FUTURELAB+

AG/ENVIRONMENTAL

Solution Seeking Microbes

Uses of CRISPR and Bioethical Decision-Making

Developed in partnership with:
Discovery Education and Ignited

In this Lesson Plan:

Print the **Teacher Section** → 🖨

Print the **Student Section** → 🖨

This document is separated into two sections, For Teachers [T] *and* Student Resources [S]*, which can be printed independently.*

Select the appropriate printer icon above to print either section in its entirety.

Follow the tips below in the Range field of your Print panel to print single pages or page ranges:

Single Pages (use a comma): T3, T6

Page Range (use a hyphen): T3–T6

This is an image of CRISPR Genome editing plant cells (protoplast) used for coronavirus vaccine.

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Cover Image

Lactobacillus casei is one of many friendly bacteria in your gut microbiome.

AG/ENVIRONMENTAL / SOLUTION SEEKING MICROBES

Uses of CRISPR and Bioethical Decision-Making

DRIVING QUESTION

Why are bioethical considerations important when making decisions about biotechnology?

OVERVIEW

Human research is an important component of both the advancement of science and the assurance of safety and efficacy of new medicines and technologies. The process of human research is complex and requires both information and reasoning tools, and has evolved due to the analysis of accepted practices. By analyzing our past and the mistakes that have been made, we can understand why rules and regulations have been put into place, and make our own decisions about human research by using the bioethical principles that guide scientists.

In this lesson, students will consider the principles of bioethics and how difficult decisions are made using a decision-making framework. An example case study (or case studies) that are focused on the historical context of bioethics and the Belmont Report will be explored as small groups and whole class discussion with teacher scaffolding. Students will then apply the principles to CRISPR technology (connecting to the previous lesson) in small groups. Students will analyze other groups' decisions using a rubric.

ACTIVITY DURATION

Three class sessions
(45 minutes each)

ESSENTIAL QUESTIONS

What are values, morals, and stakeholders, and how do they influence decision-making processes in difficult situations?

How does one come to a justified decision based on an ethical question?

How have conditions improved for human research subjects in the United States?

OBJECTIVES

Students will be able to:

Identify the components of bioethics: stakeholders, morals, values.

Make a justified decision based on facts from the case and the values of all stakeholders.

Understand why the principles of bioethics are used in decision-making processes.

Materials
Computers with Internet Access
Career Profile: Lydia M.Contreras, PhD
Decision-Making Framework Capture Sheet
Ethical Case Study
Values and their Definitions
CRISPR Twins: Bioethical Decision-Making Article
Bioethical Decision-Making Capture Sheet
Example Ethical Justification
Toolkit

Pedagogical Framing

Instructional materials are designed to meet national education and industry standards to focus on in-demand skills needed across the full product development life cycle—from molecule to medicine— which will also expose students and educators to the breadth of education and career pathways across biotechnology.

Through this collection, educators are equipped with strategies to engage students from diverse racial, ethnic, and cultural groups, providing them with quality, equitable, and liberating educational experiences that validate and affirm student identity.

Units are designed to be problem-based and focus on workforce skill development to empower students with the knowledge and tools to be the change in reducing health disparities in communities.

SOCIAL-EMOTIONAL LEARNING

Students have the ability to develop empathy by identifying the values and taking the perspective of stakeholders from various backgrounds, cultures, and contexts. They will have the opportunity to develop compassion for others, understanding historical and social norms in the setting of human research. They will see how scientists, citizens, research participants, and consumers are all necessary in making decisions in research. Students will utilize a scaffolded decision-making process to make caring and constructive choices about personal and societal behaviors across diverse situations. They will evaluate the benefits and consequences of CRISPR research as it affects both individual and collective well-being.

CULTURALLY AND LINGUISTICALLY RESPONSIVE INSTRUCTION

Students will engage with real-world historical examples of human research and the injustices that existed (and still exist) in certain communities; specifically, indigenous groups and people of color. The Belmont Report was written in 1979 as a response to the Tuskegee Syphilis Case. It established guidelines for basic ethical principles, as well as informed consent, the assessment of risks and benefits, and subject selection.

ADVANCING INCLUSIVE RESEARCH

In this lesson, students do a deep dive into bioethical decision making. They are introduced to the Belmont Report, which outlines the basic ethical principles that should underlie the conduct of research involving human subjects. Students are challenged to consider what type of research should and should not be allowed in the context of the Henrietta Lacks case and for embryonic CRISPR research, and which stakeholders' views might be taken into consideration when making these decisions.

COMPUTATIONAL THINKING PRACTICES

In order to make complex ethical decisions, bioethics professionals need to develop tools such as decision-making frameworks. These frameworks utilize the computational thinking strategy of developing algorithms in order to create objective processes.

CONNECTION TO THE PRODUCT LIFE CYCLE

In this lesson, students use an ethical decision-making framework to consider the implications of CRISPR technology around embryonic development. This discussion relates to both the **commercialize** phase of the product life cycle, as government agencies and other bodies are involved with regulating new technology, and to the **develop** phase of the product life cycle when industries are considering the safety and ethics (cost/benefit) of new potential products.

Have you ever wondered…

Just because a new technology, tool, or scientific knowledge emerges, should we use it?

Scientists are often excited about new technologies, but they should always be wary and considerate of how they may be utilized. The scientific community must remain cautious of how new technologies may be used regardless of how they are meant to be implemented by their creators. We continue to improve with the intent to help people, but we also must use bioethical principles to determine if and when these technologies should be implemented.

MAKE CONNECTIONS!

## How does this connect to the larger unit storyline?

Any time new scientific information or techniques emerge, the question of "should we do this?" can be explored. A class in biotechnology is an ideal course to learn the bioethical decision-making process. The previous lesson focuses on CRISPR-Cas9 genome editing as a tool derived from microbes. As much as this tool has tremendous potential, there are difficult questions that need to be answered surrounding its use, especially when thinking about embryonic or germ-line genome editing. Furthermore, the next lesson in this unit will focus on using microbes (*Wolbachia*) to eradicate disease. CRISPR gene drives could also do the same. Bioethics can be explored again in the next lesson, when the ethical question of *"Should we eradicate certain disease-transmitting insects?"* will be explored.

How does this connect to careers?

Bioethicists use narratives and quantitative data to determine whether specific policies or actions are ethical. For example, when there are conflicting values or stakeholder interests with patient care or policy implications, bioethicists help evaluate the situation and provide a recommendation. People from various fields (philosophy, social work, medicine, and law) could fulfill a role on a bioethics committee.

How does this connect to our world?

With new technologies constantly emerging and evolving, scientists need to evaluate not only "if" something can be accomplished, but also "should" research be funded to develop this technology. Also, humans need to make sure technologies are developed and implemented ethically.
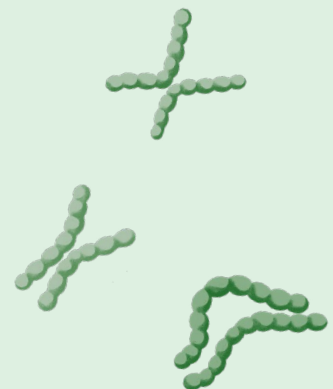
Day 1

Procedure

LEARNING OUTCOMES

Students will be able to:

Outline the four basic principles of bioethical decision making.

INDUSTRY AND CAREER CONNECTION

You may wish to begin this lesson by highlighting the Career Profile: Lydia M. Contreras, PhD, of the University of Texas at Austin. Bioengineering and understanding the regulation of DNA and RNA are at the heart of her research. It is when these novel phenomena are discovered that we are faced with bioethical decisions.

Whole Group (15 minutes)

Teacher Note > *This section was heavily influenced by NWABR's Bioethics 101, especially the first lesson: Introduction to Bioethics. For a deeper understanding of the context, please visit the lesson directly. If time permits, consider using it.*

1. Hand out the *Decision-Making Framework Capture Sheet* to students. Tell students that they will be discussing a difficult hypothetical situation where there is no correct answer. Propose this scenario: *How should one choose who should get access to a lifesaving vaccine when facing imminent infection by a highly contagious, deadly virus?* Give students five minutes to work with a partner to decide which six people they would give the vaccine to, and which four will likely die.

    - Woman who is pregnant
    - Recently orphaned two-year-old
    - Nurse
    - Senior citizen who has 15 grandchildren
    - Recent graduate
    - Doctor
    - Researcher
    - Elementary school teacher
    - Mother who is refusing treatment
    - Owner of a local grocery store

2. Once students have made their decisions, provide the following information:

    - The nurse works at an assisted living facility.
    - The mother refusing treatment is in her 60s.
    - The doctor is a podiatrist.
    - The woman who thinks she is pregnant works a minimum wage job to support her growing family.

    Students may be shocked or want to change their answers after having more information. Emphasize that there are always facts and questions to ask about an ethical situation before a decision could be made (of course, they were only given five minutes).

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Day 1
Continued

Procedure

3   Show students the three Basic Ethical Principles of the *Belmont Report* (Respect for Persons, Maximizing Benefit/Minimizing Harm, and Justice). A graphic or shortened version may be more appropriate. Students should form one-sentence summaries of each principle and add it to the graphic on their *Decision-Making Framework Capture Sheet*. After students have written their definitions, show them the following to help them understand how they made their choices. These are not exhaustive, but will help students understand the principles they used to make their choices.

    a.   Save the Youngest: Maximize benefits/Minimize harm

    b.   Draw Straws: Justice

    c.   Save the Weakest: Respect for Persons

    d.   Save the Most Useful: Maximize benefits/Minimize harm

    e.   Respect Relationships: Respect for Persons

4   Tell students that this was meant to be an exercise that was difficult and did not have any correct answers. Ethics is the study of the human basis for moral behavior, and bioethics is the study of how best to use new scientific knowledge (policymaking regarding medical treatments, applications in life sciences, etc.) when there are conflicting or difficult choices to be made. **Bioethicists** use narratives and quantitative data to determine whether specific policies or actions are ethical.

5   Tell students that there is a decision-making framework that can help to make decisions when people have conflicting morals and values. Explain that they will use this framework to understand what morals and values are, and how they shape decision making. Remind students that there is no correct answer when making an ethical decision and all students' opinions should be respected.
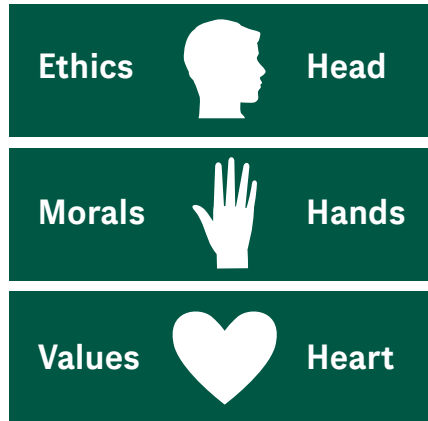
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Day 1
Continued

Procedure

6   Post the following image on the board as the case study is explored.

- **Ethics** is represented by the head. Ethics rely on **reasoned judgment**, and provide a systematic, rational way to determine the best course of action in the face of conflicting choices.
- **Morals** are represented by the hands. They are demonstrated by our **behavior**. They signify how values are "put into practice" as actions.
- **Values** are represented by the heart. They signify what is **important**, meaningful, and true for each of us.

COMPUTATIONAL THINKING IN ACTION

By developing a decision-making framework, students are using the computational thinking strategy of developing algorithms to outline a process for making complicated ethical decisions.

Small Group (15 minutes)

1   Hand out the *Ethical Case Study*. As a group, select one of the historical case studies from *NWABR's Humans in Research* (Henrietta Lacks and HeLa Cells, The Havasupai Indians, The Tuskegee Syphilis Study, or The Willowbrook Study, found on page 27 to 30 of the *downloadable curriculum*). Have all students read the case study, or read it as a group.

2   As a group, ask students to come up with a bioethical question that begins with the word SHOULD. For example, students might say, *"Should Henrietta Lacks' children be compensated for their mother's cells being used without her permission?"* Or *"Should something be done to ensure that something like that does not happen again?"*

3   Ask the class who they think would be affected by or care about this decision being made? Tell them that such people are called stakeholders. Have students work in their groups to come up with as many stakeholders as possible.

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Day 1
Continued

Procedure

Whole Group (20 minutes)

1 As a whole-class discussion, work through the charts in the *Ethical Case Study*. Have one student volunteer to be a "scribe" and write the class' answers on the board. (Students will be completing one of these as a small group later in the lesson, so modeling as a whole group first will prepare them.) Point out the atrocities of each case, and that the Belmont Report was written as a response to the Tuskegee Syphilis Case in order to protect humans and their rights in regards to scientific research. Make sure to point out that this was not that long ago, being written in 1979.

2 Ask students to look at a list of values in *Values and their Definitions* and identify a few that may be important to each stakeholder on the board. Tell students that it may be easy to think of values as what we hold in our "hearts." These values direct our actions and behaviors, and this combination is called our morals (represented by the hand). Bioethics helps us make decisions when there are conflicting morals and values amongst stakeholders, to come to a "best" decision (ethics are represented by the head—where decisions are made).

3 Ask students to divide into small groups and choose a stakeholder to represent. Students will identify how their stakeholder would answer the bioethical question the class generated.

4 Have students volunteer to share their responses to the bioethical question.

Homework/Extension

As possible homework, ask students to consider how best to answer the bioethical question to focus on satisfying all stakeholders. They do not need to complete all parts of the chart, as they will be doing so later in the lesson, but should consider how they might approach it. Remind them that there can be some grey area in coming up with their answers, it does not need to simply be "yes or no." The best answers are those that fall in the grey area, as they might satisfy the most stakeholders.

Day 2

LEARNING OUTCOMES

Students will be able to:

Identify and **represent** a stakeholder in an ethical situation.

Make a bioethical decision that represents the values of a single stakeholder.

Procedure

Whole Group (10 minutes)

1. Review with students the main concepts from Day 1 by having them work with a partner to define the important terms, including *stakeholders, morals, values, ethics, three bioethical principles*, noting that they now apply these principles to a case involving genetically altering embryos.

2. Post a continuum on the board from "STRONGLY DISAGREE to STRONGLY AGREE." (Alternatively, students can copy this down or it can be in a Slide Deck.) Then, post the question on the board or on a slide in Google Slides or Pear Deck: *Should embryonic genetic editing be allowed?* Ask students to place a mark on their continuum where they identify best prior to this activity. Inform them that they will look back on placement after reading a case study to see if they have changed their mind or think their placement should be the same.

Strongly agree	Agree	Neutral	Disagree	Strongly disagree
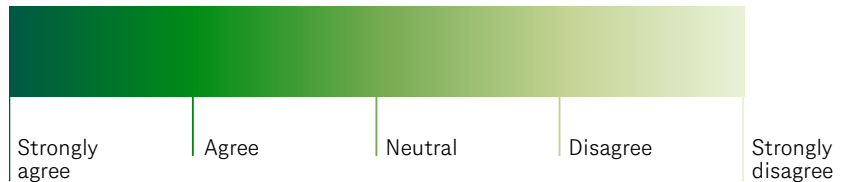
Individual Work (15 minutes)

Give students time to read the *CRISPR Twins: Bioethics Article*. It may be helpful to define the ethical considerations that students could choose to focus on in this article. If so, this would be a good time to do that.

Small Group (15 minutes)

Give students the *Bioethical Decision-Making Capture Sheet*. In groups of four, tell students to analyze the CRISPR Twins case. Have students first choose an ethical consideration on which they will focus, and then define the question, list facts, and identify questions they still have about the case. Once stakeholders are identified, assign each student in the group a stakeholder to represent. Stakeholders will share their positions in the next class meeting so that groups can come to a justified overall decision.

Day 3

LEARNING OUTCOMES

Students will be able to:

Make a bioethical decision that represents the values of all stakeholders.

Procedure

Small Group (30 minutes)

1. Inform students that they will be sharing their stakeholder's values and what their stakeholder's decision would be at the start of class.

2. Ask each group to discuss a justified decision that best represents all stakeholders involved. Students in each group will also record their personal decisions (not as stakeholders), and indicate if they are in agreement with the group's decision, explaining their reasoning. Students may review the *Example Ethical Justification* to see an answer to the question *Should school start one hour later?*

3. Have student groups exchange their *Bioethical Decision-Making Capture Sheet* with another group, and grade each other's strong justifications based on *NWABR's Bioethics 101* Scoring Rubric (found on page 71 and 72 of the *downloadable curriculum*). Whole groups should grade together, with the following roles: reader, recorder, manager, and reporter (reader reads the justification, recorder circles the grade on the rubric, manager makes sure the group is working in a timely manner and everyone's voice is being heard, and reporter communicates with the other group why they were given the grade they were).

4. Tell students to revisit the continuum board from Day 2 and reevaluate their decisions. Discuss with students why they chose to move their decision or to keep it in the original position.

Whole Group (10 min)

Invite students to answer the Lesson 6 questions relating to CRISPR and bioethics, on their **Toolkit**. Give students an opportunity to read the scientist profile on *Lydia Contreras* if they have not already, focusing on what she does in her field and what might be most relatable or what resonates most with the students. They should log their thoughts in the **Toolkit**: *Based on the career profile in this lesson, what does this tell you about the types of people who do science? What did you find most relatable?* If time permits, you may ask students to share their thoughts.

Teacher Note > *As an optional extension, allow students to research or read about the moratorium on CRISPR embryonic research and how the NIH and other entities will not fund this type of research in the United States. A deeper dive into what and who is on an Institutional Review Board (IRB) or the Belmont Report could also be done.*

National Standards

Next Generation Science Standards	**ESS3-2 Earth and Human Activity** Evaluate competing design solutions for developing, managing, and utilizing energy and mineral resources based on cost-benefit ratios.
	LS3-3 Heredity: Inheritance and Variation of Traits Apply concepts of statistics and probability to explain the variation and distribution of expressed traits in a population.
	Science and Engineering Practices Engaging in argument from evidence Compare and evaluate competing arguments or design solutions in light of currently accepted explanations, new evidence, limitations (e.g., trade-offs), constraints, and ethical issues.
Career and Technical Education (CTE)	**A2.0** Understand the ethical, moral, legal, and cultural issues related to the use of biotechnology research and product development. Know the relationship between morality and ethics in the development of biotechnology health care products.
	A2.1 Know the relationship between morality and ethics in the development of biotechnology health care products.
	A2.2 Know the difference between personal, professional, and organizational ethics.
	A2.3 Understand the necessity for accurate documentation and record keeping.
	A2.4 Understand the critical need for ethical policies and procedures for institutions engaged in biotechnology research and product development.
	A2.5 Describe the dilemma of health care costs related to advancements in biotechnology and public access to treatments.

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National Standards

CTE
Continued

A2.6
Prepare a presentation comparing the benefits and harm that can be the result of biotechnology innovations in both the research and application phases and which course of action will result in the best outcomes.

4.1
Use electronic reference materials to gather information and produce products and services.

4.3
Use information and communication technologies to synthesize, summarize, compare, and contrast information from multiple sources.

5.6
Read, interpret, and extract information from documents.

7.4
Practice time management and efficiency to fulfill responsibilities.

7.8
Explore issues of global significance and document the impact on the Health Science and Medical Technology sector.

Decision-Making Framework Capture Sheet

Directions
As a group, discuss the following difficult hypothetical scenario. There is no correct answer.

1. How should one choose who should get access to a lifesaving vaccine when facing imminent infection by a highly transmissible, deadly virus?

   Vaccine supply is low. There are only enough to treat six of every ten people. With a partner, decide which six people you would give the vaccine to, and which four will likely die. You have five minutes to make this decision.

Answers will vary.

Who receives the vaccine?

	Description of the Person	Yes	No
1	Woman who is pregnant	☐	☐
2	Recently orphaned two-year old	☐	☐
3	Nurse	☐	☐
4	Senior citizen who has 15 grandchildren	☐	☐
5	Recent graduate	☐	☐
6	Doctor	☐	☐
7	Researcher	☐	☐
8	Elementary school teacher	☐	☐
9	Owner of a local grocery store	☐	☐
10	Mother who is refusing treatment	☐	☐

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Decision-Making Framework Capture Sheet

Continued

2. After reviewing the *Belmont Report*, summarize the three
    principles of bioethics below. Place the name of the
    principle in the first column, and a one-sentence summary
    of what it means in the column next to it.

	Bioethics Principle	Summary of the Principle
1	Respect for Persons	Emphasizes the rights of a person to self-determine, acknowledges a person's right to make a choice based on personal values and beliefs. Values the autonomy of individuals.
2	— Maximize Benefit — Minimize Harm	Do good/do no harm. Requires positive action to directly benefit others, it obligates others to avoid inflicting harm intentionally. Relates to the Hippocratic Oath of physicians to "do no harm."
3	Justice	Giving to each that which is due (Aristotle) or fairness/equal treatment. Resources, risk, cost should be distributed equally.

Ethical Case Study

A N S W E R K E Y   **Do not share with students**

Directions

*As your group or class works through the bioethical case,
fill in the information below to help you reach a justified
decision to answer the bioethical question.*

1. Complete this table as a group.

Bioethical Case Title	Answers will vary. Example: Responsibility for Vaccines	
Bioethical Question Come up with a question about your group's case study that begins with the word SHOULD.	Example: Should the government be morally responsible for prioritizing which citizens are vaccinated?	
Stakeholders	List four people who would be affected by or care about this decision being made.	List at least one value important to each stakeholder.
	19-year-old girl	Answers will vary.
	63-year-old man	Answers will vary.
	Government officials	Answers will vary.
	People who can afford the vaccine	Answers will vary.
	People who cannot afford the vaccine	Answers will vary.
	Doctors	Answers will vary.
As a group, list one stakeholder to represent.	Answers will vary.	
As a group, identify how that person would answer the bioethical question you wrote.	Answers will vary.	

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Ethical Case Study

Continued

2. After hearing the answers from other group's selected
    stakeholders, work as a group to come up with one answer
    that meets the needs of as many stakeholders as possible.

Answers will vary, but should include aspects of all
components. See the *Example Ethical Justification*
for a completed example.

A strong justification includes...	Which means...	Your answer
A Decision	A position relating to the ethical question that is clearly stated.	
Facts	Science facts that can be used as evidence to support your claim.	
Ethical Considerations	Respect for persons Maximize benefits Minimize harm Justice and fairness	
Stakeholder Views	The views and interests of people that are affected by the decision or outcome.	
Alternative Options and Rebuttals	Strengths and weaknesses of all decisions that could be made, understanding that no decision will please all parties.	
Reasoning and Logic	A logical explanation connecting the evidence back to the claim.	

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Career Profile

*Associate Professor
of Chemical Engineering*

Lydia M. Contreras, PhD
*The University
of Texas at Austin*

What is your current role, and how did you get there?

I was born in the Dominican Republic, so my first language is Spanish. I moved to New York City at about 11 years old, and learned that people would think of me as an Afro-Latina. When I was young I really liked science, so people told me I should be a doctor. But I really liked to create and build things so I was blessed to have people encourage me to go into engineering, even though it is a male-dominated industry. Actually, when I heard I wouldn't have to wear dresses all the time, and that it was a profession to wear a hard hat and get dirty (my perception of engineering as a child), I got even more excited about it!

When I was an undergrad student, I got involved in doing research with one of my professors. Biomedical engineering appealed to me because I wanted to help people. I was able to see how biotechnology can translate fundamental science into real products to solve a need. And the idea of being the first person in the world to figure out the answer to a question was so exciting. Growing up, becoming a professor was a pretty illusive idea for me. I never had a Latina or Black professor. In fact, I only had three women in science that I interacted with: my postdoc advisor, who was amazing, and two professors, one at Princeton and one at Cornell. So that research experience in college really impacted me.

My current lab studies the chemistry of biological materials like DNA and RNA to understand how they are regulated, with the ultimate goal of learning how the environment impacts health.

If you could advise your younger self, what would it be?

I have always loved music and Salsa dancing has always been my escape. My advice would be to create and seek out those positive moments that you enjoy to help you get through the tough times.

What skills do you use on a daily basis?

Clear and concise written and verbal communication—I write clearly to communicate new ideas and help others understand the importance and value of what we do. This includes oral presentations, writing, creating clear and helpful figures to help others see what I see, etc.

Ability to bounce back and learn from failures—good science is about risk taking to explore the most exciting ideas and things don't always work. There are a lot of failures in my work. Learning quickly from mistakes and not letting them compromise the excitement of moving forward is key.

What's most fulfilling about your job/ career?

Learning something new every day is extremely fulfilling, especially when at times it could be that my research team might be the only one in the world to understand a given phenomenon—that is very exciting!

What was your favorite subject in high school, and why did you love it?

I loved chemistry in High School. It was fascinating to learn about the properties of molecules and understand how those properties relate to the reactions that the molecules can most likely undergo.

What's a social cause you care about?

Equal access to clean environmental resources (water, air, etc).

If you could learn any language, which would you choose and why?

Sign language, to be truly inclusive of everyone in a room.

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Decision-Making Framework Capture Sheet

Directions
As a group, discuss the following difficult hypothetical scenario. There is no correct answer.

1. How should one choose who should get access to a lifesaving vaccine when facing imminent infection by a highly transmissible, deadly virus?

    Vaccine supply is low. There are only enough to treat six of every ten people. With a partner, decide which six people you would give the vaccine to, and which four will likely die. You have five minutes to make this decision.

	Who receives the vaccine?		
	Description of the Person	Yes	No
1	Woman who is pregnant	☐	☐
2	Recently orphaned two-year old	☐	☐
3	Nurse	☐	☐
4	Senior citizen who has 15 grandchildren	☐	☐
5	Recent graduate	☐	☐
6	Doctor	☐	☐
7	Researcher	☐	☐
8	Elementary school teacher	☐	☐
9	Owner of a local grocery store	☐	☐
10	Mother who is refusing treatment	☐	☐

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Decision-Making Framework Capture Sheet

Continued

2. After reviewing the *Belmont Report*, summarize the three
   principles of bioethics below. Place the name of the
   principle in the first column, and a one-sentence summary
   of what it means in the column next to it.

	Bioethics Principle	Summary of the Principle
1		
2		
3		

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Ethical Case Study

Directions
As your group or class works through the bioethical case, fill in the information below to help you reach a justified decision to answer the bioethical question.

1. Complete this table as a group.

Bioethical Case Title		
Bioethical Question Come up with a question about your group's case study that begins with the word SHOULD.		
Stakeholders	List four people who would be affected by or care about this decision being made.	List at least one value important to each stakeholder.
As a group, list one stakeholder to represent.		
As a group, identify how that person would answer the bioethical question you wrote.		

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Ethical Case Study

Continued

2. After hearing the answers from other group's selected stakeholders, work as a group to come up with one answer that meets the needs of as many stakeholders as possible.

A strong justification includes...	Which means...	Your answer
A Decision	A position relating to the ethical question that is clearly stated.	
Facts	Science facts that can be used as evidence to support your claim.	
Ethical Considerations	Respect for persons Maximize benefits Minimize harm Justice and fairness	
Stakeholder Views	The views and interests of people that are affected by the decision or outcome.	
Alternative Options and Rebuttals	Strengths and weaknesses of all decisions that could be made, understanding that no decision will please all parties.	
Reasoning and Logic	A logical explanation connecting the evidence back to the claim.	

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Values and their Definitions

Directions
Use this list of values and their definitions to complete the
Bioethical Decision-Making Capture Sheet.

Value	Definition
Accomplishment	Completing a task successfully
Allegiance	Loyalty to a person, group, or cause
Altruism	Selfless concern for the well-being of others
Beauty	Aesthetically pleasing
Benevolence	The quality of doing good to others
Charity	Voluntarily giving help to those in need
Collaboration	Working with someone to produce or create something
Compassion	A feeling of sympathy for another accompanied by a desire to alleviate their misfortune
Competition	A rivalry between two or more people for an object desired in common
Conscientiousness	Done according to one's inner sense of what is right
Cooperation	Working together for a common purpose
Courtesy	Excellence of manners; polite behavior
Diligence	Persistence to accomplish what is undertaken
Diversity	The state or fact of being different or having unique characteristics
Duty	Something that one is expected to do by moral or legal obligation
Education	Imparting general knowledge
Equity	The quality of being fair or impartial
Generosity	Willingness and desire to give
Honesty	Truthfulness, sincerity, or frankness
Honor	Honesty, fairness, or integrity in one's beliefs and actions

Value	Definition
Independence	Freedom from the control or influence of others
Knowledge	Facts, information and skills; the understanding of a concept
Lawfulness	Acting or living according to the law
Leadership	A person who guides or directs a group
Moderation	Avoidance of extremes or excesses
Practicality	Being adapted or designed for actual use
Productivity	Being able to generate, create or enhance
Reconciliation	The action of making one view or belief compatible with another
Resourcefulness	Able to deal skillfully and promptly with new situations
Sacrifice	To surrender or give up for the sake of something else
Safety	Not causing injury, danger, or loss
Self-Control	Control or restraint of one's actions or feelings
Service	An act of helpful activity; help; aid
Status	The social or professional position of an individual in relation to others
Technology	The creation and technical means and their application
Tolerance	The acceptance of one whose beliefs differ from one's own
Tradition	A long-established custom or belief passed on from previous generations
Truth	A certified or indisputable fact, proposition, principle, or the like
Wisdom	Scholarly knowledge or learning

Sources: *Definitions Of The 125 Values Accountability/Ethics Achievement Adaptability/Flexibility Administration/Control Affection Art/Be*; *Bioethics 101 Reasoning and Justification*

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CRISPR TWINS: Bioethical Decision-Making Article

Directions

After reading this article, answer the question on the
Bioethical Decision-Making Capture Sheet.

In October 2018, a team of researchers led by He Jiankui of the Southern University of Science and Technology in Shenzen, China used the gene editing tool CRISPR to alter the genome of twin girls in an effort to make them immune to HIV infection. The researchers used CRISPR to delete the CCR5 gene from human embryos, which has been shown to be required for HIV to enter blood cells during infection. The CCR5 gene encodes a cell surface receptor on white blood cells. The embryos were edited in vitro, or outside of a living organism, and implanted into the mother and carried to term. The twin's father is HIV positive, and while HIV transmission from father to child occurs seldomly, gene editing provides a new strategy for HIV prevention.

New research has shown that deletion of the CCR5 gene may improve mental cognition and brain recovery after stroke based on studies conducted in mice. Published in 2016 in Elife, Zhou et al. found removing the CCR5 gene from mice significantly improved memory. Another study by Joy et al. (2019) in *Cell* found that people who lack CCR5 recover quicker following stroke and may be correlated to improved performance in school. While the study highlights a unique role of CCR5 in human cognition, UCLA biologist and leader of the study, S. Thomas Carmichael, asserts that further studies are needed to validate their findings. Scientists believe that the CRISPR mutations will impact the twins' cognitive function, but it's impossible to predict the magnitude of their effects since prior research has never been conducted in humans; a far more complicated organism than a mouse.

Dr. He has since been fired by the Southern University of Science and Technology and is under investigation in China. Dr. He's experiment has been widely condemned by scientists and policymakers worldwide. It has sparked a discussion to define the much-needed ethics of gene editing in humans

that cannot be left to a single entity to decide. While the issue is largely concerned with research ethics, many believe the issue is rather one of self-governance and the decision to perform research without public consideration. Without public discourse, scientists control the circumstances under which they can genetically engineer humans, but the discussion must include where, how, and when the first genetic modifications in humans should take place. Other considerations must include whether it is acceptable to genetically engineer children by introducing heritable changes to their genome that they can pass on to their own offspring. Many of these questions cannot solely be answered by scientists but must include all of humanity.

Ethical considerations for gene editing must include safety, informed consent, justice and equality, and gene-editing research using human embryos. Safety must be considered because of off-target effects, in which some cells contain a mutation that was unintended or mutations are unequally carried amongst all cells. Until researchers and ethicists can prove gene editing to be safe without off-target effects, it should not be used for clinical research purposes. Many researchers are concerned that gene editing for therapeutic purposes will inevitably create opportunities for non-therapeutic and enhancement purposes. Additionally, regulations for gene editing internationally must be standardized among different countries before it is widely accepted. Obtaining informed consent is nearly impossible because the patients affected are embryos and future generations. In terms of equality, many fear that gene editing will only be accessible to wealthy populations thereby increasing disparities in health care. In addition to people's moral and religious objections, creating circumstances in which researchers can conduct research on embryos proves to be a major barrier.

Sources:
Brain Enhancement
Self Governance
Ask Whether, Not How
Ethical Concerns
Why Did the Parents Consent?
Bioethics for the Gene Editing Age

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Bioethical Decision-Making Capture Sheet

Directions
After reading the Gene-Editing Twins: CRISPR Bioethical Analysis Article, complete this activity as a group.

1. First, decide which ethical consideration from the list below you want to address. (If your group decides on one not listed below, please check with your teacher before proceeding.)

Human Research Integrity and Consent	Patient Welfare
Any Use of CRISPR-Cas9	Public Safety
Regulatory Integrity	Edited Gene Choice
Timing Of Deployment (Use of New Technology Despite the Unknown)	Germ-Line Human Genetic Modifications
Distributive Justice and the Cost of Medical Care	The Bystander Effect

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Bioethical Decision-Making Capture Sheet

Continued

2. As a group, complete the table.

a	Ethical Consideration Topic			
b	Ethical Question			
c	Facts	What is known?		What is unknown?
d	Stakeholders			☐
				☐
				☐
				☐

3. As a group, decide which stakeholder each member will represent. Remember, you do not need to agree with the stakeholder to represent that person's values and voice his or her position. Mark the stakeholder you will represent in the checkbox to the right.

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Bioethical Decision-Making Capture Sheet

Continued

4. As an individual, list at least three values your stakeholder might bring to the issue and at least two positions that the particular stakeholder might take. Refer to *Values and their Definitions*.

Values	Positions

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Bioethical Decision-Making Capture Sheet

Continued

5. As a group, each person should share the stakeholder's values and positions they came up with. Then, agree upon the best decision to answer the ethical question you posed. As an individual, write your own version group's of the justified decision. Read the *Example Ethical Justification* as a model for your answer.

A strong justification includes…	Which means…	Your answer
A Decision	A position relating to the ethical question that is clearly stated.	
Facts	Science facts that can be used as evidence to support your claim.	
Ethical Considerations	Respect for persons Maximize benefits Minimize harm Justice and fairness	
Stakeholder Views	The views and interests of people that are affected by the decision or outcome.	
Alternative Options and Rebuttals	Strengths and weaknesses of all decisions that could be made, understanding that no decision will please all parties.	
Reasoning and Logic	A logical explanation connecting the evidence back to the claim.	

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Bioethical Decision-Making Capture Sheet

Continued

6. Do you (personally, not as the role of a stakeholder) agree with the group's justified decision? Why or why not?

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Example Ethical Justification

Directions

Use this example of a justification as a model to how you answer your ethical question in the Bioethical Decision-Making Capture Sheet.

A strong justification includes…	Which means…	An example to the question "Should school start one hour later?"
A Decision	A position relating to the ethical question that is clearly stated.	*School should start one hour later than it currently does.*
Facts	Science facts that can be used as evidence to support your claim.	*A recent poll conducted by the National Sleep Foundation found that 60% of children under the age of 18 complained of being tired during the day, according to their parents, and 15% said they fell asleep at school during the year.*
Ethical Considerations	Respect for persons Maximize benefits Minimize harm Justice and fairness	*This stands on the foundation of maximizing benefit and minimizing harm.*
Stakeholder Views	The views and interests of people that are affected by the decision or outcome.	*Students want and need to sleep more.* *Parents want their kids in school so they can get to work.* *Teachers want students to arrive at the time they will best learn.*
Alternative Options and Rebuttals	Strengths and weaknesses of all decisions that could be made, understanding that no decision will please all parties.	*If school were to start later, extracurriculars would run later into the evening, delaying dinner with families, or eliminating potential job opportunities, or time for homework.*
Reasoning and Logic	A logical explanation connecting the evidence back to the claim.	*Since scientific evidence suggests students learn better when well rested, most stakeholders will be pleased if school starts later.*