A Human Factors Approach to Securing Information Technology in Healthcare

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Vision:

• “ Electronically exchanged information... can significantly contribute to improvements in health and health care for individuals and populations.”
  – National Center for Vital and Health Statistics.
Vision assumes you give me your data

• What kind of data?
... and more.
vision

• unpack the vision
  – using (your!) data to provide better care

• BIG assumption: good data
  – understanding privacy is key
everyday privacy behavior
Background

• “Patients may desire a greater degree of choice to determine, at a granular level, which personal health information should be shared, with whom, and for what purpose. Applications must propose a breakthrough approach for achieving more granular patient control.”
  – Health Information Exchange Challenge Program CFP
Team: Privacy Enhanced EHRs
Goal: Develop Privacy Enhanced EHR

• Generate discrete data elements
  – Allows **providers** to **access** the **relevant data** while providing the **minimum amount of information necessary to provide care**

• Embody Fair Information Principles in EHR
Fair Information Practices

- FIPs are meant to maintain the level of individual privacy afforded by existing non-information-technology-enabled systems (i.e., an IT system should provide an equivalent level of individual privacy as a paper based system).
Research Questions

• Do patients desire a degree of choice to determine, at a granular level, which personal health information is shared?
  – With whom?
  – For what purpose?

• What user interface (UI) options would enable patients to achieve granular control?
Method: Card Sort & Contextual Interview
Why control access?

- P18: “Is there anything that lab technician has to know .. Let’s say you had something they needed to know. Then they would have limited access to that health information, but they wouldn’t have to see everything, all the medical records.”

- P20: “There’s just so much stuff in mine! I wouldn’t want everybody to see all that.”
Why control access?

- P5: “I think some information is just naturally on a need to know basis. I don't think an eye doctor needs to know your gynecological health or something.”

- P17: “should be on a need to know basis that would have to be articulated and privileges and consequences and for violating it should be in place.”
Summary

• Do patients desire a degree of choice to determine, at a granular level, which personal health information should be shared?
  – Yes.

• With whom?
  – Sharing preferences differ across recipient type.

• For what purpose?
  – As needed for MY treatment...
Implications for Design

• Offer many options for control
  – Hierarchical
    • Recipient level
    • Category level
    • Item level
  – Time based
    • Nothing before I was 18 or 21
    • Everything from the last 6 months

• Provide visualizations of access
  – Facilitates the maintenance of trust: P4: “I just trust that a physician that's going to keep that information to themselves and hopefully they would have a valid reason for looking at it.”
Next Steps

• Build UI
• Usability tests
• Eventually...
  – Integrate with Regenstrief Medical Record System & Indiana State Health Information Exchange
Acknowledgements

I’m especially thankful to:

• co-author
  – Rima Hanania

• collaborators
  – William Tierney
  – Sheri Alpert
  – Eric Meslin
  – Et al.

• phitlab co-director and members
  – Kay Connelly
  – Ginger White
  – Michele Degges
  – Morgan Soladine
  – Nathan Mihcalik
  – Mary Carter
  – and the rest of the phitlab team