Performance Task

Weighing Benefits and Harms: Ethical Issues in Genetic Testing

Modeled after Smarter Balanced ELA Performance Tasks
Weighing Benefits and Harms:
Ethical Issues in Genetic Testing

Introductory Classroom Activity (25 minutes)

- Present on a projector (or distribute a handout) of images of thyroids and thyroid cancer (see attached example).
- After giving students a moment to look at the images, ask, “Have you heard in the news about the increase of thyroid cancer cases in the Pacific Northwest?” Do you know of someone that has had thyroid cancer and or had to have their thyroid eradicated or removed?
- Let students know that they are going to watch two short video clips that address thyroid related health problems and cancer. The first video consists of an animated video that discusses the most common thyroid problems (hypothyroidism, hyperthyroidism, and goiter) and their causes are explained. Symptoms which occur in these disorders are mentioned, as well as possible treatments (Health Channel TV). The second video consists of David Goldenberg, M.D., discussing the various types of thyroid cancer, how they’re detected and how the prognosis can vary depending on the type. Dr. Goldenberg is the director of head and neck surgery at Penn State Hershey Medical Center.
  
  [http://www.youtube.com/watch?v=SVSBo065hmw](http://www.youtube.com/watch?v=SVSBo065hmw)

  [http://www.youtube.com/watch?v=J7Fes1ByMZM](http://www.youtube.com/watch?v=J7Fes1ByMZM)

- Following the two videos, engage students in a brief classroom discussion using some of the following as discussion questions:

  - What information was provided about the different thyroid related medical issues (causes, symptoms, and treatment)?
  - Why are some individuals more susceptible of acquiring thyroid cancer than others?
  - Why do you think thyroid cancer cases are increasing not only here in the Pacific Northwest, but also across the United States?
  - What causes thyroid cancer?
  - What are the two different types of thyroid cancer? Why is one type of thyroid cancer more likely to reoccur?

- Say to the students, “In the performance task that you are going to participate in this week, you learn more about thyroid cancer and new genetic testing that can assist in predicting whether a person is more susceptible of becoming a thyroid cancer patient. You will also learn more about the debate over the pros and cons of genetic screening tests. Eventually, you will need to take a position on whether we should encourage or discourage the use of genetic screening tests in medicine. It is important to know that, as some of the resources you will be using point out, that some people support genetic testing while others are adamantly opposed to it.”
Student Directions

Weighing Benefits and Harms: Ethical Issues in Genetic Testing

Task:

In your health and science classes, you have been discussing the increase of thyroid cancer in the Pacific Northwest. You have learned about what role the thyroid has in regard to our body, as well as about some medical conditions that can occur if the thyroid isn’t functioning correctly. You have also learned about the causes and symptoms of thyroid cancer and about how there are genetic screening tests that can be given to a patient in order to determine if they are susceptible to cancers that involve the thyroid. You have also learned that genetic screening tests are supported by some, but adamantly opposed by others. As part of your research on this topic, you have found four sources giving additional information about thyroid cancer, genetic screening and the potential causes of thyroid cancer.

After you have reviewed these sources, you will answer some questions about them. Briefly review these resources and the three questions that follow. Then, go back and read the sources carefully so you will have the information you need to answer the questions and complete your research. You may take notes in the margins as you find information in the sources to capture your thoughts, reactions and any questions you might have, as you read.

In Part 2, you will write an argumentative essay on a topic related to the sources.

Directions for Beginning;
You will now examine several resources. You can re-examine the sources as often as you like.

Initial Questions:
After examining the research sources, use the rest of the time in Part 1 to answer the three questions about them. Your answers to these questions will be part of your score for the reading portion of the assessment. Also, your answers will help you think about the information you have read and viewed, which should help you write your argumentative article. Both your margin notes and your answers to the questions will be available to you as you work on your article.
Early detection of thyroid cancer significantly improves the possibility of successful treatment. Although thyroid cancer sometimes has no symptoms, many tumors are found in the early stages when patients find lumps or nodules in their throats. Doctors sometimes find lumps or nodules during routine checkups.

No screening tests are recommended for the general population. Some experts suggest that people examine their own necks carefully twice annually. If you notice symptoms, you should see your doctor immediately. Be sure your doctor includes a cancer-related checkup in your annual physical.

People with a family history of familial medullary thyroid carcinoma should have a blood test and genetic screening done as early as possible to find out if they have the gene that causes this cancer. If they have the gene, they may want to have the thyroid surgically removed to decrease the risk of thyroid cancer.

**Physical Examination**

If you have symptoms of thyroid cancer, you should visit your doctor as soon as possible. He or she will examine your neck and throat, feeling for lumps or swelling. Your doctor will also complete a medical history. This involves asking questions about your symptoms, other health problems, and health problems in other members of your family. If anyone in your family has ever had thyroid cancer or parathyroid or adrenal tumors, be sure to tell your doctor.

If your doctor thinks you have a thyroid nodule or nodules, you may have a fine-needle aspiration biopsy. In this procedure, a thin needle is inserted into the nodule. Then cells are withdrawn and examined under a microscope.

This procedure usually is done in the doctor's office. In many cases, no anesthesia is needed. Sometimes, an injection of local anesthetic, similar to what is used in a dentist's office, may be given in the skin over the nodule.

Fine-needle aspirations are safe, and the only complication is bleeding. This is not common, however, unless the patient has a bleeding disorder. Tell your doctor before the test if you have a bleeding disorder.
The needle is inserted into the nodule for about 10 seconds. It usually is inserted in two or three locations on the nodule. If nodules are too small to be felt, an ultrasound image may help guide the needle.

After the cells are removed, they are analyzed under a microscope to see if they are cancerous. Most thyroid nodules are proved by FNAs to be benign (noncancerous).

If the FNA is inconclusive—not showing clearly whether the nodule is cancerous—more testing may be needed.

**Imaging**

Imaging tests give doctors a picture of the thyroid. There are several types of tests.

**Ultrasound.** This test uses sound waves to make images of the body. The healthcare provider holds a small device called a transducer close to the throat. The transducer emits silent high-frequency sound waves that bounce off the thyroid. These bounces create echoes that are analyzed by a computer.

Ultrasound is useful for finding thyroid nodules, guiding a needle for biopsy, and imaging the neck after surgery. When examined by ultrasound, some nodules have suspicious findings that make the diagnosis of cancer more likely.

**Radioactive thyroid scan.** If a nodule is papillary or follicular cancer, a radioactive thyroid scan may be used after thyroid surgery to determine if cancer remains or has spread to other parts of the body. Medullary thyroid cancer cells don't absorb iodine.

First, you will swallow a small amount of radioactive iodine. The thyroid tissue absorbs the radioactive iodine. Then a special camera is pointed at the body. The camera does not touch the skin. The camera measures the amount of iodine that was absorbed by the body.

Patients may be given an injection of thyroid stimulating hormone before a radioactive thyroid scan to increase their level of the hormone and make a scan more effective.

**Computer tomography scan (CT scan).** This diagnostic test uses an X-ray machine and a computer to create detailed pictures of the body, including three-dimensional images. As part of a CT scan, you may be asked to drink contrast dye fluid or have an IV (intravenous) line for injection of contrast dye fluid. Although not commonly used to diagnose thyroid cancer, a CT scan can help find out the size of a tumor or whether the cancer has spread.
**Magnetic resonance imaging (MRI).** This diagnostic test uses magnetic fields and radio waves to create computerized pictures of the body. You may be placed in a tube, which can feel confining to people who have a fear of enclosed spaces. The MRI is noisy while it is operating, and you will probably be given earplugs. You may receive an injection or be asked to swallow contrast dye fluid. Although not commonly used to diagnose thyroid cancer, MRI may be used to determine the size of a tumor or determine if the cancer has spread.

**Positron emission tomography (PET).** This test uses a radioactive atom, which is included in liquid glucose (a type of sugar). You will receive an injection of the glucose, which is absorbed by cancer cells. A special camera captures images of the cells. PET is used to evaluate thyroid cancer that has metastasized and is not responsive to radioactive iodine. It appears to be less useful in evaluating medullary carcinoma.

**Blood Tests**

Blood tests are not used to diagnose thyroid cancer, but they are useful in determining the type of cancer and activity of the thyroid.

Thyroid stimulating hormone is measured to check the activity of the thyroid cancer. Blood calcitonin testing will be done if medullary thyroid carcinoma is suspected.

Thyroglobulin, a protein made by the thyroid, is measured after surgical removal of the thyroid. Its presence may suggest that differentiated thyroid cancer is still present or returning.

**Genetic Testing and Recurrence of Cancer**

If you have medullary thyroid cancer, you will be given a blood test to determine if you carry a gene that sometimes causes this cancer. If the test is positive, your children and parents should be tested to see if they have the gene or thyroid cancer. More than 90 percent of people who have the gene will eventually develop the cancer.

If your child has the gene, the doctor will probably suggest removal of the thyroid. Although children rarely develop cancer before 5 years of age, one type of MTC (known as MEN-2B) can develop in the early months of life. If the thyroid is removed, a person will take daily thyroid medication for the rest of his or her life.

**Recurrent thyroid cancer** is cancer that returns after the original cancer has been treated. Although it usually comes back in the neck, thyroid cancer can appear in other parts of the body. When thyroid cancer returns, it is classified as the same stage as the original cancer.
Source #2: Thyroid Cancer- Risk Factors

This source from the Cancer.net website (last reviewed May 2014) you will find out more about the factors that increase the chance of developing thyroid cancer. ([http://www.cancer.net/cancer-types/thyroid-cancer/risk-factors](http://www.cancer.net/cancer-types/thyroid-cancer/risk-factors))

A risk factor is anything that increases a person’s chance of developing cancer. Although risk factors often influence the development of cancer, most do not directly cause cancer. Some people with several risk factors never develop cancer, while others with no known risk factors do. However, knowing your risk factors and talking about them with your doctor may help you make more informed lifestyle and health care choices.

The following factors can raise a person’s risk of developing thyroid cancer:

**Gender.** Women are two to three times more likely to develop thyroid cancer than men.

**Age.** Thyroid cancer can occur at any age, but about two-thirds of all cases are found in people between the ages of 20 and 55. Anaplastic thyroid cancer is usually diagnosed after age 60. Older infants (10 months and older) and adolescents can develop MTC, especially if they carry the *RET* proto-oncogene mutation (see below).

**Genetics.** Some types of thyroid cancer are associated with genetics. Below are some key facts about this disease, genes, and family history; read more about the genetic testing.

- An abnormal *RET* oncogene, which can be passed from parent to child, may cause MTC. Not everyone with an altered *RET* oncogene will develop cancer. Blood tests and genetic tests can detect the gene. Once the altered *RET* oncogene is identified, a doctor may recommend surgery to remove the thyroid gland before cancer develops. People with MTC are encouraged to have genetic testing to determine if a mutation of the *RET* proto-oncogene is present. If so, genetic testing of siblings and children will be recommended.
- A family history of MTC increases a person’s risk. People with MEN2 syndrome are also at risk for developing other cancers.
- A family history of goiters increases the risk of developing papillary thyroid cancer.
- A family history of precancerous polyps in the colon (large intestines) increases the risk of developing papillary thyroid cancer.
Radiation exposure. Exposure to moderate levels of radiation may increase the risk of papillary and follicular thyroid cancers. Such sources of exposure include the following:

- Low-dose to moderate-dose x-ray treatments used before 1950 to treat children with acne, tonsillitis, and other head and neck problems may increase the risk of papillary and follicular thyroid cancers.
- People who have been treated with radiation therapy for Hodgkin lymphoma or other forms of lymphoma in the head and neck are at an increased risk for developing papillary or follicular thyroid cancer.
- Exposure to radioactive iodine (also called I-131 or RAI), especially in childhood, may increase the risk of papillary and follicular thyroid cancers. Sources of I-131 include radioactive fallout from atomic weapons testing during the 1950s and 1960s, nuclear power plant fallout (for example, the 1986 Chernobyl nuclear power plant accident and the 2011 earthquake that damaged nuclear power plants in Japan), and environmental releases from atomic weapon production plants.

Diet low in iodine. Iodine is needed for normal thyroid functioning. In the United States, iodine is added to salt to help prevent thyroid problems.

Race. White people and Asian people are more likely to develop thyroid cancer, but this disease can affect a person of any race or ethnicity.

Source #3: Genetic Testing for Hereditary Cancer Syndromes

This FactSheet developed by the National Cancer Institute (Reviewed 4/11/2013), explain how genetic mutations play a role in the development of all cancers. Most of these mutations occur during a person’s lifetime, but some mutations including those that are associated with hereditary cancer syndromes, can be inherited from a person’s parents. (http://www.cancer.gov/cancertopics/factsheet/Risk/genetic-testing)

What is genetic testing?

Genetic testing looks for specific inherited changes (mutations) in a person’s chromosomes, genes, or proteins. Genetic mutations can have harmful, beneficial, neutral (no effect), or uncertain effects on health. Mutations that are harmful may increase a person’s chance, or risk, of developing a disease such as cancer. Overall, inherited mutations are thought to play a role in about 5 to 10 percent of all cancers.

Cancer can sometimes appear to “run in families” even if it is not caused by an inherited mutation. For example, a shared environment or lifestyle, such as tobacco use, can cause similar cancers to develop among family members. However, certain patterns—such as the types of cancer that develop, other non-cancer conditions that are seen,
and the ages at which cancer typically develops—may suggest the presence of a hereditary cancer syndrome.

The genetic mutations that cause many of the known hereditary cancer syndromes have been identified, and genetic testing can confirm whether a condition is, indeed, the result of an inherited syndrome. Genetic testing is also done to determine whether family members without obvious illness have inherited the same mutation as a family member who is known to carry a cancer-associated mutation.

Inherited genetic mutations can increase a person’s risk of developing cancer through a variety of mechanisms, depending on the function of the gene. Mutations in genes that control cell growth and the repair of damaged DNA are particularly likely to be associated with increased cancer risk.

**Does someone who inherits a cancer-predisposing mutation always get cancer?**

**No.** Even if a cancer-predisposing mutation is present in a family, it does not necessarily mean that everyone who inherits the mutation will develop cancer. Several factors influence the outcome in a given person with the mutation.

One factor is the pattern of inheritance of the cancer syndrome. To understand how hereditary cancer syndromes may be inherited, it is helpful to keep in mind that every person has two copies of most genes, with one copy inherited from each parent. Most mutations involved in hereditary cancer syndromes are inherited in one of two main patterns: autosomal dominant and autosomal recessive.

With autosomal dominant inheritance, a single altered copy of the gene is enough to increase a person’s chances of developing cancer. In this case, the parent from whom the mutation was inherited may also show the effects of the gene mutation. The parent may also be referred to as a carrier.

With autosomal recessive inheritance, a person has an increased risk of cancer only if he or she inherits a mutant (altered) copy of the gene from each parent. The parents, who each carry one copy of the altered gene along with a normal (unaltered) copy, do not usually have an increased risk of cancer themselves. However, because they can pass the altered gene to their children, they are called carriers.

A third form of inheritance of cancer-predisposing mutations is X-linked recessive inheritance. Males have a single X chromosome, which they inherit from their mothers, and females have two X chromosomes (one from each parent). A female with a recessive cancer-predisposing mutation on one of her X chromosomes and a normal copy of the gene on her other X chromosome is a carrier but will not have an increased risk of cancer. Her sons, however, will have only the altered copy of the gene and will therefore have an increased risk of cancer.
Even when people have one copy of a dominant cancer-predisposing mutation, two copies of a recessive mutation, or, for males, one copy of an X-linked recessive mutation, they may not develop cancer. Some mutations are “incompletely penetrant,” which means that only some people will show the effects of these mutations. Mutations can also “vary in their expressivity,” which means that the severity of the symptoms may vary from person to person.

What genetic tests are available for cancer risk?

More than 50 hereditary cancer syndromes have been described. The majority of these are caused by highly penetrant mutations that are inherited in a dominant fashion. The list below includes some of the more common inherited cancer syndromes for which genetic testing is available, the gene(s) that are mutated in each syndrome, and the cancer types most often associated with these syndromes.

**Hereditary breast cancer and ovarian cancer syndrome**
- Genes: *BRCA1, BRCA2*
- Related cancer types: Female breast, ovarian, and other cancers, including prostate, pancreatic, and male breast cancer

**Li-Fraumeni syndrome**
- Gene: *TP53*
- Related cancer types: Breast cancer, soft tissue sarcoma, osteosarcoma (bone cancer), leukemia, brain tumors, adrenocortical carcinoma (cancer of the adrenal glands), and other cancers

**Cowden syndrome (PTEN hamartoma tumor syndrome)**
- Gene: *PTEN*
- Related cancer types: Breast, thyroid, endometrial (uterine lining), and other cancers

**Lynch syndrome (hereditary nonpolyposis colorectal cancer)**
- Genes: *MSH2, MLH1, MSH6, PMS2, EPCAM*
- Related cancer types: Colorectal, endometrial, ovarian, renal pelvis, pancreatic, small intestine, liver and biliary tract, stomach, brain, and breast cancers
Familial adenomatous polyposis

- Gene: APC
- Related cancer types: Colorectal cancer, multiple non-malignant colon polyps, and both non-cancerous (benign) and cancerous tumors in the small intestine, brain, stomach, bone, skin, and other tissues

Retinoblastoma

- Gene: RB1
- Related cancer types: Eye cancer (cancer of the retina), pinealoma (cancer of the pineal gland), osteosarcoma, melanoma, and soft tissue sarcoma

Multiple endocrine neoplasia type 1 (Wermer syndrome)

- Gene: MEN1
- Related cancer types: Pancreatic endocrine tumors and (usually benign) parathyroid and pituitary gland tumors

Multiple endocrine neoplasia type 2

- Gene: RET
- Related cancer types: Medullary thyroid cancer and pheochromocytoma (benign adrenal gland tumor)

Von Hippel-Lindau syndrome

- Gene: VHL
- Related cancer types: Kidney cancer and multiple noncancerous tumors, including pheochromocytoma

Who should consider genetic testing for cancer risk?

Many experts recommend that genetic testing for cancer risk should be strongly considered when all three of the following criteria are met:

- The person being tested has a personal or family history that suggests an inherited cancer risk condition
- The test results can be adequately interpreted (that is, they can clearly tell whether a specific genetic change is present or absent)
- The results provide information that will help guide a person’s future medical care
The features of a person’s personal or family medical history that, particularly in combination, may suggest a hereditary cancer syndrome include:

- Cancer that was diagnosed at an unusually young age
- Several different types of cancer that have occurred independently in the same person
- Cancer that has developed in both organs in a set of paired organs, such as both kidneys or both breasts
- Several close blood relatives that have the same type of cancer (for example, a mother, daughter, and sisters with breast cancer)
- Unusual cases of a specific cancer type (for example, breast cancer in a man)
- The presence of birth defects, such as certain noncancerous (benign) skin growths or skeletal abnormalities, that are known to be associated with inherited cancer syndromes
- Being a member of a racial/ethnic group that is known to have an increased chance of having a certain hereditary cancer syndrome and having one or more of the above features as well

It is strongly recommended that a person who is considering genetic testing speak with a professional trained in genetics before deciding whether to be tested. These professionals can include doctors, genetic counselors, and other health care providers (such as nurses, psychologists, or social workers). Genetic counseling can help people consider the risks, benefits, and limitations of genetic testing in their particular situation. Sometimes the genetic professional finds that testing is not needed.

**How is genetic testing done?**

Genetic tests are usually requested by a person’s doctor or other health care provider. Although it may be possible to obtain some genetic tests without a health care provider’s order, this approach is not recommended because it does not give the patient the valuable opportunity to discuss this complicated decision with a knowledgeable professional.

Testing is done on a small sample of body fluid or tissue—usually blood, but sometimes saliva, cells from inside the cheek, skin cells, or amniotic fluid (the fluid surrounding a developing fetus).

The sample is then sent to a laboratory that specializes in genetic testing. The laboratory returns the test results to the doctor or genetic counselor who requested the test. In some cases, the laboratory may send the results to the patient directly. It usually takes several weeks or longer to get the test results. Genetic counseling is recommended both before and after genetic testing to make sure that patients have accurate information about what a particular genetic test means for their health and care.
What do the results of the genetic testing mean?

Genetic testing can have several possible results: positive, negative, true negative, uninformative negative, false negative, variant of unknown significance, or benign polymorphism. These results are described below.

A “positive test result” means that the laboratory found a specific genetic alteration (or mutation) that is associated with a hereditary cancer syndrome. A positive result may:

- Confirm the diagnosis of a hereditary cancer syndrome
- Indicate an increased risk of developing certain cancer(s) in the future
- Show that someone carries a particular genetic change that does not increase their own risk of cancer but that may increase the risk in their children if they also inherit an altered copy from their other parent (that is, if the child inherits two copies of the abnormal gene, one from their mother and one from their father).
- Suggest a need for further testing
- Provide important information that can help other family members make decisions about their own health care.

Also, people who have a positive test result that indicates that they have an increased risk of developing cancer in the future may be able to take steps to lower their risk of developing cancer or to find cancer earlier, including:

- Being checked at a younger age or more often for signs of cancer
- Reducing their cancer risk by taking medications or having surgery to remove “at-risk” tissue (These approaches to risk reduction are options for only a few inherited cancer syndromes.)
- Changing personal behaviors (like quitting smoking, getting more exercise, and eating a healthier diet) to reduce the risk of certain cancers

A positive result on a prenatal genetic test for cancer risk may influence a decision about whether to continue a pregnancy. The results of pre-implantation testing (performed on embryos created by in vitro fertilization) can guide a doctor in deciding which embryo (or embryos) to implant in a woman’s uterus.

Finally, in patients who have already been diagnosed with cancer, a positive result for a mutation associated with certain hereditary cancer syndromes can influence how the cancer is treated. For example, some hereditary cancer disorders interfere with the body’s ability to repair damage that occurs to cellular DNA. If someone with one of these conditions receives a standard dose of radiation or chemotherapy to treat their cancer, they may experience severe, potentially life-threatening treatment side effects. Knowing about the genetic
disorder before treatment begins allows doctors to modify the treatment and reduce the severity of the side effects.

A “negative test result” means that the laboratory did not find the specific alteration that the test was designed to detect. This result is most useful when working with a family in which the specific, disease-causing genetic alteration is already known to be present. In such a case, a negative result can show that the tested family member has not inherited the mutation that is present in their family and that this person therefore does not have the inherited cancer syndrome tested for, does not have an increased genetic risk of developing cancer, or is not a carrier of a mutation that increases cancer risk. Such a test result is called a “true negative.” A true negative result does not mean that there is no cancer risk, but rather that the risk is probably the same as the cancer risk in the general population.

When a person has a strong family history of cancer but the family has not been found to have a known mutation associated with a hereditary cancer syndrome, a negative test result is classified as an “uninformative negative” (that is, does not provide useful information). It is not possible to tell whether someone has a harmful gene mutation that was not detected by the particular test used (a “false negative”) or whether the person truly has no cancer-predisposing genetic alterations in that gene. It is also possible for a person to have a mutation in a gene other than the gene that was tested.

If genetic testing shows a change that has not been previously associated with cancer in other people, the person's test result may report “variant of unknown significance,” or VUS. This result may be interpreted as “ambiguous” (uncertain), which is to say that the information does not help in making health care decisions.

If the test reveals a genetic change that is common in the general population among people without cancer, the change is called a polymorphism. Everyone has commonly occurring genetic variations (polymorphisms) that are not associated with any increased risk of disease.

**Who can help people understand their test results?**

A genetic counselor, doctor, or other health care professional trained in genetics can help an individual or family understand their test results. Such counseling may include discussing recommendations for preventive care and screening with the patient, referring the patient to support groups and other information resources, and providing emotional support to the person receiving the results.
In some cases, a genetic counselor or doctor may recommend that other family members consider being tested for specific gene changes that indicate an increased risk of cancer. The decision to test other family members is complicated. It requires a careful evaluation of family history and other factors as well as advice from a genetic counselor or other professional trained in genetics. In general, physicians rely on the family member who has been tested to share the genetic information with their relatives so that family members will know that a genetic condition has been identified in their family. Then, each family member will need to make their own decision regarding whether or not to be tested themselves.

**Source #4: Genetic Testing for Cancer: Pros and Cons**

This article written by Nick Zagorski for the National Cancer Institute (February 23, 2005), gives an overview of the pros and cons of genetic testing for cancer. It gives both a medical perspective, but also takes into account the human emotional impact the results of a genetic screening test could have.

It can be difficult enough to hear a doctor tell you that you have been diagnosed with cancer, but how would someone react if a doctor told them that while they might be healthy now, they are likely to have cancer in the future? Most cancers arise from spontaneous DNA mutations that accumulate in a cell over time, whether due to environmental exposure, lifestyle factors, or random chance. Individual cells will pick up different genetic mutations, and in some cases a cell can acquire the right—or wrong, as the case may be—combination of mutations to trigger carcinogenesis.

However, approximately 5-10 percent of all cancers are hereditary, or familial. These cancers arise in certain individuals that carry a defective gene or genes which they inherited from their parents and could then pass on to their offspring. Since they have a copy of this defective gene in every cell in their body, carriers of familial cancer genes are far more likely to develop cancer. Joyce Seldon, a certified genetic counselor at UCLA’s Jonsson Comprehensive Cancer Center, points out, though, “that unlike other hereditary diseases such as cystic fibrosis, inheriting one of these genes does not automatically mean that a person will get cancer.”

Still, the increased cancer risk these individuals face is tremendous. For example, women who carry a defective BRCA1 gene, which is critical for repairing mutated DNA, have as much as an 85 percent risk of developing breast cancer and a 65 percent risk for ovarian cancer; they also have an increased risk of developing secondary cancers after they get breast or ovarian cancer, and generally develop cancer at an earlier age than non-carriers.

“Normal recommendations call for regular mammography screenings beginning at age 40,” says Jeffrey Weitzel, M.D, City of Hope Comprehensive Cancer Center, “but this is
often too late for BRCA1 carriers; they should begin surveillance at age 25 instead of 40. So it is important to understand who is at risk.”

Fortunately, advances in genetics make it possible to identify some of those people at increased risk. In addition to BRCA1, susceptibility genes have been identified for numerous cancers. For other cancers exact genes aren’t known, but susceptibility loci, or the general location on a chromosome, have been identified. NCI researchers have even identified a susceptibility locus for lung cancer, which has traditionally been viewed primarily as a lifestyle disease. Because affected people have these mutations in all of their cells, genetic tests of blood samples can look at the genes, or markers near the genes, to identify people who may have an increased risk of cancer.

But while genetic testing can be done, a more pertinent issue is whether it should be done, and how the results should be used. Positive results can be psychologically overwhelming, and create difficult long-term decisions. “Right now there is no effective early detection for ovarian cancer,” says Seldon, “which is why it’s known as the silent killer. BRCA1 carriers, especially those with a family history of ovarian cancer, may have to choose between risking cancer or removing their ovaries and no longer being able to have children.”

“The results of genetic testing affect whole families and not just the individual,” Seldon adds. Relatives discover they may also carry an increased risk, while parents may worry whether they have passed the mutant gene on to their children. For Seldon, and other genetic counselors, they have the sometimes difficult job of presenting genetic test results to patients, and they provide both comfort and professional guidance as the individual explores all possible options.

Genetic testing, regardless of whether it turns out positive, negative, or even inconclusive, brings up some ethical issues as well. “There’s the potential issue of physician liability,” says Weitzel, “in cases where they fail to diagnose cancer predisposition, and no screening is offered, and then that person goes on to get cancer.” Weitzel believes physicians need to be more proactive in assessing individuals that have a strong chance to be carriers and recommending testing and counseling.

A bigger dilemma is how to incorporate genetic testing with health insurance. ” Many people fear that a positive result will make them a target of genetic discrimination if the insurance finds out,” says Dr. Weitzel. “However, most patients and their physicians are unaware of existing protective legislation or the lack of problems identified to date.” The confidentiality of the patient is a two-way street, however, since insurance companies can also fear that individuals may take advantage of their private knowledge of their increased risk. Genetic tests are also expensive, (“Although it is far cheaper to get this test than to get cancer,” Seldon points out), which brings up the question of whether insurance should cover a procedure that may not qualify as preventive or therapeutic. “This is complicated on all sides of the issue,” says Weitzel, “but we don’t want a system that hinders people for trying to prevent cancer.”
Question #1: All of the sources provided information about cancer. Which source would most likely be relevant to students researching about the risk factors that can cause cancer? Support your response with two details from the source. Justify your answer and support it with information from the source.

Question #2: In source #4 (Genetic Testing for Cancer: Pros and Cons), the author gave both a medical perspective and a human-driven perspective of the pros and cons of genetic testing for cancer. In the table below, list 2-3 pros and 2-3 cons that were stated in the article. Make sure to document which paragraph each pro or con was present in, with your response.

<table>
<thead>
<tr>
<th>Paragraph #</th>
</tr>
</thead>
</table>

Pros:

Cons:
**Question #3:** Paraphrase information from Source #1 that provides similar/different information from Source #2 in regard to thyroid cancer screening testing without plagiarizing.

**Similar Information:**

**Contradicting Information:**
Part 2

You will have the opportunity to review your notes and sources, plan, draft and revise your argumentative article. You may use your notes, and refer to the sources during this part of the task. You may also refer to the answers you wrote to the questions in part 1. Now read your assignment and begin your work.

Your Assignment

You are completing an argumentative article for a major magazine about a teenager (Max) who has many family members on his mother’s side that have died at an early age from thyroid cancer. The article will focus on whether he should/shouldn’t be genetically tested for the presence of the MEN II (multiple endocrine neoplasia type 2) gene based on numerous factors. Be sure your article acknowledges both the pros and cons of the proposed genetic testing, so that people know that you have considered this bioethical topic carefully. You do not need to use all of the sources, only the ones that most effectively and credibly support your decision and your consideration of the opposing view.

Max

Max is 15 years old. Many of Max’s relatives on his mother’s side died quite young (20s, 30s, and 40s) from thyroid cancer. Max’s mom died several years ago, but not from thyroid cancer. There are many genetic reasons for thyroid cancer, including an inherited mutation that leads to a rare disorder called MEN II (multiple endocrine neoplasia 2). The MEN II-causing mutation leads to a 100-percent chance of a kind of thyroid cancer that will be fatal if left untreated. The thyroid cancer arises early in life, sometimes even during adolescence.

Max’s doctor informs Max and his father that there is a genetic test for this inherited mutation. (None of Max’s other relatives have ever been tested). If Max tested positive, he could soon have surgery to remove his thyroid gland so that he would never develop thyroid cancer. Without his thyroid, Max would have to take a daily pill containing a hormone called thyroxine, an important chemical produced by the thyroid gland, for the rest of his life. The doctors would determine the appropriate dosage for Max. if the dosage isn’t quite right, Max could temporarily experience side effects such as sweating, muscle cramps, and severe headaches. However, if he experienced these symptoms, the doctors would adjust the dosage, and the side effects normally disappear. If people without thyroids fail to take their medication for long periods of time, their metabolism is dangerously affected; eventually, failure to take the medication can be fatal.

Max refuses to have the genetic test, insisting it is his life. He doesn’t want this information, says he wouldn’t want preventive surgery and doesn’t like the idea of daily medication after surgery. Max’s father and doctor still insist that he should have the genetic test. Max’s family pedigree is available to assist you with your decision as well.