

CONTEXTUAL ISSUES

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DATA PRIVACY IS *CONTEXT-SENSITIVE*.

research-specific concerns

- healthcare and other services,
- research efficiency
- selection bias
- participant willingness
- access to health records and other vital information,
- the quality of data sets



DISCUSSION OUTLINE



**OPERATIONAL
CHALLENGES**



DATA SHARING



**PRIVACY AND
FILIPINO
CULTURE**



**THE RESEARCH
CONTEXT**

OPERATIONAL CHALLENGES

Selection Bias

Compliance with privacy regulation potentially entails selection bias when individuals who give their consent do not accurately reflect the target population.

Rothstein and Shoben (2013) argue, 'beneficial scientific ends do not justify oppressive means'

Solution: Research and Statistical Methods

OPERATIONAL CHALLENGES



Timely Access to Health or Other Vital Information



Conservative readings of privacy regulation, therefore, can potentially threaten life-saving research that needs to be done within a specific time frame. As one researcher succinctly and grimly puts it, 'We study a disease that will kill you in three months. If we wait a year, we won't have any subjects to study.'



Example: Ebola Outbreak

OPERATIONAL CHALLENGES



Research Efficiency



Privacy compliance entails additional costs and staff hours for research projects.



The fear of incurring criminal liability

DATA SHARING



In the Philippines, the National Privacy Commission only allows data sharing “when there are adequate safeguards for data privacy and security,” using “contractual or other reasonable means to ensure that personal data is covered by a consistent level of protection when it is shared or transferred.”



Who can access your data?

DATA SHARING



The Marginalized



Is there strong privacy protection for marginalized individuals and groups in society whose personal data are shared among researchers?

DATA SHARING



Persistence of Sharedness



Destruction of data in one source does not guarantee complete destruction at all. Ownership of data is not the same as access to data.

PRIVACY AND FILIPINO CULTURE



Filipinos are a “highly relational people.



pakikisama



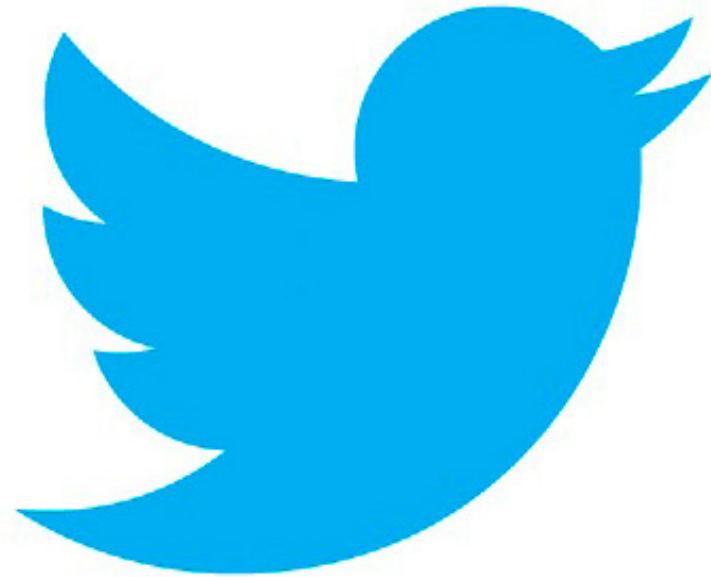
2008 Cebu Canister Scandal



‘pervasiveness of tsismis (gossip) in Filipino culture’

THE RESEARCH CONTEXT

- Each situation has its own contextual integrity that people are emotionally or personally invested in. It's not merely the sharing of personal information *per se* that upsets people but the breaking of its contextual integrity.
- #alterph



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