

Privacy and Confidentiality Challenges in Health Survey Research

Discussion

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Three Challenges Related to Assurances In the Digital/Social Media Era

Challenges Related to Assurances

› Respondent beliefs

- Widespread belief that government shares FSS data (Gerber, 2003)
- Belief in confidentiality of data in FSS by ~50% (Childs et al, 2018)
- Belief that government tracking (privacy) unavoidable ~60% (Pew, 2019)

The gov't already knows a lot about me

› Contrasting protections (Social Media, Technology, Apps)

- Informed Consent vs Terms of Service & Privacy Policies
 - IC driven by protecting respondent / ethics in research
 - TOS/PP driven by protecting company / legal requirements
 - About 20% read privacy policies (Pew, 2019)

Challenges Related to Assurances (2)

› Respondent ignorance

- Knowing when data is being collected
- Knowing what data is being collected
- Knowing who has data, or when shared



The Verge

Thousands of Android apps can track your phone — even if you deny permissions

Even if you say “no” to one app when it asks for permission to see those personally identifying bits of data, it might not be enough: a second app ...
Jul 8, 2019



AppleInsider

Ring's app caught spying on users, sharing data with third-parties

The Electronic Frontier Foundation has discovered that third-party tracking software within the Ring doorbell app is sending customer data to ...
1 month ago



MarketWatch

Fitness and health apps may be sharing the most private details about your life

“Monitoring yourself with a fitness tracking app that is collecting data is like publishing your own medical autobiography online. These neat little ...
Mar 5, 2019



Washington Post


Smoking and depression apps are selling your data to Google and Facebook, study finds

Smoking and depression apps are selling your data to Google and ... The problem: Many of the apps designed to track a user's progress are ...
Apr 22, 2019



Effect on Perception of Assurances


- › Respondent privacy concerns shaped by perception and experiences
- › Commercial interactions more common/influential than government
- › Lack of control over information is common experience, expectation

 The Verge

Health apps can change their terms of service without users' knowledge

These apps collect health data, but often, they are not governed by HIPAA, the law that ... That's health information, so HIPAA should apply.

1 week ago



- › Do expectations of privacy persist?
 - Use of information consequence of product or service.
 - Blurring of “protected health” data and “user health” data

Result of Experiences

› Growing Privacy Landscape

- EU General Data Protection Regulation (GDPR)

Aims to give persons *some* control over data

- California Data Privacy Protection Act (CDPP)

Persons required to identify misuse/breach

Possibly lead to incentivizing personal disclosure

› Will respondents want something similar for FSS data?

Confidentiality – Differential Privacy

› Differential Privacy:

- A mathematical mechanism for ensuring confidentiality of collected data.
 - Permits public use of information / secure use by more data users
 - More data available to researchers?
 - Could this encourage broader collection of information – overconfidence of *privacy*?
 - Doesn't eliminate the need for data security – still collecting private information.
 - 55% view hacking as biggest threat to medical privacy (CHCF, 1999)

Confidentiality – Differential Privacy

› Differential Privacy:

- Challenging in assurances
 - If my data will not change findings, then why do you need it?
 - Your vital to accurate data, then we'll make it less accurate.
- Creates opposing interest: researchers want $\epsilon = 1$; participants want $\epsilon = 0.1$.
 - 31% not willing at all to risk privacy (Eggleston, HSRM)

Thank You

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References

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