

Perception of risk of disclosure of health information

Ester Moher

Children's Hospital of Eastern Ontario; University of
Ottawa
401 Smyth Rd, Ottawa, Canada
estermoher@gmail.com

Khaled El Emam

University of Ottawa, Faculty of Medicine; Children's
Hospital of Eastern Ontario
401 Smyth Rd, Ottawa, Canada
kelemam@ehealthinformation.ca

ABSTRACT

In this paper, we describe one experiment examining how and when individuals assess risk of disclosure of personal health information. Ironically, giving individuals more information about security practices discourages disclosure, in part because thinking about security practices also primes thinking about security breaches.

General Terms

Measurement, Experimentation, Security, Legal Aspects.

Keywords

Health risk, privacy, confidentiality.

1. INTRODUCTION

Health professionals looking to estimate prevalence rates of notifiable diseases (e.g., influenza, sexually transmitted infections (STIs)) often run into a problem of under-reporting [1], [2]: individuals do not like to report a case of such a disease.

Arguably, informing individuals that information collected is anonymous and confidential should decrease under-reporting. However, it seems that communication of security practices is not regarded as a decrease in risk (encouraging disclosure), but is treated as an increase in risk (decreasing disclosure).

1.1 Anonymity and Confidentiality Concerns

Some evidence suggests that when identity is anonymous, participants should report increased incidence of sensitive or embarrassing behaviours [3], [4], [5], [6], [7], [8], [9], [10]. Some literature further suggests that confidentiality assurances do increase response rates [11, p. 199] Esposito et al., 1984; Ford, Millstein, Halpern-Felsher, & Irwin Jr., 1997).

However, other studies have demonstrated that when anonymous, individuals are less accurate or inconsistent reporters of their behaviour [12], [14]. It is possible that complete anonymity promotes a sense of freedom from punishment of lying or misreporting. As such, one consequence of guaranteed anonymity is the possibility of reduced accountability of responses (see also [15]). Further, informing individuals of the strength of security protecting their data (i.e., confidentiality) actually counter-intuitively and ironically encourages them to withhold more information than when those securities are not mentioned [4], [16], [17], [18], [19], [20], [21], [22, p. 2]. Individuals may thus see a privacy policy as a warning instead of as a notice of safety, which may induce skepticism and careful assessment of the potentially unsafe environment [23], [24]. As a consequence, individuals may “clam up” and fail to take advantage of a safe outlet for information sharing.

2. STUDY: EFFECTS OF SECURITY PRACTICES ON DISCLOSURE

2.1 Participants

Participants ($N = 418$) were recruited through Crowdfunder (<http://crowdfunder.com/>), and were compensated with \$0.25 for participation. Participants were selected from Canada and the US. No other limits (i.e., age, gender) were in place.

2.2 Methods

Participants read a consent letter before completing a short survey on personal health information. We experimentally manipulated anonymity, confidentiality, and research sector in a 2 (Anonymity: Anonymous (no identifying information asked), Non-anonymous (name and city asked of participants)) x 2 (Confidentiality: Confidential (detailed description of confidentiality statement), Non-confidential (no statement)) x 2 (Sector: Private (private research firm), Public (university hospital-affiliated research group)) factorial design.

Following consent, participants were taken to a separate webpage, where they were asked to disclose health information. Responses were coded as a personal admission, family admission, denial, or non-response.

2.3 Results

We first examined any differences in time spent completing the study. We observed a marginal main effect of Anonymity on time-on-task, $F(1, 277) = 3.57$, $MSE = 68.72$, $p = .06$, $\eta^2 = .01$, reflecting that participants took somewhat longer to complete the survey when they were asked to give their name. This difference suggests that perhaps asking participants for their name encouraged them to take some extra time to consider privacy concerns [14].

As a first measure of disclosure, we examined the number of “Prefer Not to Say” response selections by participants across the study. There was a marginally significant Anonymity x Confidentiality interaction, $F(1, 387) = 2.89$, $MSE = 14.62$, $p = .09$, $\eta^2 = .008$. Post hoc comparisons reveal that when participants are anonymous, confidentiality assurances may cause greater suspicion and less disclosure of personal health information (as in John et al, 2011).

As a second measure of disclosure, we examined how self-related health behaviours were reported to be. We assigned higher scores to more “proximal” responses (e.g., “I have had an STI”), and lower scores to more “distal” responses (e.g., “A distant family member has had an STI”). When participants feel that their privacy is threatened, they will be less likely to admit to having personally engaged in an unsavoury health activity, and may instead be more likely to group themselves more broadly, such as with extended family, when admitting.

We observed a significant Anonymity x Confidentiality x Sector interaction, $F(1, 387) = 4.26$, $MSE = 245.16$, $p < .05$, $\eta^2 = .01$, such that when disclosing to a public institution (i.e., a university), participants stated that health-specific behaviours were more distal to themselves when anonymity and confidentiality were assured. That is, participants were less likely to admit to sensitive health behaviours when anonymity and confidentiality were assured. There were no significant differences when the institution was Private.

Finally, we examined the role of trust. There were no significant effects of trust by condition, $F < 1.5$, $p > .20$. However, trust was significantly negatively correlated with disclosure of health-related behaviours, $r(422) = -.14$, $p < .01$. One possibility is that increased trust hurts disclosure. Another is that participants did not consider trust concerns while disclosing. However, when asked about trust at the end of the study, participants had difficulty remembering trust cues (given that more disclosure was associated with lack of Anonymity or Confidentiality assurances); as such, they rated trust as relatively low.

2.4 Discussion

When anonymity and confidentiality are explicitly assured, individuals are less inclined to disclose sensitive health information, and are more likely to actively choose non-response options. This work suggests that individuals may have a hard time overcoming their intuitive (but incorrect) responses to risk information; as such, future work should focus on developing informative and functional consent forms that effectively communicate risk, but do not shift disclosure preferences unintentionally.

3. ACKNOWLEDGMENTS

Our thanks to the EHIL research group for insightful discussion on this work.

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