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.)

	DATE of Disclosure	Entity/Person receiving disclosure	Description of PHI disclosed	Purpose of Disclosure	Address of Entity/person receiving disclosure
1					
2					

User Name	Pt MRN	Patient Name	Day	Date	Time	Module	Action
LT	XXXXXXXX	Doe, John	Sun	XX/12/11	7:24 PM	Patient Select	View
LT	XXXXXXXX	Doe, John	Sun	XX/12/11	7:24 PM	Related Encounters	View
LT	XXXXXXXX	Doe, John	Sun	XX/12/11	7:24 PM	Flowsheet	View
LT	XXXXXXXX	Doe, John	Sun	XX/12/11	7:24 PM	ED VN Arrival	View
LT	XXXXXXXX	Doe, John	Sun	XX/12/11	7:24 PM	Flowsheet	View
LT	XXXXXXXX	Doe, John	Sun	XX/12/11	7:24 PM	Flowsheet	View
LT	XXXXXXXX	Doe, John	Sun	XX/12/11	7:24 PM	Report(146020)	View

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AW	XXXXXXXX	Doe, John	XX/15/11	View	Report
AW	XXXXXXXX	Doe, John	XX/15/11	View	Report
AW	XXXXXXXX	Doe, John	XX/15/11	View	Chart Review Notes tab
AW	XXXXXXXX	Doe, John	XX/15/11	View	Chart Review Imaging tab
AW	XXXXXXXX	Doe, John	XX/15/11	View	Chart Review Encounters tab
CG	XXXXXXXX	Doe, John	XX/15/11	Exit	Inpatient Notes

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

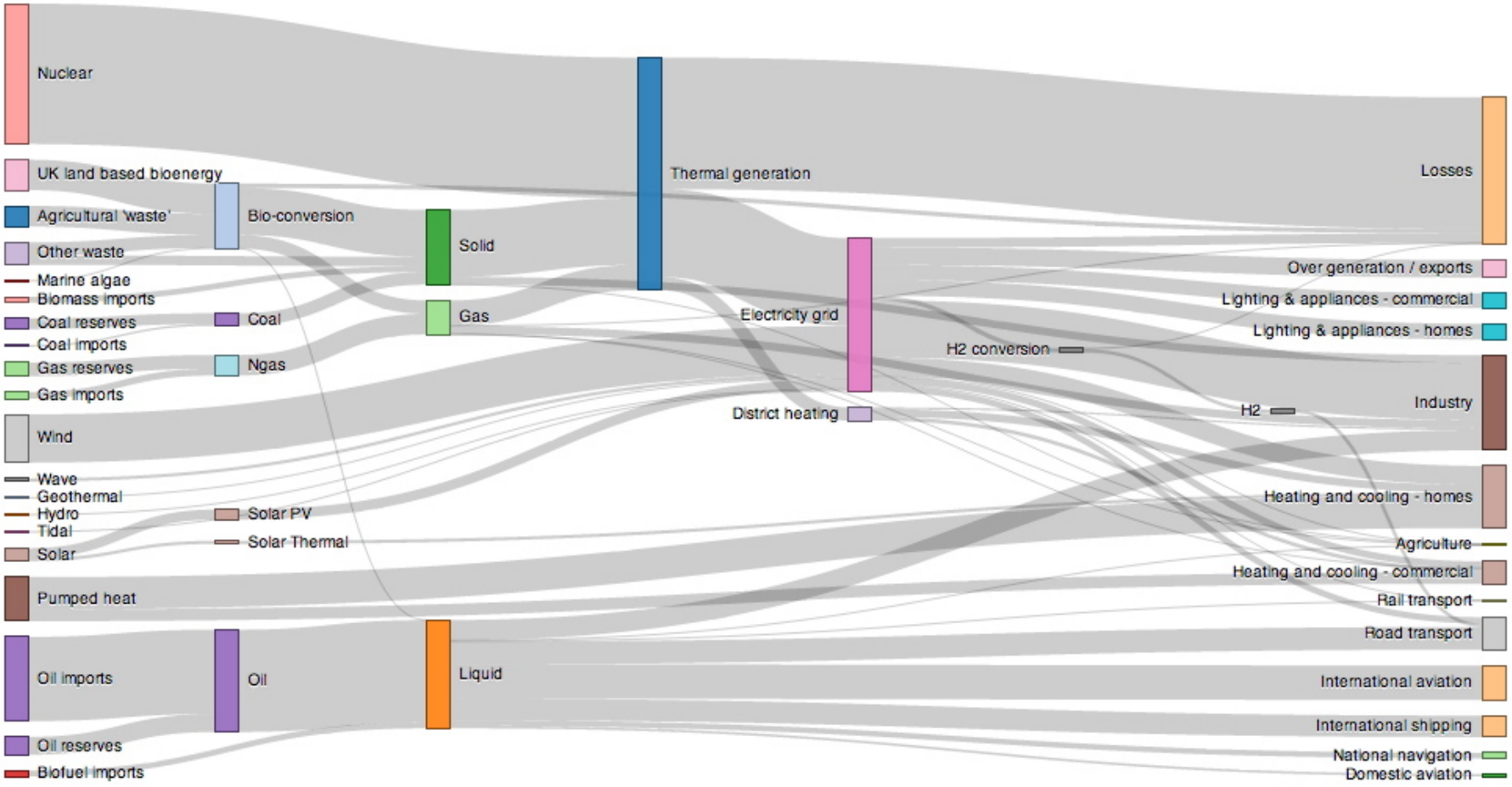
Proposal: the AOR

- 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

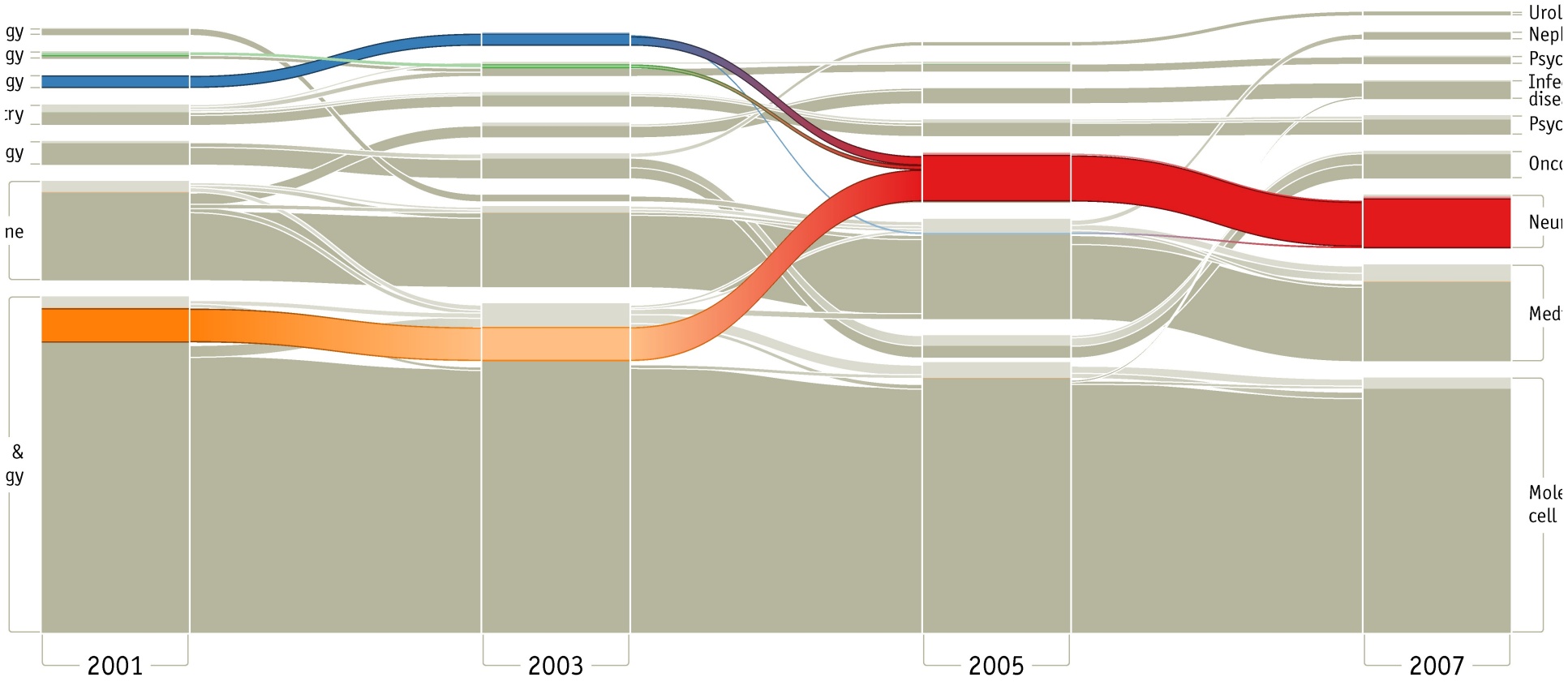
- Sankey Diagrams
  - Visualization of network flows
- Alluvial Diagrams
  - Visualization of flows over time

Sankey Diagrams



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

Alluvial Diagrams



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

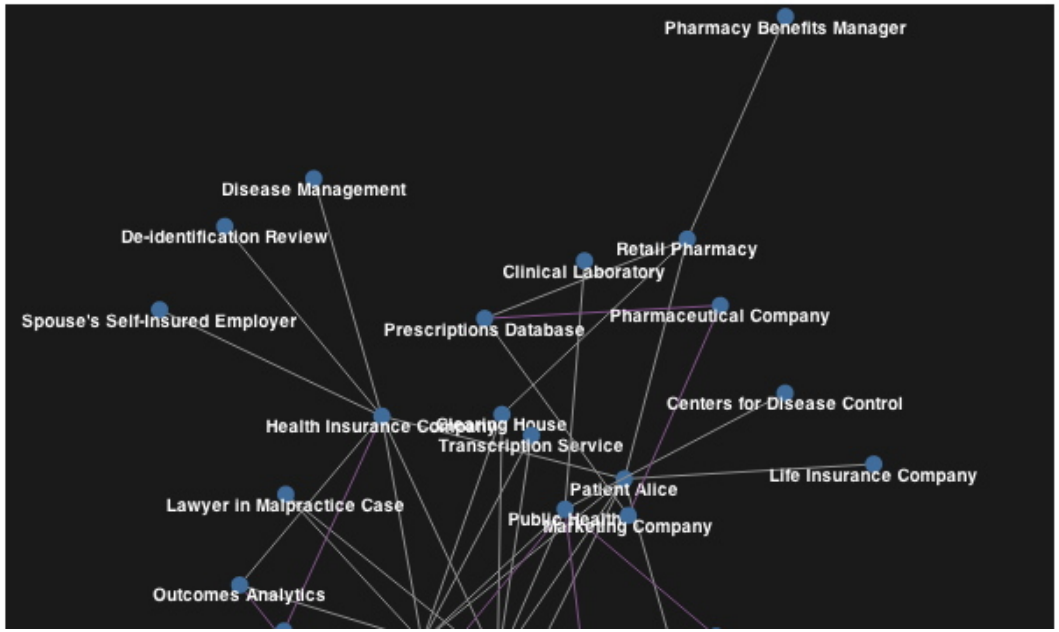
Related: TheDataMap

theDataMap™

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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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