

## **FACULTY MENTOR**

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## **PROJECT TITLE**

Impact of Privacy Environments for Personal Health Data on Patients

## **PROJECT DESCRIPTION**

### Abstract

A big data ecosystem is evolving in our society in which people may have, or feel they have, little control over the flow of their personal health information, and thus their privacy. Further, although there has been significant discussion related to big data and privacy at the highest levels of government, there is little consensus among scholars and stakeholders as to what privacy actually is, not to mention a lack of data from individuals as to personal conceptions of privacy. While much has been written about the potential harms of this and the rapidity with which the divide between health-related big data capabilities and privacy controls and protections is widening, we have little systematic knowledge of the nature and impacts of individual-level privacy concerns, and no reliable and valid tools for acquiring such knowledge from patients. The goal of this project is to conceptualize, measure, and understand individual privacy affinities and responses to privacy environments in the context of health-related big data technologies. The primary deliverable of the project will be a psychometrically sound instrument: the Privacy Affinities and Privacy Environment Responses (PAPER) scale. Privacy has been the subject of several proposed theoretical frameworks in many different fields including philosophy, sociology, and law. Considering privacy from a behavioral and psychological perspective, we propose a preliminary conceptual model in which privacy is a combination of stable individual privacy affinities or predilections and changing individual responses to different privacy environments. We propose a three-phase project using qualitative and quantitative methods: In Phase One, we will refine our conceptual model through comprehensive literature review, individual interviews, focus groups, consultation with experts, and analyses of preliminary data from two previous studies. In Phase Two, we will develop a psychometrically sound instrument to measure individual privacy affinities and privacy environment responses related to personal health data information technologies according to established practices for measuring patient-reported outcomes. We will leverage an established instrument development platform. In Phase Three, we will administer this instrument to an online patient community of over 2,000 individuals. We will explore the relationship between privacy and propensity to adopt health-related big data technologies, willingness to share personal health data for research, and disease type and stage. To accomplish these goals, we have assembled a team of experts in bioethics, law, information and computer science, clinical psychology, medicine and public health, psychometrics and instrument development, privacy theory and technology, online survey research, and health policy. Development of an instrument to assess privacy will catalyze patient- and community-engaged research on this important topic. In turn, this will inform and promote development of transparent, patient- and user-centered privacy policies and practices, which are critically needed at this time of unprecedented technological advancement.

### Public Health Relevance

The divide between health-related big data capabilities and individual privacy controls and protections is widening, and we have little systematic knowledge of the privacy concerns of individuals, and no reliable and valid tools for acquiring such knowledge from patients. The goal of this project is to refine a conceptual model of privacy and develop and test a psychometrically sound instrument to measure individual privacy affinities and privacy environment responses with respect to personal health big data.

### **INTERNS NEEDED**

1 BS or MS student

### **PREREQUISITES**

None