

UFHCC Research Day 2017 | Abstract Template

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TITLE

Perceptions of Privacy Assurance among Patients with Cancer: Exploring Factors that Influence Consent2Share Research Registry Retention

HYPOTHESIS:

Cancer patients' intention to remain enrolled in the Consent2Share (C2S) research registry will be influenced by perceptions regarding the collection, control, and awareness of personal health information.

BACKGROUND/AIMS:

Increasing enrollment, active participation, and retention of patients with cancer into research registries is a national and institutional priority at the University of Florida (UF). Although government entities require that research registries have carefully vetted safeguards in place to minimize the possibility of a privacy or security breach, patients' subjective perceptions of these protections may not be accurate. A constellation of factors may influence patients' awareness of such safeguards to protect privacy during the process of collecting and managing personal health information for the registry database. One empirically supported factor is comprehension of informed consent materials. Other factors include trust in medical doctors who are recruiting them, and patients' beliefs about the risks to disclosing personal information that will be available within an online database. Currently, the relationship between these factors within the context of retaining active patients with cancer in an institutional research registry is unknown. Therefore, the purpose of this study is to explore risk beliefs about the collection and control of personal health information within research registries among patients with cancer and how beliefs contribute to patients' decisions to remain active and enrolled within the Consent2Share (C2S) research registry.

METHODS:

A sample of 1,800 adults currently enrolled in the UF C2S research registry is being recruited to participate in an online survey. The online survey includes items to assess standard socio-demographics, health literacy, cancer-type diagnosis, and intention to remain enrolled in C2S and participate in a study if asked. Items were adapted from scales assessing online information privacy concerns, trust in medical doctors, and risk beliefs of sharing personal information that will be stored within an online repository. These analyses will include frequency and descriptive statistics to describe the sample, with specific attention to patients with a presence and absence of a cancer diagnosis. Further statistical analyses will be conducted to identify how risk beliefs, trust in medical doctors, and comprehension of the C2S informed consent form mediates the relationship between privacy and intention to remain in C2S research registries.

RESULTS & CONCLUSIONS

Findings of this study will have important implications for enrolling and retaining patients living with cancer into research registries. Specifically, this study will examine the systemic privacy concerns that shape patients' beliefs and subsequent intentions to remain an active potential participant with cancer within the C2S research registry. Findings will also describe how trust in doctors, risk beliefs, and comprehension of C2S informed consent further explain the relationship between patient's perceptions of privacy and their intention to remain enrolled within the C2S research registry.