

Possible Benefits and Risks of Genetic Screening



Age-Based Genomic Screening

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Website: go.unc.edu/abgs



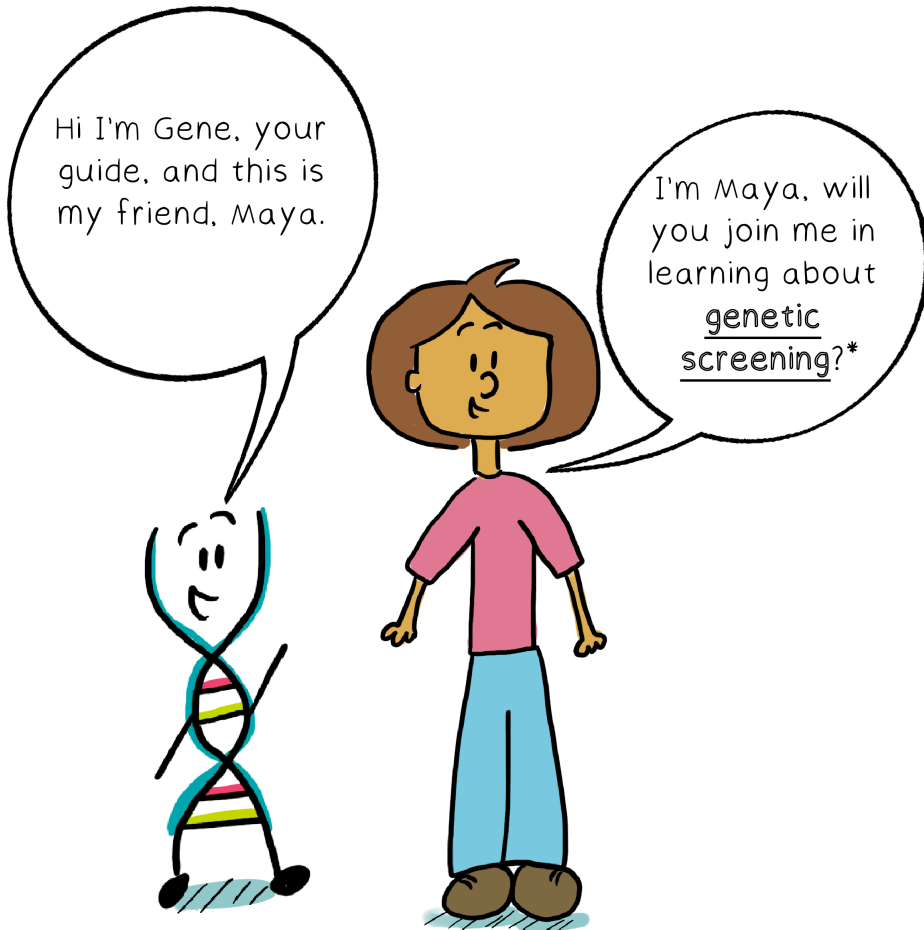
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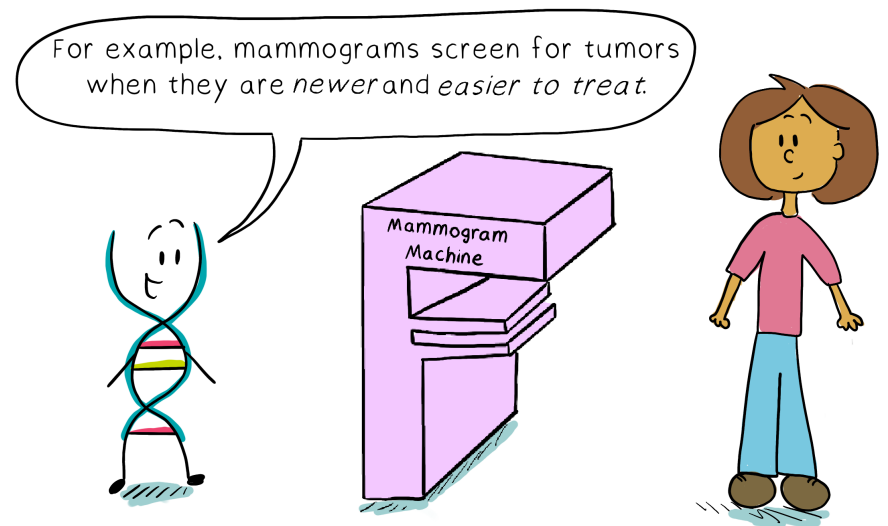
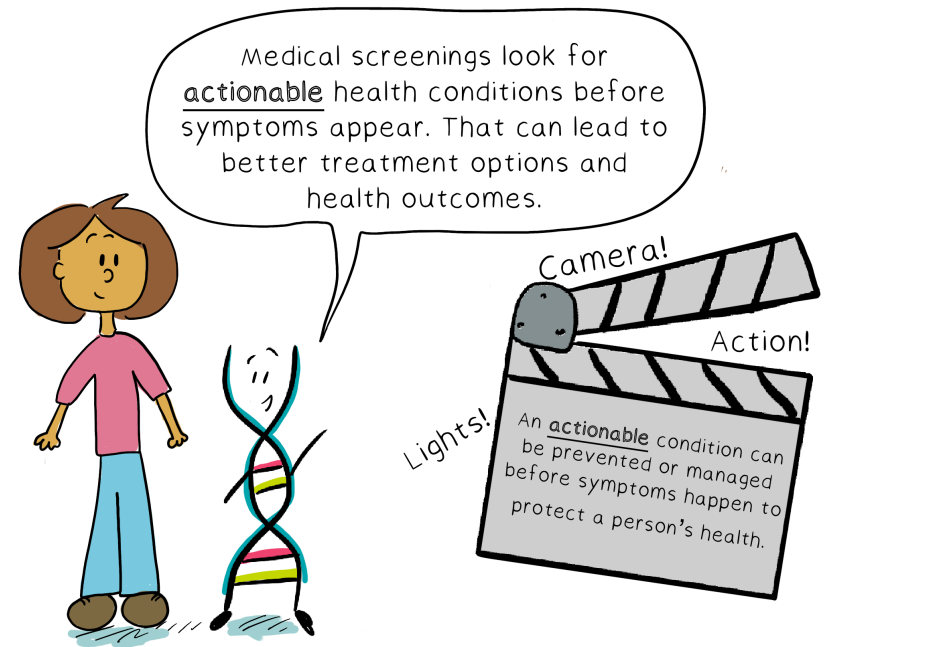


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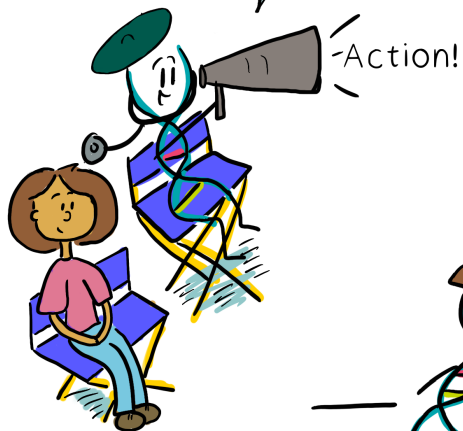
Chapter 1: What is genetic screening?



*Highlighted vocabulary words are defined in the Glossary at the end of this comic.



Genetic screening is one type of medical screening. It uses DNA sequencing to look for differences in the spelling of a gene's "ATGC" alphabet.



Some spelling differences cause the gene not to work correctly and are called disease-related genetic variants. They may cause disease.

The Case of the Disease-Related Variant!



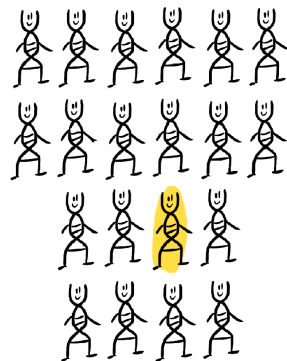
Certain cancers can be caused by inherited disease-related genetic variants in two well-known genes called *BRCA1* and *BRCA2*.



The job of the *BRCA1* and *BRCA2* genes is to help our body stop tumors from growing.

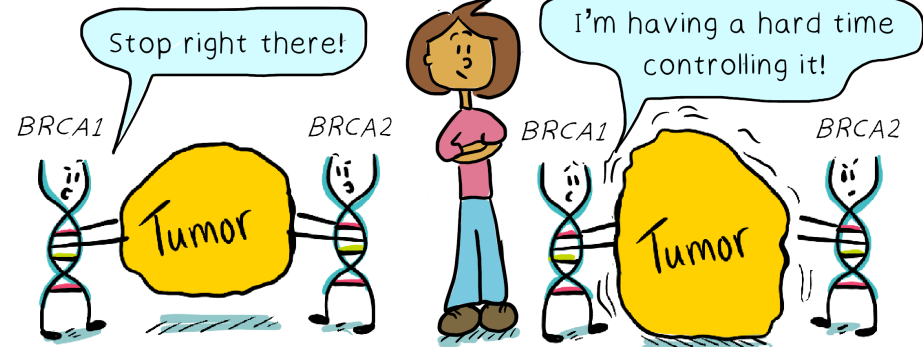
People who inherit disease-related variants in their *BRCA1* or *BRCA2* gene are more likely to develop breast and ovarian cancer.

Genetic screening can help find people who are at higher risk of an actionable genetic condition, but don't know it yet.



About 1 in 20 people has an actionable genetic condition

If someone learns about their risk, they can stay ahead of possible health problems by working with their doctor.



Genetic screening can check for harmful variants in these and certain other genes to catch any issues early.

Chapter 2: Benefits of Screening

Maya has learned she has a *BRCA1* variant.
This means her risk of breast cancer is *much higher* than average.
Now she and her doctor are taking steps to *lower her risk* and keep her healthy.



Let's talk about
next steps.

Maya's Genetic Screening Findings

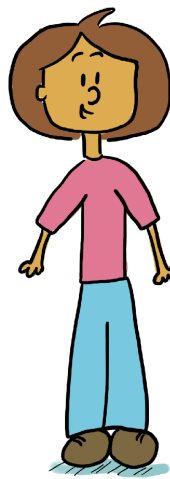
+ *BRCA1* disease-related
genetic variant



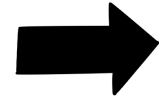
Normal
risk



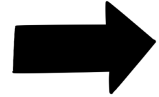
Maya's
risk



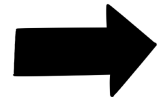
1. Genetic screening can find health risks early so you and your doctor can plan checkups or early treatment before symptoms start.



Act early

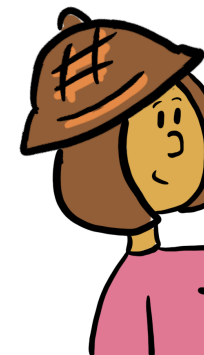


Plan care



Stay healthy

2. Since we share genes with *blood relatives*, your genetic screening results can give your family *helpful clues* about their own health.

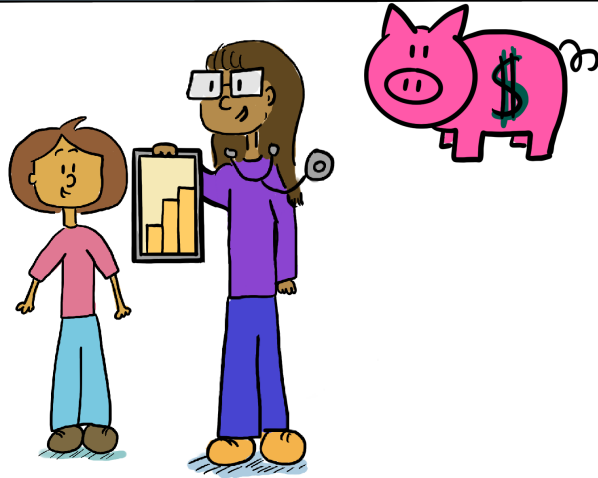


Health of Family Tree



3. Genetic screening can also provide information about health risks for people who *don't know their family medical history*, like those who are adopted.

4. Genetic screening gives your doctor a clearer view of your overall health.



5. This may help prevent serious illness or lower medical costs.



Chapter 3: Risks of Screening

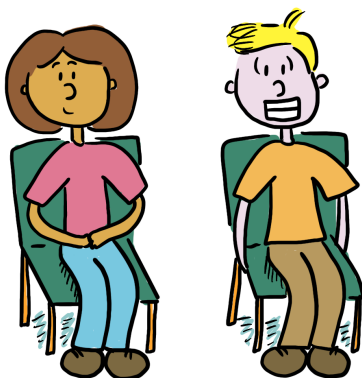
Genetic screening has risks, especially for children. What you learn from a genetic screening can shape your health journey for life!



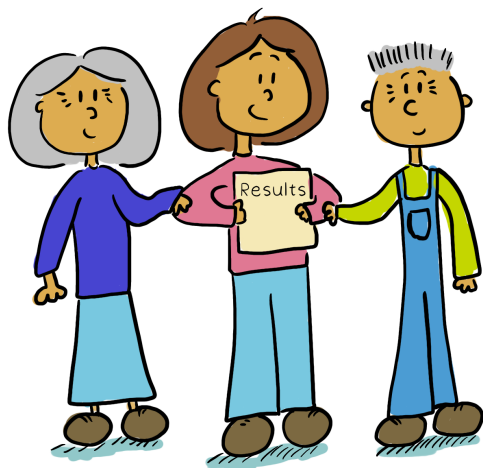
1: Your DNA carries sensitive information about your health, your family, and even your future.
Ask where your data will go and what control you'll have over it.

2: Waiting for results or learning about a possible health risk can feel *overwhelming*. Some people feel *empowered*, others feel *anxious*.

Waiting Room



3: Your results could show something that also matters for your family members' health.



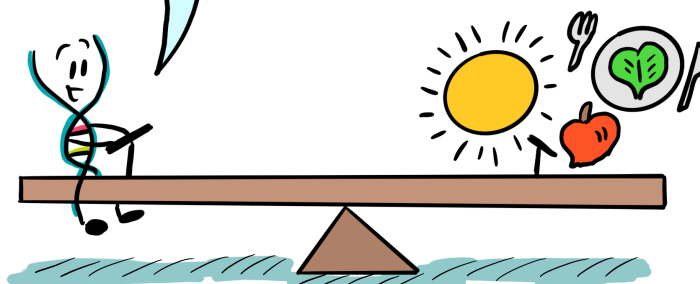
4. Sometimes results aren't clear or they need more follow-up.



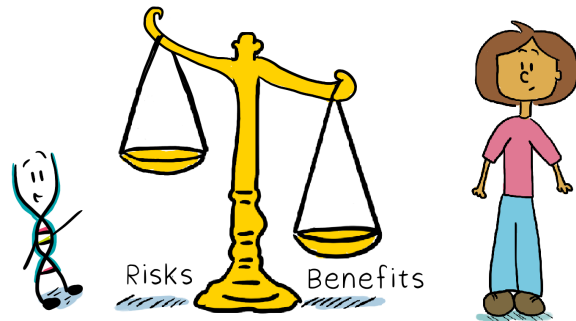
Symptoms (later)
Symptoms (mild)
Symptoms (?)

5. Not everyone experiences a harmful gene variant the same way. One person may have mild symptoms, another more serious ones, or not at all.

That's why genes aren't the whole story. Lifestyle, environment, and other factors matter too.



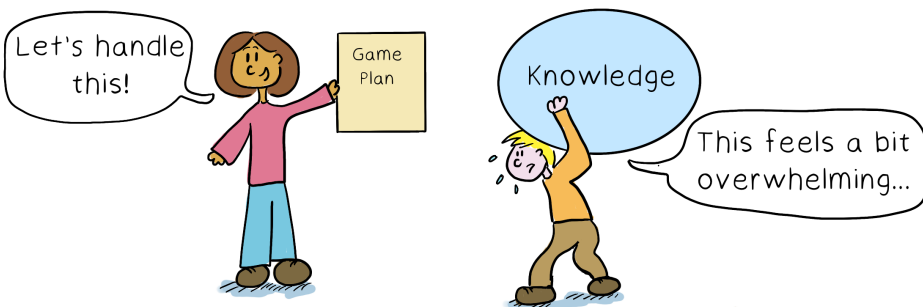
Deciding about screening means weighing both the benefits and the risks and having support to choose what feels right for you and your family.



Your doctor can help you make an informed decision before you move forward with a genetic screening. You may also want to consult with a genetic counselor.



Genetic screening gives you a chance to *plan for* and possibly *prevent* future health problems, but it also means learning about them sooner, which can be *stressful*! Ask what support is available to deal with anxiety or worry this might cause.



You can also ask about a law called the Genetic Information Nondiscrimination Act or **GINA** that protects against genetic discrimination in health insurance and employment, but not in life, disability, or long-term care insurance.



Ask how much the screening and follow-up care might cost and if insurance will help cover it.



Genetic screening can't find everything that could make you sick, so make sure you understand what it does and doesn't look for. And remember, even with a 'normal' result, you may still have some chance of health issues in the future.

Screening

Looks for

Doesn't look for



Results
↑ Risk
= Lifestyle Changes



An abnormal result may mean more doctor visits or lifestyle changes. Ask what kind of follow-up would be needed and decide if it is manageable for your family.

Abnormal

Extra Doctor Visits and Mammograms

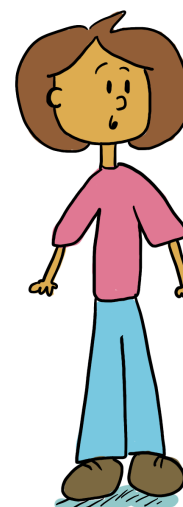
Genetic Screening Results

Game Plan



Right now, genetic screening is not yet widely available in everyday healthcare. For now, the most common way to get genetic screening is through research studies.

Why should you consider joining a research study? Because results could give you information you can act on, not just for cancer, but for other conditions too.



Interested in learning more about your DNA?
Join a research study!



Chapter 4: Research Studies

If you are getting genetic screening as part of a research study, you will start with 'informed consent.' That's a conversation with the research team to explain what the screening involves, the possible benefits and risks, and how your information will be used and protected.



Informed Consent	
Risks	Benefits
<input type="checkbox"/> _____	<input type="checkbox"/> _____
<input type="checkbox"/> _____	<input type="checkbox"/> _____
<input type="checkbox"/> _____	<input type="checkbox"/> _____

The decision to participate is yours alone. Informed consent helps you choose what feels right, so ask questions and get any guidance you need before deciding.

Sign me up!

No thanks.
I'm not
interested.

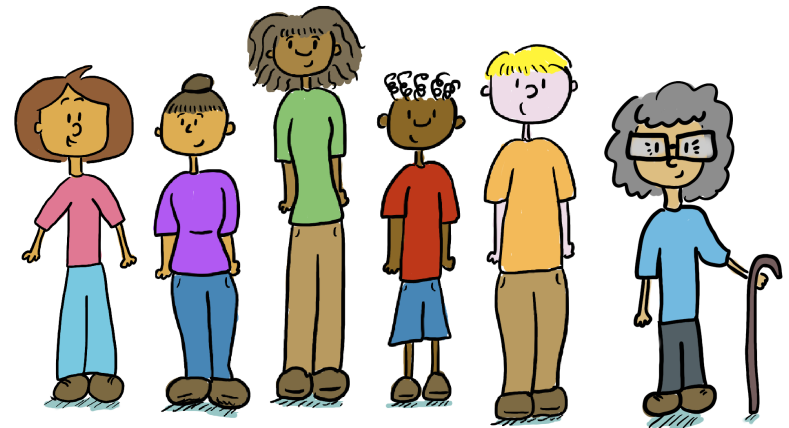
I'm done
participating.
thank you!



By participating in a research study, you are helping to make health care better for everybody! Not everyone has had the same access to research or health care. When studies leave out certain groups, results don't reflect everyone's needs and that can lead to care that doesn't work as well for everyone.

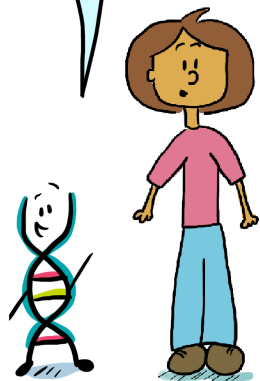


Genetic Screening for everyone!



A key goal of modern research programs is to make genetic screening more understandable, available and useful to everyone. For screening to truly benefit all communities, everyone needs a fair chance to access it.

Research teams are working with community members to improve health care for people from all backgrounds.



You can help too. Joining a study or sharing what you learn helps include more voices and builds a healthier future for everyone.



Your participation can help to improve medicine for all!

Genetic screening can help people find hidden health risks, even if they feel healthy now.

It's a personal choice, and talking with your doctor can help you figure out what's best for you and your family.

Plain Language Glossary

- **Actionable**: a condition that can be prevented or managed before symptoms happen in order to protect health
- **Disease-related genetic variant**: a spelling difference that causes the gene to not work correctly and can cause disease.
- **DNA**: the blueprint for a person which is written in letters "A, G, C, T" and inherited across each generation
Gene: a small piece of DNA that provide the code for specific functions or traits
- **Gene**: a small piece of DNA that provides the code for specific functions or traits.
- **Genetic and genomic research**: Research that looks at DNA and other types of data to help us learn more about how to detect and treat diseases in people
- **Genetic Information Non-discrimination Act ((GINA))**: A US law that provides protections against genetic discrimination in health insurance and employment
- **Genetic screening**: a specific type of population screening that involves reading a person's DNA to see if they have any potentially disease-causing or "pathogenic" variants
- **Inherited**: a trait, disease, or condition that is passed down through a family by each generation
- **Informed consent**: A conversation between a researcher and person interested in being part of a research study. The researcher will explain the risks and benefits of being a part of the study and answer any questions before a person can join the study.