

# The Penn-CMU Digital Health Privacy Initiative

PIT-UN Challenge Grant Year 2 (Initiative year 1) - Final Narrative Report

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## Goals, Objectives, and Results Achieved

### [Built an interdisciplinary research group across 2 PIT-UN institutions](#)

The PIT-UN Year 2 funds (year 1 of Penn-CMU Digital Health Initiative funding) were instrumental in forging deep connections between Penn and CMU, across geographic and disciplinary barriers. The Initiative is now thriving and growing, as evidenced by the growing number of trainees, broadening research and policy impact, and successfully competing for an additional year of PIT-UN funding. We have also been able to leverage PIT-UN funding to secure additional grant funding from Penn's Medical Communication Research Institute to further scale and sustain our efforts.

### [Produce high-impact research on privacy and discrimination in the online health ecosystem.](#)

In year 1 of the Penn-CMU Digital Health Initiative (PIT-UN Year 2), we measured tracking across the websites of thousands of key health care entities including hospitals, government agencies, medical journals, and media outlets. We are currently concluding our study of differential exposure to hospital website tracking across axes of disadvantage and preparing two additional manuscripts for submission as we transition towards the Initiative's second-year goals (PIT-UN Year 3), which we are enthusiastically pursuing. The first year of funding has yielded 2 high-impact publications (JAMA Network Open, JAMA Health Forum), and 2 manuscripts in preparation. Our work has already been cited as the canonical measurement strategy and helped establish digital health privacy as a topic of first-order importance in medical journals.

### [Train students from underrepresented groups to conduct technology policy research.](#)

In year 1 of the Initiative, we partnered with Penn's Summer Undergraduates Minority Research (SUMR) to recruit and train 3 undergraduate research assistants (RAs), whose deep involvement has given them skills in PIT research and inspired future career plans focusing on health, technology, and policy. These students have chosen to remain involved in the analysis and publication process even after the conclusion of their summer research experience, and they are all authors on the 2 manuscripts being prepared for submission, meaning that whether they apply for public-interest technology jobs, graduate school focused in the public interest, or medical school with the intent to bring their technological experience and skills to the field of medicine, they will have a significant credential to bolster their early career success. We have also trained two additional students outside of our partnership with the SUMR program, both of whom co-authored papers related to digital health privacy, bringing the total number of first-year trainees to 5.

## Advocate for evidence-based policy reform to enhance privacy and equity.

We have engaged advocacy organizations (EFF), media journalists (Financial Times, Consumer Reports), and allies at technology firms (Google, Wikimedia Foundation, Ghostery) to share data, disseminate research findings, and pursue public education and policy reform.

## Challenges encountered/lessons learned

**Personnel challenges:** During year one of the initiative, project team member Tim Libert left CMU to take a position in the privacy office at Google, creating some challenges and delays in our work. Most notably, we had planned to recruit and train 2 research assistants through CMU's REUSE program. Without an available faculty sponsor for REUSE students during the first year of the initiative, we reallocated the training funds to recruit an additional SUMR student. Nonetheless Penn SUMR students worked on projects spanning both universities. Dr. Libert introduced us to Dr. Bauer, who joined the initiative as co-lead, took over administration of the webXray tool developed by Dr. Libert, and is now co-authoring manuscripts with us. In year 2 of the initiative, Dr. Bauer will mentor REUSE students at CMU. Thus, while Dr. Libert's departure created a temporary hurdle we were able to adapt and continue growing the initiative. In the long run, Dr. Libert's move to Google also gives a key contact to help amplify some of our findings and recommendations to privacy engineers working in the tech industry.

**Technical challenges:** WebXray as initially conceived was unable to create parent corporation reports by sub-group and unable to report certain summary statistics suitable for publication. Through a combination of R code (Dr. Friedman) and Python code (Drs. Libert and Bauer), the webXray code and analysis capabilities were enhanced. The enhancements to webXray have been open-sourced, consistent with best practices in public interest technology development, and will facilitate growth of privacy measurement for academic and media purposes.

## Copies of publications

These are provided in the report submission, as follows:

1. Friedman AB, Miller E, McCoy MS. Prevalence of Medical Journal Websites That Deny Access to Users Who Block Browser Cookies. *JAMA Netw Open* 2021;4(3):e213492.
2. Gupta R, Friedman AB, McCoy MS. Prevalence of Third-Party Tracking on Medical Journal Websites. *JAMA-Health Forum* [In press]. 2022. DOI: 10.1001/jamahealthforum.2022.0167
3. Friedman AB, Pathmanabhan C, Glicksman A, Demiris G, Cappola AR, McCoy MS. Addressing Online Health Privacy Risks for Older Adults: Ethical Considerations and Recommendations. [Under review]

## Certification

All University of Pennsylvania activities conducted with the Grant funds were and are consistent with charitable purposes as set forth in Section 501©(3) of the Internal Revenue Code, and University of Pennsylvania complied with all provisions and restrictions contained in this Agreement, including, for example and without limitation, those provisions relating to lobbying and political activity.