

CONSENT TO PARTICIPATE IN RESEARCH

Title of Project: Language Research Registry

Principal Investigator(s): Amanda Owen Van Horne, PhD CCC-SLP

KEY INFORMATION

Important aspects of the project you should know about first:

- **Purpose:** The purpose of this project is to create a registry of potential research participants. This includes children and adults, both with and without suspected language impairments.
- **Procedures:** If you choose to participate, you will be asked to complete a survey with basic information about you.
- **Duration:** This will take about 5-10 minutes.
- **Risks:** The main risk or discomfort is that you may worry about others finding out you have enrolled in a research registry. Another risk is that the confidentiality of your data could be compromised. We will do our best to protect your privacy throughout the life of the registry.
- **Benefits:** There are no direct benefits to you for participating in this registry.
- **Alternatives:** The alternative is that you may choose not to enroll in this registry.
- **Costs and Compensation:** If you decide to participate, there will be no additional cost to you. You will not be compensated for enrolling in the registry.
- **Participation:** Taking part or not in this registry is your decision. You can decide to participate and then change your mind at any point.

Please carefully read the entire document. You can ask any questions you may have before deciding if you want to participate.

You are being invited to participate in a research registry. This consent form tells you about the registry including its purpose, what you will be asked to do if you decide to take part, and the risks and benefits of being in the registry. Please read the information below and ask us any questions you may have before you decide whether or not you want to participate.

PURPOSE OF THE PROJECT

The purpose of this project is to create a registry of potential research participants. This includes children and adults, both with and without suspected language impairments. We may also look back at registry data in the future to learn more about language and cognition in children and adults.

WHO IS BEING ASKED TO PARTICIPATE?

You will be one of approximately 3000 participants in this registry. You are being asked to enroll in the registry because you may be interested in participating in future research studies with our labs.

PROCEDURES: WHAT WILL YOU BE ASKED TO DO?

You will be asked to complete a survey with basic information about you, including:

- Contact information
- Background information about you, such as your occupation, education, gender, race, and date of birth
- Information about the language(s) you know
- Any suspected or diagnosed disabilities

You may complete the survey on paper or online. You may skip any survey question(s) you do not wish to answer.

You can choose which information will be included in the registry. You may contact us at any time to request that some or all of your data be removed from the registry, without giving a reason. Registry data may exist in perpetuity if you do not ask for it to be removed.

If you complete additional testing with us as part of other research studies, we will ask you at that time if we can add your test scores to the registry. This will help us to better match you with studies in the future. If you do not want us to add any test scores, you may ask us to leave this data out of the registry.

If a new opportunity for you to participate in one of our studies comes up, we may contact you using the information in the registry. You are free to say yes or no to participating in any studies we ask you about.

WHAT ARE POSSIBLE RISKS AND DISCOMFORTS?

The main risk or discomfort is that you may worry about others finding out you have enrolled in a research registry. Another risk is that the confidentiality of your data could be compromised. We will do our best to protect your privacy throughout the life of the registry. All of your information will be stored on encrypted, password-protected servers. Nothing will be shared outside of the registry-affiliated labs at UD.

WHAT ARE POTENTIAL BENEFITS FROM THE REGISTRY?

The main benefit to you is that enrolling in the registry could make it easier for you to learn about and participate in research studies that interest you. This registry may also help others in the future by making it easier for researchers to find participants for their studies. Future research could contribute to a better understanding of people with and without language impairments.

CONFIDENTIALITY: WHO MAY KNOW THAT YOU PARTICIPATED IN THIS RESEARCH?

We will keep your registry data as confidential as possible, with the exception of certain information that we must report for legal or ethical reasons. Examples include child abuse or intent to hurt yourself or others. If required, your records may be inspected by authorized personnel in the University of Delaware Institutional Review Board. This is to ensure compliance with university and governmental policies. We also must let you know that if during your participation in this registry our research team was to observe or suspect, in good faith, child abuse or neglect, we are required by Delaware state law to file a report to the appropriate officials.

All of your information will be stored in an encrypted, password-protected online database. We will keep hard copies of consent forms and surveys for as long as required, then they will be shredded.

We will only include information in the registry that researchers need to use it effectively. Only current members of our research team will have access to the registry. If results of this project are published or presented, individual names and other personally identifiable information will not be used.

By agreeing to participate in this registry, you understand that any qualified researcher at UD may be given access to the registry at a later date. Faculty members in charge of UD labs may apply for registry access on a project-by-project basis. They must first agree to follow procedures that ensure the integrity and confidentiality of your data. The faculty member then nominates individuals to enter data into the registry, contact potential research participants, and carry out registry searches. These individuals may be undergraduate students, graduate students, or staff. Before they can access registry data, they must first complete training in research ethics and proper registry use. They must also sign a confidentiality agreement. Each lab member will only have access to the data needed for their job, not the entire registry.

If you want any personal information to be left out of the registry, we will do so. You may contact us at any time to request that some or all of your information be removed from the registry, without giving a reason.

USE OF DATA COLLECTED FROM YOU IN FUTURE RESEARCH

Identifiers about you might be removed from registry data and after such removal, the data could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from you or your legally authorized representative.

COSTS AND COMPENSATION

There are no costs to you for enrolling in this registry. You will not receive any compensation for your enrollment.

DO YOU HAVE TO TAKE PART IN THIS REGISTRY?

Taking part in this research registry is your decision. You do not have to enroll yourself in this registry. If you choose to enroll, you have the right to change your mind at any time. If you decide later to have your information removed from the registry, there will be no penalty or loss of benefits to which you are otherwise entitled. Your decision to stop participation, or not to participate, will not influence current or future relationships with the University of Delaware.

INSTITUTIONAL REVIEW BOARD

This research registry has been reviewed and approved by the University of Delaware Institutional Review Board (UD IRB), which is a committee formally designated to approve, monitor, and review biomedical and behavioral research involving humans. If you have any questions or concerns about your rights as a research participant, you may contact the UD IRB at hsrb-research@udel.edu or (302) 831-2137.

CONTACT INFORMATION

If you have any questions about the purpose, procedures, or any other issues related to this research registry you may contact the Principal Investigator, Dr. Amanda Owen Van Horne at ajovh@udel.edu or (302) 831-3982.

CONSENT TO PARTICIPATE IN THE RESEARCH REGISTRY:

I have read and understood the information in this form and I agree to enroll myself in the registry. I am 18 years of age or older. I have been given the opportunity to ask any questions I had and those questions have been answered to my satisfaction. I understand that I will be given a copy of this form for my records.

Printed Name of Participant
(PRINTED NAME)

Signature of Participant
(SIGNATURE)

Date

Person Obtaining Consent
(PRINTED NAME)

Person Obtaining Consent
(SIGNATURE)

Date