connects the evidence to the claim is provided.					

For our purposes, the justification for the decision is more important than the position on the decision.

Possible Answers for STUDENT HANDOUT 4.2

Elements of a Strong Justification

What Makes a Strong Justification for a Decision on an Ethical Question?

Read through possible justifications for *Dennis's Decision* found on Student Handout 4.1. Evaluate each justification (A – E) using the following decision chart. If a justification contains the needed element, write "Y" for Yes in the box. If not, write "N" for No.

A good justification includes:	Which means...	A Decision for Dennis Justifications				
		A	B	C	D	E
A DECISION	A position (claim) has been clearly stated. The decision relates directly to the ethical question.	Y	Y	Y	N	Y
FACTS	The facts and science content can be confirmed or refuted regardless of personal or cultural views. This can be used as evidence to support the claim.	Y	N	Y	SOME	SOME
ETHICAL CONSIDERATIONS	Ethical considerations may include Respect for Persons, Maximize Benefits/Minimize Harm, and Justice, in addition to others. This can be used as evidence to support the claim.	Y	N	Y	Y	N
STAKEHOLDER VIEWS	There are a variety of views and interests in the decision and more than one individual or group will be affected by the outcome.	N	N	N	Y	N
ALTERNATIVE OPTIONS and REBUTTALS	No one decision will satisfy all parties. A thorough justification considers strengths and weaknesses of various options.	N	N	N	Y	N
REASONING and LOGIC	A logical explanation that connects the evidence to the claim is provided.	Y	N	Y	N	N

For our purposes, the justification for the decision is more important than the position on the decision.

STUDENT HANDOUT 4.3

Your Decision and Justification

Name_____ Date_____ Period_____

You may refer to Student Handout 3.3—*Facts, Values, and Stakeholders* if needed.

1. What is your position on this issue? Write out your claim in a complete sentence.
2. What is the factual content that can be used as evidence to support your position? This factual content should be able to be confirmed or refuted regardless of cultural or personal views.
3. What are the views and interests of the individuals or groups affected by the decision that you think are most relevant to your position?
4. What ethical considerations can be included as evidence to support your position? (Respect for Persons, Maximize Benefits/Minimize Harms, Justice)

5. What are the alternative options and why are they not as strong as your position? (Some of these options may be proposed by different stakeholder groups.)

6. Take the answers to *Questions #1-5* and write a strong justification paragraph for your decision on the topic. Make sure to use the evidence (such as the scientific facts and ethical considerations) in support of your claim in a way that shows your reasoning

LESSON 5:

Putting it all Together

INTRODUCTION

In this lesson, students consider the case of a young doctor hired by a U.S. pharmaceutical company to test a new antibiotic in Nigeria during a meningitis epidemic. Students work through a **Decision-Making Framework** in small groups, in which they identify the ethical question, determine which facts are known or unknown, consider the values of different stakeholder groups, generate possible solutions, and then make and justify a decision about the case. This is a jigsaw exercise, in which students first meet in “like” stakeholder groups to become experts in the values and concerns of that group. Teams are then rearranged into “mixed” stakeholder groups so that each new group has students from different stakeholder viewpoints. After sharing the views and values of each stakeholder group with their peers, groups work together to generate options for solutions to the case study. Lastly, students come to individual decisions about the case and write a thorough justification.

KEY CONCEPTS

- A decision-making framework provides a structured format for logical student thought.
- Difficult decisions can be “reasoned through” in a systematic way, even if the different solutions are not without challenges for diverse stakeholder groups.
- Not all of the Principles of Bioethics will be equally relevant to any one situation.

LEARNING OBJECTIVES

Students will be able to:

- Reason through a case study using a decision-making framework.
- Apply bioethical principles to a case study.
- Create a strong justification for their decision about the case study.

CLASS TIME

One class period of 55 minutes.

MATERIALS

Materials	Quantity
Student Handout 2.1— <i>The Principles of Bioethics</i> (handed out in <i>Lesson Two</i>)	1 per student
Student Handout 4.3— <i>Justify The Answer</i> (from <i>Lesson Four</i>)	1 per student
Student Handout 5.1— <i>Case Study: The Time and the Place?</i>	1 per student
Student Handout 5.2— <i>Ethical Decision-Making Framework</i>	1 per student
Possible Answers for Student Handout 5.2— <i>Ethical Decision-Making Framework</i>	1
Student Handout 5.3— <i>Elements of a Strong Justification</i>	1 per student

TEACHER PREPARATION

Make copies of the *Student Handouts*, one per student

NOTE TO THE TEACHER

Although the case study presented in this lesson highlights what might be considered a questionable action by a pharmaceutical company, please note for students that we have all benefitted enormously from the drugs and therapies developed by the pharmaceutical industry. Pharmaceutical companies are regulated by the Food and Drug Administration (FDA). A number of regulations are in place regarding appropriate actions and behavior in testing and marketing new drugs.

FRAMING THE LESSON

Students are **not introduced** to any new concepts in this lesson but **put into practice** what they have learned throughout the unit. They apply to a new case study their knowledge of ethical questions, bioethical principles, stakeholders, generating options, and writing a thorough justification.

As students read the case study, it may be helpful for them to color code elements of the decision-making framework. For example, **facts** could be highlighted in yellow, and **stakeholders** could be highlighted in green.

PROCEDURE

Part I: Ethical Question, Facts, and Stakeholders

Activity Time: 15 minutes

1. Distribute copies of Student Handout 5.1—*Case Study: The Time and the Place?*, one per student. Allow time for students to read the case study.
2. Distribute copies of Student Handout 5.2—*Ethical Decision-Making Framework*, one per student. As a class, decide the ethical question. Guide the class to this question:
“Should Rezip conduct this clinical trial research?”
3. Give students approximately five minutes to write down the facts from the case and any questions that they have on Student Handout 5.2—*Ethical Decision-Making Framework*.
4. Have individual students brainstorm a list of stakeholders in the case.
5. Ask for student volunteers to provide names of stakeholders.

Field test teachers suggest using the term **developing country** rather than **third world**.

6. List the stakeholders on the board. They could include:
 - You (the doctor)
 - Rezip
 - The children
 - The families of the children
 - Other sick people in Kano
 - The U.S. government
 - The Nigerian government
 - *Doctors without Borders*
 - Rezip shareholders
 - Other pharmaceutical companies
 - Other doctors employed by Rezip
 - Kano ethics committee

7. Choose the top four stakeholders that are most affected by the decision and have students list these on their decision-making framework. Four groups that work well are:

- You (the doctor)
- The sick children (and their families)
- Rezip
- Kano

Part II: “Like” Stakeholder Groups

Activity Time: 10 minutes

8. Divide the class into groups of four and assign one stakeholder to each small group (more than one group can represent the same stakeholder, if needed).
9. First, students should consider the values and concerns of that stakeholder group and record them on Student Handout 5.2—*Ethical Decision-Making Framework*. What are their concerns? What do they care about?

Students may want to refer to Student Handout 1.2—*Values Definition Table* and Student Handout 2.2—*The Principles of Bioethics*.

10. Next, each group should also consider the Principles of Bioethics from the perspective of that stakeholder. How does Respect for Persons relate to the group? Maximize Benefits/Minimize Harms? Justice? Do all the principles apply equally to each stakeholder group?
11. Allow about five minutes for each stakeholder group to delve into the values and concerns of that stakeholder.

Part III: “Mixed” Stakeholder Groups

Activity Time: 10 minutes

12. Rearrange the class into groups of four, so that each new small group has one representative from each stakeholder set. If there are extra students, two students can represent the same stakeholder in the same group, if needed.
13. Each stakeholder should share, in turn, their values and concerns with the other students in the group until each stakeholder has reported.
14. Students should record basic information about each stakeholder group on Student Handout 5.2—*Ethical Decision-Making Framework*.

15. While staying in the stakeholder roles, have students proceed to “Generating Options” on the handout. What are the options for the case? What would each stakeholder group do, if the decision were only up to that group?
16. Tell students to drop their stakeholder roles and explore, as a group, any additional options, if available. Have the extreme positions been expressed? Have the middle-ground options been expressed?
17. Each team member should come to an individual decision. This does not have to be a group consensus, nor does the student have to share his or her decision.

Part IV: Student-Written Justification

Activity Time: 20 minutes

18. Each student should write a thorough justification for his individual decision, using the decision chart found on Student Handout 5.3—*Elements of a Strong Justification*. Note for students that a good justification will touch upon all parts of the Decision-Making Framework. Student Handout 5.3—*Elements of a Strong Justification* is organized the same way as the framework, beginning with the question and ending with the solutions.
19. If time permits, have students discuss their justifications in pairs. Students can give each other feedback on the strength of their justifications based on the justification template. Students should **not** critique each other’s positions directly, but focus on the strength of the reasoning.
20. Collect the justifications.
21. Ask students to reflect on their experiences by asking, “Do you have a better ability to make a well-justified decision?” and, “Were you able to listen to and respect other viewpoints?”

Part V: Variations on the Story (Optional)

22. Once students have come to a decision about the case and have justified their decision, have them consider the following variations to the story. In pairs or small groups, have students discuss whether any of these additional pieces of information would change their decision. Why or why not?

Would students feel differently if they knew...

- A. The outcome of the trial?
 - Eleven children died during the drug trial—five of whom had been given Trovan, six of whom had been given the other approved antibiotic.

- Families of the children who received Trovan claim that many of them suffered serious side effects from the drug, such as brain damage and organ failure. Rezip claimed that these effects were from the meningitis itself.
- Rezip claimed that Trovan clearly saved lives since the survival rate from the epidemic went from 80% at the beginning to 94% after the trial.

B. Some doubts existed as to the legitimacy of the ethics committee?

- Some documents suggest that the ethics committee referenced by Rezip was actually set up a year **after** the doctors conducted the trial.

C. Trovan is now banned?

- The “blockbuster antibiotic” Rezip was testing did not live up to expectations. The European Union later banned the drug and it is no longer in production or for sale in the U.S.

The Rest of the Story

[**Note:** Share *The Rest of the Story* **only if** the students have finished writing their own decisions and justifications.]

Each of the variations to the story (above in *Part V*) is true. In April 2009, the pharmaceutical company that is featured in this case agreed to pay a \$75 million out-of-court settlement to the families of the children who participated in the drug trial. In August 2009, the company and Kano State reached an agreement in which Kano State dropped all claims, and the company denied any wrongdoing or liability in connection with the Trovan study. Under terms of the settlement, the pharmaceutical company agreed to establish a healthcare/meningitis fund to support study participants, provide \$30 million in healthcare initiatives for Kano State, and reimburse Kano State government for legal costs.

This pharmaceutical company also became the first to be accredited by the Association for the Accreditation of Human Research Protection Programs for ensuring the protection of human subjects taking part in early-stage clinical trials in four major sites across the globe. To earn this accreditation, the company participated in a rigorous, 15-month examination of the clinical research practices at these sites.

This case reportedly inspired the book *The Constant Gardener* by John Le Carre. The story was also made into a film of the same name, starring Ralph Fiennes and Rachel Weisz.

CLOSURE

23. Share with students that the decision-making framework and bioethical analysis tools that students have learned over the week are conceptual models that will help them as they examine subsequent bioethical cases. They may also find them helpful as they consider dilemmas they may encounter in the future.

EXTENSION

Additional discussion points could include:

- The challenge of getting informed consent. (How do researchers conduct studies in populations with high rates of illiteracy? In cultures where the voice of a community leader might outweigh the voice of an individual?)
- Study design for international human clinical trials. (How do researchers control for the many variables inherent to the study? What if the amount of compensation in one region would unduly influence participants in another region?)

ADDITIONAL RESOURCES FROM AN ETHICS PRIMER

Additional information and discussion about using ethical decision-making frameworks in class can be found in the section *Decision Frameworks*. Alternate frameworks are also included.

SOURCES

"Pfizer to pay \$75m after death of Nigerian children in drug trial experiment." Howden, Daniel. *The Independent*, April 6, 2009. <http://www.independent.co.uk/news/world/africa/pfizer-to-pay-16350m-after-deaths-of-nigerian-children-in-drug-trial-experiment-1663402.html>.

"Pfizer, Kano State Reach Settlement Of Trovan Cases." Loder, Chris. Pfizer, Inc. Press Release, July 30, 2009. <http://mediaroom.pfizer.com/news/pfizer/20090730005769/en>.

"Pfizer Becomes The First Pharmaceutical Company To Be Accredited For Protection Of Human Rights In Clinical Research." Neese, Kristen. Pfizer, Inc. Press Release, April 3, 2009. <http://mediaroom.pfizer.com/news/pfizer/20090403005547/en>.

Trovan Fact Sheet. Pfizer, Inc. http://media.pfizer.com/files/news/trovan_fact_sheet_final.pdf.

STUDENT HANDOUT 5.1

Case Study: The Time and the Place?

Name _____ Date _____ Period _____

You have recently completed years of medical training—undergraduate work, medical school, internships, and residency—and are excited to have gotten a job with Rezip, one of the largest pharmaceutical companies in the world. Based in the United States but operating in 150 countries, Rezip discovers, develops, manufactures, and delivers prescription medicines to patients. Many Rezip drugs make life easier and healthier for millions on a daily basis.

You have been interested in global health since middle school, and chose to focus on infectious diseases during your medical training. It seems unbelievable to you that each year hundreds of thousands of people die from bacterial diseases like meningitis, cholera, and pneumonia, especially in developing countries. Your passion for global health and your new job at Rezip seem like the perfect match. Rezip has developed what it hopes will be a “blockbuster antibiotic” – an antibiotic that would fight a wide range of bacteria and could be taken in tablet form. The drug, called Trovan, is in the late stage of development and so far has been successfully tested on over 5,000 adult patients in the United States, Europe, and elsewhere. The results are very promising, and Rezip anticipates that the drug will receive approval for adult use. However, additional clinical trials with younger patients are needed to prove its effectiveness and safety for children; otherwise the drug will not receive approval for pediatric use. Rezip is sending you to Africa for two weeks to dispense Trovan to children as part of this needed clinical trial. If Trovan proves successful overall, millions of adults and children suffering from a variety of deadly bacterial diseases could be cured easily by taking a few pills. Rezip also projects its total sales could reach over a billion dollars a year as a result.

Drug clinical trials are heavily regulated by the FDA (Food and Drug Administration). In Phase I trials, the drug dosage must be proven to be **safe** in 20–80 healthy volunteers. Phase II trials then prove **effectiveness** of the drug in 100–300 patient volunteers sick with the disease the drug will treat. Finally, Phase III trials prove **widespread safety and effectiveness** of the drug in 1,000–3,000 patient volunteers. Clinical trials must be conducted in target populations – in other words, if the drug will be used on women, it must be tested on women; if the drug will be used on children, it must be tested on children. Certain drugs have been known to affect different populations differently, and therefore the FDA demands rigorous clinical trials on all target populations. In the United States, the full clinical trials cycle can take two to ten years depending on how many people sign up to be in the trial, the way the trials are conducted, and whether the results are decisive.

Your boss tells you that you are going to Nigeria, which is experiencing the most serious meningitis outbreak ever recorded—hundreds are dying each month. In the first weeks of the epidemic, only about 80% of those with the disease have survived. Understandably, this presents a severe public health crisis for the government of Nigeria. When you arrive at the Nigerian slum city of Kano, you are overwhelmed by the needs of the people—many of whom are children—and the huge crowds gathered at the Kano Infectious Diseases Hospital.

Nearby, an aid group called *Doctors Without Borders* has set up a medical station and is dispensing treatments to ease the epidemic. Despite their efforts, the lines at the medical station are overwhelmed with people needing treatment. You and your team have been instructed to set up camp close to the *Doctors Without Borders* station to aid in the relief efforts and collect data for the clinical research study. As a Rezip doctor, you will choose 200 children with serious symptoms. Half will be given doses of the experimental drug Trovan, while others will be treated with an antibiotic from a rival company for comparison (this rival drug has already gone through standard clinical trials and has been shown to be effective and safe). The children and their families will not know which of the two drugs they are receiving. If Trovan has a very negative effect on the children, the other drug can be administered. Given the chaos of the crowds gathered, it is decided that getting consent from individual families will be impractical, so it is agreed that permission from a Kano ethics committee will serve as consent for everyone. Rezip sought and received permission and consent for the study from a Kano ethics committee made up of local doctors, health officials, and tribal elders. Culturally, tribal elders often represent their communities.

You look around at the malnourished and severely ill children from the slum city raging with meningitis, cholera and measles. These are the children you will dispense medicine to and gather data from for the clinical trial. You have some concerns about how the trial will be conducted, but you also recognize the potential health benefits of the drug. Should Rezip conduct this clinical trial research?

This is a fictionalized account of a true story. Contributed by Rosetta Eun Ryong Lee, Seattle Girls' School.

STUDENT HANDOUT 5.2

Ethical Decision-Making Framework

Name_____ Date_____ Period_____

Part I: Ethical Question

Part II: Facts and Questions

Relevant facts (known)

Questions that remain (unknown, need to know)

Part III: Stakeholder Values

Stakeholders (people/entities affected by the decision)

Values/concerns of each stakeholder

Bioethical Principle(s) given priority



5. Generating Options

(What are some possible options to resolve the ethical question?)

6. Write a strong justification paragraph for your decision on the topic. Make sure to answer the following questions while using the evidence (such as the facts and ethical considerations) to support your claim in a way that shows your reasoning.

- a. What is your position on this issue?
- b. What is the factual content to support your position that can be confirmed or refuted regardless of cultural or personal views?
- c. What ethical considerations can be included to support the position? (Respect for Others, Maximize Benefits/Minimize Harms)
- d. What are the views and interests of the individuals or groups affected by the decision that you think are most relevant to your position?
- e. What are the alternative options and why are they not as strong as your position?

Possible Answers for STUDENT HANDOUT 5.2

Ethical Decision-Making Framework

Answers can vary widely. Possible answers are below.

Part I: Ethical Question		
Should Rezip conduct this clinical research trial?		
Part II: Facts and Questions		
<p>Relevant facts (known)</p> <ul style="list-style-type: none"> • Rezip, a large pharmaceutical company, wants to test an experimental drug in Kano, Nigeria during a meningitis outbreak. • Hundreds of thousands of people die each year due to bacterial infections. • Trovan has already been successfully tested on over 5,000 adults. • Additional clinical trials are needed with children. • Millions of people could benefit from Trovan. • If approved by the FDA, Trovan could earn over a billion dollars a year for Rezip. • Clinical trials happen in three stages. • Clinical trials must be conducted on target populations to get FDA approval for the drug. • Children in the trial would be given either Rezip's experimental drug or a standard antibiotic. • 200 children would be picked for the trial. • Rezip set up its camp meters from the DWB station. • An ethics committee gave permission for the trial to take place, but individuals were not asked for their consent. 	<p>Questions that remain (unknown, need to know)</p> <ul style="list-style-type: none"> • Were there any negative outcomes for the 5,000 adults who took Trovan during earlier testing? • How dangerous is meningitis? • How healthy does a child have to be to participate in a clinical trial? • Who gave consent for the children to participate? How? • How much will the drug sell for if it is approved? Will people in Kano be able to afford it, if approved? • Is two weeks enough to gather data on how effective a drug is? • What are the side effects from the standard antibiotic that had already been proven safe and effective? • What drug(s) was Doctors without Borders using? 	
Part III: Stakeholder Values		
Stakeholders (people/entities affected by the decision)	Values/concerns of each stakeholder	Bioethical Principle(s) given priority
You (and/or other doctors)	You are concerned that the children not be treated as a means to an end but respected for their inherent worth. You also see the benefit of the drug and the need for clinical trials.	Respect for Persons Maximizing Benefits/ Minimizing Harms
The sick children and their families	Both value the children's health and well-being. Families may be concerned that their children are treated fairly, and that they are not bearing an unequal share of the risks.	Justice
Rezip Pharmaceutical Company	Rezip is being practical in finding a population who could potentially benefit from their experimental drug, while getting the trial results they need quickly.	Maximizing Benefits/ Minimizing Harms
Kano State	They are concerned that their citizens are protected and not being used as a "means to an end." They may also value positive relationships with U.S. corporations.	Respect for Persons Justice

5. Generating Options

(What are some possible options to resolve the ethical question?)

The trial should not proceed at this time of intense need and the doctors should return to the U.S.

The trial should proceed as planned.

The trial should proceed only if the families of the children give their fully informed consent to participate in the clinical trial.

The trial should proceed under the oversight of the Nigerian government.

The trial should proceed but only if Rezip stays in Nigeria for longer than two weeks to offer ongoing medical care for the study participants and their families.

6. Write a strong justification paragraph for your decision on the topic. Make sure to answer the following questions while using the evidence (such as the facts and ethical considerations) to support your claim in a way that shows your reasoning.

- What is your position on this issue?
- What is the factual content to support your position that can be confirmed or refuted regardless of cultural or personal views?
- What ethical considerations can be included to support the position? (Respect for Others, Maximize Benefits/Minimize Harms)
- What are the views and interests of the individuals or groups affected by the decision that you think are most relevant to your position?
- What are the alternative options and why are they not as strong as your position?

Example justifications:

No, Rezip should not conduct this trial. Although hundreds of thousands of people die each year due to bacterial infections and the drug has already been successfully tested on over 5,000 adults, more studies are needed with children who are not already dangerously ill and living during a meningitis epidemic. Rezip will violate the principle "Respect for Persons" by not obtaining informed consent from the families of the children. Furthermore, they are not respecting the vulnerable population in Kano since they are scheduled to leave the area after only two weeks, even though the need for medical care will still be acute. The principle of Justice states that risks, costs, and resources should be equally distributed, but the children of Kano would take the risk of participating, while Rezip would benefit by collecting the needed data. Although the drug may prove to be beneficial to the children, the potential harms to the children in this population at this time outweigh the benefits to Rezip.

OR

Yes, Rezip should conduct this trial. The company has already undergone preliminary clinical trials that have shown the drug's effectiveness in adults. This drug could ultimately be beneficial in this geographical region and health situation—a meningitis outbreak—and the fatality rate may be lowered. Rezip could be "Maximizing Benefits" of study participants by testing an antibiotic that could potentially alleviate much pain and suffering. By having such a short trial period, the drug could be put on the market sooner and made available to the people who need it. Meningitis is a serious disease with devastating and sometimes deadly effects; all parties (stakeholders) should support the development of drugs against it.

STUDENT HANDOUT 5.3

Elements of a Strong Justification

Name_____ Date_____ Period_____

A strong justification should have the following elements:

✓	A good justification includes:	Which means...
<input type="checkbox"/>	A DECISION	A position (claim) has been clearly stated. The decision relates directly to the ethical question.
<input type="checkbox"/>	FACTS	The facts and science content can be confirmed or refuted regardless of personal or cultural views. This can be used as evidence to support the claim.
<input type="checkbox"/>	ETHICAL CONSIDERATIONS	Ethical considerations may include Respect for Persons, Maximize Benefits/ Minimize Harm, and Justice, in addition to others. This can be used as evidence to support the claim.
<input type="checkbox"/>	STAKEHOLDER VIEWS	There are a variety of views and interests in the decision and more than one individual or group will be affected by the outcome.
<input type="checkbox"/>	ALTERNATIVE OPTIONS and REBUTTALS	No one decision will satisfy all parties. A thorough justification considers strengths and weaknesses of various positions.
<input type="checkbox"/>	REASONING and LOGIC	A logical explanation that connects the evidence to the claim is provided.

For our purposes, the justification for the decision is more important than the position on the decision.



APPENDIX

TABLE OF CONTENTS

- 63 **Creating Discussion Ground Rules**
- 64 **Student Handout—*Elements of a Strong Justification***

Pre-/Post-Test Materials

- 65 **Ashley's Case Overview**
- 66 **Student Handout—*Assessment Questions***
- 69 **Scoring Rubric**
- 71 **Teacher Support Materials**



APPENDIX

Creating Discussion Ground Rules

INTRODUCTION

The study of ethics involves consideration of conflicting moral choices and dilemmas about which reasonable people may disagree. Since a wide range of positions is likely to be found among students in most classrooms, it is especially important to foster a safe classroom atmosphere by creating some discussion ground rules. These ground rules are often referred to as “norms.” An agreed-upon set of ground rules should be in place before beginning the *Bioethics 101* curriculum.

LEARNING OBJECTIVES

Students will be able to:

- Create and agree to classroom discussion norms.

PROCEDURE

Ask the students, “What can we do to make this a safe and comfortable group for discussing issues that might be controversial or difficult? What ground rules should we set up?” Allow students some quiet reflection time, and then gather ideas from the group in a brainstorming session. One method is to ask students to generate a list of ground rules in small groups and then ask each group to share one rule until all have been listed. Clarify and consolidate the ground rules as necessary.

Post norms where they can be seen by all and revisit them often. If a discussion gets overly contentious at any time, it is helpful to stop and refer to the ground rules as a class to assess whether they have been upheld.

Some possible student ground rules/norms could include:

- A bioethics discussion is not a competition or a debate with a winner and a loser.
- Everyone will respect the different viewpoints expressed.
- If conflicts arise during discussion, they must be resolved in a manner that retains everyone’s dignity.
- Everyone has an equal voice.
- Interruptions are not allowed and no one person is allowed to dominate the discussion.
- All are responsible for following and enforcing the rules.
- Critique ideas, not people.
- Assume good intent.

APPENDIX

Student Handout—*Elements of a Strong Justification*

Name_____ Date_____ Period_____

A strong justification should have the following elements:

✓	A good justification includes:	Which means...
<input type="checkbox"/>	A DECISION	A position (claim) has been clearly stated. The decision relates directly to the ethical question.
<input type="checkbox"/>	FACTS	The facts and science content can be confirmed or refuted regardless of personal or cultural views. This can be used as evidence to support the claim.
<input type="checkbox"/>	ETHICAL CONSIDERATIONS	Ethical considerations may include Respect for Persons, Maximize Benefits/ Minimize Harm, and Justice, in addition to others. This can be used as evidence to support the claim.
<input type="checkbox"/>	STAKEHOLDER VIEWS	There are a variety of views and interests in the decision and more than one individual or group will be affected by the outcome.
<input type="checkbox"/>	ALTERNATIVE OPTIONS and REBUTTALS	No one decision will satisfy all parties. A thorough justification considers strengths and weaknesses of various positions.
<input type="checkbox"/>	REASONING and LOGIC	A logical explanation that connects the evidence to the claim is provided.

For our purposes, the justification for the decision is more important than the position on the decision.

APPENDIX

Ashley's Case Overview

The following case study and support materials were created as a pre-/post-test for a research study designed to investigate the relationship between explicit instruction in bioethical reasoning and resulting student outcomes.

Lesson Five of the curriculum is designed to assess students' ability to synthesize what they have learned throughout the curriculum module, and results in a written paragraph showing student reasoning. Teachers may use *Ashley's Case* as a pre-/post-test for the *Bioethics 101* curriculum, if desired. For the *Ashley's Case* assessment, students are not asked to integrate their justification into a final paragraph detailing how evidence from the case is used to support their claim, although elements of student reasoning will be apparent in the assessment questions.

Name _____ Date _____ Period _____

Ashley's Case

Ashley, at age 6½, could not roll over, sit up or hold her head up, or use language. Developmentally, she was like an infant. Ashley's parents, who have two other healthy children, had cared for Ashley in their home since birth. Ashley was diagnosed with "static encephalopathy," meaning that her brain had stopped developing. Doctors determined that there was no chance of Ashley improving over time.

Ashley's parents grew concerned over their abilities to continue to care for Ashley at home. With continued growth and development, she would eventually become too large for them to manage her needs, including feeding her, changing her, bathing her, and positioning her during the night. Additionally, they were concerned at the prospects of her sexual development, including menstruation, breast development, and fertility.

Ashley's parents made three requests of doctors at Children's Hospital and Regional Medical Center in Seattle, Washington. First, they wanted Ashley to have a hysterectomy (removal of her uterus) to prevent any risk of menstruation and/or pregnancy. Although there are methods like birth control pills to address these issues, they are accompanied by the possibility of long-term side effects. One risk, blood clots, is considerable in a patient who is bed-bound and unable to move herself. Second, they requested the removal of her breast buds, which would eliminate the development of breasts altogether. Ashley's parents argued that her breasts would cause discomfort with the straps used to hold her in her chair, and that breast discomfort was a known problem for some adult women in the family. There was also a family history of fibrocystic breast disease and breast cancer. Without breasts, Ashley would be spared future mammograms and possible biopsies. Finally, Ashley's parents requested medical treatment to limit her final adult height and weight through hormone therapy. High dose hormone therapy to limit height was a common treatment for "tall girls" in the 1960s and 70s and the medical risks over the long term are known to be limited.

The ethics committee noted that there was great need for caution with such procedures, as there have been many documented cases of past abuses of people with physical and developmental disabilities. Dr. Doug Diekema (who, with Dr. Daniel Gunther, published their paper on Ashley in the *Archives of Pediatric and Adolescent Medicine*) acted as ethicist on this case, and was part of the group that decided the outcome of the parent's requests. Dr. Diekema noted that there were few medical risks involved with the hysterectomy and removal of breast buds (standard surgical procedural risks), and only slightly higher risks associated with the hormone therapy (such as blood clotting).

Critics noted that this combination of surgery and hormones to prevent a person from maturing into an adult was unprecedented in medical history. There were also worries about Ashley's rights as a patient, as her parents were making this decision without her ability to contribute. There was a general debate about the potential "slippery slope" of adapting the bodies of the disabled to suit the needs of the caregivers, unless it could be justified that this change was also in the patient's (Ashley's) best interests. An ethics consultation involving about 20 individuals was performed before making the decision. The consultation included a developmental specialist, Ashley's primary care provider, and her hormone specialist. Although Ashley's parents attended the consultation, they were not a part of the deliberation.

Please see the Teacher Resource section for source information. Originally developed by Jacob Dahlke.

Ethical Question: Should one or more medical interventions be used to limit Ashley's growth and physical maturation? If so, which interventions should be used and why?

1. What is your position on this issue?

SCORE

2. What is the factual content to support your position that can be confirmed or refuted regardless of cultural or personal views?

SCORE

3. What are the views and interests of the individuals or groups affected by the decision that you think are most relevant to your position?

SCORE

4. What ethical considerations can be included to support the position? (Respect for Persons, Maximize Benefits/Minimize Harms, Justice)

SCORE

5. What are the alternative options and why are they not as strong as your position?

SCORE

APPENDIX

Scoring Rubric

Ethical Question:

Should one or more medical interventions be used to limit Ashley's growth and physical maturation?
If so, which interventions should be used and why?

Dimension	Exemplary (4 Points)	Proficient (3 Points)	Partially Proficient (2 Points)	Developing (1 Point)
1. What is your decision ? Why is that the best option? (A position that relates directly to the ethical question has been clearly stated and explained.)				
Decision	<p>Student states the best option and discusses all of the interventions with pros/cons, or student states the best option and uses ethical principles to support decision.</p> <p>Student shows thoughtful consideration and organized thinking. Student uses accurate information to support his/her decision.</p>	<p>The student's choice of best option is clearly stated, but may not mention all options. Student shows clear thinking.</p> <p>Student states the best option, and provides accurate information to support his/her decision, or student discusses other interventions.</p>	<p>Student does not clearly state the best option or does not state the best option as what should be done (e.g., "If I were Ashley, I would want the procedures," or "The procedures seem unnecessary."). Student does not give any reasons to support his/her decision.</p>	<p>Student states an option that is not one of the options for the case (e.g., assisted suicide) or student response shows no understanding of the situation or the question being asked.</p>
2. What facts support your decision? Is there information missing that could be used to make a better decision? (The facts and science content can be confirmed or refuted regardless of personal or cultural views.)				
Facts	<p>The justification uses the relevant scientific reasons to support student's answer to the ethical question. Student demonstrates a solid understanding of the context in which the case occurs, including a thoughtful description of important missing information. Student shows logical, organized thinking.</p> <p>Both facts supporting the decision and missing information are presented at levels exceeding standard (as described above).</p>	<p>The main relevant facts are identified. All scientific concepts are correctly presented. Student shows clear thinking. Information missing from the case that would influence decision-making is referenced.</p> <p>Both facts supporting the decision and missing information are presented at levels meeting standard (as described above).</p>	<p>Factual information relevant to the case is described but some key facts may be missing and some irrelevant information may also be included. Student may not have noted information missing from the case that would influence decision-making.</p> <p>Student presents only facts or missing information.</p>	<p>Factual information relevant to the case is incompletely described or is missing. Irrelevant information may be included and student demonstrates some confusion.</p>

Dimension	Exemplary (4 Points)	Proficient (3 Points)	Partially Proficient (2 Points)	Developing (1 Point)
3. Which stakeholders will be impacted by the decision and how will they be impacted? (There are a variety of views and interests in the decision, and more than one individual or group will be affected by the outcome.)				
Stakeholder Views	Three or more stakeholders, the ways in which they are impacted, and their values, interests, and/or concerns are identified OR four or more stakeholders and the ways in which they are impacted are identified.	Three stakeholders and the ways in which they are impacted are identified OR four stakeholders are identified without mention of impacts on them.	Two stakeholders and the ways in which they are impacted are identified OR three stakeholders are identified without mention of impacts on them.	Only one stakeholder and the way in which this stakeholder is impacted is identified OR two stakeholders are identified without mention of impacts on them.
4. What are the main ethical considerations ? (Ethical considerations may include Respect for Persons, Do Good/Do No Harm, Justice, and Care.)				
Ethical Considerations	The student evaluates the case in depth using one or more ethical considerations . The student shows exceptional understanding of how one or more ethical considerations relates to the case. The student's decision is supported by the thorough, thoughtful application of the consideration(s) to the case. The student demonstrates organized thinking, and his/her conclusions flow logically from premises. Student response includes analysis/evaluation of the case with regard to issues of consent, best interest, and/or benefits/harms.	The student demonstrates an understanding of the ethical consideration(s) related to the case. The student provides clear explanation of how ethical considerations support his/her decision. Student response includes issues of consent, best interest, and/or benefits/harms.	The student demonstrates a general awareness of ethical considerations and how they relate to the case, but may not articulate the relationship clearly or provide enough explanation. The student demonstrates mostly clear and organized thinking, but portions of the answer may be unclear, disorganized, or incomplete. Student response seems to refer to issues of consent, best interest, and/or benefits/harms.	The student lacks an awareness of ethical principles or does not properly relate them to the case. The student demonstrates some confused or disorganized thinking. Student response does not include ethical considerations (e.g., legal considerations).
5. What are the strengths and weaknesses of alternate solutions ? (No one decision will satisfy all parties. A thorough justification considers various positions.)				
Alternate Solutions	Provides a thorough analysis of the alternate solutions that includes multiple strengths and weaknesses and/or multiple alternate solutions. The writing is clear and organized.	Presents both the strengths and the weaknesses of the alternate solution(s).	Discusses only the strengths or the weaknesses of the alternate solution or contains either misconceptions or unrealistic strengths or weaknesses (e.g., Ashley's brain will start to develop or being able to mature normally is a strength for her).	No alternate solutions are discussed, or does not present strengths and/or weaknesses of alternate solutions or presents unrealistic alternatives (e.g., assisted suicide).

Key Facts and Scientific Concepts

- Ashley was a 6.5-year-old girl with static encephalopathy which means she is developmentally like an infant with no chance of improvement in the future.
- Ashley's parents cared for her in their home since birth.
- As Ashley grows, she will become harder to move, change, bathe, and position at night.
- Ashley's parents asked her doctors to help them keep her at home under their care by performing three procedures:
 - Hysterectomy to prevent menstruation and/or pregnancy.
 - Removal of breast buds to prevent breast development (family history of breast discomfort and breasts get in the way of straps used to hold her in a sitting position).
 - Hormone therapy to limit her final adult height and weight.
- Doctors note there are few risks involved with a hysterectomy and removal of breast buds besides standard surgical procedural risks and only slightly higher risks associated with hormone therapy. High-dose hormone therapy has a long history of use in children and risks (such as blood clotting) are known to be limited.
- This procedure to prevent a person from maturing into an adult is unprecedented in medical history.

Stakeholders Impacted by Decision	Interests/Values
Ashley	Since she is developmentally an infant, her interests are similar: comfort; the need for the familiar faces of those who love/care for her; family.
Ashley's parents	Want to keep their child in their home; concerned for her comfort, safety, and well being; concern for her future; they would like to care for her as long as possible.
Advocates for the rights of disabled persons	Concerned that this could become accepted practice in the care for disabled persons; focus of care should be on patient's needs, not those of caretakers, when considering medical treatments.
Ashley's doctors and care team	Concern for Ashley's health and future care; want to provide ethically sound treatments that benefit her without undue risk to her health.
Families with similar situations	If the treatment is successful, this could inform other families with disabled children about their choices for care; increases the options available to them for keeping children in the family home rather than in an institution.

Main Ethical Considerations: Sample Student Responses

Exemplary	Proficient	Partially Proficient	Developing
<p>Student chooses to proceed with only the least invasive treatment.</p> <p>The main ethical considerations are Do Good/Do No Harm and Respect for Persons. Hormone therapy has a slightly higher risk of complications (blood clots) than the surgeries but doesn't require her to be under anesthesia and is not invasive. The hormone therapy will keep her small so that her parents will be able to care for her more easily which will be the major benefit to her. In this way, the most good can be done for Ashley with the least amount of harm.</p> <p>The best people to care for her are those who love and know her the most. By keeping her body whole but limiting her growth, she is kept safe and secure in the family home while at the same time respecting Ashley as a person and allowing the natural path of her development into an adult female.</p>	<p>Student chooses the option to deny all treatments.</p> <p>We should respect Ashley as a person and not something to be changed surgically to make it easier on the caretakers. There are other ways they can take care of her like getting a home nurse to do all the difficult work. She could have serious complications with the surgeries and that wouldn't be worth it.</p> <p>Student chooses to proceed with all three treatments.</p> <p>Ashley can't decide so her parents who care for her should be able to make the decision they think will be best for her. They know her family history and how to make her comfortable. If breasts will make her uncomfortable in seat straps then they should prevent the pain by removing her breast buds. If they know menstruation will be hard on her, then she should have a hysterectomy. And if she is small, she will be at home with her loving family because they will be able to take care of her easily. This will be a benefit (doing good) for all involved and respect the family's wishes and needs.</p>	<p>Student chooses to proceed with all three treatments.</p> <p>We need to respect her parent's ability to make choices about Ashley since they have authority over her as a child.</p>	<p>Student chooses the option to deny all treatments.</p> <p>Ashley wouldn't be able to have babies otherwise. She should be able to have babies if she wants to. It's not fair.</p>

Strengths and Weaknesses of Alternate Solutions

Exemplary	Proficient	Partially Proficient	Developing
<p>Example: Since she wears diapers anyway, menstruation shouldn't be too much of a problem to care for and if she stays in the family home, pregnancy shouldn't be a risk so there is no need for the hysterectomy. The family can't predict she will have the same discomfort with breasts as other females in the family so an invasive surgery like breast removal should wait until a real problem arises.</p>	<p>Example: All of the procedures carry some risk to Ashley's health and none of them are medically necessary. The hormone therapies in particular, with their risk of clotting, are too dangerous.</p>	<p>Example: The surgeries won't hurt her that much. She's never going to get pregnant anyway so she doesn't need her uterus and she won't need breasts either.</p>	<p>No alternate solutions are discussed.</p>

Case Study Follow-up (to be related to students *after* the post-test)

After a lengthy consultation with parents, family, physicians, and the Seattle Children's ethics committee, a consensus was reached to perform the full treatment. (The parents contributed to the discussion, but were not a part of the decision-making process.) A simple hysterectomy was performed on Ashley, although her ovaries were preserved in order to allow for normal hormonal production throughout her life. Her breast buds were removed without complication, and Ashley's height-limiting treatment included an estrogen skin patch applied daily for 2.5 years without complication. Estrogen is the primary female hormone that, when used in high doses, shortens the amount of time that growth can occur.

One year after her treatments, at the age of 9, Ashley was 4'5", about 12 inches shorter than predicted without therapy. It is estimated that her weight—65 pounds—was almost half of what it would have been without the hormone treatments. She continues to live under the care of her family.

Sources:

"Disabled girl's parents defend growth-stunting decision." Burkholder, Amy. *CNN.com*, March 13, 2008. <http://www.cnn.com/2008/HEALTH/conditions/03/12/pillow.angel/index.html>

"Commentary: Is 'Peter Pan' treatment right?" Caplan, Arthur, PhD. *MSNBC.com*, January 5, 2007. <http://www.msnbc.com/id/16472931/>

"Doctor at crux of stunting debate kills self." Dahlstrom, Linda. *MSNBC.com*, October 11, 2007. <http://www.msnbc.com/id/21225569/>

Diekema, Doug. The Case of Ashley X. NWABR Ethics in Science Online Course. 2007.

"Pillow Angel Ethics." Gibbs, Nancy. *Time*, January 7, 2007. <http://www.time.com/time/nation/article/0,8599,1574851,00.html>

"Pillow Angel Ethics, Part 2." Gibbs, Nancy. *Time*, January 9, 2007. <http://www.time.com/time/nation/article/0,8599,1574851,00.html>

"The other story from a 'Pillow Angel'." McDonald, Anne. *Seattle Post-Intelligencer*, June 17, 2007. http://www.seattlepi.nwsource.com/opinions/319702_noangel17.html