Consent Form for Participation in a Research Study
University of Massachusetts Amherst and Carnegie Mellon University

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Study Title: An observational study of neurodiverse programmers

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1. WHAT IS THIS FORM?

This form is called a Consent Form. It will give you information about the study so you can make an informed decision about participation in this research. We encourage you to take some time to think this over and ask questions now and at any other time. If you decide to participate, you will be asked to sign this form and you will be given a copy for your records.

2. WHAT ARE SOME OF THE IMPORTANT ASPECTS OF THIS RESEARCH STUDY THAT I SHOULD BE AWARE OF?

Your consent is being sought for participation in a research study on understanding the behaviors of neurodiverse programmers, and your participation is entirely voluntary.

In this study, we will observe you while you complete a session of software development. This session can be at a time and of a duration of your choosing (up to three hours) and can involve any software development that you routinely work on and can share with the research team (e.g., personal projects, work tasks, research code). While you do this, we will record your screen and make notes. If you are on campus at UMass Amherst, your eyes will also be tracked during the session. After the session, we will ask you questions about your process. The goal is to understand development patterns across a spectrum of neurotypes, with a focus on developers with ADHD so that we can design future development tools.

This study poses the possibility of a breach of confidentiality, psychological boredom and stress. You may not directly benefit from this research, but the findings may inform future developmental tools and understandings of neurodiversity in a software context.

3. WHY ARE WE DOING THIS RESEARCH STUDY?

The purpose of this study is to understand differences in programming patterns between programmers with and without ADHD. Many programmers have ADHD, and recent work has shown that ADHDers can face significant software-specific challenges while programming. However, this evidence relies entirely on self-reported data including qualitative textual analysis and subjected self-reported data. There is thus a need for understanding patterns of development through direct observation. By observing developers both with and without ADHD programming in their natural development environment, we hope to learn insights that can directly lead to better scaffolding and outcomes for neurodivergent developers.

4. WHO CAN PARTICIPATE IN THIS RESEARCH STUDY?

To participate in this research study, you must be:

- 18 or older

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- Have been professionally employed as a software developer, and currently work professionally or as a hobbyist on software development (PhD work/research is included under this definition of professional)
- Regularly complete programming sessions that last at least 30 minutes on software that is non-confidential / can be shared with the research team (e.g., open-source software, personal projects, academic research)

5. WHERE WILL THIS RESEARCH STUDY TAKE PLACE AND HOW MANY PEOPLE WILL PARTICIPATE?

This research study will either take place remotely (over UMass zoom), or on campus in a private room at UMass or Carnegie Mellon University. If it takes place remotely, you can be in any private place where you like to work (e.g., your home office, living room, etc.).

We expect to enroll 15-30 participants.

6. WHAT WILL I BE ASKED TO DO AND HOW MUCH TIME WILL IT TAKE?

If you agree to take part in this study, you will be asked to:

1) Schedule a study session with the research team. This session can be of a length of your choosing, up to 2 hours. All but 30 minutes of the session will be reserved for you to do work. The remaining 30 minutes will be for study set-up and a post study interview. Thus, for example, if you plan to work for 1 hours, you will be asked to schedule a 1.5 hour session.

2) At the start of the session, we will go through this informed consent.

3) Next, we will start the zoom recording (screen + audio only, no video), if you are at UMass, we will set up the eye-tracker. We will also ask you what you plan on working on in this work session. Consent and set-up will take around 10 minutes.

4) Next, we will observe your programming work session for a duration of your choice (up to 1.5 hours). As a result, we ask that you choose a programing project where you are comfortable with an observer. We ask that you choose a work session duration that is be realistic for your average programming work session. The work session will be screen-recorded (via zoom). We will also collect audio recordings via zoom. However, we will not use the zoom camera to record participant faces. If you are in-person at UMass Amherst, we will also ask you to have your gaze tracked by eye tracking glasses. During the work session, the study runner will either sit in the same workspace or watch a zoom screen recoding. The researcher is there to observe but not intervene.

5) When you decide they are done with their work session, we will ask you to let the study runner know, and then a post-session interview will take place (~20 minutes). This post session interview will be recorded via zoom as well. Questions will include asking about your software development process and your perceptions of the work process. You may skip or not answer any question you feel uncomfortable answering.

The full study will take at most two hours (up to 1.5 hour session, 30 minute interview + setup)

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7. WILL BEING IN THIS RESEARCH STUDY HELP ME IN ANY WAY?

You may not directly benefit from this research; however, we hope that your participation in the study may lead to findings that inform future developmental tools and understandings of neurodiversity in a software context.

8. WHAT ARE MY RISKS OF BEING IN THIS RESEARCH STUDY?

You may experience boredom, feel distress when thinking about a potentially sensitive topic such as ADHD, or realize you do not feel comfortable having your software development recorded. To minimize this risk, you are able to drop out of the study at any point (e.g., if you plan on a 1.5-hour work session, but end up deciding to stop after an hour, this is totally fine). In addition, should you feel any distress as a relation to topics discussed in the interview that persists after the study, there are national hotlines for mental health where you can reach out to for support, such as the Crisis Text Line (text HOME to 741741).

As this study will be focused on neurodiversity, if you are participating on-site, you may not want your participation made public if you do not want to disclose your neurotype to friends or co-workers. To minimize this risk, we will conduct all in-person work sessions and interviews in a closed, private room.

While we will do our best to protect your data, there always exists a potential for a breach of confidentiality, including of neurodiversity-related status, personally identifying information, and the software content of the work sessions we are observing. Even though one of our inclusion criteria is that the work must be sharable / non confidential (e.g., not under an NDA, etc.), you may still not want the content of your work made public. We will minimize this risk by only collecting personal information that is essential to the research and labeling personal research data with a code (e.g., de-identification). In addition, zoom recordings will not be shared with other research teams, even should our findings be made public. Instead, we will only share de-identified transcripts and qualitative notes. Your name and personally identifying information will be destroyed at the completion of the study. In the qualitative analysis in any resulting publication, your work-specific factors will be generalized.

9. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?

Your privacy and confidentiality is important to us. The following procedures will be used to protect the confidentiality of your study records. These study records include audio recordings of your work session and interview, zoom screen recordings of your work session, transcripts of the interview and work session recordings, questions about your neurotype, and (if at UMass) eye-tracking data.

The researchers will keep all study records, including any codes to your data, in a secure location. Physical consent forms will be in a locked cabinet in a PI's office. For UMass and remote participants, all data will be stored using UMass cloud storage (google drive and one drive). We will use UMass zoom to record the meetings. On these platforms, access can be controlled via direct email addresses. We will only give researchers on our research team access to identifying data, and we will remove access should any research team members leave the project. Audio interview recordings will be stored only until we can make a transcript (at most one month after the study session). They will then be deleted, and we will retail only the transcript. Zoom recordings will be stored on a UMass managed computer owned by the PI. CMU participant data will also be stored on UMass cloud sites, however, Zoom recordings will be saved temporarily on a CMU managed computer, before they are uploaded to UMass OneDrive. They will be deleted at this point.

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Research records will be labeled with a code. A master key that links names and codes will be maintained in a separate and secure location. The master key will be destroyed six years after the close of the study. All electronic files (including audio recordings of your sessions and consent documents) containing identifiable information will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords. At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format, and you will not be identified in any publications or presentations.

10. WILL MY INFORMATION (BIOSPECIMENS OR PRIVATE INFORMATION) BE USED FOR RESEARCH IN THE FUTURE?

Identifiers might be removed and the de-identified information may be used for future research without additional informed consent from you.

11. WILL I BE GIVEN ANY MONEY OR OTHER COMPENSATION FOR BEING IN THIS RESEARCH STUDY?

We will compensate you $15 per hour of work session observed. As you can elect to participate for up to two hours, the maximum compensation is $30. We will compensate you via an egift card to your choice of Amazon, Barns and Nobel, Dunkin Doughnuts, or Starbucks.

Since you are being compensated for your participation in this study, your personal information may be released to the accounting officials at University of Massachusetts, Amherst. If payment to a research participant is $600 or more in any one calendar year, the University of Massachusetts, Amherst is required to report this information to the IRS as taxable income. This information will be kept confidential and will only be used to process payment.

12. WHO CAN I TALK TO IF I HAVE QUESTIONS?

Take as long as you like before you make a decision. We will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the researcher(s):

Madeline Endres, UMass Amherst, mendres@umass.edu
Kaia Newman, CMU, kaian@cmu.edu

If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or humansubjects@ora.umass.edu.

13. WHAT HAPPENS IF I SAY YES, BUT I CHANGE MY MIND LATER?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

14. WHAT IF I AM INJURED?

The University of Massachusetts does not have a program for compensating subjects for injury or complications related to human subjects research, but the study personnel will assist you in getting

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treatment. CMU will not reimburse you for any additional costs that you may incur from participating in this research or for medical treatment if you become injured or ill while participating in the research.

15. SUBJECT STATEMENT OF VOLUNTARY CONSENT

When signing this form I am agreeing to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use. I have had the opportunity to ask questions and have received satisfactory answers. I have been informed that I can withdraw at any time. A copy of this signed Informed Consent Form has been given to me.

_____	_____	_____
Participant Signature:	Print Name:	Date:

By signing below I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

_____	_____	_____
Signature of Person Obtaining Consent	Print Name:	Date:

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