

# Contextual Privacy by Design for Integrated EHRs

Timothy Kariotis *@timothykariotis* 

School of Computing and Information Systems



#### Team







#### Assistant Professor Darakhshan Mir

Department of Computer Science



#### Associate Professor Shanton Chang School of Computing and Information Systems

Bucknell







#### Dr Megan Prictor

Melbourne Law School



Centre for Health, Law and Emerging Technologies at Oxford



#### ONCE UPON & TIME...

A researcher was designing an electronic health record. Being a responsible researcher they decided to undertake a contextual integrity evaluation before implementing this EHR.

The research found that the EHR looks to be breaching contextual integrity. However, they thought this breach was justified, due to the EHR upholding the values and ends of the healthcare context.

So the technology was implemented...BUT THEN...



#### TO BE CONTINUED

## Evaluative $\rightarrow$ Design

ТК

How do we take the evaluative/analytical power of contextual integrity and apply it in the design space?



### Context of Work



- A fragmented health system
  - Healthcare
  - Mental healthcare
  - Social care
  - Informal supports
- Poor information sharing
- Electronic Health Record solution



## Contextual Integrity of EHR

- Transmission principles
  - Push to Pull
  - Event-based
  - Context-aware (?)

- Justified
  - Benefits to patient and clinician

Kariotis, T., Prictor, M., Chang, S., & Gray, K. (2019). Evaluating the Contextual Integrity of Australia's My Health Record. *Studies in health technology and informatics*, *265*, 213-218. doi: 10.3233/SHTI190166







## Privacy by Design



Pro-active consideration of privacy in both the technical and governance of information technologies.

Cavoukian, A. (2009). Privacy by Design in Law, Policy and Practice. Retrieved from http://www.ontla.on.ca/library/repository/mon/25008/312239.pdf

## Contextual Integrity



- Appropriate flow of information
- Context-specific information norms
- Does a new technology breach these norms?

- 1. Information flow
- 2. Prevailing Context
- 3. Actors
- 4. Transmission Principles
- 5. Entrenched Information norms vs designed-in-norms
- 6. Initial Assessment Prima Facie breach...
- 7. Evaluation I: Key Interests
- 8. Evaluation II: Moral and Political Interests
- 9. Evaluation III: Contextual values, goals, ends
- 10. Outcome





How can we take the evaluative power of contextual integrity and use it to consider the design of new technologies?

## Appropriation of Technology

- Technology is shaped by social/organisational context
- Social/organisational context shaped by technology

"Technology is never purely technological; it is also social. The social is never purely social; it is also technical. This is something easy to say but difficult to work with."

J. Law, and W. Bijker, Postscript: Technology, Stability, and Social Theory, in: Shaping Technology / Building Society, The MIT Press, London, UK, 1992. (p305).



## Adaptive Structuration Theory

• Technology has....



**Structural Features** 





G. DeSanctis, and M.S. Poole, Capturing the complexity in advanced technology use: Adaptive structuration theory, Organization Science. 5 (1994) 121–147.

## Adaptive Structuration Theory

• Technology has....

**Structural Features** 



**Appropriation Moves** 



Faithfulness



ΤK



Org structure



#### Context-of-Design

- Designers bring together a number of stakeholder values/ends/goals/norms
- Interpretation of the context



A. Albrechtslund, Ethics and technology design, Ethics and Information Technology. 9 (2007) 63–72. doi:10.1007/s10676-006-9129-8.

# ТК

#### Context

- What do we actual mean by context?
- Context-as-symbolised
- Context-as-experienced
- Context-as-framed
- Context-as-designed
- Context-through-appropriation



P. Dourish, What We Talk About when We Talk About Context, *Personal Ubiquitous Comput.* **8** (2004) 19–30. doi:10.1007/s00779-003-0253-8.



#### Context

"Contexts are sets of connections construed as relevant to someone, to something, or to a particular problem, and this process yields an explanation, a sense, an interpretation for the object so connected."

R.M. Dilley, The problem of context in social and cultural anthropology, Language & Communication. 22 (2002) 437–456.





#### Designed-In Norms



- Through structural features and spirit, technology has 'designed-in-norms.'
- Not actual norms but inscribed norms or rules...



#### Linking Context and Tech





#### Social

I. van de Poel, Translating Values into Design Requirements, in: D.P. Michelfelder, N. McCarthy, and D.E. Goldberg (Eds.), Philosophy and Engineering: Reflections on Practice, Principles and Process, Springer Netherlands, Dordrecht, 2013: pp. 253–266. doi:10.1007/978-94-007-7762-0\_20.

Technical



#### Social

I. van de Poel, Translating Values into Design Requirements, in: D.P. Michelfelder, N. McCarthy, and D.E. Goldberg (Eds.), Philosophy and Engineering: Reflections on Practice, Principles and Process, Springer Netherlands, Dordrecht, 2013: pp. 253–266. doi:10.1007/978-94-007-7762-0\_20.

Technical

#### Method for Contextual PbD

- Participatory Design
- Co-Design
- Living Labs
- LIVED EXPERIENCE
- Design-in-use



C. A. Le Dantec, E. S. Poole, and S. P. Wyche, "Values as lived experience: evolving value sensitive design in support of value discovery," presented at the Proceedings of the SIGCHI conference on human factors in computing systems, 2009, pp. 1141–1150.

D. J. Mir, Y. Shvartzshnaider, and M. Latonero, "It Takes a Village: A Community Based Participatory Framework for Privacy Design," in 2018 IEEE European Symposium on Security and Privacy Workshops (EuroS&PW), 2018, pp. 112–115.

#### Participation





"Participation is a transformative concept. It is a way of life, a way of seeing the world and a way of being in the world."

M. Ledwith and J Springett, *Participatory practice: Community-based action for transformative change*. Policy Press, 2010.

"The oppressed, having internalized the image of the oppressor and adopted his guidelines, are fearful of freedom." P. Freire, "Pedagogy of the oppressed (revised)," *New York: Continuum*, 1996.

#### Let's continue the conversation

ΤK

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<u>Timothy.Kariotis@unimelb.edu.au</u> @timothykariotis <u>www.linkedin.com/in/timothy-kariotis/</u>

Also...if you want to work on,

- Actor-Network theory + context
- Participation and norms
- Appropriation theory

Let me know!