

Johns Hopkins Clinical Data Opportunities for Clinical and Translational Research

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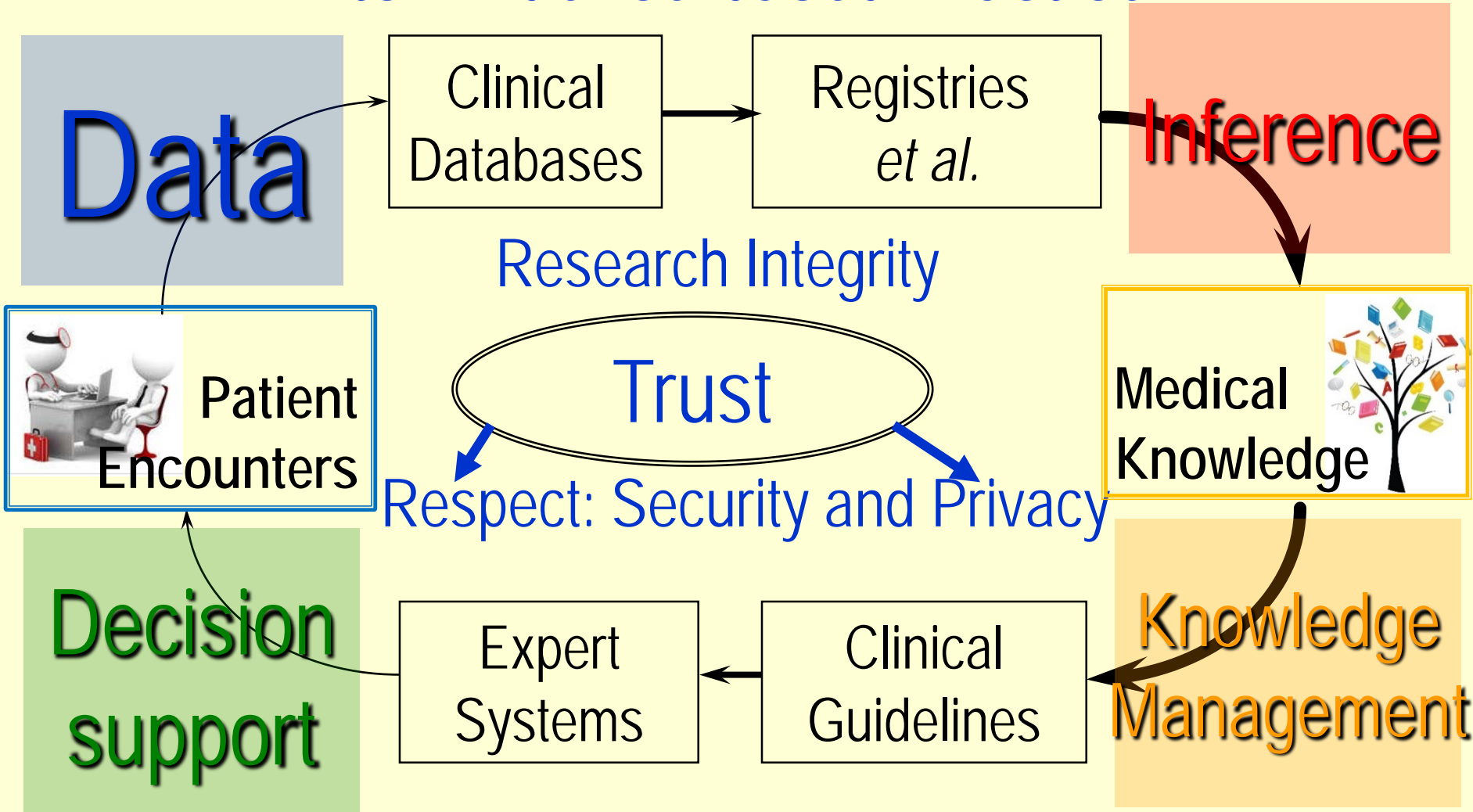
Recent History

- 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



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

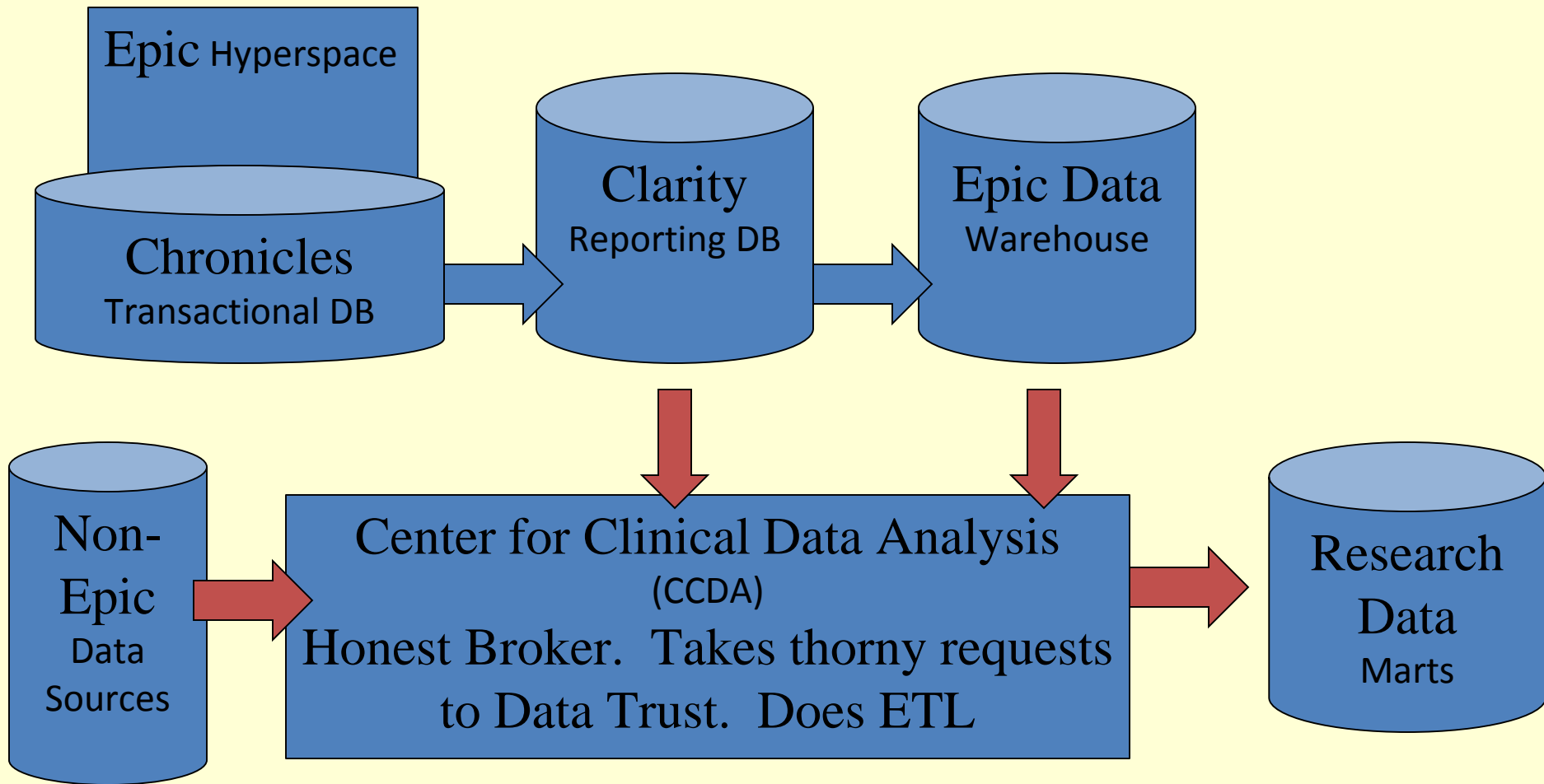
- Good intentions are not sufficient
- There are local and national standards for appropriate management of clinical data
- Simple message: Treat data respectfully
 - Maintain in secure environment
 - Account for content and flow
 - De-identify where possible
 - Encrypt at rest
 -

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



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

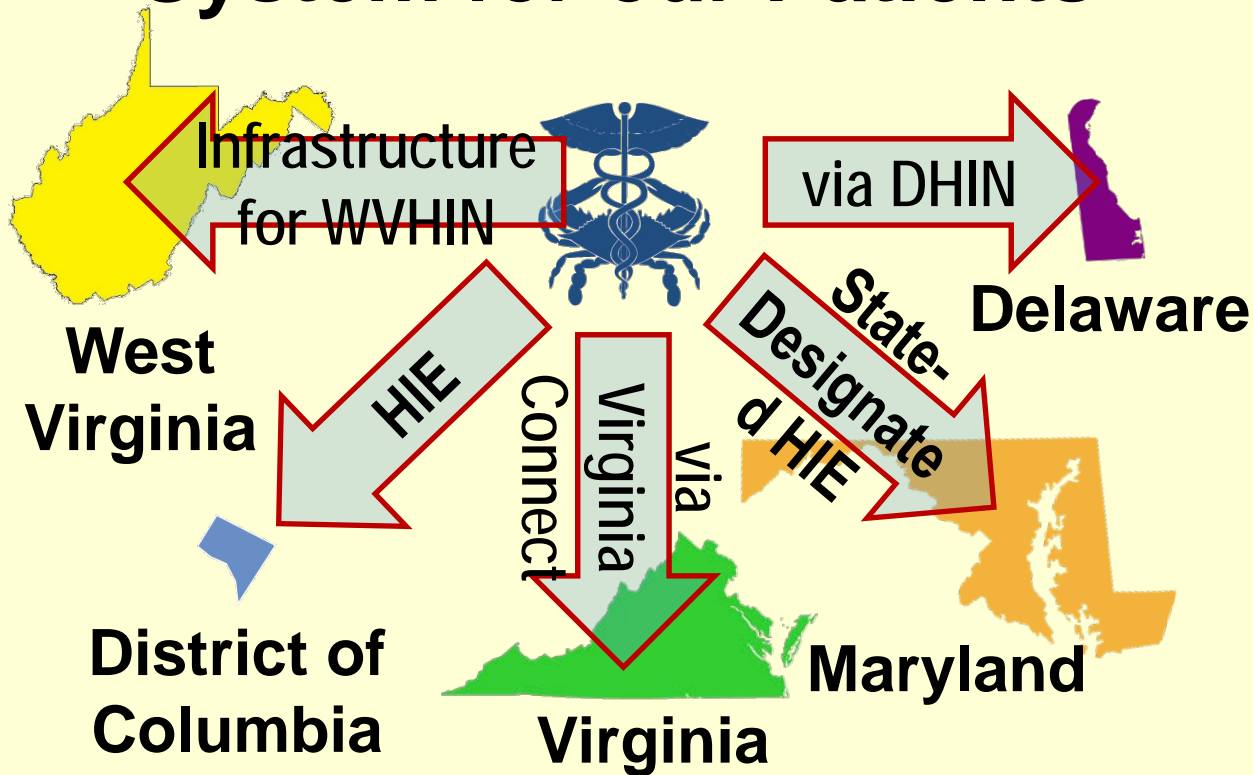
- New SlicerDicer website [graphical browser]
<http://slicerdicer.johnshopkins.edu>
 - Includes IRB guidance for researchers
- Synthetic derivative of Epic data warehouse for training & exploration
- Successful pilots using Epic Clarity/MyChart to support study *recruitment*
- Newly established: Center 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



<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) ¹⁴



Changing Face of Medicine: Continuous Learning



Prototype Platform

DATA SOURCES

Microsoft
SQL Server



Epic

REDCap
Research Electronic Data Capture

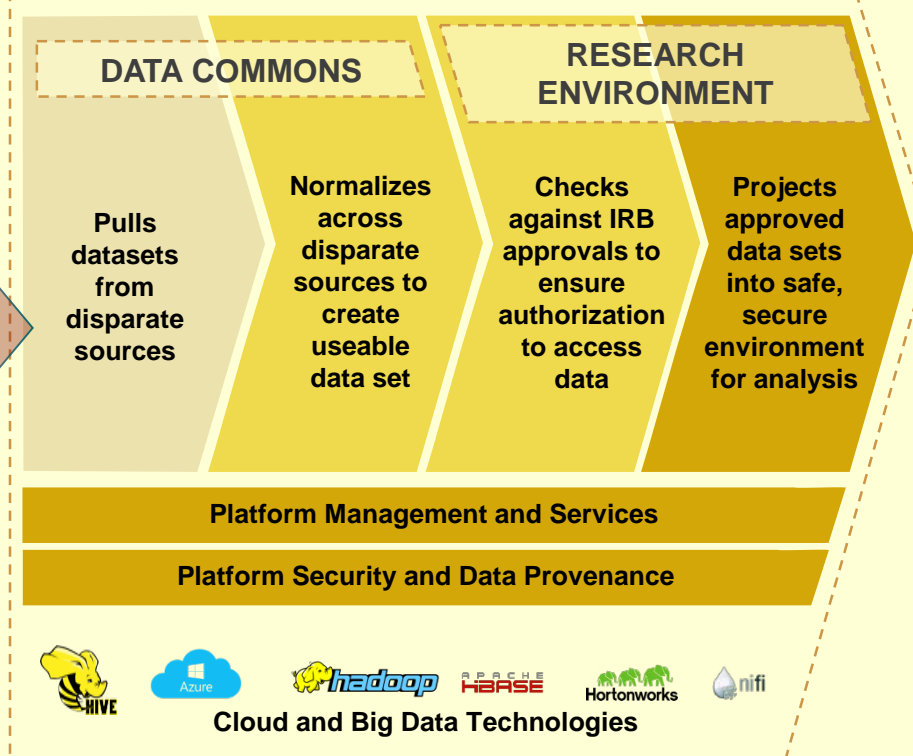


Systems of Record

Reusable
Pipelines



DISCOVERY



LEGEND

- 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