

PrivacyCon 2018 – Proposed Presentation

Authors: Jodyn E Platt, MPH, PhD^{1*}; M. Grace Trinidad, MS, MPH²; Sharon L.R. Kardia, PhD³

* Corresponding/ presenting author

1. Assistant Professor
University of Michigan Medical School
Department of Learning Health Sciences
Division of Learning and Knowledge Systems

2. Doctoral Student
Health Infrastructures and Learning Systems
University of Michigan Medical School
Department of Learning Health Sciences

3. Senior Associate Dean for Administration
Millicent W. Higgins Collegiate Professor of Epidemiology
School of Public Health
University of Michigan

Title: Public Willingness to Participate in Health Information Exchange Networks

Background: The 21st Century Cures Act and evolving healthcare industry create strong incentives for connecting and sharing big health data across institutional and political boundaries. As the nation's information systems work toward being findable, accessible, interoperable, and reusable (FAIR), our research investigates the willingness of the general public to share their health information in pursuit of these goals. Specifically, we investigate willingness of the general public to participate in health information networks, and the individual-level characteristics that predict willingness to share electronic health information.

Methods: We conducted a survey in November 2016 using GfK's probability-based, nationally representative sample of U.S. adults (n=1,014). To measure willingness to share with different entities, we asked whether participants were "comfortable having my electronic health information being a part of a network that includes": other healthcare providers involved in my care, all healthcare providers in my state, social service agencies, mental health services, research networks, and quality improvement networks. Responses were combined to create a single index of willingness to share health information. Hypothesized predictors of willingness to participate included **demographic** variables and variables evaluating **privacy concerns, confidence in research, trust in the health system, security of health insurance coverage, and beliefs about policy and governance** such as informed consent. Weighted Ordinary Least Squares (OLS) stepwise regression was used to identify predictors of willingness to participate in health information networks.

Results: Just over half of participants indicated willingness to participate in health information networks that included their providers only (54.0%), while only about a third indicated willingness to be a part of a research (30.6%) or quality improvement network (31.0%). Fewer respondents were willing to be part of a health information network that includes mental health services (27.4%), all providers in their state (25.5%), or social service agencies (20.1%). Of the hypothesized **demographic** predictors of willingness to participate, we found that those with at least a college degree were more likely to be willing participants in health information networks than those with a high school degree or less ($b^* = -0.11$; $p = 0.003$). **Privacy concerns** were negatively associated with willingness to participate ($b^* = -0.11$; $p = 0.008$). Measures of **confidence in research** associated with willingness to participate included the belief that people have an obligation to participate in research ($b^* = 0.22$; $p < 0.001$), and the belief that health researchers are sufficiently accountable for conducting ethical research ($b^* = 0.19$; $p < 0.001$). **Trust in the health system** ($b^* = 0.22$, $p < 0.001$) was positively associated with willingness to participate. Concern about one's **security of health insurance coverage** was a negative predictor measured as the belief that their health insurer could use private health information against them ($b^* = -0.12$, $p = 0.001$). Statistically significant factors evaluating **beliefs about policy and governance** included the belief that access to electronic health information is adequately regulated ($b^* = 0.22$; $p < 0.001$), and preference for giving permission ($b^* = 0.12$; $p = 0.001$). Preference for notification each time health information is shared ($b^* = -0.07$; $p = 0.037$) was negatively associated with willingness to share information. The regression model accounted for 41.8% of the variability in willingness to participate.

Conclusion: We found that the public is generally unwilling to be part of a health information network that extends beyond their care providers. Decision makers should be cautious of assuming acceptability of widespread information sharing and seek input from those who are skeptical. Our results suggest that confidence in the policies governing health information networks and confidence in the consent process are associated with greater willingness to share electronic health information. Public engagement should thus include demonstrating and communicating accountable systems and responsible regulation where appropriate. Building trust and health networks that are FAIR to the public should be a priority for expanding health information networks.

The proposed paper extends previous work on:

1. **Public trust in health information sharing**, e.g.:
Platt JE, Jacobson PD, and Sharon LR Kardia. "Public Trust in Health Information Sharing: A Measure of System Trust." *Health Services Research* (2017).
2. **Public engagement and policy preferences for public health biobanking**, e.g.:
Thiel DB, Platt J, Platt T, King SB, Fisher N, Shelton R, et al. Testing an online, dynamic consent portal for large population biobank research. *Public Health Genomics*. 2015; 18(1):26-39. PMID: 25359560, and
3. **Informed consent for large population longitudinal cohort studies**, e.g.:
Platt J, Bollinger J, Dvoskin R, Kardia SL, and Kaufman D. Public preferences regarding informed consent models for participation in population-based genomic research. *Genet Med*. 2014;16(1):11-8. PMID: 23660530

On behalf of my co-authors, thank you for your consideration.