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SHARING PERSONAL HEALTH INFORMATION: A MOTIVATION-HYGIENE MODEL

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ABSTRACT

The promise of personalized medicine hinges on individuals sharing their personal health information (PHI) for research purposes. However, the motivations behind individuals' decisions to share their health information remain unclear. Increasingly, many organizations are now using both monetary and non-monetary incentives to encourage individuals to share their electronic PHI for research purposes. However, the effectiveness of such incentives is uncertain; research indicates that incentives may help or hinder as they can dampen the motivation to share. Utilizing Herzberg's motivation-hygiene theory, this study explores how individuals' perception of 'value fit' with the recipient organization interacts with incentives to determine their motivation.

Keywords

Personal health information, Motivation, Value fit, Herzberg's motivation-hygiene theory

EXTENDED ABSTRACT

Sharing personal health information is essential for the development of advanced healthcare services. The advent of preventive and personalized medicine hinges on the aggregation and analysis of health data from a multitude of individuals, which in turn identifies trends in wellness and disease. The realization of this promise is contingent upon individuals sharing their personal health information (PHI) and storing it digitally for research purposes.

Individuals are more inclined to donate or share when there is a congruence between their personal values and those of the recipient organization (Kesberg & Keller, 2021). A salient example within the healthcare context is patient-established biobanks. These specialized repositories, established and managed by individual patients or patient organizations thrive on the mutual understanding and shared values between the individual (patient) and the organization (biobank). This synergy fosters a community where patients are more motivated to share data. Accordingly, the literature on person-organization fit suggests that value fit, defined as the congruence between an individual's personal values and those endorsed by an organization, is a significant motivator for sustained contributions, particularly within volunteer-driven organizations (Van Vianen et al., 2007).

Increasingly many organizations are now using incentives, both monetary and non-monetary, to encourage individuals to share their electronic PHI for research purposes. However, the practice of offering incentives to recruit volunteers for health-related research is contentious, given the potential ethical and legal implications (Slomka et al., 2007). On one hand, incentives are considered customary and expected in settings where individuals share PHI in return for personal gain (Halpern et al., 2021). Conversely, research suggests that the prospect of receiving incentives is sometimes perceived negatively, potentially dampening motivation (Ariely et al., 2009). This dichotomy foregrounds our research question: How does the interaction between individuals' perceptions of value fit with a recipient organization and the presence of incentives (monetary and non-monetary) affect their motivation to share personal health information for research purposes?

We employ Herzberg's motivation-hygiene theory to elucidate the factors influencing individuals' motivation to share PHI (Herzberg, 1966). Herzberg distinguishes factors that facilitate psychological growth (motivation factors) from those that fulfill physiological needs (hygiene factors). We hypothesize that the perception of value fit with the organization serves as a motivation factor, while the provision of incentives acts as a hygiene factor. Our study aims to explore how the tension between value fit and incentives influences individuals' motivation to share PHI, potentially revealing the limits of this motivation. We propose to employ a scenario-based factorial survey for data collection, as proposed in the work of Vance et al. (2015). Factorial surveys differ from traditional scenario-based surveys in that they experimentally alter and vary scenario descriptions (Vance et al., 2015). A factorial survey consists of several levels of dimensions, which are similar to treatments in an experimental method. In this method, these dimensions and different levels are transformed into textual scenarios that replicate realistic situations for judgment and decision-making.

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