

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)

PARAT trial



- Problem: not increasing quality or quantity of data

**Q: Are assurances
encouraging non-disclosure?**



Study

- Participants (N = 418) were recruited through Crowdfunder

The screenshot shows the Crowdfunder website homepage. At the top, the Crowdfunder logo is on the left, and navigation links for 'Products', 'Company', 'Blog', and 'Docs' are in the center. A 'Log in' button is on the right. The main heading is 'The World's Largest Workforce' in large orange letters. Below it is the tagline 'Instantly hire millions of people to collect, filter, and enhance your data.' There are three main content areas: 1) 'RTFM Real Time Foto Moderator' with a description 'Crowdsourced image moderation with a simple real-time API.' 2) 'Senti Sentiment Analysis' with a description 'Fast, accurate human review of user-generated social media content.' 3) 'Real-time Crowd Labor' featuring a world map and a statistics box showing 'judgments/sec current velocity' as 515.107,994 and 'total judgments' as 515,107,994.

Crowdfunder Products Company Blog Docs Log in

The World's Largest Workforce

Instantly hire millions of people to collect, filter, and enhance your data.

RTFM
Real Time Foto Moderator
Crowdsourced image moderation with a simple real-time API.

Senti
Sentiment Analysis
Fast, accurate human review of user-generated social media content.

Real-time Crowd Labor

— judgments/sec current velocity: **515.107,994**
total judgments: **515,107,994**

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!



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