Weighing Benefits and Harms: Ethical Issues in Genetic Testing

Four Key Questions to Always Ask Yourself

- What is the ethical question?
- What are the relevant facts?
- Who or what could be affected by the way the question gets resolved?
- What are the relevant ethical considerations?

Ethical Considerations Relevant to This Module*

Respect for Persons

- How can genetic tests be done in a way that is respectful of the individual being tested?
- Under what circumstances should the results of a genetic test be shared with others? Under what circumstances should the results of a genetic test be kept confidential?

Harms and Benefits

- What harms and benefits do genetic tests bring to the individual being tested and his or her family members?

Fairness

- Should all people have equal access to genetic tests?
- Should all people have equal access to the appropriate medical interventions to manage the results of genetic tests?

*Bold items are emphasized in this module.
Issues Explored

- What are the potential harms and benefits of getting genetically tested?
- Who should get to decide whether an adolescent will get genetically tested?
- How do factors such as age at disease onset, the predictive value of the test, and whether there is effective medical therapy for the condition affect how much decision-making power an adolescent should have for a genetic test?
- How can genetic testing be done so that the confidentiality of an individual’s personal medical information is protected?

At a Glance

Purpose and Rationale

As scientists discover more and more about human genetics, individuals and their family members will have more opportunities to have genetic testing. It is critical that everyone involved understand the difference between inherited and somatic genetic mutations and be able to successfully interpret the meaning of mutations deemed to be genetic risk factors. Because genetic testing has the potential to bring benefits and harms, patients, families, and policy makers will face difficult choices about how and when to get tested and how to use the results.

Overview

In Module 4, students use a range of examples and case studies involving genetic tests. These examples and case studies serve to help students understand the range of available genetic tests, as well as grapple with how best to respect persons while simultaneously minimizing harms and maximizing benefits. How do diseases like Alzheimer’s disease and particular cancers compare with one another, and what information can (or cannot) be learned from associated genetic tests? Is more information always desirable, or better? Who should decide whether a person should have a genetic test? Should a teenager be forced to have a genetic test whose results he or she doesn’t want, even if they could pave the way for preventive treatment?

Over the course of much of this module, students explore a case in which there is a conflict between a father and his adolescent son over whether the son should be tested for a particular genetic mutation. If a person has the mutation, the chance is 100 percent that he or she will develop a form of thyroid cancer that will be fatal if left untreated. This form of thyroid cancer arises during a person’s adolescence, 20s, or 30s. Students attempt to understand how the father and the son might think about this choice. Ultimately, each student must state and justify who the final decision maker should be.
An optional extension activity includes a case in which an employer wants to use a genetic test to screen out potential applicants, and students must determine whether the employer’s actions are ethically appropriate.

**Learning Objectives**

Students will

- recognize that while genetic tests can bring benefits, they also pose potential harms for the individual getting tested and for family members;
- understand that genetic testing involves a broad range of potential benefits and harms—including physical, psychological, social, and economic;
- recognize that respect for a person’s ability to make his or her own decisions will affect who has a genetic test as well as who gains access to the results of that test; and
- understand that decision making about genetic tests varies according to factors such as age at disease onset, the predictive value of the tests, and whether anything effective can be done for the condition.

**Major Concepts**

Through engagement with two distinctly different cases, students learn that there are many factors to consider when faced with the option to get genetically tested, including the following:

- The predictive value of the test. Some tests can demonstrate an increased risk for a disease that may never materialize (as in the Alzheimer’s case), while others are fully predictive of a future disease (as in the case of the thyroid cancer associated with multiple endocrine neoplasia type 2 [MEN II]).
- Whether there is effective therapy or another intervention for the condition. In some cases, a genetic test reveals the inevitability or risk of a disease for which there is currently no helpful medical or lifestyle intervention (such as Alzheimer’s disease), while in other cases, there are clearly helpful and even completely preventive interventions (such as for MEN II).
- The age of disease onset. While Alzheimer’s disease arises later in life, MEN II can arise during adolescence. Students also come to see that inherited mutations (as opposed to somatic mutations) mean that one person’s test result will likely be relevant to other family members.

**Assessment Outcome**

Students apply relevant facts and ethical considerations to a third case, about a genetic test for a particular type of colon cancer. Students use what they have learned from the earlier case studies to write well-justified statements about how much control an adolescent should have over decision making for this genetic test and who should learn of any newly discovered genetic information.
Key Science Knowledge*

- Alzheimer’s disease
- Cancer biology
- DNA: structure and mutations
- Genetic testing: predictive vs. diagnostic
- Mendelian genetics: recessive vs. dominant
- Mutations: inherited vs. somatic
- Pedigree interpretation
- Relationship among genes, proteins, and traits

*Bold items are explicitly addressed in this module.

Teaching Sequence Preview

Day 1—Deciding to Know or Not to Know: This day focuses on two key questions: What is the ethical question? and What are the relevant facts? The day begins with exercises aimed at helping students realize that more information is not always better. In one, students must decide whether they want to learn the results of a hypothetical genetic test for their risk of developing Alzheimer’s disease. Next, students are introduced to a case involving a conflict between an adolescent boy, Max, and his father over a genetic test. Should Max be tested for a gene mutation that is 100-percent predictive of a type of thyroid cancer that is fatal if left untreated? Students air their preliminary views about who should get to make this decision and gather relevant scientific information. They learn that diseases and genetic tests vary according to factors such as age at disease onset, the predictive value of the test, and whether there is anything effective that can be done for the condition.

Day 2—Identifying Stakeholders and Taking Two Key Ethical Considerations into Account: Students complete their discussion of the scientific facts and concepts relevant to Max’s case, and then address another of this supplement’s four key questions: Who or what will be affected by how this situation is resolved? By reviewing and applying their understanding of Mendelian genetics and patterns of inheritance, students realize that Max’s genetic-testing result could have a ripple effect on his entire biological family. Next, they begin to address the key question, What are the relevant ethical considerations? Students identify potential harms and benefits (physical, psychological, social, and economic) associated with Max taking the test.

Day 3—What Is Your Recommendation?: Each student makes and justifies recommendations for the Max case, stating who should decide whether Max is genetically tested and why. Next, assuming for argument’s sake that Max takes the test and the results are positive, students must decide who (besides Max and his father) should have access to the results. Throughout, students must consider how to minimize harm, maximize benefit, and best protect the confidentiality of an individual’s genetic information while respecting the individual’s right to decide.
Preparing the Envelopes for Day 1, Activity 1

For Day 1, each student will need a sealed envelope labeled “Medical Records: Alzheimer’s Test Result.” Inside each envelope should be a slip of paper with his or her hypothetical test result—telling the student which two of the alleles linked to Alzheimer’s disease (E2, E3, and E4) he or she has. To approximate the human population as a whole, prepare the envelopes in the following ratio (numbers can be modified according to the total number of students; numbers below add up to up 50 total envelopes):

<table>
<thead>
<tr>
<th>Number of envelopes</th>
<th>What the slip of paper should say</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>E2/E2</td>
</tr>
<tr>
<td>7</td>
<td>E2/E3</td>
</tr>
<tr>
<td>28</td>
<td>E3/E3</td>
</tr>
<tr>
<td>1</td>
<td>E2/E4</td>
</tr>
<tr>
<td>12</td>
<td>E3/E4</td>
</tr>
<tr>
<td>1</td>
<td>E4/E4</td>
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</tbody>
</table>


Copies, Equipment, and Materials

<table>
<thead>
<tr>
<th>Activity</th>
<th>Photocopies and Transparencies</th>
<th>Equipment and Materials</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Day 1</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>• 1 transparency each of Masters 4.1 (optional) and 4.2 for the class</td>
<td>1 overhead projector, 1 sheet poster paper, 1 marker for teacher use</td>
</tr>
<tr>
<td></td>
<td>• 1 copy of Master 4.2 for each student</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 1 sealed envelope (marked “Medical Records: Alzheimer's Test Result”) for each student</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>1 transparency of Master 4.3 for the class</td>
<td>1 overhead projector, 1 sheet poster paper, 1 marker for teacher use</td>
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<tr>
<td>3</td>
<td>• 1 transparency of Master 4.4 for the class</td>
<td>1 overhead projector, 1 sheet poster paper, 1 marker for teacher use</td>
</tr>
<tr>
<td></td>
<td>• 1 copy each of Masters 4.4, 4.5, and 4.6 for each student</td>
<td></td>
</tr>
<tr>
<td><strong>Day 2</strong></td>
<td></td>
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<tr>
<td>4</td>
<td>1 transparency of Master 4.6 (optional) for the class</td>
<td>1 overhead projector (optional) for teacher use</td>
</tr>
<tr>
<td>5</td>
<td>• 1 transparency each of Masters 4.3 and 4.7 for the class</td>
<td>1 overhead projector for teacher use</td>
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<tr>
<td></td>
<td>• 1 copy each of Masters 4.3 and 4.7 for each student</td>
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<tr>
<td>6</td>
<td>• 1 transparency of Master 4.8 for the class</td>
<td>1 overhead projector for teacher use</td>
</tr>
<tr>
<td></td>
<td>• 1 copy each of Masters 4.8 and 4.9 for each student</td>
<td></td>
</tr>
</tbody>
</table>
Activity | Photocopies and Transparencies | Equipment and Materials
--- | --- | ---
Day 3 | | |
7 | — | • 6 small stickers for each student
• 3 sheets poster paper and masking tape for the class

8 | — | At least 6 sheets poster paper, 6 red markers, 6 green markers, masking tape for the class

Reflection | — | • Posters from Day 1 and masking tape for the class
• 1 marker for teacher use

Final Assessment | 1 copy of Master 4.10 for each student | —

Extensions (optional) | 1 copy of Master 4.11 for each student | —

Masters

Master 4.1: Should I Tell Chantal?
Master 4.2: Alzheimer's Disease and Genetic Testing—Relevant Facts
Master 4.3: Max's Case—Thyroid Cancer, MEN II, and Genetic Testing
Master 4.4: Thyroid Cancer, MEN II, and Genetic Testing—Relevant Facts
Master 4.5: Genetic Testing—Key Concepts
Master 4.6: Thyroid Cancer, MEN II, and Genetic Testing—Checking for Understanding
Master 4.7: What Impact Would Max's Newly Discovered Mutation Have on Him and Others?
Master 4.8: Thyroid Cancer and Genetic Testing—Harms and Benefits
Master 4.9: Your Tentative Thoughts
Master 4.10: Camilla's Case—Colon Cancer and Genetic Testing
Master 4.11: Extension (Optional)—About Retinitis Pigmentosa

Teacher Support Materials*

Master 4.3 Answer Key
Master 4.6 Answer Key
Master 4.7 Answer Key
Master 4.8 Answer Key
Who Should Decide Whether Max Gets Tested?
Who Should Have Access to the Results?
Supplementary Information on Alzheimer's Disease and MEN II
Supplementary Information on HNPCC
Comparison of Alzheimer's Disease, MEN II, and HNPCC
Evaluative Criteria for the Final Assessment
Extension (Optional): Should Employers Have Access to Genetic Test Results?

*Available only online at http://science.education.nih.gov/supplements/bioethics/teacher.
Teaching Sequence

DAY 1: Deciding to Know or Not to Know

Purpose

The purpose of Day 1 is to demonstrate that genetic knowledge can bring benefits but can also pose harms and that reasonable people can disagree about whether they would want such knowledge. During the activities, students come to realize that the availability of such tests raises questions about who should have decision-making authority, especially when the person considering testing is an adolescent. They address two of this supplement’s four key questions and gain an understanding that diseases and genetic tests vary according to several key factors: age at disease onset, the predictive value of the test, and whether there is anything effective that can be done for the condition.

Activity 1:

Estimated Time: 20–25 minutes

Procedure

Introductory Movie Analogy (Optional)

Estimated Time: 5 minutes

1. Using an overhead projector, display Part I of the transparency of Master 4.1: Should I Tell Chantal? Read Part I to students, and keep other parts hidden until you are ready to move on.

This analogy asks students to consider whether they should tell a friend about the ending of a movie. Through this discussion, students will think about whether more information is better and when it is appropriate and inappropriate to share information. These same concepts arise when considering genetic testing.

2. Show and read Part II of Master 4.1, and listen to students’ questions.

Students might ask questions like the following:

• In the past, what has happened to Chantal after watching scary movies?
• Why is Chantal so afraid of scary movies?
• Will anyone else overhear if you tell Chantal the ending to the movie?

Note

You may skip this brief analogy, but it will help your students connect genetic testing more concretely to their everyday lives. If you decide to skip it, move to the Envelope Exercise on page 4-8.
Tip from the Field

Students might react differently if you tell them that Chantal is afraid of scary movies after a horribly traumatic childhood experience, rather than that she is typically very dramatic and seeks attention by claiming to hate scary movies. In this way, students begin to appreciate the importance of background information to forming and justifying an opinion.

Assessment

Asking your students, “What is a genetic test?” functions as an informal preassessment of their background knowledge about genetic testing.

3. Show Part III of Master 4.1 and discuss the questions listed there with students. Allow students to offer a range of answers.

4. Transition from the movie scenario to genetic testing.

A possible transition could include your saying something like this: “In this analogy, you could have told Chantal that you know the ending to the movie and offered to tell her if she wanted to know. This is a bit like genetic testing, in that doctors can find out information about what is likely to happen later in a patient’s life and can then share that information with the patient. How would you respond if your doctor asked whether you’d want to know the results of such testing? In both cases, reasonable people will disagree about whether this additional information is wanted and useful.”

Envelope Exercise

Estimated Time: 15–20 minutes

1. Depending on your class, you may want to ask students, “What is a genetic test?”

2. Explain that genetic medicine is advancing. In the future, students will face many choices about whether, when, and how to use genetic tests.

Many genetic tests do not predict a disease with certainty but allow people to learn about whether they have an increased chance of a particular disease or condition arising later in life. Different people will decide differently about whether they would want that information.

3. Ask students to imagine having a crystal ball, such as an available genetic test, that could let them know whether they were more likely than many other people to develop Alzheimer’s disease. Would they want to know?

4. Explain that this exercise will give students a chance to consider whether they would want information about their chances of developing Alzheimer’s disease.

5. Give each student a sealed envelope labeled “Medical Records: Alzheimer’s Test Result.” Tell students not to open their envelopes until you tell them to.
6. Explain that each student should imagine that the envelope contains information about his or her chance of getting Alzheimer’s disease; students should pretend they have received their own personal genetic test results.

7. Give each student a copy of Master 4.2: Alzheimer’s and Genetic Testing—Relevant Facts, and display the overhead transparency of Part I of the master.

8. Tell students that their “test results” contain information about the gene for apolipoprotein E (APOE), found on chromosome 19, which is known to be a predictor of Alzheimer’s disease. Referring to the transparency, briefly instruct students about the different varieties of the APOE gene and how they affect lifetime chances of contracting Alzheimer’s disease. Suggest that students take notes on their copies of Master 4.2, as needed.

You may want to draw on the following points, as well as the information in Master 4.2, as you present information about the APOE gene:

• The difference between the three varieties (alleles) of the APOE gene is only a single nitrogenous base; these are substitution mutations. While 
\( E2 \) offers protection against developing Alzheimer’s disease, \( E4 \) increases a person’s chance of developing it.

• The majority of humans have inherited a copy of \( E3 \) from each of their biological parents. This means that their APOE gene does not affect their risk of developing Alzheimer’s disease.

• Some people have inherited a copy of \( E4 \) from one parent, and a very small percentage (1 to 2 percent of the total population) has inherited a copy of \( E4 \) from both parents. People who have inherited a copy of \( E4 \) from both parents have the greatest increased chance of developing Alzheimer’s, as seen on the chart on Master 4.2, Part I.

• APOE results for the class reflect the distribution of the three APOE alleles in the human population as a whole. Just as only 1 to 2 percent of the total human population has inherited two copies of the \( E4 \) version, the class should expect only one student’s envelope to contain the slip of paper with \( E4/E4 \) on it. Most students who open their envelopes will find that they have inherited two copies of the \( E3 \) version.

9. Explain that in a few minutes, students will choose whether to open their envelopes. Tell them that before they make that decision, though, they need to gather more relevant, scientific information. Do not yet give permission for students to open their envelopes.
**Note**
Remember that the goal here is not to achieve classroom consensus but to provide an opportunity for students to practice justifying responses within the context of genetic testing.

**Assessment**
- Recording students’ initial ideas about the pros and cons of genetic testing will help you better gauge how your students are thinking about the issue of genetic testing.
- As part of the envelope exercise, each student gives a reason for his or her choice to open the envelope or not. Listening carefully to these reasons gives you a valuable chance to gauge students’ abilities to defend their answers, one of the primary goals of the Exploring Bioethics modules. It also gives you a chance to see how much students already understand about genetic information and testing.

**Tip from the Field**
If students need time to debrief their reactions to their envelopes, they can quickly pair up and talk about them. If you have time for a class discussion, you could ask students, “If you had E4, how did you feel?” or “Should people with E4 share their results with their parents, partners, or siblings?”

10. Group students into pairs, and tell them they have five minutes to read Part II of Master 4.2, underline information that might influence their decisions, and record their decisions and supporting reasons on the master. By the end of the five minutes, each student should develop an answer to the question, Do you want to open your envelope? and be ready support the answer with at least one reason. Emphasize that there is no right or wrong answer. Reasonable people will disagree. What is important is that each student use scientific knowledge to offer a clear reason for why he or she will or will not open the envelope.

11. Lead a relatively brief (about five minutes) classroom discussion about reasons for and against opening the envelope. Use a chart format to record responses on a piece of poster paper that can be saved and reexamined on Day 3.

The purpose of this step is simply to record students’ ideas, not to lead them in any one direction. Do not try to lead them toward the idea of confidentiality at this point. On Day 3, when students see this list again, they will have the opportunity to revise and add ideas.

12. Ask students who decided not to open their envelopes to raise their hands, and collect their envelopes. Announce that students who decided to open their envelopes may do so now.

13. Give students a minute or two to discuss their reactions to their open envelopes and testing results.
Activity 2:
Introducing Max’s Thyroid Cancer Case—What Is the Ethical Question?
Estimated Time: 5–10 minutes

Procedure

1. Introduce Max’s case. Explain that different tests yield different kinds of information and that medical intervention is possible in response to some genetic tests but not others.

   In the Alzheimer’s disease case, students confronted a genetic test with limited predictive value; in other words, the test only tells about the likelihood of developing the disease. A person with a positive result might remain free of Alzheimer’s throughout his or her entire life. Until recently, Alzheimer’s disease was considered untreatable. Little or nothing was known about preventing the disease or slowing or reversing its course. However, the latest studies indicate that certain lifestyle activities, such as avoiding jars to the brain, staying engaged in social activities, exercising the mind and body, and eating a healthy diet, may slow down or prevent its onset. In addition, studies suggest that certain anti-inflammatory drugs may slow down the course of the disease. There is no set of actions that will guarantee later onset or prevention of Alzheimer’s disease, though. Therefore, genetic indicators of a predisposition to Alzheimer’s disease may be useful in encouraging individuals to alter their lifestyles.

   Now, students will look at a genetic test for a different kind of disease, multiple endocrine neoplasia type 2 (MEN II). This very rare disease is caused by an autosomal dominant mutation, which means that you inherit a copy of the gene from each of your biological parents and the gene is not associated with the sex chromosomes, X and Y. If you inherit a mutated version (allele) of the gene from just one of your parents, you will certainly develop this disease.

2. Read out loud Part I of Master 4.3: Max’s Case—Thyroid Cancer, MEN II, and Genetic Testing while also displaying only Part I using the overhead projector. For now, be sure to keep Parts II and III hidden from view.

   Make sure that students understand Part I of the master, and take a minute or two to have them pose ethical questions that arise from it.
3. Read Part II of Master 4.3 while displaying it on the overhead projector.

For now, be sure to keep Part III hidden from view; you will return to it during Day 2.

4. Help students draw a comparison between their decision about the envelopes and Max’s situation. They should arrive at something like this:

- Who should decide whether the envelope is created vs. Who should decide whether Max has the test?
- Who should have permission to see the contents of the envelope vs. Should Max’s father or doctor be allowed to learn Max’s results without Max’s permission?

5. Ask each student to turn to his or her neighbor so that students can air their preliminary views to a partner. Tell them that they have one minute of uninterrupted time to speak to their partners. After one minute, their partners should have one minute to speak.

**Activity 3:**
Gathering Relevant Facts and Concepts

Estimated Time: 15 minutes

**Procedure**

1. Remind students that gathering relevant facts is always one of the first things bioethicists do as they contemplate an ethical question.

Many students may already have shared some questions with their neighbors in Step 5 above. With that in mind, the class will now begin to learn more about this disease and the test available to Max.

2. Give each student a copy of Master 4.4: Thyroid Cancer, MEN II, and Genetic Testing—Relevant Facts. Tell students to take five minutes to read Master 4.4 in pairs and underline the most important information.

Display the transparency of Master 4.4. Show students that the format is similar to Master 4.2’s, which should make it relatively easy for them to compare the two diseases and gain access to the relevant facts. Encourage students to use the blank spaces toward the bottom of Master 4.4 to record additional questions.
From this point forward, the work focuses on thyroid cancer (specifically the kind caused by MEN II), not Alzheimer’s disease. Whenever considering the science behind a genetic test, it’s important to know the age at disease onset, the predictive value of the test, and whether there is anything effective that can be done for the condition.

MEN II thyroid cancer and the genetic test for it have unique attributes:
- disease onset at a very young age (teens to 30s),
- nearly 100-percent positive predictor of future thyroid cancer, and
- preventive surgery is available.

Students should be reminded that most genetic tests are not so definitive and do not necessarily offer the opportunity for preventive medical care. One final important aspect of MEN II is that it can also lead to cancer of the liver, bones, brain, and adrenal glands, because the cancer may spread from the thyroid gland if it is not caught early.

As students proceed through the rest of the module, they will be developing well-justified stances about testing for MEN II specifically. The MEN II and Alzheimer’s genetic tests contrast well in terms of age at onset of disease, predictive ability of the test, and opportunity for followup medical care:
- This type of Alzheimer’s arises much later in life (after age 65), whereas MEN II can arise as early as adolescence.
- The Alzheimer’s genetic test does not predict with certainty, whereas the MEN II test is fully predictive.
- The Alzheimer’s genetic test does not lead to any preventive actions (although there are actions one can take to lessen one’s chance of getting it or delay its onset), whereas a positive MEN II test result can lead to surgery (thus eliminating the chance of thyroid cancer) and medication.

3. Remind students that they need to be satisfied that they understand all relevant information before continuing with the ethical question at hand. Give students a few more minutes to brainstorm new, relevant questions they need answers to before they arrive at a full set of relevant facts.

If students come up with other relevant questions, assign individual students to research the answers overnight.
Teaching Strategies: Offering Examples

If students have trouble coming up with questions to clarify key facts and concepts, you might want to offer some examples. Students may want to know more about relevant scientific facts and concepts, social science issues, economics, legal issues, and/or historical ones. Whatever the domain, challenge students to explain why the additional information could be relevant to the main ethical question at hand. In the examples provided below, the type of question (that is, the type of information sought) is marked in parentheses.

- Is MEN II associated with any other types of cancer besides thyroid cancer? (scientific question)
- Do any complications arise as a result of thyroid removal? If so, what are they? (scientific question)
- How does one detect existing thyroid cancer in a patient? Is this an invasive procedure? (scientific question)
- How is thyroid cancer treated? (scientific question)
- How old do you need to be to make your own medical decisions? (legal question)
- How much would this genetic test cost? Who would pay for it? (economic question)
- If Max tests positive, how might this knowledge affect his relationship with his family? (social science question)
- If Max tests positive and has the surgery, who will be responsible for administering the daily medication? Will Max have to take the medication against his will? How might this affect his relationship with his family? (social science question)

4. Give each student a copy of Master 4.5: Genetic Testing—Key Concepts. Read Master 4.5 aloud with students or assign it as part of the homework.

5. Give each student a copy of Master 4.6: Thyroid Cancer, MEN II, and Genetic Testing—Checking for Understanding. Ask students to fill in the blanks in class or as homework.

Master 4.6 gauges students’ comprehension of key facts about thyroid cancer and the MEN II test. These questions could be used as an “exit ticket” from the classroom.

Assessment

The questions in Master 4.6 function as an embedded, formative assessment. It’s critical that all students comprehend relevant facts before moving on with ethical considerations. If students answer these questions in class at the end of Day 1, you’ll be able to review their answers before moving on with Day 2.

Note

On Master 4.6, the first four questions are the most concrete ones; their answers are located in one spot in the reading. To answer the fifth question—a synthesis, or comparison, question—students must reference multiple spots in the reading. The final question requires inferential thinking; students must move beyond the readings.
**Closure**

To close the class, remind students that they must understand the key facts (Master 4.4) and the key concepts (Master 4.5) really well. Announce that the next session will begin by pulling together the relevant concepts and facts and then move to figuring out who all the stakeholders are—that is, who will be affected if Max gets tested.

**Homework**

Make sure that each student has one copy of Masters 4.5 and 4.6. Students should reread Master 4.5 and answer the questions on Master 4.6 for homework (unless they filled out Master 4.6 in class). Some students may also be responsible for researching answers to additional relevant questions (see Activity 3 Procedure, Step 3, page 4-13).
**Organizer for Day 1: Deciding to Know or Not to Know**

### Activity 1: Introducing Genetic Testing—Is More Information Always Better?

Estimated Time: 20–25 minutes

#### Introductory Movie Analogy (optional)

<table>
<thead>
<tr>
<th>Using an overhead projector, display only Part I of the transparency of Master 4.1. Read Part I to students.</th>
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<tbody>
<tr>
<td>Page 4-7, Step 1</td>
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<table>
<thead>
<tr>
<th>Show and read Part II and then Part III of Master 4.1. Listen to students’ questions about Part II; discuss their answers to Part III.</th>
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</thead>
<tbody>
<tr>
<td>Page 4-7, Steps 2–3</td>
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</table>

<table>
<thead>
<tr>
<th>Explain why this is a good analogy for genetic testing.</th>
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<tbody>
<tr>
<td>Page 4-8, Step 4</td>
</tr>
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</table>

#### Envelope Exercise

<table>
<thead>
<tr>
<th>Ask students, “What is a genetic test?” Tell them that they will face many choices about whether, when, and how to use genetic tests.</th>
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</thead>
<tbody>
<tr>
<td>Page 4-7, Steps 1–2</td>
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</table>

<table>
<thead>
<tr>
<th>Explain that a genetic test can tell whether a person has a higher-than-average chance of getting Alzheimer’s disease. Ask, “Would you want to know?”</th>
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<tbody>
<tr>
<td>Page 4-8, Steps 3–4</td>
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</table>

<table>
<thead>
<tr>
<th>Give each student a sealed envelope. Tell them not to open them yet. Ask them to pretend that the envelope contains information about their chance of getting Alzheimer’s disease.</th>
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<tr>
<td>Page 4-8, Steps 5–6</td>
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<table>
<thead>
<tr>
<th>Give each student a copy of Master 4.2, and display the overhead transparency of only Part I of Master 4.2.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-9, Step 7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tell students that their “test results” are about the gene for apolipoprotein E (APOE), known to be a predictor of Alzheimer’s disease. Briefly explain the table in Part I.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-9, Step 8</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Explain that before they decide whether to open their envelopes, students need to gather more relevant, scientific information.</th>
</tr>
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<tbody>
<tr>
<td>Page 4-9, Step 9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Group students into pairs. Tell them they have five minutes to read Part II of Master 4.2, underline information that might influence their decision, and record their decision and reasons on the master.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-10, Step 10</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Lead a brief classroom discussion about reasons for and against opening the envelope. Record responses on a piece of poster paper that can be saved and revisited on Day 3.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-10, Step 11</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Collect sealed envelopes from students who chose not to open them. Tell those who chose to open them to do so now.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-10, Step 12</td>
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</table>

<table>
<thead>
<tr>
<th>Give students a minute or two to discuss their reactions to their open envelopes and test results.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-10, Step 13</td>
</tr>
</tbody>
</table>
### Activity 2: Introducing Max’s Thyroid Cancer Case—What Is the Ethical Question?

**Estimated Time: 5–10 minutes**

<table>
<thead>
<tr>
<th>Introduce Max’s case. Explain that genetic tests yield different kinds of information and that medical intervention is possible in response to some genetic tests but not others.</th>
</tr>
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<tbody>
<tr>
<td>Page 4-11, Step 1</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Using an overhead projector, display only Part I of Master 4.3. Read Part I aloud, and ask students to pose ethical questions about it. Then, display and read aloud Part II.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-11, Steps 2–3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Help students connect Max’s situation to the envelope activity. Ask them to air their preliminary views to a partner.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-12, Steps 4–5</td>
</tr>
</tbody>
</table>

### Activity 3: Gathering Relevant Facts and Concepts

**Estimated Time: 15 minutes**

<table>
<thead>
<tr>
<th>Remind students that gathering relevant facts is always one of the first things bioethicists do as they contemplate an ethical question.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-12, Step 1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Give each student a copy of Master 4.4, and display the transparency. Tell students to take five minutes to read it in pairs and underline the most important information.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-12, Step 2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Remind students that they need understand all relevant information before continuing with the ethical question. Ask students for new, relevant questions, and assign individuals to research the answers.</th>
</tr>
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<tbody>
<tr>
<td>Page 4-13, Step 3</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Give each student a copy of Master 4.5. Read it aloud, or assign it as homework.</th>
</tr>
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<tbody>
<tr>
<td>Page 4-14, Step 4</td>
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</table>

<table>
<thead>
<tr>
<th>Give each student a copy of Master 4.6. Ask them to complete it in class or as homework.</th>
</tr>
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<tbody>
<tr>
<td>Page 4-15, Step 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Closure: Remind students that they must understand the key concepts (Master 4.5) and the key facts (Master 4.6) really well.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-15</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Homework: Reread Master 4.5 and answer the questions on Master 4.6. Some students may also be researching answers to questions from Step 3.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Page 4-15</td>
</tr>
</tbody>
</table>
**DAY 2: Identifying Stakeholders and Taking Two Key Ethical Considerations into Account**

**Purpose**

Day 2 addresses the other two of this supplement’s four key questions. First, students consider the question, Who or what could be affected by how the situation gets resolved? by identifying who else in addition to Max and his father have a stake in the outcome of this case. Once the stakeholders are identified, students proceed to the question, What are the relevant ethical considerations?—and think about how they matter. They begin to think systematically about two of the main ethical considerations to take into account—respect for persons and harms and benefits—before they draw a final conclusion on Day 3 about who should get to make this decision. Students apply their knowledge of Mendelian genetics and pedigree interpretation to identify who else is likely to be affected if Max is tested. Note that Day 2 is meant to reinforce, rather than introduce, Mendelian genetics.

**Activity 4: Checking for Understanding**

**Estimated Time: 5–10 minutes**

**Procedure**

1. As a full class or in small groups, give students time to discuss their answers on Master 4.6. Make sure that students understand the content of Master 4.6 before proceeding to Activity 5.

   See Teacher Support Materials


**Teaching Strategies**

You may want to make an overhead transparency of Master 4.6 and write answers as students say them aloud.

2. If any students have researched answers to relevant questions, give them a chance to share their answers with the class. Ask the class to record this information on their copies of Master 4.4.
Activity 5: Who or What Will Be Affected by How the Situation Is Resolved?
Estimated Time: 20 minutes

Procedure

1. Introduce this section by explaining to students that now that they have educated themselves about the main scientific and medical facts, it is time for them to turn to the key question, Who or what will be affected by the way the question gets resolved—in this case, who besides Max stands to be affected by whether Max is tested?

   Emphasize that identifying these stakeholders is one important element in identifying the potential harms and benefits of the test, as well as the confidentiality issues.

2. Use the overhead projector to display Max’s family pedigree on his mother’s side—Part III of Master 4.3—and distribute one copy of Master 4.3 to each student.

3. Read Part III aloud and explain the family tree to students.

   All students should notice the key and note located below the pedigree, as well as Max’s sibling (Sally) and cousin (Lindsey). Students should come to the realization that a positive test result for Max means that others in his family might also have inherited the mutation, but a negative test result does not rule out that other family members have inherited this mutation by other family members. Thus, although Max’s test result does not directly reveal genetic information about others in the family, multiple people could nevertheless be affected by new genetic information discovered about Max.

4. Remind students that there are many forms of thyroid cancer and that Nick, Harriet, and James could have died of a form of thyroid cancer unrelated to the one associated with MEN II.

   MEN II accounts for only a fraction of thyroid cancer cases in the world, so it is impossible to know from the pedigree whether Nick, Harriet, and James had MEN II. On Day 3, there will be an opportunity to discuss whether Max should share any newly discovered genetic information with his family members. If Max were to test positive, others in the family might want to get their own genetic testing immediately.

Tip from the Field

If students seem stuck or confused, call their attention to the key and the note below the pedigree. Make sure that students understand that shaded individuals have been diagnosed with thyroid cancer but that no one in the family has been tested for this particular mutation.
5. Give students a few minutes to answer the questions accompanying the pedigree on Master 4.3 (Question 6 is already answered there), and when they have finished, review the answers as a class.

### See Teacher Support Materials
An answer key for Master 4.3 is available online at http://science.education.nih.gov/supplements/bioethics/teacher.

6. To help students understand that information about an inherited mutation can affect an entire biological family, give each student a copy of Master 4.7: What Impact Would Max’s Newly Discovered Mutation Have on Him and Others?

Here, students should suppose that Max was tested and that he tested positive for the mutation associated with MEN II thyroid cancer. They need to apply their knowledge of Mendelian genetics to figure out the chance that other family members also inherited this mutation.

You might want to use the following information to review Mendelian genetics:

\[ T = \text{MEN II thyroid cancer, as a result of a specific mutation} \]
\[ t = \text{no MEN II thyroid cancer} \]

Assume Max is \( Tt \) because of no family history on his father’s side of the family.

Assume Max’s dad (Pierre) is \( tt \).

7. Have students work in small groups to complete Master 4.7, applying Mendelian genetics to the case at hand.

Students should complete column 3 of Master 4.7 by placing a percentage chance in each box.

### See Teacher Support Materials
A sample answer key for Master 4.7 is available online at http://science.education.nih.gov/supplements/bioethics/teacher.

8. Bring students back together and review their answers. Use the overhead transparency of Master 4.7 to record answers (in percentage form) as students contribute them.

You may also want to have students suggest other ways that family members might be affected by Max’s testing positive. For example, his father will now have to pay for thyroid removal, so he will be financially and emotionally affected.
Activity 6: Exploring the Relevant Ethical Considerations
Estimated Time: 20–25 minutes

Procedure

1. Remind students of the ethical question at hand: Who should decide whether Max will have the MEN II thyroid cancer genetic test?

2. Explain that while there are many ethical considerations to take into account in answering this question, the class will focus on two main ones: respect for persons, and minimizing harms and maximizing benefits.

   Respect for Persons: Not treating someone as a mere means to a goal or end. This is often a matter of not interfering with a person’s ability to make and carry out decisions. In some cases, it is also a matter of enabling a person to make choices or supporting the person in the choices he or she makes.

3. Explain that the class will begin with respect for persons.

   Point out that U.S. society usually attempts to give adults as much choice and as much ability to decide their own course of action as possible. In bioethics, the belief is that one very important way to respect adults is to allow them to make their own choices so they can lead the lives they feel are best for them. However, Max is less than 18 years old, so there’s tension between Max, who wants to make his own decisions, and the law, which gives his parents that authority.

4. Ask students, “What are some reasons for why Max should be able to decide whether he takes the test?”

   Students might suggest the following reason: Max has the same abilities to think through this decision as someone who is 18. Since 18-year-olds are allowed to decide for themselves, so, too, should Max be allowed to decide for himself.

5. Ask students, “What are some reasons why Max’s father should be the decision maker and, therefore, limit Max’s ability to choose his own course of action?”

You may want to consider referring to Table 2, Tips for Conducting Ethics Discussions, on pages 16–19 of the Introduction for very helpful strategies for what you can say during discussions.
Students might offer a variety of reasons:

- His father is more likely to understand the implications of this test and make a more informed decision. It’s not like the Alzheimer’s disease case, in which nothing can be done. His thyroid cancer can be prevented if he tests positive and has the surgery now. This surgery is lifesaving, less taxing on his body, and less expensive than radiation or chemotherapy later. Even though good treatments for thyroid cancer exist, some people still die of it, especially if it’s detected in more advanced stages.

- It is his dad’s responsibility to protect him.

**Harms and Benefits:** Acting to lessen negative outcomes and promote positive outcomes.

6. After this preliminary discussion, ask students to hold their thoughts and turn to another important set of ethical considerations: minimizing harms and maximizing benefits.

In trying to decide whether Max’s father should trump Max’s preference and insist on the test, it’s important to determine what benefits and harms are associated with the test. Therefore, students will now have the chance to identify the full range of harms and benefits associated with having the genetic test.

7. Tell students they will be building a justification for their final recommendation, which will bring in the key medical and scientific facts they have learned and their ability to anticipate harms and benefits of all kinds—physical, psychological (emotional), social, and even economic.

8. Discuss the meaning of physical, psychological, social, and economic harms and benefits.

It’s important to stress that the results of the genetic test do not bring physical benefit to the person. Rather, it’s the followup medical care that does this.

9. Give each student a copy of Master 4.8: Thyroid Cancer and Genetic Testing—Harms and Benefits. Divide students into pairs or small groups, and give them time in class to work on it.

10. After students have had enough time to complete the chart, reconvene the class. Have a full-class discussion about harms and benefits, and record them on a transparency of Master 4.8.

Emphasize that the goal here is not classroom consensus, but to have each student develop a stance supported by reasons.
11. Give each student a copy of Master 4.9: Your Tentative Thoughts, to be completed during class or for tonight’s homework.

If students complete Master 4.9 during class, you can collect and read their answers overnight before Day 3 of the module. This would give you the chance to preview the range of students’ responses before moving on to the next day’s work. Whether you choose to assign Master 4.9 for classwork or homework, emphasize that these are tentative answers that will help prepare students for the next session’s discussion.

CLOSURE

Remind students that over the past two days, they have considered an ethical question, gathered relevant facts, identified who stands to be affected by the decision about whether or not to have a genetic test, and applied the ethical considerations of respect for persons and minimizing harms and maximizing benefits. For tonight’s homework and tomorrow’s class, it’s time to move toward decision making.

HOMEWORK

If students did not complete Master 4.9 during class, have them do it as homework.
**Organizer for Day 2: Identifying Stakeholders and Taking Two Key Ethical Considerations into Account**

### Activity 4: Checking for Understanding
Estimated Time: 5–10 minutes

As a full class or in small groups, have students discuss their answers on Master 4.6. Page 4-18, Steps 1–2

### Activity 5: Who or What Will Be Affected by How the Situation IsResolved?
Estimated Time: 20 minutes

Explain that now it’s time for students to turn to this key question: Who or what will be affected by the way the question gets resolved? Who besides Max stands to be affected by whether he is tested? Page 4-19, Step 1

Give each student a copy of Master 4.3. Using the overhead projector, display the transparency of Part III of Master 4.3. Read Part III aloud and explain the family tree to students. Page 4-19, Steps 2–3

Remind students that there are many forms of thyroid cancer, and that Nick, Harriet, and James could have died of a form unrelated to the one associated with MEN II. Page 4-20, Step 4

Give students a few minutes to answer the pedigree questions on Master 4.3 and then review the answers as a class. Page 4-20, Step 5

Give each student a copy of Master 4.7. Have students work in small groups to complete it. Page 4-20, Steps 6–7

Bring students back together. Using the overhead projector, record students’ answers (in percentage form) on the transparency of Master 4.7. Page 4-20, Step 8

### Activity 6: Exploring the Relevant Ethical Considerations
Estimated Time: 20–25 minutes

Remind students that the ethical question at hand is, Who should decide whether Max will have the MEN II genetic test? Page 4-21, Step 1

Explain that the class will focus on two ethical considerations: respect for persons, and minimizing harms and maximizing benefits, starting with respect for persons. Page 4-21, Steps 2–3

Ask students, “What are some reasons for why Max should be able to decide whether he takes the test?” Page 4-21, Step 4
<table>
<thead>
<tr>
<th>Step 5</th>
<th>Ask students, “What are some reasons why Max’s father ought to be the decision maker and, therefore, limit Max’s ability to choose his own course of action?”</th>
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</thead>
<tbody>
<tr>
<td>Step 6</td>
<td>After this preliminary discussion, ask students to hold their thoughts and turn to this ethical consideration: minimizing harms and maximizing benefits.</td>
</tr>
<tr>
<td>Step 7</td>
<td>Tell students that they will be building a justification for their final recommendation. It will bring in the key medical and scientific facts they have learned and their ability to anticipate harms and benefits.</td>
</tr>
<tr>
<td>Step 8</td>
<td>Discuss the meaning of physical, psychological (emotional), social, and economic harms and benefits.</td>
</tr>
<tr>
<td>Step 9</td>
<td>Give each student a copy of Master 4.8. Divide students into pairs or small groups, and give them enough time in class to complete the master.</td>
</tr>
<tr>
<td>Step 10</td>
<td>Reconvene the class. Discuss harms and benefits, and record them on a transparency of Master 4.8.</td>
</tr>
<tr>
<td>Step 11</td>
<td>Give each student a copy of Master 4.9, to be completed during class or for tonight’s homework.</td>
</tr>
<tr>
<td>Step 12</td>
<td><strong>Closure:</strong> Remind students that over the past two days, they have considered an ethical question, gathered relevant facts, identified who stands to be affected by the decision to have a genetic test, and applied the ethical considerations of respect for persons and minimizing harms and maximizing benefits.</td>
</tr>
<tr>
<td>Step 13</td>
<td><strong>Homework:</strong> If students did not complete Master 4.9 during class, have them do it as homework.</td>
</tr>
</tbody>
</table>

*M* Involves copying a master  
*T* Involves making a transparency
**Purpose**

During Day 3, each student forms well-justified answers to two questions: 1) Who should decide whether Max will be genetically tested? and 2) Who should have access to the results if Max is tested? Students should use scientific information as well as the ethical considerations of respect for persons and minimizing harms and maximizing benefits. They should understand that their answers depend on factors regarding the specific disease and genetic test, including age at disease onset, the predictive value of the test, and whether the condition is treatable.

**Activity 7:**
Who Should Get to Decide Whether Max Gets Tested?

Estimated Time: 25 minutes

**Procedure**

1. **Before students arrive, hang up three posters in the classroom and title them “Max,” “Max’s father,” and “Max’s doctor.”**

2. **Ask students, “Who should get to decide whether Max gets this test?”**

   In light of the importance of respect for persons (in this case, the ability to decide one’s own course of action) but also recognizing potential harms and benefits to Max and his father and the fact that Max is only 15, who should decide whether Max should have this test? Remind students that they considered this question last night for homework (or during the previous class).

3. **Remind students that although some may think that Max should have the test, they may nevertheless decide that Max should have decision-making power.** Some students may feel that although the test has more benefits than harms, respect for Max’s autonomy and decision-making power trumps the benefits of the test.

4. **Give students six small stickers each and tell them to place their stickers on the three posters in a way that indicates their opinions about who should make the decision about Max’s test.**

   Explain that the stickers are units of decision-making power and that a student could place all six stickers on one poster or split the stickers between two or three posters.
5. Have students, in pairs, quickly discuss where they placed their stickers and why.

6. Bring students back together and engage them in a full-class discussion.

Possible discussion questions include:
- What do you notice when looking at the three posters around the room?
- Why do you think the ________ poster received so many votes?
- Would you have voted differently if a positive result on the genetic test—that is, having the mutation—only signaled an increased risk for the thyroid cancer but not 100-percent certainty?
- Would you have voted differently if medicine could offer nothing to Max if he had the mutation?
- Looking at the ________ poster (with so many votes), what arguments might people make against this person having so much power?

See Teacher Support Materials
If the discussion becomes too one-sided, elicit counter opinions using tips from Who Should Decide Whether Max Gets Tested? available online at http://science.education.nih.gov/supplements/bioethics/teacher. This resource provides possible probing questions to help students clarify, deepen, and challenge their thinking.

ACTIVITY 8: Who Should Have Access to the Results?
Estimated Time: 15–20 minutes

In this activity, students consider who should be able to access the results of a genetic test. Emphasize that shared knowledge isn’t necessarily public knowledge. In other words, if genetic information is shared with another person, that person would typically be expected to keep the information confidential.

PROCEDURE

1. Tell students that they will continue to look at the ethical consideration of respect for persons, but now will examine this consideration within the context of confidentiality. To what extent should Max’s request that the information not be shared with other family members be honored?

2. Ask students, “Should Max’s father be able to distribute—without Max’s permission—Max’s genetic information to different members of the family?” Here, remind students of the need to balance these aspects: Max’s request for confidentiality, whether other family members would want this additional information, and the
Tip from the Field

When students are doing this activity, you will also want to make sure that they have access to Max’s family pedigree (Master 4.3). If you made a transparency of this pedigree, you can display it for the class.

Assessment

This is a good chance for a formative assessment. Listening to students’ poster presentations will enable you to assess whether your students are able to incorporate scientific knowledge and ethical considerations when justifying a decision.

Teaching Strategies

You could assign roles within the group (or have students self-assign the roles): one person to write in each color and one to three people to present to the class.

6. Give each group about one minute to present its poster to the class.

7. After each group has presented, have a brief full-class discussion about the posters.

Possible discussion questions include

- Would anyone add other reasons to any of the posters?
- Did anyone disagree with the reasons mentioned? Which one(s)? Why?
- Are there justifications for overriding Max’s request for confidentiality? If so, identify these justifications. If not, why not?
- What if Max’s test were for an infectious disease? Would you treat his request for confidentiality any differently? Why or why not?

See Teacher Support Materials

If the discussion becomes too one-sided, elicit counter opinions using tips from Who Should Have Access to the Results?—available online at http://science.education.nih.gov/supplements/bioethics/teacher.
Reflection

Display the posters from Day 1 listing the pros and cons of opening the envelope containing information about the risk of Alzheimer's disease. Students can view the posters to revisit prior beliefs. Now that students have had two additional days of this module, they should have a more developed sense of the issues associated with genetic testing. Ask students to reread the posters and consider what additional pros and cons they would now add about opening the envelope. Record students' additions on the posters.

Closure

Reinforce to students that the goal of this module (and the other modules in this supplement) is not consensus. Instead, the goal is well-supported decision making using scientific facts and concepts as well as ethical considerations. With this in mind, students’ stances will be very dependent on the specific disease, the nature of the specific genetic test, and their own well-considered judgments.

Final Assessment

Give each student a copy of Master 4.10: Camilla's Case—Colon Cancer and Genetic Testing, which explains the final assessment. Emphasize to students that this assessment is a “transfer” activity, meaning that they have never before studied this particular disease or genetic test. To be successful on the final assessment, students must transfer their learning from the Alzheimer's and MEN II genetic tests to this new situation.

Extensions (Optional)

1. Ask students to discuss the pros and cons of opening an envelope that contains test results for the MEN II-causing mutation. In what ways are their pro-con lists (one pro-con list for Alzheimer's, another for MEN II) similar? In what ways are their lists different?

2. Have students consider the role of genetic testing in the workplace. Give each student a copy of Master 4.11: About Retinitis Pigmentosa, and ask students to examine whether a hypothetical airline company should be able to require its prospective employees to get a genetic test for retinitis pigmentosa, a vision disorder.
Organizer for Day 3: What Is Your Recommendation?

**Activity 7: Who Should Get to Decide Whether Max Gets Tested?**
Estimated Time: 25 minutes

Hang up three posters in the classroom and title them “Max,” “Max’s father,” and “Max’s doctor.”

Ask students, “Who should get to decide whether Max gets this test?” Remind them that even if they think that Max should get tested, they may nevertheless decide that he should have decision-making power.

Give each student six small stickers. Tell them to place their stickers on the posters in a way that indicates their opinions about who should get to decide.

Have students, in pairs, quickly discuss where they placed their stickers and why.

Bring students back together and engage them in a full-class discussion. Ensure that all opinions are mentioned.

**Activity 8: Who Should Have Access to the Results?**
Estimated Time: 15–20 minutes

Tell students that they will continue to look at respect for persons, but now in the context of confidentiality.

Ask students, “Should Max’s father be able to distribute—without Max’s permission—Max’s genetic information to different members of the family?”

Ask students, “Who in Max’s family might benefit from knowing this newly discovered information?” Write each person’s name on a different piece of poster paper.

Divide the students into six small groups. Give each group a piece of poster paper with a relative’s name on it, one red marker, and one green marker.

Instruct students to use the red marker to record reasons in favor of not telling that person about Max’s mutation and the green marker to record reasons in favor of telling that person.

Give each group about one minute to present its poster to the class.

Have a brief full-class discussion about the posters. If it becomes too one-sided, refer to “Who Should Have Access to the Results?” (online).
**Reflection:** Have students view the pros and cons posters from Day 1 to revisit prior beliefs. Ask students what additional pros and cons they would now add about opening the envelope.

**Closure:** Reinforce that the goal of this module (and the other modules in this supplement) is *not* consensus. It is well-supported decision making using scientific facts and concepts as well as ethical considerations.

**Final Assessment:** Give each student a copy of **Master 4.10.** Emphasize that this assessment is a “transfer” activity.

**Extensions (optional)**

1. Ask students to discuss the pros and cons of opening an envelope that contains test results for the mutation that causes MEN II. In what ways are their pro-con lists for Alzheimer’s and MEN II similar? Different?

2. Ask students to consider the role of genetic testing in the workplace by starting a new activity about testing prospective pilots for a vision disorder. (Instructions are online.) Give each student a copy of **Master 4.11.**

*M* Involves copying a master