

Building Consensus on Privacy Budgets for Record Linkage: Template Language for Privacy Statement

INFORMATION SHEET FOR PARTICIPANTS

Thank you for your interest in this project. This sheet provides more information about the study to help you decide whether you desire to participate. Before you participate in this study, we will review this information with you and ask you to sign an informed consent form. We will send the informed consent form to you ahead of our meeting for your review. If you decide not to participate, there will be no disadvantage to you and we thank you for considering our request.

What are the research aims?

The purpose of this research study is to aggregate opinions, feedback and comments of patients, on a prototype privacy statement for future study protocols that will use the Minimum Necessary Disclosure for Interactive Record Linkage (MINDFIRL) framework for patient-centered effectiveness research that requires record linkage. The study will inform us in developing and finalizing a privacy statement in patient voice that will accompany the MINDFIRL software once it is released.

Who is being invited to participate?

You are eligible to participate if:

- 1) you see one physician for a chronic condition at least three times per year,
- 2) you are over 18 years old,
- 3) you are fluent in English

Who is conducting the research?

The study is being conducted by three academic researchers at Texas A&M University. The study is funded by the Patient-Centered Outcomes Research Institute (PCORI), a non-profit organization that funds research in order to help patients and those who care for them make better-informed decisions about their healthcare choices. Dr. Hye-Chung Kum is an associate professor at Texas A&M University and is cross-trained in computer science and social work. Dr. Kum holds expertise in data science and data mining in support of accurate evidence-based decisions for policy, management, legislation, evaluation and research. Dr. Alva O. Ferdinand is an assistant professor at Texas A&M University and is cross-trained in public health (DrPH) and law (JD) with expertise in using large secondary data sources for population-level research. Drs. Kum and Ferdinand will be joined by Professor Cason Schmit, who is also an assistant professor at Texas A&M University and the HIPAA compliance officer at the university's School of Public Health. The research team consists of avid researchers and experts in the role of law and data in health systems. You can read more about their work at the web addresses listed below:



Hye-Chung Kum, PhD

<https://sph.tamhsc.edu/hpm/faculty/kum.html>



Alva O. Ferdinand, DrPH, JD

<https://sph.tamhsc.edu/hpm/faculty/ferdinand.html>



Cason Schmit, JD

<https://sph.tamhsc.edu/hpm/faculty/schmit.html>

What will participants be asked to do?

Should you agree to take part in this project, you will be participating in a three-round Delphi session with Professors Kum, Ferdinand, and Schmit, which will be held on an online platform. You will be given 7 days to complete each round at our own pace. There are no right or wrong answers to any questions. We are interested in your views and experiences. You will be asked to individually comment, raise concerns, and provide suggestions for improvement of the privacy statement based on your experiences. We will gather your feedback, prepare copies of all the information captured through the first round and proceed to edit the privacy statement. In the next two rounds, this procedure will be repeated as needed until consensus is reached that the privacy statement reflects patient voice and captures all the information a typical patient would want to see concerning the use of their data for research. The research team will finalize the privacy statement and share it with you for the last time during the third round.

Who will see my interview responses?

No identifying information, such as your name, will be shared with other participants or anyone else. We also will not share information about who participated in the study. We will not use your name in any study publications or presentations.

Will I be compensated for participating?

Yes. You will receive graduated payments for each round that will total \$100 as payment for your participation. You will be compensated with \$20 for the first round, \$30 for the second round, and \$50 for the third round.

What if I have further questions or want to participate?

We would be delighted to tell you more about the study. The contact information for the research team is listed below. A member of the research team will follow up with you in a few days' time with a reply.

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This study has been approved by the Texas A&M University Institutional Review Board, which is charged with protecting the welfare of participants in human research. Should you wish to speak with them, you can call 979-458-4067 or toll free at 1-855-795-8636.

Thank you for your consideration! We look forward to meeting you!