Genes and Choices

Researching benefits and limits of genetic technologies

FB.4.5 "Research and report on genetic technologies that may improve the quality of life (e.g., genetic engineering, cloning, gene splicing, DNA testing)."

NAME _____ DATE _____

1 READ AND MARK

Read it twice

YOUR JOB Underline evidence of how each technology could improve quality of life. Circle a limit or risk for each one so you can report both benefits and concerns.

Two Ways Genetic Technology Can Help

1. A person with sickle cell disease can have sudden pain episodes when misshapen red blood cells block small blood vessels. In 2023, the U.S. Food and Drug Administration (FDA) approved a gene-editing treatment for some patients aged 12 and older. Doctors collect a patient's blood-forming stem cells, edit them outside the body, and return them after chemotherapy. The edit helps the body make more fetal hemoglobin, which can reduce severe pain episodes. This is not an edit to eggs or sperm, so it is not passed to children. Approval does not mean the treatment works equally well for everyone.

2. Genetic technology can also guide decisions without changing DNA. A DNA test can show whether someone carries one copy of the gene variant linked to sickle cell disease. A carrier usually does not have the disease, but two carriers can have a child with the disease. A genetic counselor can help people understand what a result does and does not mean. A carrier result alone cannot predict exactly whether a future child will have sickle cell disease. Testing may improve quality of life by helping families plan, but private results could be misused if shared without care.

3. To report on these technologies, a researcher might start with FDA treatment information and CDC guidance on sickle cell trait. Those sources describe different kinds of evidence: treatment studies measure health outcomes, while testing guidance explains inherited risk. For the edited-cell treatment, fewer severe pain episodes are evidence of a possible benefit, but chemotherapy can cause serious side effects, and long-term effects need continued study. For DNA testing, a useful report would distinguish knowing a risk from preventing a disease. It would also name whose quality of life might change, such as a patient managing pain or a family making plans.

2 ANSWER WITH EVIDENCE

Use the passage

1. What evidence from the passage supports reporting that gene editing may improve a patient's quality of life? Include one limit to that claim.

2. Which source named in the passage would you consult for treatment outcomes, and which would you consult for inherited risk? Explain your choices.

3. How could DNA testing improve quality of life without changing DNA? Include one concern a report should mention.

4. Why would it be misleading to report that either technology guarantees a child will not have sickle cell disease?

3 YOUR TURN

Your own words

Choose one technology in the passage and write a brief research plan about a question the passage does not answer. State your question, name a reliable source you would consult, describe the evidence you would seek, and explain how it would help you report on quality of life and one limitation.

Genes and Choices

PART 1 · READ AND MARK

Underline evidence of how each technology could improve quality of life. Circle a limit or risk for each one so you can report both benefits and concerns. Accept any marking that follows this job and points at the right text.

PART 2 · ANSWERS

#	QUESTION	ANSWER
1	What evidence from the passage supports reporting that gene editing may improve a patient's quality of life? Include one limit to that claim.	**The edit can increase fetal hemoglobin and reduce severe pain episodes. It may not work equally well for everyone, and its long-term effects need continued study.**
2	Which source named in the passage would you consult for treatment outcomes, and which would you consult for inherited risk? Explain your choices.	**Consult FDA treatment information for outcomes of gene editing and CDC guidance on sickle cell trait for inherited risk.**
3	How could DNA testing improve quality of life without changing DNA? Include one concern a report should mention.	**A carrier result can help families understand inherited risk and plan. A report should mention that private results could be misused if shared without care.**
4	Why would it be misleading to report that either technology guarantees a child will not have sickle cell disease?	**The described gene edit is not passed to children, and a carrier test provides information rather than preventing disease.**

PART 3 · YOUR TURN (SAMPLE ANSWER)

How many people can return to school or work five years after gene-editing treatment? I would look for a peer-reviewed follow-up study of treated patients. I would seek data on school or work attendance and on serious side effects. Those findings could show whether daily life improved while also revealing a limitation, such as side effects that make school or work difficult.

Accept other benefits, limits, and reliable sources supported by the passage. For the research plan, the question must go beyond the passage, and the proposed evidence must connect to both quality of life and a limitation.