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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 and Cognitive DevelopmentSM Study or ABCD Study®! (If you are joining us for the first time, welcome!) We are talking with parents and caregivers of teens to get their perspectives on parts of a research study with other parents and caregivers of teens. This activity is part of your participation in the feedback teams. We are asking for your help because we would like to hear the perspectives of parents and caregivers of teens from different backgrounds from all over the country. Your honest feedback will help the investigators ask questions in the best way possible.

You will be asked for your feedback on questions about health, life experiences, activities, and parts of your identities. Surveys will take no longer than 30 minutes to complete. You will have several days to complete the survey.

Parts of this activity are a little different from other surveys you may have taken. We are interested in your thoughts on *how the 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 [PROJECT LEAD] at [PROJECT LEAD EMAIL.]

Would you like to participate in this activity?

- ☐ Yes
- ☐ No [\[Exit page\]](#)

ABCD Study Background

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 DevelopmentSM Study.

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.

Feedback on Survey Questions

[Instructions:] We would like you to review some survey questions. This is a little different than other surveys you may have taken: we don't need to know your answers to the questions. Instead, we want your feedback on how these questions are written.

The following questions are about your family and household:	
Is there another household in which the child spends a significant amount of time?	<ul style="list-style-type: none">• Yes• No• Declined to answer
About how much time does the child spend at this other household? Approximately how many hours per week?	<p>_____ Hours/Week (168 hours = 1 week; 84 hours = half the week)</p> <ul style="list-style-type: none">• Refuse to answer• Don't know
Which of these categories best describes your TOTAL COMBINED FAMILY INCOME for the past 12 months? This should include income (before taxes and deductions) from all sources, wages, rent from properties, social security, disability and/or veteran's benefits, unemployment benefits, workman's compensation, help from relative (include child payments and alimony), and so on.	<ul style="list-style-type: none">• Less than \$5,000• \$5,000 through \$11,999• \$12,000 through \$15,999• \$16,000 through \$24,999• \$25,000 through \$34,999• \$35,000 through \$49,999• \$50,000 through \$74,999• \$75,000 through \$99,999• \$100,000 through \$199,999

	<ul style="list-style-type: none">• \$200,000 and greater• Refuse to answer• Don't know
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1. 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

1a. *[If "I could pick..." or "I do NOT..."]* What makes it challenging to find a choice that matches? [\[Open-ended text box\]](#)

2. Were any choices missing from the response options?
 - ☐ Yes
 - ☐ No

2a. *[If "Yes"]* What response options should be added? [\[Open-ended text box.\]](#)

3. Is anything confusing or difficult to understand?
 - ☐ Yes
 - ☐ No

3a. *[If "Yes"]* 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. [\[Select text highlight tool.\]](#)

4. Did any statements or phrases use the wrong words – out of date, not how you would say it?
 - ☐ Yes
 - ☐ No

4a. *[If "Yes"]* Which ones? You can click on any part of the text to highlight it. Click again to remove the highlight. [\[Select text highlight tool.\]](#)

4b. *[If "Yes"]* What changes would you make to those statements or phrases? [\[Open-ended text box\]](#)

5. Were any of these statements offensive?

- ☐ Yes
- ☐ No

5a. [\[If "Yes"\]](#) Which ones? [\[Select text highlight tool\]](#)

5b. [\[If "Yes"\]](#) Please share more about wh. [\[Open-ended text box\]](#)

	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?				

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

- ☐ Yes
- ☐ No

6a. [\[If "Yes"\]](#) What in the wording would make it hard to respond? You can click on any part of the text to highlight it. Click again to remove the highlight. [\[Select text highlight tool.\]](#)

6b. [\[If "Yes"\]](#) Why does that make it hard to respond? [\[Open-ended text box\]](#)

7. Is anything confusing or difficult to understand?

- ☐ Yes
- ☐ No

7a. [\[If "Yes"\]](#) 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. [\[Select text highlight tool.\]](#)

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

- ☐ Yes
- ☐ No

- 8a. *[If “Yes”]* Which ones? You can click on any part of the text to highlight it. Click again to remove the highlight. [\[Select text highlight tool.\]](#)
- 8b. *[If “Yes”]* What changes would you make to those statements or phrases? [\[Open-ended text box\]](#)
9. Are there any terms on this topic that are missing that should be included? [\[Open-ended text box\]](#)
10. These questions ask about some experiences, but this might not cover every experience. What else would you add? [\[Open-ended text box\]](#)

Feedback on Study Materials and Instructions

These next few questions will ask you for your feedback on materials, instructions, or graphics used by the ABCD Study.

11. Please review this page. Click to highlight any areas that are confusing. To remove the highlight, click again. [\[Select text highlight tool.\]](#)
- 11a. *[If any areas selected]* Tell us a little more about the area or areas you selected. What changes would be helpful? [\[Open-ended text box\]](#)
- 11b. *[If no areas selected]* Do you have any comments or questions about this page? [\[Open-ended text box\]](#)

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.

12. Please review this page. Click to highlight any areas that are confusing. To remove the highlight, click again. [\[Select text highlight tool.\]](#)

12a. [\[If any areas selected\]](#) Tell us a little more about the area or areas you selected. What changes would be helpful? [\[Open-ended text box\]](#)

12b. [\[If no areas selected\]](#) Do you have any comments or questions about this page? [\[Open-ended text box\]](#)

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.



What is a genetic counselor?

A genetic counselor is a health care professional trained to talk with people about how the differences in their DNA may affect their health. They help people understand information about their DNA differences and the options available for genetic testing, but they do not provide treatment.

Watch [a video](#) to learn more about genetic counselors.

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.

13. Please review this page. Click to highlight any areas that are confusing. To remove the highlight, click again. [\[Select text highlight tool.\]](#)

13a. [\[If any areas selected\]](#) Tell us a little more about the area or areas you selected. What changes would be helpful? [\[Open-ended text box\]](#)

13b. [\[If no areas selected\]](#) Do you have any comments or questions about this page? [\[Open-ended text box\]](#)

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.

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.



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.

14. Please review this page. Click to highlight any areas that are confusing. To remove the highlight, click again. [\[Select text highlight tool.\]](#)

14a. [\[If any areas selected\]](#) Tell us a little more about the area or areas you selected. What changes would be helpful? [\[Open-ended text box\]](#)

14b. [\[If no areas selected\]](#) Do you have any comments or questions about this page? [\[Open-ended text box\]](#)

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.

15. Please review this page. Click to highlight any areas that are confusing. To remove the highlight, click again. [\[Select text highlight tool.\]](#)

15a. [\[If any areas selected\]](#) Tell us a little more about the area or areas you selected. What changes would be helpful? [\[Open-ended text box\]](#)

15b. [\[If no areas selected\]](#) Do you have any comments or questions about this page? [\[Open-ended text box\]](#)

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.

[Instructions:] For these next few questions, we would like your feedback on graphics that may be used in the ABCD Study communications to participants and their families. In this part of the survey, you can click on parts of the images.

16. Please review this image. What parts do you like? You can click on sections to highlight them. Click again to remove the highlight. [\[Select image section highlight tool\]](#)

16a. [\[If any areas selected\]](#) Tell us a little more about the area or areas you selected. What do you like about them? [\[Open-ended text box\]](#)

16b. [\[If no areas selected\]](#) Do you have any comments or questions about this image? [\[Open-ended text box\]](#)

B



17. What parts of the image do you dislike? You can click on sections to highlight them. Click again to remove the highlight. [\[Select image section highlight tool\]](#)

17a. [\[If any areas selected\]](#) Tell us a little more about the area or areas you selected. What do you dislike about them? What changes would you make? [\[Open-ended text box\]](#)

17b. [\[If no areas selected\]](#) Do you have any comments or questions about this image? [\[Open-ended text box\]](#)

B



18. Please review this image. What parts do you like? You can click on sections to highlight them. Click again to remove the highlight. [\[Select image section highlight tool\]](#)

18a. [\[If any areas selected\]](#) Tell us a little more about the area or areas you selected. What do you like about them? [\[Open-ended text box\]](#)

18b. *[If no areas selected]* Do you have any comments or questions about this image?
[Open-ended text box]

2



19. What parts of the image do you dislike? You can click on sections to highlight them. Click again to remove the highlight. [\[Select image section highlight tool\]](#)

19a. *[If any areas selected]* Tell us a little more about the area or areas you selected. What do you dislike about them? What changes would you make? [\[Open-ended text box\]](#)

19b. *[If no areas selected]* Do you have any comments or questions about this image?
[Open-ended text box]

2



20. Please review this image. What parts do you like? You can click on sections to highlight them. Click again to remove the highlight. [\[Select image section highlight tool\]](#)

20a. *[If any areas selected]* Tell us a little more about the area or areas you selected. What do you like about them? [\[Open-ended text box\]](#)

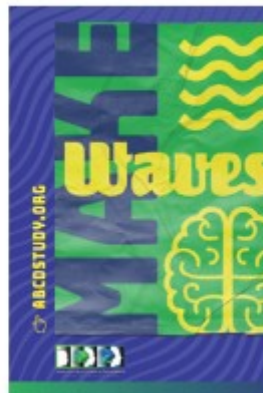
20b. *[If no areas selected]* Do you have any comments or questions about this image?
[\[Open-ended text box\]](#)



21. What parts of the image do you dislike? You can click on sections to highlight them. Click again to remove the highlight. [\[Select image section highlight tool\]](#)

21a. *[If any areas selected]* Tell us a little more about the area or areas you selected. What do you dislike about them? What changes would you make? [\[Open-ended text box\]](#)

21b. *[If no areas selected]* Do you have any comments or questions about this image?
[\[Open-ended text box\]](#)



22. Please review this image. What parts do you like? You can click on sections to highlight them. Click again to remove the highlight. [\[Select image section highlight tool\]](#)

22a. *[If any areas selected]* Tell us a little more about the area or areas you selected. What do you like about them? [\[Open-ended text box\]](#)

22b. *[If no areas selected]* Do you have any comments or questions about this image? [\[Open-ended text box\]](#)



23. What parts of the image do you dislike? You can click on sections to highlight them. Click again to remove the highlight. [\[Select image section highlight tool\]](#)

23a. *[If any areas selected]* Tell us a little more about the area or areas you selected. What do you dislike about them? What changes would you make? [\[Open-ended text box\]](#)

23b. *[If no areas selected]* Do you have any comments or questions about this image? [\[Open-ended text box\]](#)



24. Which image is your favorite?

- ☐ Image G
- ☐ Image Z
- ☐ Image R
- ☐ Image B

G



R



Z



B



25. Which image is your LEAST favorite?

- ☐ Image G
- ☐ Image Z
- ☐ Image R
- ☐ Image B

G



R



Z



B



Additional Participant Data

26. 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

27. The study team 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.

[\[Open-ended text box\]](#)

28. 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, contact information, or anything else that would connect you as an individual with your responses. [\[Open-ended text box\]](#)
-

Thank You Page

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 [PROJECT LEAD] by email at [PROJECT LEAD EMAIL].

Exit Page

We thank you for your time spent completing this activity. Your response has been recorded.