

Paperwork Reduction Act Statement: The public reporting burden for this information collection has been estimated to average 30 minutes per response, including the time to review instructions and respond to questions. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, Attn: OMB-PRA XXXX-XXXX.

Why Are We Asking These Questions?

This project includes questions about health, life experiences, and identities. This activity is the first part of your help with the teen feedback team. The team will also discuss some of these questions with you in live, virtual discussions with other teens of your same age. We are asking for your help because we would like to hear the perspectives of teens from different backgrounds from all over the country. Later this year, teens like you from across the country will answer these questions. Your honest feedback will help the investigators ask questions in the best way possible.

Parts of this activity are a little different from other surveys you may have taken. We are interested in your thoughts on how study materials or questions are written instead of your answers to the questions themselves. If something feels uncomfortable or confusing—we want to know. Please don't worry about being polite or holding back. We value your feedback, whether you agree or disagree, as we want to hear a wide range of opinions.

Your responses will be kept private. For open-ended questions, please do not enter any information that could identify you, such as your name or email address.

If you have questions, please email Rachael Picard at rpicard@iqsolutions.com.

Would you like to participate in this activity?

Yes

No



Welcome! Thank you for participating in this exciting opportunity to contribute to research on teen health and development! We are so grateful for your commitment to this valuable project. Your role is to give feedback on questions we ask of participants in the Adolescent Brain Cognitive Development (ABCD) StudySM.

In the ABCD Study®, researchers will work with youth for 10 years starting at ages 9 and 10 to understand the different influences that affect brain development and general health. As part of the study, researchers will use questionnaires to ask youth about their physical and mental health; various life experiences such as playing sports, using social media, or trying drugs; and their family, school, and neighborhood environments, among other things.

The youth participating in the ABCD Study are as diverse as the United States. They come from 17 different states, from big cities and small towns, and from different economic backgrounds. The questions are asked of all participants regardless of their race, ethnicity, national origin, religion, sexual orientation, or gender identity. A large and diverse study like this makes it possible to investigate what contributes to differences in brain development, to understand what puts some people at risk for health problems, and to learn what makes some people able to recover from difficult experiences more easily than other people do.

Your feedback will help ensure the success of the ABCD Study in its quest to understand the many experiences that impact teen health and development and may help future generations of teens to live better, healthier lives.



This first question is about the social media platforms you use.

Which of the following social media platforms have you used in the past 30 days? Select all that apply.

- I do not have a social media account
- Facebook
- Instagram
- Snapchat
- Twitter
- YouTube
- Pinterest
- Tumblr
- Reddit
- TikTok
- Multiplayer Videogame Online Chatting
- Twitch
- WhatsApp
- Discord
- BeReal
- Other
- Don't know



The next few questions are about your experiences while driving.

<p>Do you have (or did you have) a provisional driver's license?</p> <ul style="list-style-type: none">• No• Yes <p>If YES, how old were you when you got your provisional driver's license? (Years, Months)</p> <p>_____</p>																							
<p>Do you have a driver's license with full privileges?</p> <ul style="list-style-type: none">• No• Yes <p>If YES, how old were you when you got your driver's license? (Years, Months) _____</p>																							
<p>In the last 12 months how often did you do each of the following:</p> <table border="1"><thead><tr><th></th><th>Never</th><th>Rarely</th><th>Sometimes</th><th>Often</th><th>Always</th></tr></thead><tbody><tr><td>Drove with passengers my age without having someone 25 years or older present, such as a parent or relative?</td><td></td><td></td><td></td><td></td><td></td></tr><tr><td>Drove between the hours of 11pm and 5am without having a guardian 25 years or older present.</td><td></td><td></td><td></td><td></td><td></td></tr></tbody></table>							Never	Rarely	Sometimes	Often	Always	Drove with passengers my age without having someone 25 years or older present, such as a parent or relative?						Drove between the hours of 11pm and 5am without having a guardian 25 years or older present.					
	Never	Rarely	Sometimes	Often	Always																		
Drove with passengers my age without having someone 25 years or older present, such as a parent or relative?																							
Drove between the hours of 11pm and 5am without having a guardian 25 years or older present.																							

Read, ate, talked on a cell phone, put on makeup, horsed around with passengers, or other such activities while driving.					
Drove 20 or more miles per hour over the speed limit.					
Drove after drinking alcohol or using other drugs not as prescribed.					
During the last 12 months, how many times have you ever ridden in a vehicle driven by someone else who had been drinking alcohol or using other drugs not as prescribed?					

If you were answering these questions, would you be able to complete every question?

Yes

No

Which questions would be difficult to answer? Select all that apply.

Do you have (or did you have) a provisional driver's license?	How often you: Drove between the hours of 11pm and 5am without having a guardian 25 years or older present.
If YES, how old were you when you got your provisional driver's license? (Years, Months)	How often you: Read, ate, talked on a cell phone, put on makeup, horsed around with passengers, or other such activities while driving.
Do you have a driver's license with full privileges?	How often you: Drove 20 or more miles per hour over the speed limit.
If YES, how old were you when you got your driver's license? (Years, Months) _____	How often you: Drove after drinking alcohol or using other drugs not as prescribed.
How often you: Drove with passengers my age without having someone 25 years or older present, such as a parent or relative?	During the last 12 months, how many times have you ever ridden in a vehicle driven by someone else who had been drinking alcohol or using other drugs not as prescribed?

Why would it be difficult to answer that question or those questions?

Is anything confusing or difficult to understand?

Yes

No

What word or phrase would you want the question-writers to explain?



The next few questions are going to ask about gun access in and around your home.

	Yes	No	Don't Know	Decline to Answer
Are any firearms now kept in or around your home?				
Are any of these firearms now loaded?				
Are any of these loaded firearms also unlocked?				

If you were taking this survey, would you be able to answer these questions?

Yes

No

What makes it difficult to answer those questions?

Is there anything that is confusing or difficult to understand in these questions?

Yes

No

What is confusing or needs more explanation?



Now we're going to ask about a consent form for a study activity related to DNA or genes. One of the things we can learn from our DNA is the risk of getting certain diseases. The ABCD Study looks at genetic information from people in the study including the risks of getting certain diseases. The study researchers want to give teens and their families the option of learning more about the results of those kind of genetic tests.

The next set of questions will ask you to look at a sample consent form for teens and their families to learn about their genetic test results.

What are "DNA Changes"?

All human beings share more than 99% of their DNA with each other. The tiny bit that is different is part of what makes each of us unique. Things like our hair color and eye color depend on the bits of our DNA that are different between human beings. We call these our DNA changes. We know what some DNA changes mean, but we still have a lot to learn. For example, we are still learning what role DNA plays in most health conditions. But for a small number of things, we already know a lot about the role DNA plays.

We know that certain changes in our DNA can affect our health. For example:

- Certain DNA changes can increase our risk for a few specific health conditions. This could include some cancers and types of heart disease.
- Certain changes in our DNA can increase the risk of passing specific health conditions on to our children, even if we don't have those conditions.

The more we study our DNA, the more we will learn what DNA changes mean about us. The ABCD Study will have specially trained scientists look at your DNA for changes related to hereditary disease risk.

Do you understand what they mean by "DNA changes" after reading this page?

Yes

No

What questions do you still have?

Did any of these statements use words that are out of date, not how you would say it, or were confusing?

Yes

No

Which ones and what would you use instead?



What will my Hereditary Disease Risk results tell me?

Your results will have information about your DNA and whether you may have a greater risk for developing some serious health conditions, such as certain kinds of cancer or heart disease.

About 2 out of 100 people will get a DNA result that shows that they have a higher risk of developing a disease. For example, a small number of people may find out they have a version of the BRCA1 gene that increases their risk for some kinds of cancers, like breast cancer.

We will use the current list developed by the American College of Medical Genetics. It was specially designed by a group of genetic experts to include DNA changes that are very likely to cause disease or health conditions for which medical treatment is available and for which early diagnosis is critical for effective treatment. It does not include disorders that would typically be diagnosed by a doctor or disorders where a lifestyle change would be the main treatment (e.g., avoiding tobacco use).

Do you understand what your Hereditary Disease Risk results will tell you after reading this page?

Yes

No

What questions do you still have?

Did any of these statements use words that are out of date, not how you would say it, or were confusing?

Yes

No

Which ones and what would you use instead?



What are the benefits of learning about my hereditary disease risk?

You could learn that there is something very important for your health in your DNA. Knowing this could help you work with your doctor or health care provider to prevent disease or to detect it early. We will only inform you about DNA results where there is an established medical treatment to reduce risk. In some cases, knowing this information can be lifesaving.

You could discover something that could help explain the history of a health condition among your blood relatives. Having this information could help you talk with your family. Everyone's DNA is different, but sharing your DNA results with your blood relatives can help them think about their own health. They can consider if they want to get tested themselves. This could end up helping them stay healthy.

You will be able to talk to a licensed ABCD genetic counselor about your test results. Talking to an ABCD genetic counselor is free.

Do you understand the benefits of receiving your Hereditary Disease Risk results after reading this page?

Yes

No

What questions do you still have?

Did any of these statements use words that are out of date, not how you would say it, or were confusing?

Yes

No

Which ones and what would you use instead?



Could learning about my hereditary disease risk affect my insurance?

- **Your health insurance will not be affected.** Health insurance cannot use DNA information to decide if they will cover you, change your coverage, cancel your coverage, or charge you more.
 - A federal law stops them from using DNA information in this way.
- **Disability, life and long-term care insurance is different.** In most places, disability, life and long term care insurers can use DNA information to decide if they will cover you and how much to charge you.

How could learning about my hereditary disease risk affect me emotionally?

- You could get information you weren't expecting in your results. For example: You might discover that you are at risk for a disease that has not been seen in other members of your family.
- If you have a certain DNA change, your blood relatives might have it too. They may or may not want to know this information.
- Your results could make you worried or confused. For example: You may be afraid of passing a hereditary disease risk on to your children.

If we find your DNA puts you at risk for developing a serious condition we will place you in contact with a licensed genetic counselor, free of charge, with whom you can discuss concerns or questions.

Do you understand the risks presented to you on this page?

Yes

No

What questions do you still have?

Did any of these statements use the wrong words (out of date, not how you would say it, or were confusing)?

Yes

No

Which ones? Select all that apply.

Your health insurance will not be affected. Health insurers cannot use DNA information to decide if they will cover you, change your coverage, cancel your coverage, or charge you more.

If you have a certain DNA change, your blood relatives might have it too. They may or may not want to know this information.

Disability, life and long-term insurance is different. In most places, disability, life and long term care insurers can use DNA information to decide if they will cover you and how much to charge you.

Your results could make you worried or confused. For example: You may be afraid of passing a hereditary disease risk on to your children.

You could get information you weren't expecting in your results. For example: You might discover that you are at risk for a disease that has not been seen in other members fo your family

If we find your DNA puts you at risk for developing a serious condition we will place you in contact with a licensed genetic counselor, free of charge, with whom can you can discuss concerns or questions.

What words would you use instead?



What are the limits of my Hereditary Disease Risk results from the ABCD Study?

- The ABCD Study is a research program. We analyze DNA for research purposes. If you receive health-related DNA results from the ABCD Study, those results are not diagnosis. Only a doctor or health care provider can diagnose you with a health condition and determine how to treat you. If you are concerned about your DNA results, it's always good to discuss them with your doctor or health care provider.
- These results do not tell you whether you have or will get disease. Many factors can contribute to whether or not you develop a disease. Your DNA may contribute, but it is not the only factor.
- We will not inform you of DNA results that put you at risk for disorders for which there is no current treatment.
- There are a lot of genes that can affect disease risk and we won't look at all of them. There could even be something we couldn't see or can't understand in the genes that we did look at. Scientific understanding of DNA and diseases is always growing.
- These results will be based on current scientific understanding. There is a chance they could be wrong. As we learn more information, ABCD could look at more genes in the future or look at these genes again to provide new results.

Based on this slide, do you understand the limits of the information from the genetic test results?

Yes

No

What questions do you still have about the limits of the tests or test results?

Did any of these statements use the wrong words (out of date, not how you would say it, or were confusing)?

Yes

No

Which ones? Select all that apply.

<p>The ABCD Study is a research program. We analyze DNA for research purposes. If you receive health-related DNA results from the ABCD Study, those results are not a diagnosis. Only a doctor or health care provider can diagnose you with a health condition and determine how to treat you. If you are concerned about your DNA results, it's always good to discuss them with your doctor or health care provider.</p>	<p>There are a lot of genes that can affect disease risk and we won't look at all of them. There could even be something we couldn't see or can't understand in the genes that we did look at. Scientific understanding of DNA and disease is always growing.</p>
<p>These results do not tell you whether you have or will get a disease. Many factors can contribute to whether or not you develop a disease. Your DNA may contribute, but it is not the only factor.</p>	<p>These results will be based on current scientific understanding. There is a chance they could be wrong. As we learn more information, ABCD could look at more genes in the future or look at these genes again to provide new results.</p>
<p>We will not inform you of DNA results that put you at risk for disorders for which there is no current treatment.</p>	

What words would you use instead?



What are my choices?

It is your choice whether you want to get your Hereditary Disease Risk results. You can always change this decision at a later stage.

If you say "Yes, I want my Hereditary Disease Risk results":

- One of our specially trained scientists will look closely at some of the genes in your DNA related to serious health conditions, like certain kinds of cancer and heart disease. They will generate results for you based on what they find.

If you say, "No, I do not want my Hereditary Disease Risk results.":

- You will not be contacted about any potential findings from your DNA that relate to serious health conditions

If you say, "I'm not sure right now.":

- You can come back and decide later

If you say, "I would like to speak with a genetic counselor before making a decision.":

- You will be contacted by a genetic counselor to discuss potential results before deciding if you would like to receive DNA results

We will send you messages when new result types are available.

Do you understand the choices for learning about the test results?

Yes

No

What questions do you still have?

Did any of these statements use the wrong words (out of date, not how you would say it, or were confusing)?

Yes

No

Which ones?

<p>If you say, "Yes, I want my Hereditary Disease Risk results." - One of our specially trained scientists will look closely at some of the genes in your DNA related to serious health conditions, like certain kinds of cancer and heart disease. They will generate results for you based on what they find.</p>	<p>If you say, "I'm not sure right now" - You can come back and decide later</p>
<p>If you say, "No, I do not want my Hereditary Disease Risk results," - You will not be contacted about any potential findings from your DNA that relate ton serious health conditions</p>	<p>If you say, "I would like to speak with a genetic counselor before making a decision," - You will be contacted by a genetic counselor to discuss results before deciding if you would like to receive DNA results</p>

What words would you use instead?



Your recruiter gave you an ID number containing both a letter and number (such as Q4). Please enter your ID number here so you can get credit for completing this activity.

Before we conclude, we wanted to offer one more space for you to share any additional thoughts about anything you saw in this activity. Remember, please don't share your full name, school, contact information, or anything else that would connect you as an individual with your responses.



Thank you for taking the time to complete this activity! The team greatly appreciates your feedback. What you shared today will help investigators ask questions in the best way possible to understand teens' experiences and development.

We look forward to your participation in future feedback team activities. If you have additional feedback or questions about your feedback team participation, please contact Rachael Picard by email at rpicard@iqsolutions.com.

Some of the questions or topics covered in this activity can bring up intense feelings or memories. Talking about these feelings with a trusted adult—such as a teacher, parent, or coach—can help.

If you need additional help with these feelings, or want to talk about them with someone who is trained in helping others, here are some places you can go:

- For mental health support 24/7, you can reach the Crisis Text Line by texting HOME to 741741 or on WhatsApp or Facebook messenger: <https://www.crisistextline.org/>
- If you want to talk to someone about sexual violence: the National Sexual Assault Telephone Hotline is available at 800-656-HOPE (4673) and through online chat at <https://hotline.rainn.org/online>.
- If you are thinking about suicide, worried about a friend or loved one, or need emotional support, you can reach the National Suicide Prevention Lifeline by:
 - Dialing 988 or 1-800-273-8255
 - Using the online chat: <https://suicidepreventionlifeline.org/chat/>
- The Trevor Project is a 24/7 hotline for LGBTQ young people with phone, web chat, and text options for connecting to trained counselors: <https://www.thetrevorproject.org/get-help/>
- If you need peer support and counseling services for Black, Indigenous, and People of Color, reach out to BlackLine at 1-800-604-5841. Available call times can be found at: <https://www.callblackline.com/>
- For mental health services provided by specially trained counselors, including Spanish-speaking counselors, connect with Boys Town National Hotline at 800-448-3000 or text VOICE to 20121.

Please click the arrow below to complete the survey and record your answers.



We thank you for your time spent taking this survey.
Your response has been recorded.