Adolescent Brain Cognitive Development®
*Teen Brains. Today's Science. Brighter Future.*

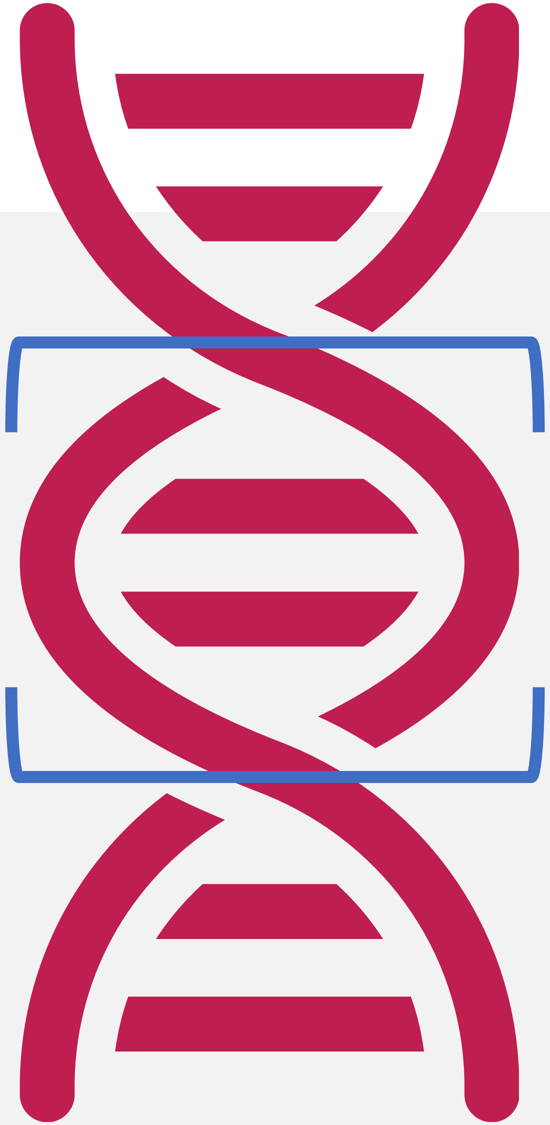
# Consenting to Receive Genetic Risk Results: What You Should Know

National Institute
on Drug Abuse

# Overview: Genetic Risk Results

We are using a new type of genetic testing with the blood or saliva samples you previously provided in ABCD. This genetic test allows scientists to study a person’s genes. The information this test provides is useful to ABCD researchers who want to understand more about how genes affect health and other outcomes in life.

With this new genetic testing, we may learn more about your chances of getting certain treatable or preventable health conditions and diseases based on what genes you have. This is known as your “genetic risk.” Participants over the age of 18 can get these genetic risk results back, if they want.



**DNA**:

A biological molecule found in cells that contains instructions for how the body works.

**Gene**:

An individual unit of DNA that is passed on from generation to generation.

# Overview: Genetic Risk Results

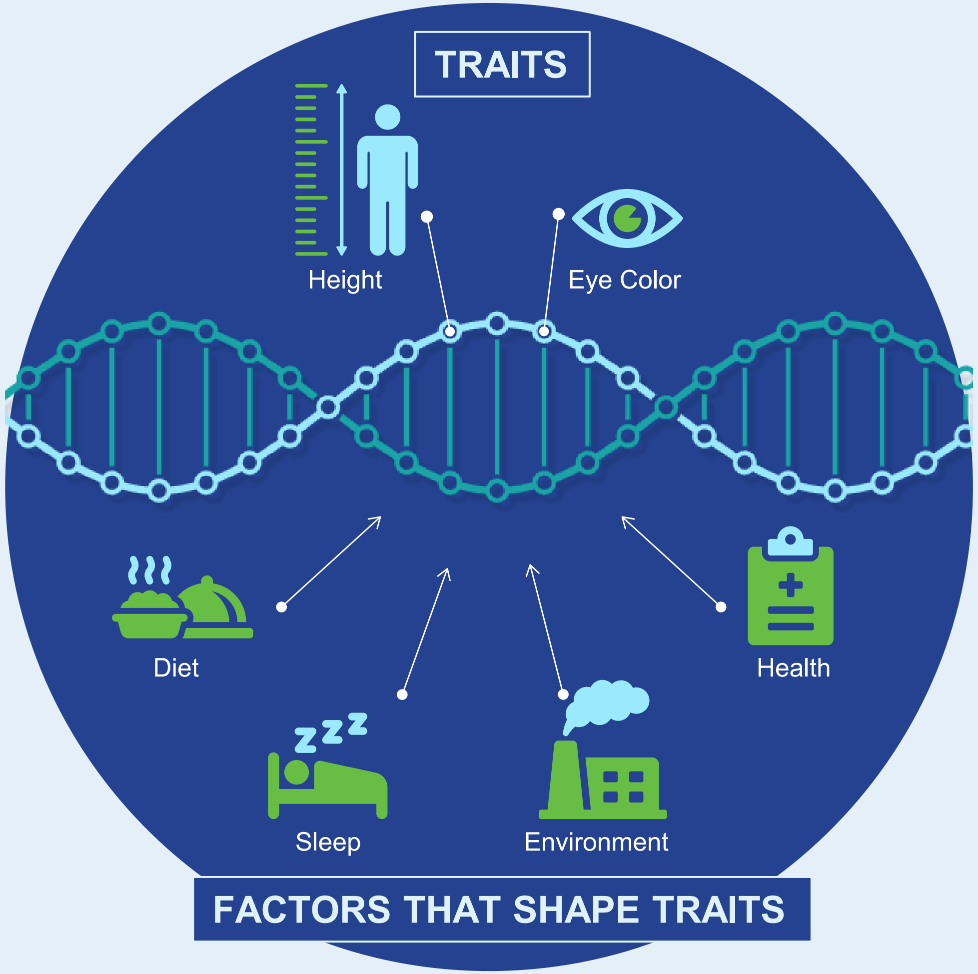
You will be asked at your upcoming ABCD visit if you want to receive these results. There are potential positives (pros) and negatives (cons) to receiving them. We want you to make the best decision for yourself. Before you decide, you will get some information that explains:

1. What DNA is, and how it can affect your risk for certain diseases or health conditions
2. How we will check your genetic risk and share the results with you if you want them
3. The possible pros and cons of getting your results
4. The choices you have about learning your results

# How does DNA affect my health?

DNA is an important part of what makes you, you! It carries information that is passed on from one generation to the next. For example, DNA determines things about you like the color of your eyes, and it's also why children often look like their parents. DNA can also influence our health and our risk of getting specific diseases and conditions.

But your DNA is not the only factor that determines your health or risk of disease. Our life experiences can play a major role in shaping traits (or characteristics), health outcomes, and risk of getting certain conditions. For example, someone with genes that would allow them to grow very tall may not reach their full height potential without proper nutrition. This is why even identical twins can sometimes have differences!



# What health conditions will I find out about?

Genetics can influence the risk of many diseases. However, we will only look at certain genes that are on the current list (3.2) developed by the American College of Medical Genetics (ACMG). This list:

- Was created by experts in medical genetics (doctors and scientists).
- Includes genes that are **very likely** to increase the risk of getting certain diseases or health conditions, like certain types of cancer and heart disease.
- Only includes diseases or conditions:
  - That are **treatable or could be preventable**.
  - Where finding out early diagnosis is helpful for treatment.
  - For which a DNA test is the main way you would learn that you are at increased risk for that condition.

ABOUT

**97%**

**of people DO NOT have genetic disease risk based on the ACMG list, so you're unlikely to have a positive risk result.**

# What health conditions are not included?

The ACMG list **does not include** conditions:

- For which there is no medical treatment option.
- That would typically be diagnosed by a doctor during routine check-ups.

Routine check-ups don’t test for many genetic diseases and conditions, and the ACMG list can fill in these gaps. **However, the list is still limited to the conditions explained above and in the previous slide.**

If you’re interested in having genetic testing for a specific condition, you should talk to your doctor or purchase a commercial test.

# What is the process? How do I get my results?

ABCD scientists will do an initial screen of your DNA through your blood or saliva to look for genetic risk factors.

**You won’t be charged for any part of this process.**

If you **do have a genetic risk** for a disease or condition based on the ACMG list screen:

- Someone from the ABCD Study team will contact you and connect you with a company that offers clinical genetic testing and genetic counseling.
- You will create an account with the genetic testing company.
- The company will send a kit for you to provide another saliva sample.
- The company will repeat the test to confirm the results from the ABCD screen.

If you **don’t have a genetic risk** for a disease or condition based on the ACMG list screen:

- You will get a report that says so and explains what this means.

# What happens if I need a repeat test?

If the **repeat test is positive**, a genetic counselor will:

- Send you a report.
- Tell you what your results mean.
- Answer your questions.
- Send a report to your health care provider (**if you want**), who can help you decide what medical treatment or tests you might need.

The repeat test will only be negative in very rare cases. If the repeat test is negative, you will receive a report that will tell you what your results mean.

## What is a genetic counselor?

A genetic counselor is a health care professional trained to help people understand how their genetics may affect their health, but they don't provide treatment.

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Watch a video to learn more about genetic counselors.

# How long will it take?

There are nearly 12,000 participants in the ABCD Study, and we still need to analyze the genetic data from a few thousand participants. This means it may take a year or more to get your results. If you agree to receive your results but you don’t hear from anyone in the ABCD Study, your sample may not have been tested yet.

**Initial test: up to 1 year to complete; already done for 75% of participants**

**If confirmatory testing is needed: 1-2 weeks from sign-up to receiving your kit**

**Once confirmatory sample is sent in:**
**3-6 weeks to get results**

# What are the possible drawbacks of getting my genetic risk results?

The next section will review some important information to think about when you're deciding whether to receive genetic risk results. We will cover how your test results might affect your:

**Health care**

**Employment or insurance coverage**

**Emotional well-being**

The possible downsides covered here are the ones people most commonly experience after genetic testing. There may be other downsides that aren't listed.

# Could learning about my genetic risk results affect my health care?

If your results indicate risk for a health condition, we recommend you talk to your health care provider or doctor about the results.

**What is a health care provider?**

They are a doctor, nurse practitioner, or physician assistant who you visit for things like check-ups, shots, or if you’re feeling sick.

You and your health care provider can decide what care is right for you based on your results. Any changes you decide to make to your health care **could cost more** than your current care.

If you don’t have a health care provider, your ABCD Study site can give you a list of local health care resources to contact.

# Could learning about my genetic risk results affect my employment or insurance?

The ABCD Study will NOT share your results with your employer or insurance companies. Employers and insurers can ONLY get this information from your medical record.

- Because our genetic tests are not performed as part of your health care, getting your results back **does not** automatically add these results to your medical record.
- If you share your results with your doctor and they diagnose you with a medical condition, that information **will** become part of your medical record.

**Currently, a federal law protects most people from their health insurance and employer using genetic results**, but some insurers and employers can use this information to inform coverage or employment decisions.

# Who can and cannot use my genetic results?

| | ✗ CANNOT use genetic results | ✓ CAN use genetic results | ! Types of actions and decisions |
|---|---|---|---|
| **Employers** | Most employers | The military or employers with fewer than 15 employees* | Hiring, firing, promotions, pay, and job assignments |
| **Insurance** | Health | Disability, life, or long-term care | Whether you can be covered or how much it costs |

* In California, the law applies to employers with fewer than five employees.

# Types of Insurance

**Life insurance** pays money to people you choose (like a spouse or children) if you die.

**Disability insurance** gives you some income if you lose the ability to work due to a disability.

**Long-term care insurance** helps pay for the cost of care to help with daily living, like in-home nurses, nursing home care, or end-of-life care.

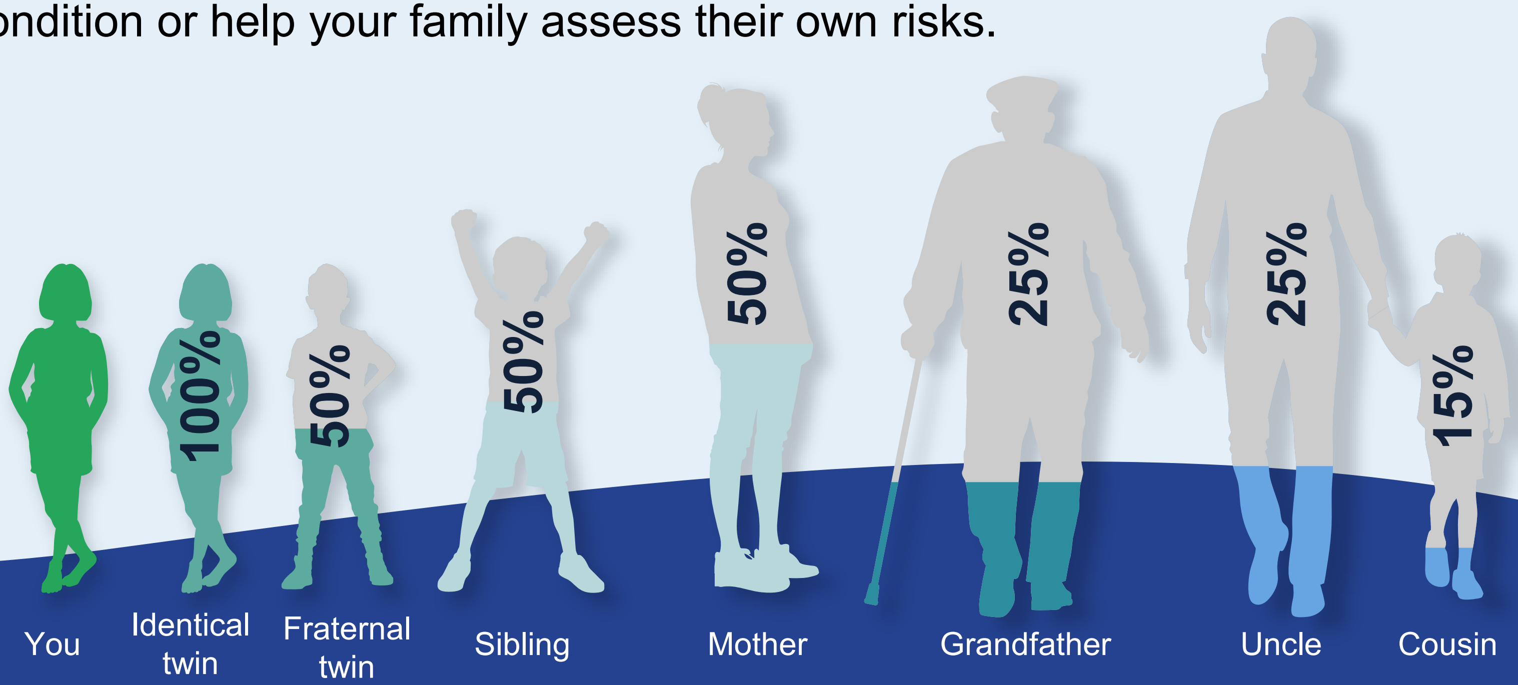
# What are the possible benefits of getting my genetic risk results?

**Your results could help you make decisions about your health care that reduce your risk of getting diseases in the future. They may also allow for earlier detection (a disease being found earlier) and treatment if you develop the disease.**

Because many of these conditions can be severe, knowing this information may be lifesaving.

**Your results could also help family members.** People that you share DNA with, like your parents and siblings, might have the same genetic risk that you do. This is especially true if you are an identical twin or triplet. Your results might help explain the history of a family health condition or help your family assess their own risks.

You may want to talk to your family before you decide whether to get your results and ask if **they** would want to learn about **your** results. Your family members may want to get tested themselves, which could help them stay healthy longer.



HOW MUCH **DNA** DO WE SHARE?

# Could learning about my genetic risk results affect me emotionally?

- You may be glad that you found out about your genetic risk because you can use this information to help make decisions about your future and inform family members.
- You may have to figure out how to tell your family this news. If your family decides to seek testing based on your results, their testing will not be covered by the ABCD Study.
- You may be surprised to discover that you are at risk for a disease that no one else in your family has.
- You may become concerned about passing a genetic risk on to your children or that other family members might be at risk.
- You may worry about how the treatment might affect you or whether you will be able to afford it.

# What DON'T my test results tell me?

**These results are NOT a diagnosis and do NOT tell you whether you have or will get a health condition. Also, a negative result does NOT mean that you won't get one of the health conditions in the future.**

- Many factors influence your risk for disease, including your DNA, family history, your habits, and your environment.
- Your DNA may contribute to your risk for health conditions, but it's only one factor.
  - For example, you may still develop high cholesterol due to diet or lifestyle factors even if you don't have a gene that elevates your risk for high cholesterol.

Only a health care provider can diagnose you and determine how to treat you.

New information may become available in the future that could impact the interpretation of your results. If you want, the genetic testing service may notify you of clinical updates related to your genetic test through their portal.

# What are my choices?

It’s your choice whether you want to get your genetic risk results. You can always change this decision later.

**Here are your choices:**

If you aren’t ready to decide right now, you can select “No, I don’t want my genetic risk results now”, and we will ask you again at your next visit.

If you have questions you want to discuss with a genetic counselor before you decide, we will connect you with a genetic counselor at no cost to you.

- ✓ **Yes, I want my genetic risk results**
- ✗ **No, I don’t want my genetic risk results now**
- ? **I’d like to speak with a genetic counselor**

# What do the different choices mean?

**Pick “Yes” if you want your genetic risk results:**

- One of our scientists will determine whether you have genetic risk related to health conditions from the ACMG list.
- If no genetic risk is found on the initial test, you will receive a report that explains what this means.
- **If genetic risk is found on the initial test, we will connect you with a clinical genetic testing and counseling company to collect an additional sample for confirmation.**
- If this **repeat test is positive**, a genetic counselor from this company will contact you to talk about your results and answer your questions.
- You are welcome to include any family members you want during the consultation with the genetic counselor. You decide whom to share your results with.

# What do the different choices mean?

**Pick “No” if you don’t want your genetic risk results, or if you aren’t sure right now:**

- You will not be contacted about any results from your DNA test.
- We will ask you again at your next visit.
- As we explain in the main consent, your anonymized genetic results will still be available to the scientific community, but your privacy is protected.

**Pick “I’d like to speak with a genetic counselor”** if you need to talk with a genetic counselor before making your choice.

- You will get a link to schedule a session with a genetic counselor.
- We will ask you for your choice at your next visit, but you can always reach out before then.

# What are the key details for me to understand?

- You can get your genetic risk results. You will be asked to make your choice at your upcoming visit.
- We are focusing on a limited list of genes that are very likely to increase your risk of getting **treatable or possibly preventable health conditions, like certain cancers and heart conditions.**
- Some of these conditions can be life-threatening, and you are unlikely to find out about them without a DNA test.
- **Only 3% to 5% of people have one of these genes,** so you are unlikely to have a positive risk result.
- **These results are NOT a diagnosis** and do NOT tell you whether you have or will get a health condition.
- If you **do NOT have** one of the genes from this list, you could still get one of the health conditions in the future.
- Your results have implications for your family, particularly for identical twins and triplets.

# Terms and Definitions

**DNA:** A biological molecule found in cells that contains instructions for how the body works.

**Gene:** An individual unit of DNA that is passed on from generation to generation.

**Genetics:** The scientific study of genes and how certain qualities or traits are passed from parents to children.

**Genetic testing:** A medical test that looks for certain genes to confirm a suspected genetic condition or help determine a person’s chance of developing a genetic disorder.

**Genetic risk:** A person’s chances of getting a certain health condition or disease based on what genes they have.

**Genetic counselor:** A health care professional trained to help people understand how their genetics may affect their health.

**Health care provider:** A doctor, nurse practitioner, or physician assistant who you visit for things like check-ups, shots, or if you’re feeling sick.