Johns Hopkins Clinical Data
Opportunities for Clinical and Translational Research

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Recent History

• The first question a Hopkins investigator would ask when confronted with the need for clinical data was always:
  • With which external organization can I collaborate for EHR data?
  • The prospect of attempting to get at Hopkins Data was rarely a consideration
Seismic Shifts in Clinical Data at Hopkins

• The Epic consolidation (so to speak)
• The Data Trust
  • Foster communication, mutual respect, synergy
• Serious restructuring of data retrieval services
  • Organization, management, tooling, training
  • Staff, skills, experience, service philosophy
• Precision Medicine Analytic Platform (PMAP)
  • President Daniels and Dean Rothman initiative
  • Twenty-first century technology
From Practice-based Evidence to Evidence-based Practice

Data

Clinical Databases

Registries et al.

Inference

Research Integrity

Trust

Respect: Security and Privacy

Patient Encounters

Decision support

Expert Systems

Clinical Guidelines

Medical Knowledge

Knowledge Management

Foundations for Learning Health System
Balancing Obligations
Big Data accompanies Big Risks

• As an academic medical center, we have an obligation to learn from our practice to improve care.

• As responsible care givers, we must first do no harm. Harm can come from inadvertent disclosure of patient data.
So What Am I Supposed to Do

- Good intentions are not sufficient
- There are local and national standards for appropriate management of clinical data
- Simple message: Treat data respectfully
  - Maintain in secure environment
  - Account for content and flow
  - De-identify where possible
  - Encrypt at rest
  - ...
What is the Process for Clinical Data Retrieval

Two fundamental modes:

- **Quality/Operations**
  - Still siloed operations across 8 Data Trust groups
  - Recent consolidation to Tableau Business Intelligence
  - Threatened harmony and synergy across groups
    - Shared Derivative data elements, Metrics, Indicators, Dashboards

- **Research**
  - CCDA: Center for Clinical Data Analytics
Epic Data Eco-system at Hopkins

- Epic Hyperspace
- Chronicles: Transactional DB
- Clarity Reporting DB
- Epic Data Warehouse
- Non-Epic Data Sources
- Center for Clinical Data Analysis (CCDA)
  Honest Broker. Takes thorny requests to Data Trust. Does ETL
- Research Data Marts
JHU Data Trust and IRB

• They are not your enemy!
• IRB: Represent patient and community interest
  • Align with NIH policy and the law (HIPAA)
• Data Trust
  • Create Hopkins policy for good practices
  • Review and assist applications for exceptional use
    • Large datasets, sending data outside Hopkins, etc
• Guard rails to keep everybody (researchers and our patient partners) safe
SAFE Desktop
Secure Analytic Framework Environment

- Virtual machine with Windows desktop interface
- Pre-configured with the usual suspect
  - SAS, Stata, R, MS SQL, etc
  - Can add custom software
- 100 Gb of storage (can be increased)
- Fully HIPAA compliant environment
- IRB Tier A environment (check the box)
- Did I say it was free?
Recent Epic/CCDA Enhancements

• New SlicerDicer website [graphical browser]
  http://slicerdicer.johnshopkins.edu
  • Includes IRB guidance for researchers

• Synthetic derivative of Epic data warehouse for training & exploration

• Successful pilots using Epic Clarity/MyChart to support study recruitment

• Newly established: Center for Clinical Natural Language Processing (NLP)
Major External Collaborations

- PCORnet
  - PCORI research network, distributed query

- CTSA Accelerating Clinical Trials (ACT)
  - Federated network, i2b2 repositories

- TriNetX
  - Commercial, pharma origins
  - Federated query model
  - ~30 CTSA’s
  - *Proposed backbone of the JHCRN*
CRISP’s Service Area

Chesapeake Regional Health Information System for our Patients

West Virginia

District of Columbia

Maryland

Virginia

via DHIN

State-Designated HIE

Connect Virginia

HIE

Infrastructure for WVHIN

https://crisphealth.org/services/crisp-research-initiative/
Research Project Status Update

For approved uses under three approved use cases:

- Patient-Consented, IRB-Approved Research
  - Multi-Ethnic Study of Atherosclerosis (JHU MESA)
  - Navigation Services to Avoid Rehospitalization (NavSTAR)
  - AIDS Linked to the IntraVenous Experience (JHU ALIVE)
- Combining CRISP Data with HSCRC Case Mix Data for Research
  - Utilizing the B’FRIEND data and platform to develop and test a predictive risk models for falls in elder adults (B’FRIEND)
- Serving as “honest broker” for data integration of authorized sources using master patient index (MPI)
Changing Face of Medicine: Continuous Learning

- Longitudinal Data
- IoT
- Wearables
- Knowledge of Basic Science
- Biological principles
- Basic Science Studies
- Clinical Cohorts Experience

Knowledge of Clinicians

Continuous Learning System

DISCOVERY

DELIVERY

- Studies
- Social Behavioral
- Biological Environmental
Prototype Platform

**DATA SOURCES**
- SQL Server
- Epic
- REDCap
- Systems of Record

**DATA COMMONS**
- Pulls datasets from disparate sources

**RESEARCH ENVIRONMENT**
- Normalizes across disparate sources to create useable data set
- Checks against IRB approvals to ensure authorization to access data
- Projects approved data sets into safe, secure environment for analysis

**LEGEND**
- JHM Deployment (Local)
- Azure Deployment (Cloud)
- Hybrid Deployment

**PLATFORM MANAGEMENT AND SERVICES**
- Platform Security and Data Provenance

**CLOUD AND BIG DATA TECHNOLOGIES**
- Apache Nifi
- Azure
- Apache Hadoop
- Hortonworks
- THOR

**SYSTEMS OF RECORD**
- JHM Deployment (Local)
- Azure Deployment (Cloud)
- Hybrid Deployment
Example of Recent Internal Synergy PhysioCloud

- High frequency (300Hz) physiologic data
  - ECG, blood pressure, ventilator monitors, EEG, etc
  - Historically ephemeral
  - Potentially hugely valuable
- Whiting Engineering prototyped robust solution
- Discussion to migrate prototype as component of PMAP
  - Independent data store analogous to Vendor Neutral Archive (VNA) for images
- Robust, unprecedented Research Resource
Where is this going

• Johns Hopkins biomedical data environment is rapidly evolving
• Services and resources for clinical investigators are getting stronger and more rich
• Hopkins is poised to be among the leaders in biomedical big data curation and analytics
• The opportunities for investigators are growing