Perception of risk of disclosure of health information

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A bit about me/EHIL

- EHIL lab: develop software to anonymize data
A bit about me/EHIL

- PARAT software
- Business benefits
  - Easier ethics applications
  - More security should improve data quality and quantity
PARAT trial (why I was hired)

- PARAT software trial (El Emam et al, in press)
  - Infection rates in long-term care facilities

- Early responders: reported low infection rates
- Late/non-responders: reported high infection rates (proxy)
Problem: not increasing quality or quantity of data
Q: Are assurances encouraging non-disclosure?

Privacy
Participants (N = 418) were recruited through Crowdflower.
Methods

- Survey: disclose health information
  - Responses: personal admission, family admission, denial, or non-response*
- Consent form:
  - Anonymity assurances: present vs. absent
  - Confidentiality assurances: present vs. absent
  - Private vs. Public research group
Results: Non-response

- When anonymous, confidentiality assurances increase *non-response rates* (*p = .09*)
  - Assurances increased suspicion (John et al, 2011)
Results: Self vs. other admissions

- When assured, rated health behaviours as more likely to have occurred to other vs. self (p < .05)
Summary

- Assurances of confidentiality and anonymity *should* encourage more honesty
  - Instead, encourage withholding information; dishonesty
  - Act as a warning, not an assurance
Follow-up studies

- Study 2: Repeated reminders of assurances
- Study 3: Real-world simulation
Discussion

- Assurances compromise the quality and quantity of information provided
- BUT they are ethically required
- AND this is irrational
Future directions

- Real-world application with real patients and consent forms

- Symbolic assurances instead of written assurances

- Debiasing techniques
  - Distancing study questions from consent
Questions?
Thank you!
References


