# INDIANA UNIVERSITY STUDY INFORMATION SHEET FOR RESEARCH

**SPOKE: Precision Medicine Knowledge Graph Visualizations (IRB #2011596050)**

**You are being asked to participate in a research study.** Scientists do research to answer important questions that might help change or improve the way we do things in the future. This document will give you information about the study to help you decide whether you want to participate. Please read this form, and ask any questions you have, before agreeing to be in the study.

**All research is voluntary.** You can choose not to take part in this study. If you decide to participate, you can change your mind later and leave the study at any time. You will not be penalized or lose any benefits if you decide not to participate or choose to leave the study later.

**This research is intended for individual 18 years of age or older. If you are under age 18, do not complete the survey.**

ADD LINK TO VIDEO TUTORIAL AND SCRIPT!

**The purpose of this study** is to test the usability and efficiency of a visualization of a so-called knowledge graph, which is a collection of a multitude of databases. The knowledge graph in question is the Scalable Precision Medicine Oriented Knowledge Engine (SPOKE), which consists of 3 million nodes, i.e., individual points, and 33 million edges, i.e., connections, between them. Because it is near impossible to derive any meaningful insights from looking at raw network data, we developed the SPOKE Visualizer to allow a variety of users to explore the SPOKE knowledge graph (<https://cns-iu.github.io/spoke-vis/home>). A tutorial for the

We are asking you if you want to be in this study because you are 18 years old and because you responded to our call for participation. The study is being conducted by Dr. Andreas Bueckle, Dr. Katy Börner (both from Indiana University) and Kilian Buehling from Technical University Dresden, Germany. It is funded by the National Science Foundation and the University of California, San Francisco.

**If you agree to be in the study, you will do the following things (in this order). Please note that the entire study will be conducted virtually and on the internet. We expect the entire study to take approximately 45 minutes of your time in one continuous session.**

1. You will fill out a pre-questionnaire so we can obtain some of your demographic information (e.g., age group, gender, employment) as well as your prior experience with different types if data visualizations.
2. You will watch and read a tutorial about the SPOKE Visualizer, where we explain its interface, how to use the controls, and how to navigate between the different parts of the SPOKE Visualizer. Importantly, this tutorial will also introduce you how to retrieve information from the SPOKE Visualizer by iteratively adjusting parameters in the interface.
3. You will explore the SPOKE Visualizer on your own for a duration of your choosing until you feel confident that you can complete a series of short information retrieval tasks.
4. You will complete assignments where we ask you to provide answers for questions about the data visualized in the SPOKE Visualizer.
5. You will fill out a post-questionnaire where we ask you for feedback about the interface, the visual encoding, and the controls of the SPOKE Visualizer.

**Before agreeing to participate, please consider the risks and potential benefits of taking part in this study.** You may be uncomfortable while answering the survey questions. While completing the survey, you can skip any questions that make you uncomfortable or that you do not want to answer. Other risks are discomfort answering questions and commenting on unfamiliar visualizations. Please be aware that you can terminate your participation in the study at any time. There is also a risk someone outside the study team could get access to your research information from this study. More information about how we will protect your information to reduce this risk is below. You might benefit from taking part in this study by learning about the visualization of large knowledge graphs. Most importantly, we hope the study will increase our understanding about the usability and efficiency of large multi-layered network visualizations

While we do not think you will have any personal benefits from taking part in this study beyond your payment (see below), but we hope to learn things that will help researchers in the future.

**You will be paid for participating in this study.**Specifically, you will receive $10 upon completion. At the end of the survey, we will display your unique Response ID to you, which you can then insert into Mechanical Turk in order to validate your participation. We will not issue a partial payment. There is no cost to participate in the study.

**We will protect your information** and make every effort to keep your personal information confidential, but we cannot guarantee absolute confidentiality. No information which could identify you will be shared in publications about this study.

Your personal information may be shared outside the research study if required by law. We also may need to share your research records with other groups for quality assurance or data analysis. These groups include the Indiana University Institutional Review Board or its designees, and state or federal agencies who may need to access the research records (as allowed by law). Additionally, your research information may be shared with our collaborators on this research study at the University of San Francisco or our sponsors at the National Science Foundation.

**If you have questions about the study or encounter a problem with the research**, please contact the lead researcher, Dr. Andreas Bueckle at [abueckle@iu.edu](mailto:abueckle@iu.edu).

For questions about your rights as a research participant, to discuss problems, complaints, or concerns about a research study, or to obtain information or to offer input, please contact the IU Human Research Protection Program office at 800-696-2949 or at [irb@iu.edu](mailto:irb@iu.edu).