

RESEARCH INFORMATION EXCHANGES IN HEALTHCARE

Federated Access for Secondary Use of EMR Data

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Study Focused Research Networks

- ▣ caBIG – National Cancer Institute
 - A collection of many software systems and standards, united by caGRID.
 - Focused on cancer and clinical trials
- ▣ BIRN – Bio-Informatics Research Network
 - Primarily focused on imaging data
- ▣ SPIN – Shared Pathology Information Network
- ▣ ePCRN – electronic Primary Care Research Network
 - Study focused, clinical trial recruitment
- ▣ All presume consented participants

Health Information Exchanges

- ▣ Focused on patient care, not research
- ▣ The basic data package to be exchanged is the individual patient record, as complete as possible to facilitate accurate, effective care
 - Obvious standards are HL7 CDA based – the CCD.
 - Completely identified.

Secondary Use Network

- ▣ CICTR – Cross Institutional Clinical Translation Research
 - Federated queries of research data warehouses across multiple institutions
 - Warehouses populated by EMR extracts
 - Patients NOT formally consented
 - The basic data package is the cohort – aggregated, summarized, and de-identified.
 - Suitable for cohort discovery, CER, Public Health studies
 - No one obvious standard for data

Clinical Data Sources for Research

- ▣ EMR, Billing, Labs, Peri-operative, ED, Scheduling, etc.
- ▣ Building a clinical research data warehouse is usually a struggle within a single institution
- ▣ Many, many governance and trust issues
- ▣ Months or years of negotiations
 - Two years at Stanford, two years at UCSF

How to Repurpose HIE Data?

- ▣ Where does HIE data reside?
 - Does it exist independently of the member institutions?
 - Is it a superset of existing EMRs?
 - ▣ A very politically charged choice.
- ▣ Who can decide?
 - Assuming HIE data can be re-used, who decides who gets to re-use it?
 - ▣ A super IRB? All IRBs in concert? What about institutions that don't have IRBs?
- ▣ Opt-in/Opt-out?
 - Using an Opt-in mechanism for the HIE creates huge scientific bias for research.