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Research Interests

PIM, Personal archiving, Personal financial information, Personal health information, Ethics, Anthropology of archives, Information and culture

Submission Summary

Question

What are the ethical implications of the collection and use of personal information (PI), especially by researchers, corporations, and governments?

Case

PatientsLikeMe.com's (PLM) Mood Disorder Community, a social networking and personal health record platform (PHR) for patients with various mental health conditions. The site is free to use but user data is collected and shared with commercial third parties.

Critical Incident

A New York-based advertising firm, Nelson, uses a bot to scrape portions of PLM. The scraping is detected. In court, PLM requests Nelson delete the stolen data. Nelson permanently quarantines

data after unsuccessful attempts at deletion. PLM issues a press release and public statement about the case in the Wall Street Journal, which grabs the attention of site members.

Member Responses

Site members openly discuss the press releases on the scraping incident. Site members respond in three broad ways:

(1) Fair Exchange

Some members consider PIM, information, and community on the site to be a fair exchange. Members use metaphors of *gift giving*, *contributions to science*, and *hope*. Participation is fully informed.

(2) Ambivalence

Some members describe *partial awareness* of the site's business model but still view their participation as consensual. They express *doubt about the value* (i.e. scientific, financial) of their PI.

(3) Exploitation

Some members saw their participation as a form of *uncompensated labor* and objected to the sale of their PI. They expressed *vulnerability* as persons with mental health conditions and raised questions about *user agreements* as appropriate vehicles for collecting *informed consent*.

Discussion Questions

- Does PIM, as a research field, need a codified stance on ethical use of PI?
- How do ethics impact the kinds of topics, methods, participants PIM researchers select?
- Should PIM researchers offer guidance to corporations, governmental agencies, and other researchers, on ethical use of PI?