Who Should Decide Whether Max Gets Tested?
(Day 3, Activity 7)

Who Should Decide Whether Max Gets Tested?

Remind students that “Who should decide?” and “Should Max get tested?” are two different questions. For example, even though a student thinks that it’s a good idea for Max to get tested and that student knows that Max is against having the test, he or she could still be in favor of Max being the decision maker.

Students overwhelmingly think it’s obvious that Max should decide: respect for Max demands that Max decide for himself.

Teacher can follow up with questions such as:
- What if Max were only five years old?
- Why is it morally permissible for a parent to decide on behalf of a 5-year-old but not a 15-year-old?

Students answer that a 15-year-old is more rational than a 5-year-old.

Teacher can follow up with questions such as:
- Is Max’s rational capacity fully developed?
- How do you know that it is developed enough to make a completely autonomous decision about a high-stakes genetic test?

Students overwhelmingly think it’s obvious that Max’s dad should decide.

Students comment that Max is still a minor, so his father should decide.

Teacher can follow up with a question such as, Is what is legal always ethical?

Students comment that the decision is too high-stakes for Max.

Teacher can respond with followup questions such as:
- Don’t teenagers make other high-stakes decisions, such as driving and playing high-risk sports? Is there a difference between letting Max make up his own mind about playing a high-risk sport and having a genetic test?
- What if Max were 18? The decision would still be high-stakes. Should Max’s dad still decide?
Additionally, the teacher can pose other hypothetical scenarios for the class to consider, including these:

- Who should get to decide whether Max should have the genetic test if the genetic test were not 100-percent predictive of a future disease or condition? What if a positive result indicated only a 70-percent chance of thyroid cancer developing?
- Who should get to decide if the medication had very prolonged and negative side effects?
- Who should get to decide if the age of onset were in the patient’s 50s, 60s, or 70s?
- Who should get to decide if no followup medical care were available for a positive test result?

Teachers should also make sure that students keep the core ethical question—Who should decide?—at the forefront of the discussion. This discussion is not about whether Max should have the test or whether it would be best for Max to have the test.