

Dear Prospective Participant,

Our research group at the National Human Genome Research Institute (NHGRI), part of the National Institutes of Health (NIH), develops and studies computer-based technologies to better understand medical conditions that have known or suspected genetic causes. Our goals are to better understand how these conditions develop, what causes them, and how to help with diagnosis and management.

One of our studies involves studying how different artificial intelligence (AI) models can identify genetic conditions. We are comparing how well different models work. We think this is important since these models may be a growing part of healthcare. People who take part will provide consent per NIH policies, but we want to give you a short description here.

For this study, we will interview patients or their parents/caregivers with a diagnosed genetic condition. We will use transcripts from these interviews to generate a description based on what you say about your or your child's genetic condition. We will analyze these de-identified descriptions with different tools. We will compare these tools, including public AI models such as ChatGPT or Bard. Even though we will not include things like your name or date of birth, once we share information with the public models, they may share or use it again.

Interviews (about 30 to 60 minutes in length) will be conducted at your convenience through video conferencing or telephone. All individuals participating in the interview need to be 18 years or older. Prior to the interview, we will contact you to provide information about the study, answer your questions, and seek your consent to participate.

Interested in participating, please contact us:

medicalgenomicsunit@nih.gov

Thank you very much. You can contact us at the addresses below if you have any questions.

Sincerely,

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