

Study to Explore Early Development (SEED) Follow-up Studies Participant Information Sheet

1. Research Study Title

Study to Explore Early Development (SEED) Follow-up Studies

2. Who is conducting the study?

The SEED Follow-up Studies are funded by the national Centers for Disease Control and Prevention (CDC). SEED staff from the CDC and their affiliates, along with their partners from seven other SEED sites located in California, Colorado, Maryland, Missouri, North Carolina, Pennsylvania and Wisconsin are working together to conduct the study.

3. What is the purpose of the study?

This study will help us learn more about different types of children as they grow older. One of our goals is to identify how we can support people with autism and other developmental delays or disabilities (DD) as they mature. To reach our goals, we need different types of families and children, adolescents and young adults to participate in the study.

4. Why am I being invited to participate?

You are being invited to take part in this study because you and your family participated in SEED in the past and agreed to be contacted again. The information we collect now will help us link early childhood factors to long-term outcomes.

We truly appreciate the previous contributions from you and your family to SEED. We are excited about the things we are learning from the study and hope you will join us again.

5. What will I be asked to do?

If you agree to take part in the study, you will be asked to complete a survey about your child's health and development. You may choose to complete the survey online via a weblink or over the phone with a study team member. If neither of those options work for you, we can send you the survey in the mail and you can return it to us.

6. How much time will the study take?

The survey will take about 1 hour to complete.

7. Do I have to take part in the study?

It is your decision whether to take part in the study. If you enroll in the study, we ask you to do as much as you can. You are free to skip any questions that you do not want to answer or that make you feel uncomfortable. You can withdraw from the study at any time.

8. What if I decide to withdraw from the study?

You can withdraw from the study at any time. If you wish to withdraw from the study, please call or email CDC at <CNI phone number> or <CNI email>. If using email, please include “Study Withdraw Request” in the subject line.

Please note that your answers to any of the survey questions or questionnaires will be saved and added to our study database unless you explicitly request that your responses be removed and permanently deleted.

9. Is it going to cost me anything to take part in the study?

There are no costs to you for being in the study.

10. What will I receive if I participate in the study?

We know your time is valuable. If you take part in this study, you will receive a \$30 gift card after we have received the completed survey to thank you for your time. You will receive additional gift cards if you complete more surveys.

11. What are the possible benefits of taking part in the study?

There is no personal benefit to you and your family for taking part in the study. Your participation will help us learn more about autism and other developmental disabilities, and how to support individuals and families.

12. Are there any risks involved with the study?

There is little risk involved with this study. You may feel nervous answering some questions because they are sensitive in nature. You are free to skip any questions that you do not want to answer or that make you uncomfortable. All answers that you give will be kept confidential.

13. How will my information be kept confidential?

Any information that you give us about you and your family will be kept private. Only SEED staff and their research partners will be able to look at any information you give us.

Your study data will be stored on a secure server at CDC. Personally identifiable information that you give will only be used for this study. Your information will remain confidential unless otherwise required by law. We will never use your name in any report or publication. The information you give will always be combined with information from all other participants in reports.

Only staff working on the study will have access to your personal information. Results from the study will not be linked to your name. Findings will only be linked to the study ID assigned to you and your family when you first participated in SEED. This link will be maintained on a database that is kept on a secure computer. All study forms that contain your study ID or any identifying information will be kept locked in the offices of study personnel.

14. Will my information be shared with others?

We may share some study data with other researchers. They will be approved by our SEED research team. We will not give them any information that could identify you. They researchers will not have access to the list that links your study ID with your name and contact information.

15. What are my rights as a study participant?

If you choose to be in this research study, you have the right to:

1. Be informed about the study and why we are doing it.
2. Have the study staff explain all study procedures.
3. Be told if there is a chance of any discomfort or risk from the study.
4. Have the study staff explain the benefits of participating in the study.
5. Ask any questions about the study.
6. Skip any question(s) that you do not want to answer or that make you uncomfortable.
7. Withdraw from the study at any time without penalty.
8. Know where your information will be stored and how it will be shared.
9. Choose whether to participate in the study without the use of any force or undue influence on your decision.

16. Will I be told about the results of the study?

Results of the research will be published. You will not be identified in any report or publication. To learn more about the SEED research findings so far, please visit our website: <https://www.cdc.gov/ncbddd/autism/seed-research.html>.

We will send your family a study newsletter up to two times per year. It will be emailed, or you can find it on our website at <https://www.cdc.gov/ncbddd/autism/seed-newsletters.html>. The newsletters will provide updates on the study and information that is relevant to your family.

17. Who can I call if I have questions about the study?

If you have questions about the study in general, you can call <site PI or PC> at <site phone number>.

If you have questions about completing the survey or to schedule an appointment to complete the survey over the telephone, you can call <CNI staff> at <CNI phone number>.

Thank you for taking part in this important research.