What is PPIRL?

- Record linkage is the process of connecting records that belong to the same real-world person in heterogeneous databases.
- Privacy and Record linkage. The absence of a common identifier across databases requires access to personally identifiable information (PII) to accurately link data, which raises privacy concerns.
- Privacy Preserving Interactive Record Linkage (PPIRL) is a novel approach to enhancing privacy when humans are interacting with PII for record linkage.

PIPI Features

- Use of pseudonyms to separate sensitive information from PII.
- Use of markup highlighting differences to facilitate decision making.
- Minimum Necessary Disclosure: Hide information that are not necessary.
- Incremental On Demand Disclosure: Enable partial disclosure of information on an ‘as needed’ basis (i.e., with a click).
- Accountability & Transparency: Measure how much information was disclosed and to whom.

PIPI Framework

- This research aims to identify patients’ and stakeholders’ perceptions of the risks and benefits associated with the use of the Privacy Preserving Interactive Record Linkage (PPIRL) framework for record linkage between heterogeneous databases.
- Identifying the perceived risks and benefits of PPIRL will facilitate the design of software that effectively balances conflicting values of information privacy and utility.
- This study will also inform strategies for effective communication with the general public and the institutional review board (IRB) community on the human subject protection aspects of the framework.

Research Objectives

- Six structured nominal group technique (NGT) sessions were conducted to identify perceived risks and benefits of the PPIRL framework and then interacted with an online record linkage and PIPI tutorial module to enable self-exploring
- Attitudes, opinions, and lingering concerns related to the PIPI framework were human subjects were then explored
- Theme development, discussion, and synthesis followed
- In the final NGT phase, participants voted on what they considered to be the most important themes.

PPI Framework

- What ELSI roles: (1) IRB administrator (program director), Board Member, Manager, Staff, Member, (2) Compliance and (3) ELSI researchers; Organizations: Academic, government, VA, hospital, and/or other.

Expert Focus Groups (N=11)

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Theoretical Framework (N=27)

- What are the things you like about the software that you would tell your neighbor? B. Software allows for minimum-disclosure - identifiers can be seen as so needed by that person.
- How do you feel about the software that you would tell your neighbor about the potential benefits of? C. Software allows for comprehensive privacy protection that is not available.
- How do you feel about the software that you would tell your neighbor about the potential risks of? D. Software allows for better accuracy in the record linkage process and the study of disease associations.
- How would you describe the framework? E. Software is configurable to optimize safe data sets per project.
- What are the things you like about the software that you would tell your neighbor about the potential limitations of? F. Software allows for tracing disclosure in each other.

Summary

- This study aimed to identify patients’ and stakeholders’ perceptions of the risks and benefits associated with the use of the Privacy Preserving Interactive Record Linkage (PPIRL) framework for record linkage between heterogeneous databases.
- Identifying the perceived risks and benefits of PPIRL will facilitate the design of software that effectively balances conflicting values of information privacy and utility.
- This study will also inform strategies for effective communication with the general public and the institutional review board (IRB) community on the human subject protection aspects of the framework.

Conclusion

- Enhancing and communicating privacy protection can eliminate existing barriers of research protocols and can enhance transparency and public trust in the scientific community.
- Future work will be to build consensus on appropriate language for communicating information about the PPIRL framework in patient voice and will inform record linkage software development efforts.