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Why Are We Asking These Questions?

Thank you for being part of the audience feedback teams to help the Adolescent Brain Cognitive Development StudySM! (If you are joining us for the first time, welcome!) This project includes questions about health topics, life experiences, and other things that influence how brains change between childhood and adulthood.

In this survey, you will see some questions or instructions that will be used in the ABCD Study® later this year. The team will also discuss some of these questions with you in live, virtual discussions with other teens 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 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.

This activity will work best on desktop or tablet screens.

If you have questions, please email [PROJECT LEAD] at [PROJECT LEAD EMAIL].

Would you like to participate in this activity?

Yes

No

ABCD Study Background

As a refresher, or if this is your first time joining us: 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.

You can provide insight into what young people think; the youth in the ABCD Study are about the same age you are now. 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.



Feedback on Survey Questions

In this section, you will be asked to review sample survey questions from the ABCD Study. We don't need to know your answers to these questions. Instead, we are interested in your feedback on how these questions are written.

Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

- Yes
- No
- Decline to answer

If you were answering this question, which scenario best describes your experience?

I found an answer choice that completely matches how I would answer

I could pick an answer choice that mostly matches, but not 100%

I do NOT see an answer choice that matches how I would answer

What makes it challenging to find a choice that matches?



Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

- Yes
- No
- Decline to answer

Were any choices missing from the response options?

Yes

No

What response options should be added?



Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

- Yes
- No
- Decline to answer

Is there anything in the wording that makes it hard to respond?

Yes

No



What in the wording makes it hard to respond?

You can click on any part of the text to highlight it. Click again to remove the highlight.

Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

Why does that make it hard to respond?



Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

- Yes
- No
- Decline to answer

Is anything confusing or difficult to understand?

Yes

No



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

You can click on any part of the text to highlight it. Click again to remove the highlight.

Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

Tell us a little more about the area or areas you selected. What changes would be helpful?



Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

- Yes
- No
- Decline to answer

Were any of these statements offensive?

Yes

No



Which ones?

Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

Please share more about why



Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

- Yes
- No
- Decline to answer

Did any statements or phrases use the wrong words – out of date, not how you would say it?

Yes

No



Which ones? You can click on any part of the text to highlight it. Click again to remove the highlight.

Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

What changes would you make to those statements or phrases?



Do you experience difficulty hearing, seeing, walking, bathing, learning, communicating, managing your household, doing errands, or concentrating because of a physical, mental, or emotional condition?

- Yes
- No
- Decline to answer

These questions ask about some experiences, but this might not cover every experience. What else would you add?



Feedback on Study Materials

In the next few questions, you will see some materials that will be used in the ABCD Study. We would like your feedback on these pages. In this part of the survey, you can click on parts of the pages.



Please read this page.

Click to highlight any areas that are confusing or use the wrong words (out of date, not how you would say it).

What will my results tell me?

Genetics can influence risk across a large number of diseases in different ways; however, we will only share results on a restricted set of DNA differences that are on a list developed by the American College of Medical Genetics (ACMG). Not all serious diseases caused by genetics are included on this list. The ACMG list was specially designed by a group of experts to include DNA differences that are very likely to increase your risk of getting certain diseases or health conditions, like some cancers and types of heart disease, and are also substantially treatable or preventable. About 97% of people DO NOT carry these disease risk DNA differences on the ACMG list.

We only want to give you test results that may be useful to your future health decisions.

For that reason, the results we will share include health conditions where:

- Medical treatment is available.
- Early diagnosis is helpful for treatment.
- A DNA test is the main way you would learn that you are at increased risk for that condition.

The results will not include conditions that:



- Do not have a medical treatment option.
- Would be treated with lifestyle change, like not using tobacco products.
- Would typically be diagnosed by a doctor.

The reason we only provide test results for DNA differences that meet these criteria is to reduce unnecessary anxiety that could arise from finding out about disease risk for which no treatment exists.





[If text selected:]

Tell us a little more about the area or areas you selected. What changes would be helpful?



[If no text selected:]

Do you have any comments or questions about this page?



Please read this page.

Click to highlight any areas that are confusing or use the wrong words (out of date, not how you would say it).

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

We are only returning results from the ACMG list. Most people (about 97 out of 100 people) will get a report that says ABCD did not find DNA differences related to diseases in the ACMG list. If we find a DNA difference from the ACMG list on our initial test, someone from the ABCD Study team will try to contact you directly to get another DNA sample to confirm the results. If the confirmation test is positive, an ABCD Study genetic counselor will reach out to you to discuss the results.

- There is no charge to talk with a genetic counselor.
- They will send you a report, tell you what your results mean, and answer your questions.
- They can send a report to your health care provider, who will help you decide what medical treatment or tests you might need.

It may take a few years to get your results. If you have not heard from anyone in the ABCD Study, your sample may not have been studied yet.





[If text selected:]

Tell us a little more about the area or areas you selected. What changes would be helpful?



[If no text selected:]

Do you have any comments or questions about this page?

Please read this page.

Click to highlight any areas that are confusing or use the wrong words (out of date, not how you would say it).

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

Most of the time, your health insurance and employment opportunities will not be affected. Under Federal law (as of 2024):

-Health insurers cannot use DNA information to decide if they will add you to an insurance plan ("cover" you), change or cancel your coverage, or charge you more for insurance.

-Employers cannot use DNA information in decisions like hiring, firing, promotions, pay, and job assignments.

The federal law does not apply to the military or employers with fewer than 15 employees. They are permitted to use DNA information obtained from your medical record to make employment decisions.

Other types of insurance are different.

-In most places, companies that offer disability insurance, life insurance, or long-term care insurance can use DNA information to decide if they will cover you and how much to charge you.

-Life insurance pays money to people you specify (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.

Employers and insurers can ONLY get this information from your medical record.



-Getting your results back from us does not automatically add them to your medical record.

-If you end up with a medical diagnosis or get treatment based on your results, that will become part of your medical record.





[If text selected:]

Tell us a little more about the area or areas you selected. What changes would be helpful?



[If no text selected:]

Do you have any comments or questions about this page?



Please read this page.

Click to highlight any areas that are confusing or use the wrong words (out of date, not how you would say it).

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 disease in the future.

-If you learn that you have a DNA difference related to diseases on the ACMG list, you may be able to work with your health care provider to prevent the disease from developing or to detect it and start treatment early.

-We will only tell you about DNA results from the ACMG list where there is a proven medical treatment to help. In some cases, knowing this information can be lifesaving.

You could discover something that helps explain the history of a health condition in your family.

If you have certain DNA differences, your blood relatives might have them too.

-“Blood relatives” are people who you typically share DNA with, such as your parents and siblings.

-Twins, triplets, and other siblings may share a lot of DNA, including DNA differences related to disease.



-Because the genetic test results might impact your blood relatives, you should discuss with your family whether you want to learn about your results and whether they would also want to learn about your results.

Having this information could help you talk with your family about their health. Everyone’s DNA is different, but sharing your results with your blood relatives can help them think about their own risks. They can decide if they want to get tested themselves. This could end up helping them stay healthy for longer.





[If text selected:]

Tell us a little more about the area or areas you selected. What changes would be helpful?



[If no text selected:]

Do you have any comments or questions about this page?



Please read this page.

Click to highlight any areas that are confusing or use the wrong words (out of date, not how you would say it).

What DON'T my test results tell me?

Any health-related results are NOT a diagnosis.

- The ABCD Study is a research program, and we study DNA for research purposes.

- The genetic counselor can explain your chances of getting a disease or health condition based on your results, but only a health care provider can diagnose you and determine how to treat you.

These results do NOT tell you whether you have or will get a health condition.

- 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 is only one factor.

- Knowing your results can help you, your family, and your health care provider decide on follow-up care and know what to look out for in the future.

The ACMG list is constantly growing as our understanding of DNA differences and their influence on disease risk grows. If you don't have one of the DNA differences from the ACMG list today, it doesn't mean you won't have one in the future. If you want to receive your results, and you have a DNA difference that gets added to the ACMG list in the future, we will attempt to contact you as long as the ABCD Study is still ongoing.



[If text selected:]

Tell us a little more about the area or areas you selected. What changes would be helpful?



[If no text selected:]

Do you have any comments or questions about this page?



[If no areas selected:]

Do you have any comments or questions about this image?





What parts of the image do you **dislike**? You can click on sections to highlight them. Click again to remove the highlight.






[If any area selected:]

Tell us a little more about the area or areas you selected. What do you dislike about them?
What changes would you make?

[If no areas selected:]

Do you have any comments or questions about this image?



Please review this image.

What parts do you **like**? You can click on sections to highlight them. Click again to remove the highlight.



[If any area selected:]

Tell us a little more about the area or areas you selected. What do you like about them?



[If no areas selected:]

Do you have any comments or questions about this image?





What parts of the image do you **dislike**? You can click on sections to highlight them. Click again to remove the highlight.




[If any area selected:]

Tell us a little more about the area or areas you selected. What do you dislike about them?
What changes would you make?

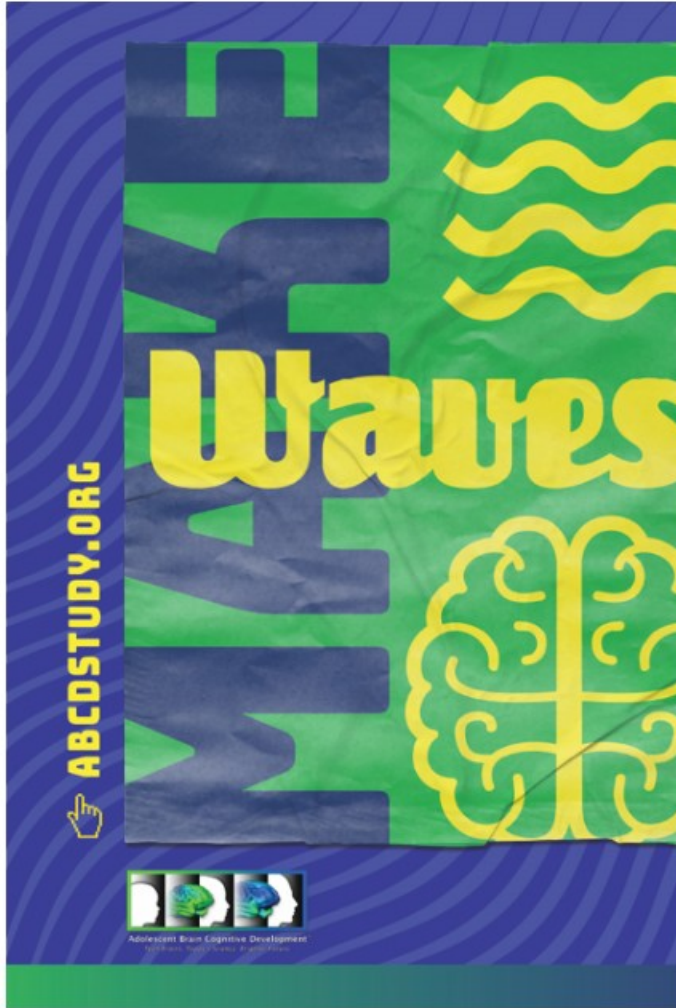
[If no areas selected:]

Do you have any comments or questions about this image?



Please review this image.

What parts do you **like**? You can click on sections to highlight them. Click again to remove the highlight.



[If any area selected:]

Tell us a little more about the area or areas you selected. What do you like about them?

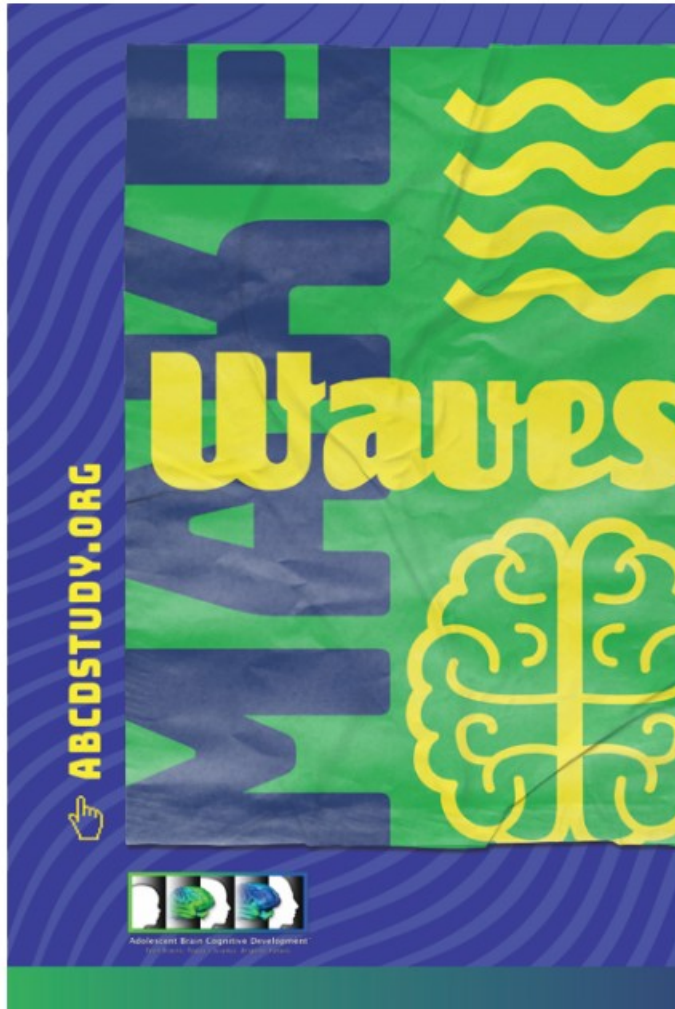
 

[If no areas selected:]

Do you have any comments or questions about this image?

What parts of the image do you **dislike**? You can click on sections to highlight them. Click again to remove the highlight.



[If any area selected:]

Tell us a little more about the area or areas you selected. What do you dislike about them?
What changes would you make?



[If no areas selected:]

Do you have any comments or questions about this image?



Please review this image.

What parts do you **like**? You can click on sections to highlight them. Click again to remove the highlight.



[If any area selected:]

Tell us a little more about the area or areas you selected. What do you like about them?



[If no areas selected:]

Do you have any comments or questions about this image?





What parts of the image you do **dislike**? You can click on sections to highlight them. Click again to remove the highlight.




[If any area selected:]

Tell us a little more about the area or areas you selected. What do you dislike about them?
What changes would you make?

[If no areas selected:]

Do you have any comments or questions about this image?

Which image is your favorite?

G



Z



R



B



Image G

Image Z

Image R

Image B



Which image is your LEAST favorite?

G



Z



R



B



Image G

Image Z

Image R

Image B



[When additional or updated details on feedback team members are needed, this question can be updated:]

Which of the following describes your race or ethnicity? [choose one or more]

American Indian or Alaska Native

Asian

Black or African American

Hispanic or Latino

Middle Eastern or North African

Native Hawaiian or Other Pacific Islander

White

← →

Participant ID and Final Comments

The research team gave you an ID number containing both a letter and number. 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.



Before you hit the arrow below to save your answers, we wanted to thank you for taking the time to complete this activity!

The team greatly appreciates your feedback. What you shared today will help researchers 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 [PROJECT LEAD] by email at [PROJECT LEAD EMAIL].



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