Accountings of Relationships

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HealthSec’12
Outline

• Motivation
• Approach
• Proposal
Motivation

• HIPAA Privacy Rule grounded in FIPs
  – “There must be a way for an individual to find out what information about him is in a record and *how it is used.*” (emph. added)

• Mechanism in Privacy Rule
  – Accounting of Disclosure (AOD)

• HHS OCR proposed a new mechanism
  – Access Report (AR)
THE UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL

ACCOUNTING OF DISCLOSURES OF PHI

Requesting Individual ________________________________

This accounting covers disclosures made by ________________________________

between the dates of _____ and _____

(name of UNC-Chapel Hill dept.)

<table>
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<tr>
<th></th>
<th>DATE of Disclosure</th>
<th>Entity/Person receiving disclosure</th>
<th>Description of PHI disclosed</th>
<th>Purpose of Disclosure</th>
<th>Address of Entity/person receiving disclosure</th>
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Analysis

• Public comments to NPRM = data!
• Can extract frustrations/use cases
• Initially, analyzed sample of 132/435
  – AODs aren’t heavily used
  – “eDRS” is a serious problem for scope
  – Employee privacy/safety problems
• Extending to a comprehensive analysis of all 435 comments
Alternatives?

• From the point of contextual integrity:
  – What do patients care about?
  – What do they want to know about accesses?
  – What could patients do with information about flows of PHI?

• Use cases:
  – Comparative medical information shopping
    • Across institutions, longitudinal comparison
  – Artifacts that can support more sterile logs
Proposal: the AOR

- Aggregate AODs across all patients
- Essentially a data structure of aggregate information flow for a given time period
  - Nodes: sources and sinks of PHI
  - Edges: type of PHI, number of patients, purpose for which disclosure made
Visualizing AORs

• Sankey Diagrams
  – Visualization of network flows

• Alluvial Diagrams
  – Visualization of flows over time
Sankey Diagrams

Example from: http://bost.ocks.org/mike/sankey/
Alluvial Diagrams

Example from: http://stanfordneuro.wordpress.com/2010/01/28/
Related: TheDataMap

theDataMap™ is under development. Sign-up for updates.

The crowd-updated and verified map of personal data flows will be here, publicly available, changing over time to show the current state of knowledge. Below is the initial map, pre-launch. (More about the project...)

Example from: http://thedatamap.org/maps.html
Challenges

- Privacy in low-N flows
- Some systems do not capture this info.
- Large amount of flows
- Highly dynamic flows
- Comparing vocabularies across institutions
Thank you!

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• NYU’s work was supported by Grant Number HHS 90TR0003/01 (SHARPS); it is solely the responsibility of the authors and does not represent the views of HHS.