



# Data Sharing for a Learning Health System

The pSCANNER  
Clinical Data Research Network

Daniella Meeker  
Mark Elson  
Barbara Filkins

# Agenda



- Clinical Data Research Networks
- pSCANNER
  - › Overview
  - › Data Architecture
  - › Governance
- pSCANNER and HIE in CA



Clinical Data Research Networks

- Clinical Data Research Networks
  - › Facilitate Comparative Effectiveness Research (CER) across large networked organizations
  - › Utilization of clinical data in EHRs and other electronic systems, and administrative data
- PCORI / PCORnet
  - › Patient-Centered Outcomes Research Institute
  - › PCORnet: National network of 13 funded CDRNs and 20 Patient Powered Research Networks (PPRNs)

# Products of a Learning Health System



- Analysis models for causal inference and program evaluation
  - › Program X is 15% more effective at preventing readmission than Program Y
  - › Drug A has a greater risk for adverse events than Drug B
- Quality measurement reports
  - › Practice N is achieving 80% of quality indicators
  - › Practice L is achieving 60% of quality indicators
- Predictive models for patient-centered medicine
  - › For patients like John, Drug C is safer and more effective than Drug D.
  - › For patients with Debbie's goals and comorbidity profile, Program Y is better than Program X

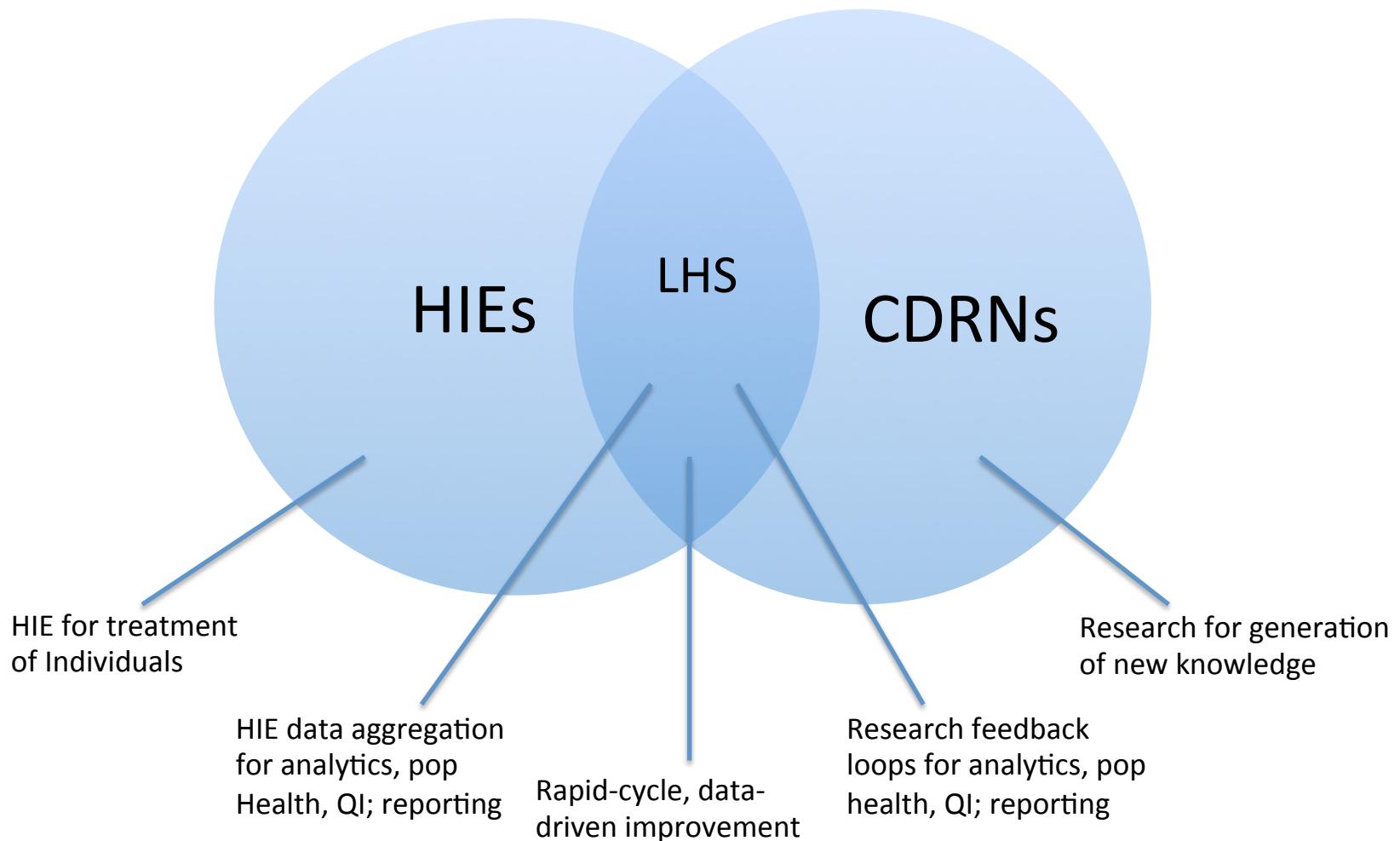
# CDRNs and HIEs



- Both facilitate data sharing
- Similar range of technical architectures
  - › pSCANNER is “hybrid-federated” with edge servers at participating sites
  - › CDRNs can also be “centralized” with a Clinical Data Repository
- Some similar governance issues given multi-stakeholder structure

# Convergence

Convergence supporting a Learning Health System (LHS)

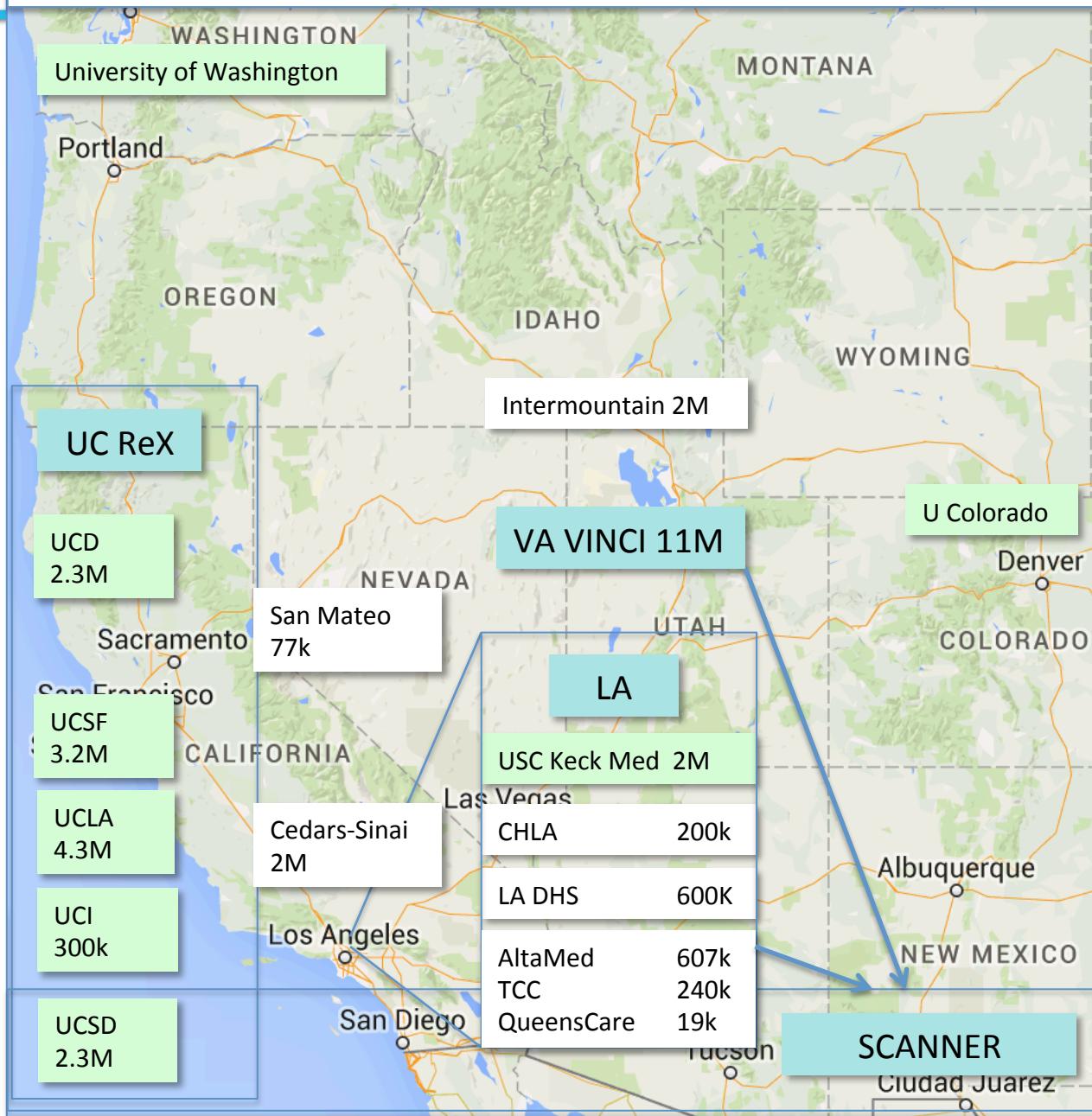


# Differences

- Many HIEs more mature from an organizational, user adoption, and governance perspective
- Greater use of standards for HIE than in data-sharing for research
- Some CDRNs pursuing cutting-edge privacy-preserving technical approaches for analytics



# pSCANNER Overview



30 Million  
People

UCSD is  
Lead  
Contractor

Primarily in  
California

# Clinical Research Focus



- pSCANNER Research Focus
  - › Congestive Heart Failure (CHF)
  - › Obesity
  - › Kawasaki disease
- Current Studies
  - › Aspirin dosage for patients with heart disease
  - › Bariatric surgery outcomes
  - › Diabetes risk
  - › Statin effectiveness study
- New Studies
  - › Researchers may propose new studies / queries

# Achieve interoperability between research and clinical care by 2019



- Patient Engagement
- Policymaker Engagement
  - › Standards Committee participation
  - › Contribute to data policy for interoperability, billing, and incentive programs
- Health System Engagement
  - › Create data resources with business value
  - › Create reporting resources with business value
- Research Engagement
  - › Participate in multisite research standards development
  - › Offer easy to use privacy-preserving infrastructure for multisite collaboration



# pSCANNER Data Architecture

# Selecting a Data Warehousing Standard

Clinical Document Architecture  
& Clinical Data Elements

Quality Data Model

OMOP

VDW

Continuity  
of Care  
Doc.

PCOR  
net  
CDM  
V1

ONC  
CMS  
Vendors\*

\*In theory

Research  
Analytics

Health Economic Domains are not represented in other research and quality information models, but value was So Cal Health Leadership Priorities

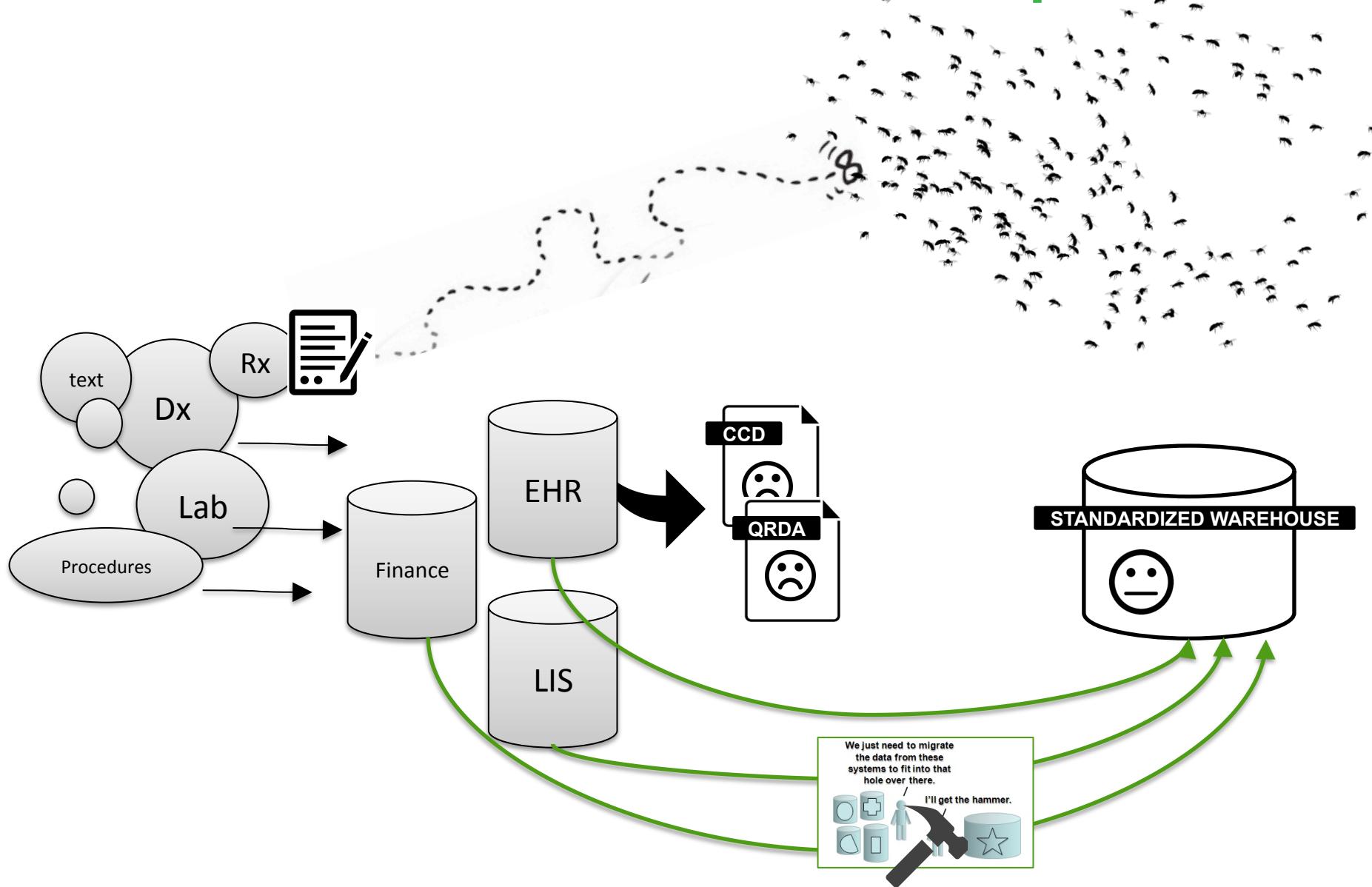
# Implementation

We just need to migrate  
the data from these  
systems to fit into that  
hole over there.



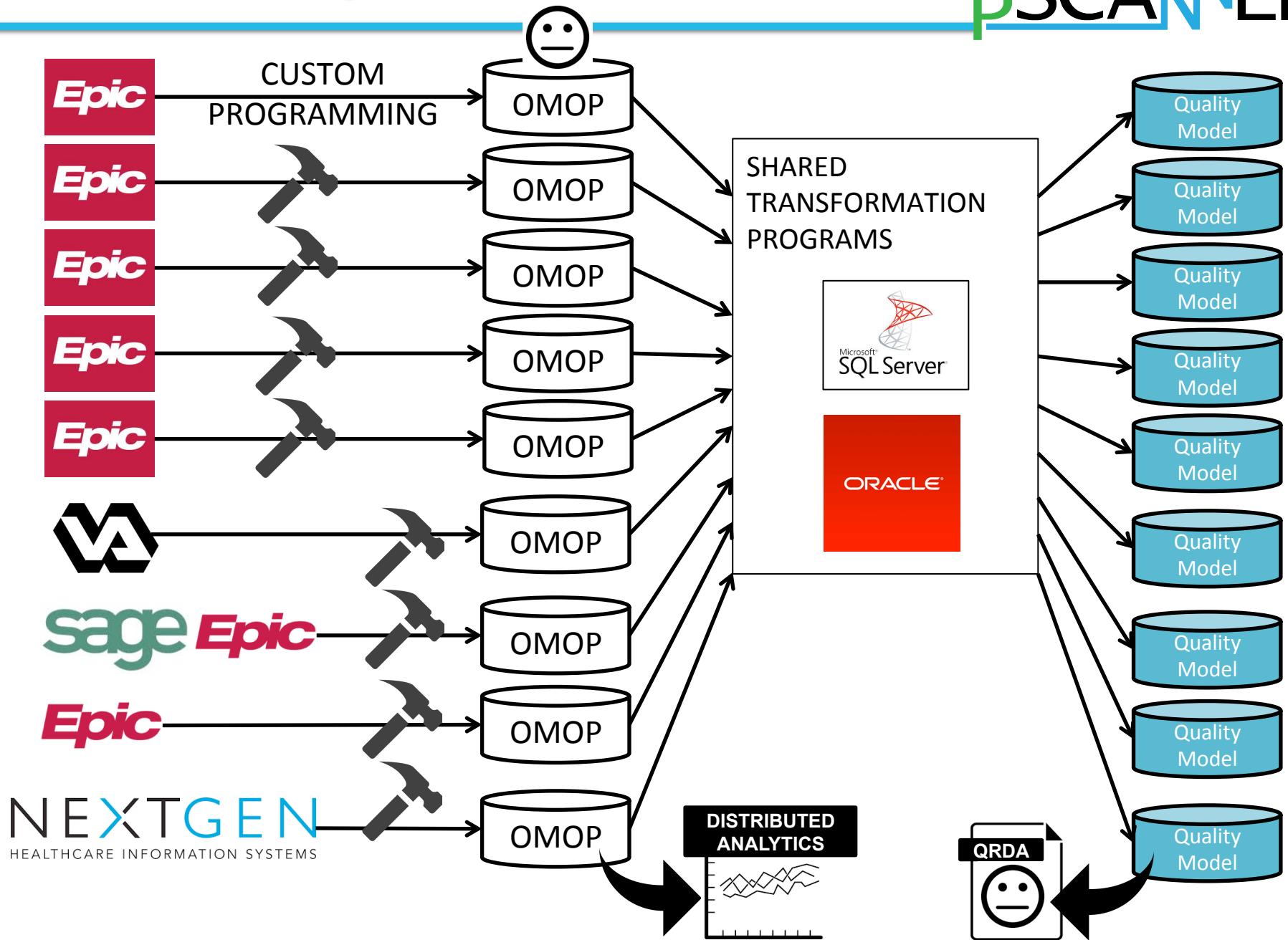
# Aside on Data Quality & Availability

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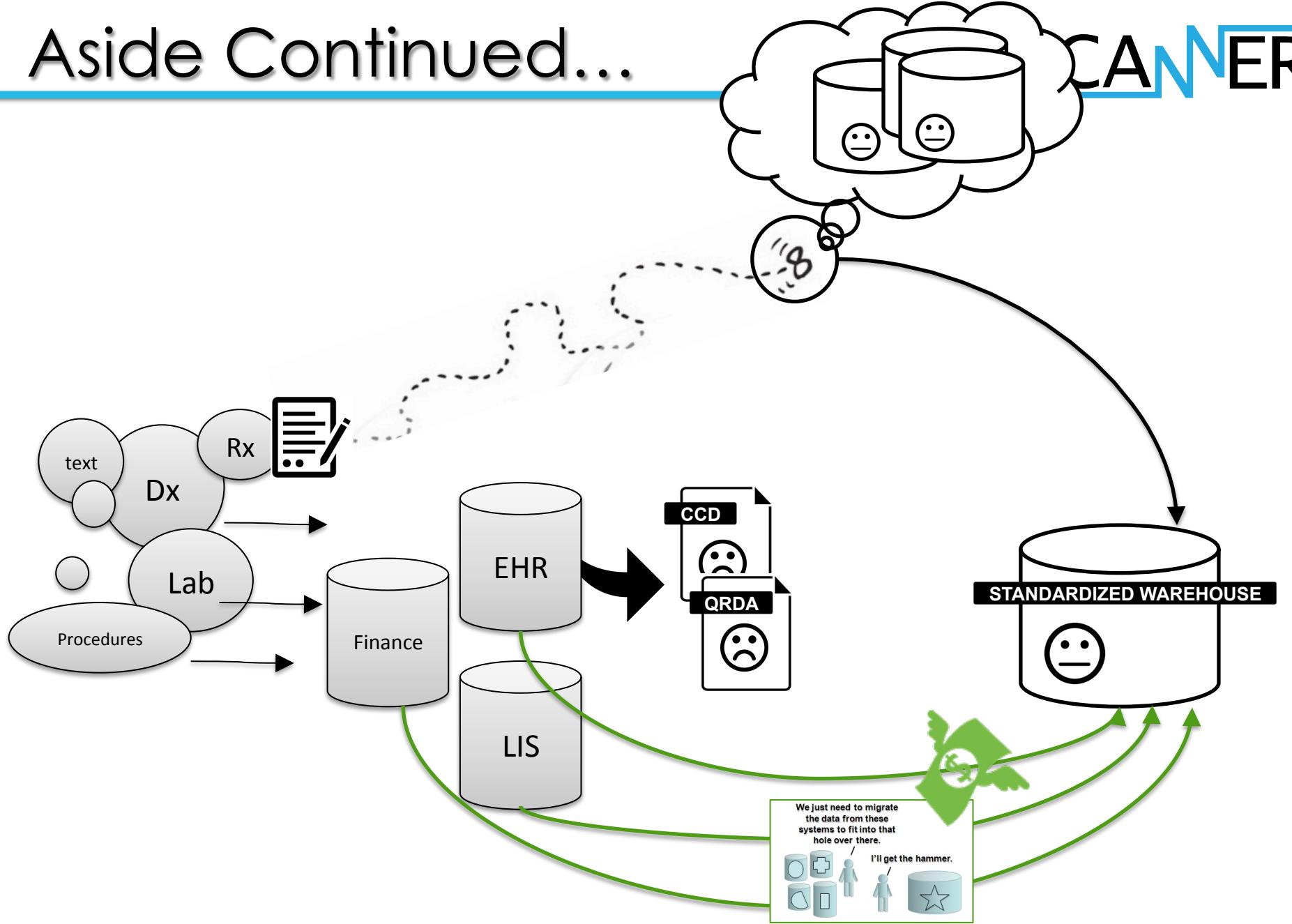
# Standardizing 11 Health Systems

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# Aside Continued...

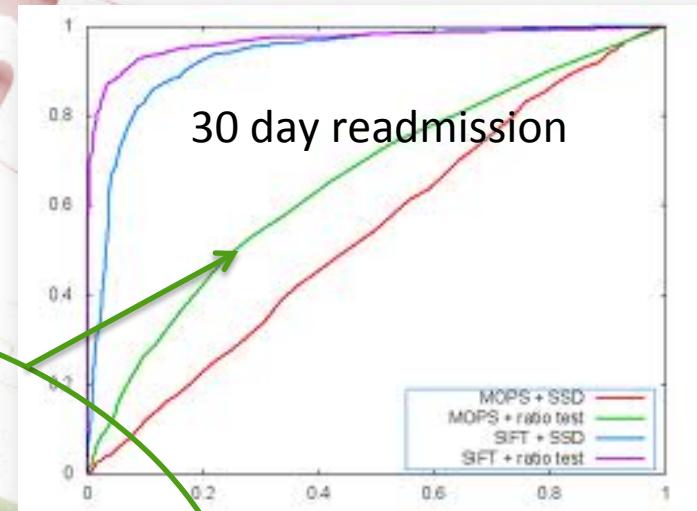
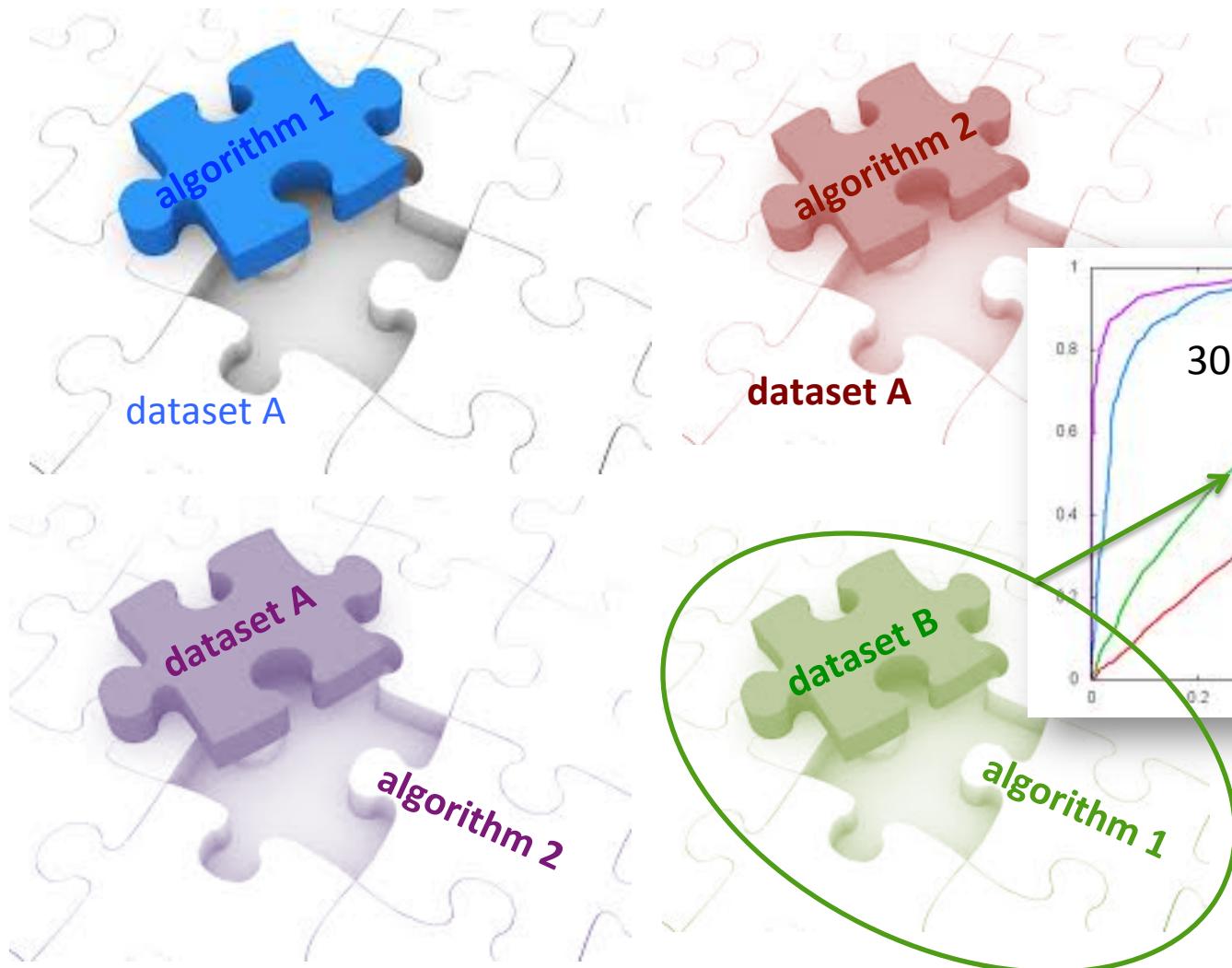
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Why do we need standards for computation if the data is already standardized?

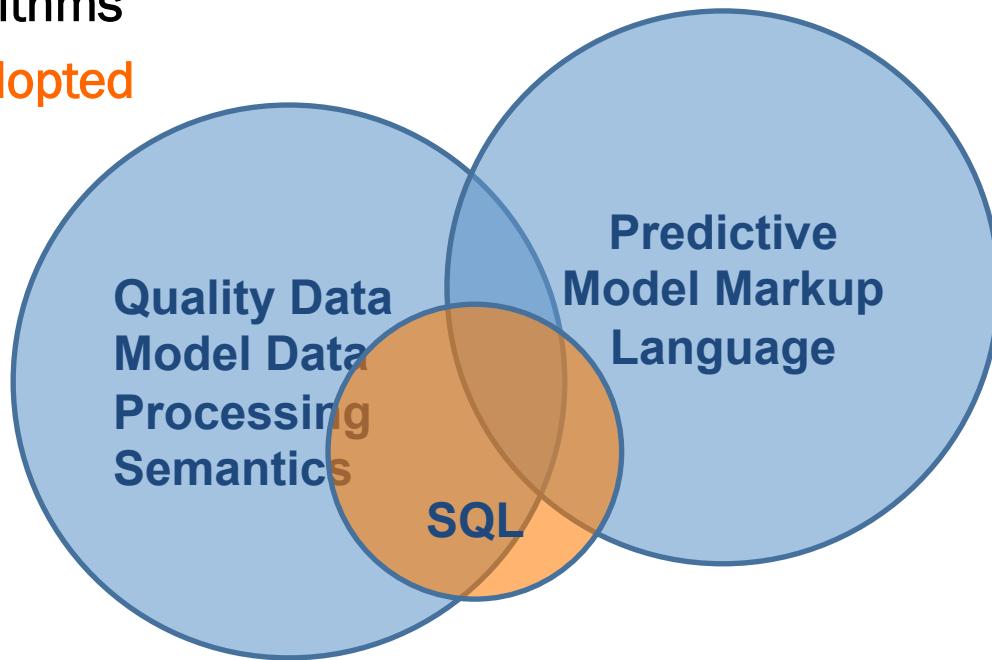
# Direct and Quantifiable Comparisons

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# Selecting a Standard for Computation Specification

- Sufficiently expressive to represent data processing concepts for transactional, time-series data (e.g. interval logic)
- Sufficiently expressive to represent data processing concepts that are **specific to healthcare** (e.g. time of administration, age of onset)
- Sufficiently expressive to represent **basic statistics** and **data analysis algorithms**
- **Supported/Adopted**



## PORTABLE DATA PROCESSING STANDARDS

Epic

VA

sage Epic

Epic

NEXTGEN  
HEALTHCARE INFORMATION SYSTEMS



OMOP

OMOP

OMOP

OMOP

OMOP

OMOP

OMOP

OMOP

OMOP



ORACLE



sas

sas

sas

R

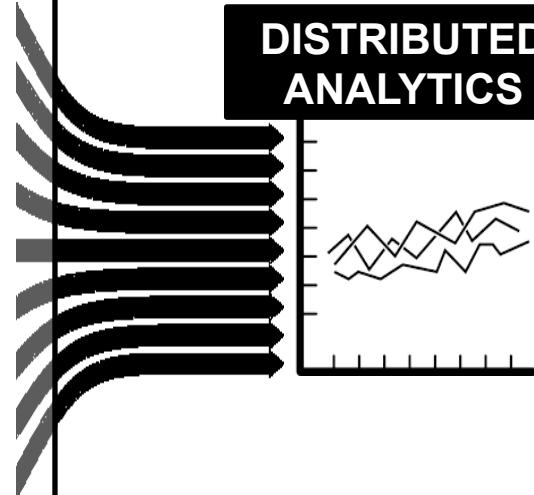
R

R

STATA

STATA

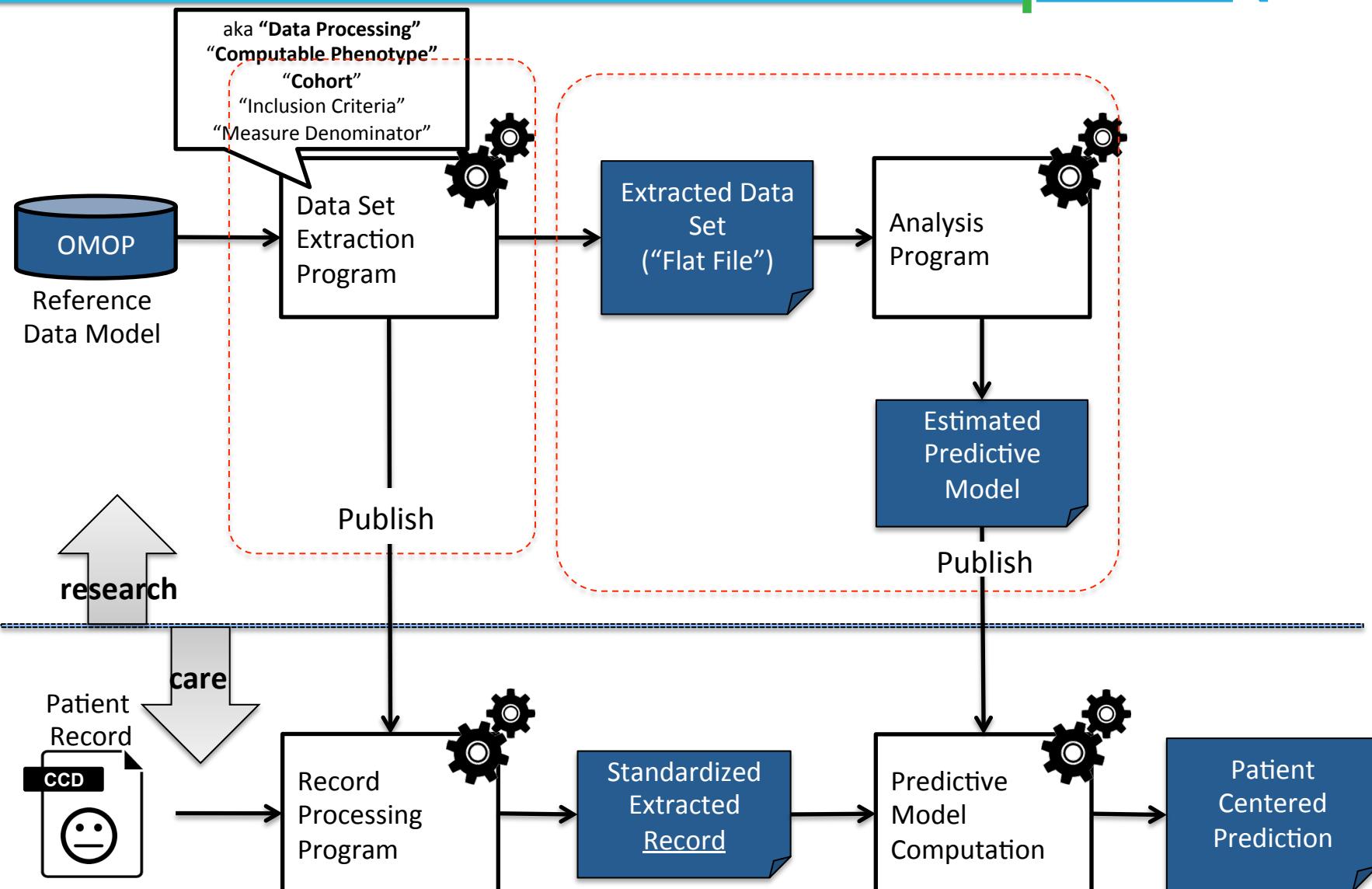
DISTRIBUTED ANALYTICS



PORTABLE DATA ANALYSIS STANDARDS

# Disseminating LHS Products

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# LHS Standards Summary



Process we need to represent	Standard	Rationale
Data processing rules	HQMF>CQL	CMS, ONC, HL7 endorsed Part of EHR certification process New standards in trial use
Cohort definition rules	HQMF>CQL	100's of established data sets 1000s of cohort criteria
Data set description	QRDA PMML	QRDA – Quality Measurement EHR Certification & CMS PMML – Data analysis
Data Analysis Methods	PMML	UCSD Data Mining Group Extensible to support model specifications
Data Analysis Results (Estimated Models, Produce Predictions)	PMML	Developed to represent results Adopted by most stats packages
Process Workflow	BPML?	TBD

Calendar – Daniella Meek... × HQMF Dashboard – Dashb... × Mail – Daniella Meeker – ... × Problem loading page × +

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Search

~ 86 years ago to ~ 2

# kibana

Discover Visualize Dashboard Settings

## HQMF Dashboard

**My measures**

measure.measure\_name: Descending Count

Children Who Have Dental Decay or Cavities	136,724
Primary Caries Prevention Intervention as Offered by Primary Care Providers, including Dentists	136,724
Cervical Cancer Screening	114,502
Colorectal Cancer Screening	60,909
Breast Cancer Screening	55,569
Diabetes: Eye Exam	23,191
Diabetes: Low Density Lipoprotein (LDL) Management	23,191
Falls: Screening for Future Fall Risk	15,406
Ischemic Vascular Disease (IVD): Use of Aspirin or Another Antithrombotic	4,351

**Measure Denominator Numerator**

Count

Category	Count
Chi...	~135,000
Prim...	~135,000
Cer...	~135,000
Col...	~95,000
Bre...	~80,000
Dia...	~35,000
Dia...	~35,000
Fall...	~15,000
Isch...	~5,000
HIV...	~2,000
Hem...	~1,000

**Patients On Map**

**Gender**

715,806 Count

**Race**

- White
- Unknown
- Asian
- Black or African Amer...
- Other Race

**Ethnicity**

- Hispanic or Latino
- Not Hispanic or Latino
- Unknown

**Patients By DOB**

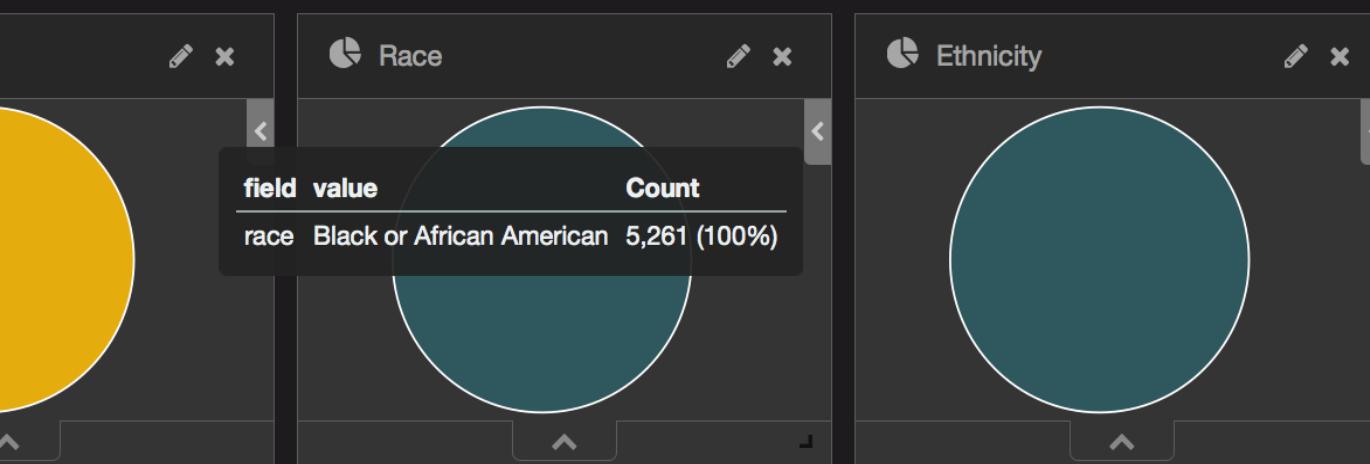
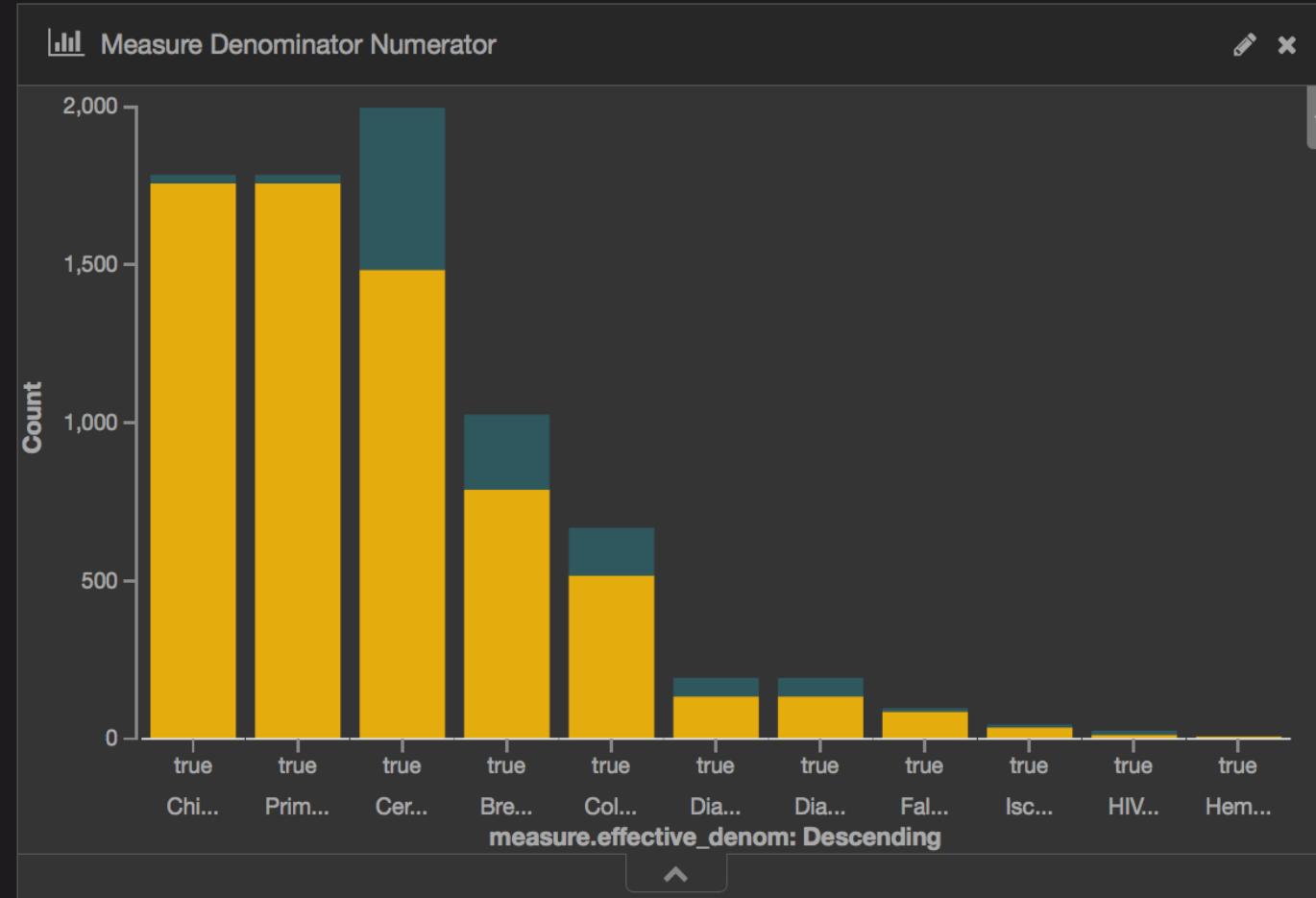
Count

dob per 3652 days

Year	Count
1939	~10,000
1949	~50,000
1959	~90,000
1969	~100,000
1979	~110,000
1989	~110,000
1999	~100,000
2009	~50,000

</> Acknowledgment

This visualization was created through Academy Health's EDM Forum, a project funded by the Agency for Healthcare Research and Quality, Grant #U18 HS022789. The tool is maintained by the University of Southern California.





pSCANNER Governance Development

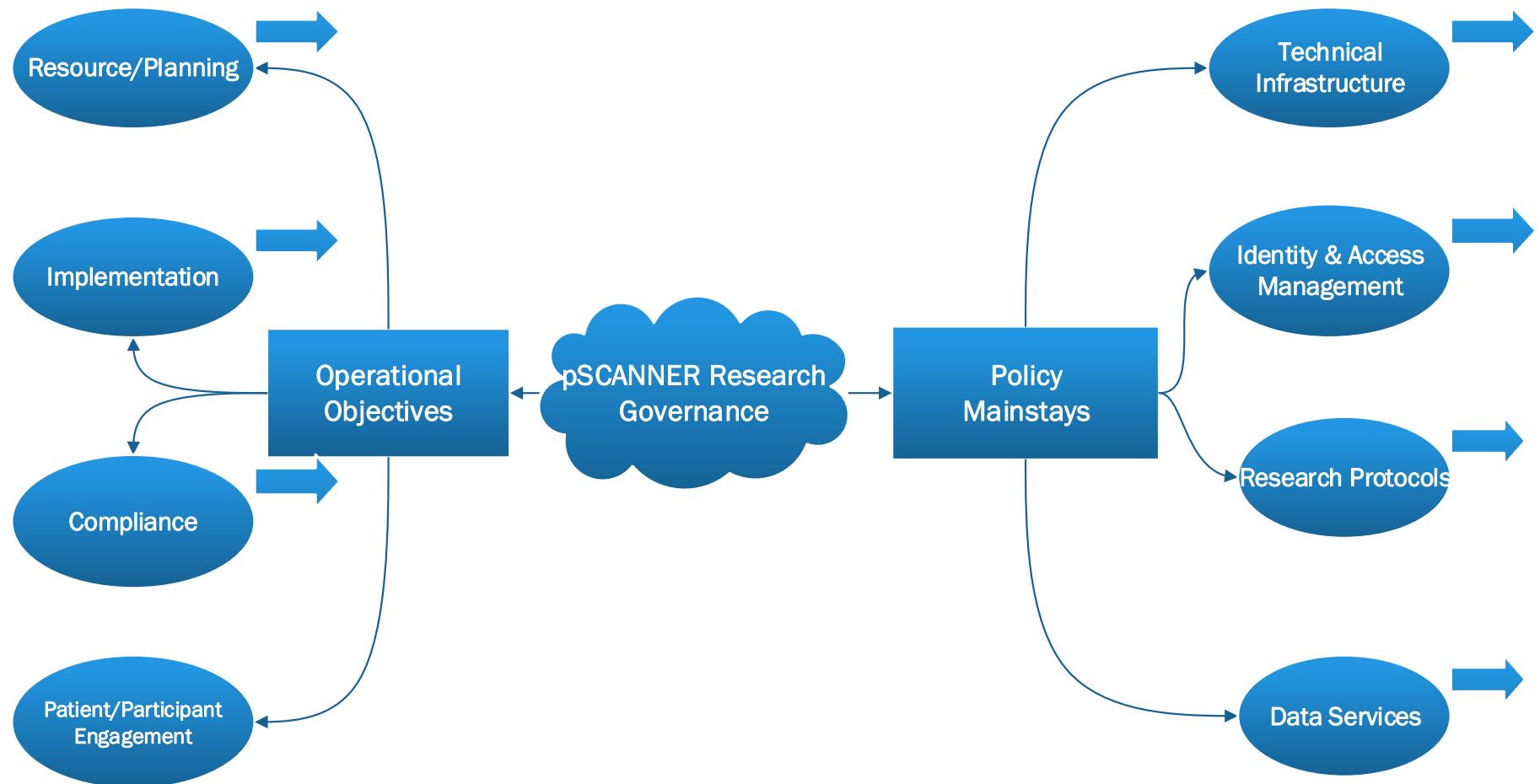
# Governance Objectives



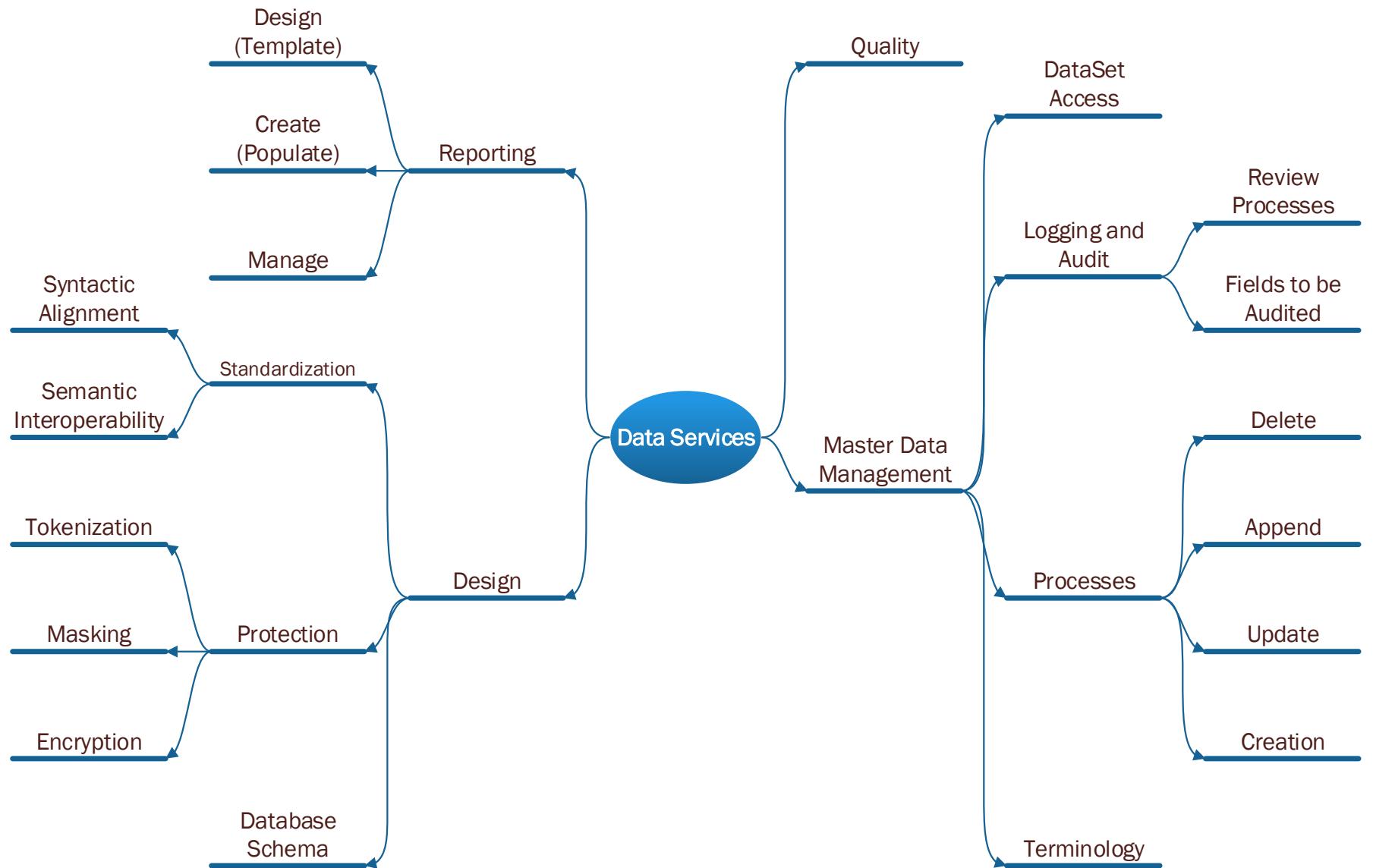
- Define processes, roles, relationships
- Support IRB streamlining and coordination
- Develop policies & operational procedures
  - » Consistent and transparent framework, able to harmonize with site P&Ps & align with PCORnet P&Ps
  - » Process to create, test, and approve pSCANNER P&Ps
  - » Specific cases: onboarding to pSCANNER, research request and approval process, informed consent
- Monitor/evaluate governance performance

# Governance Framework

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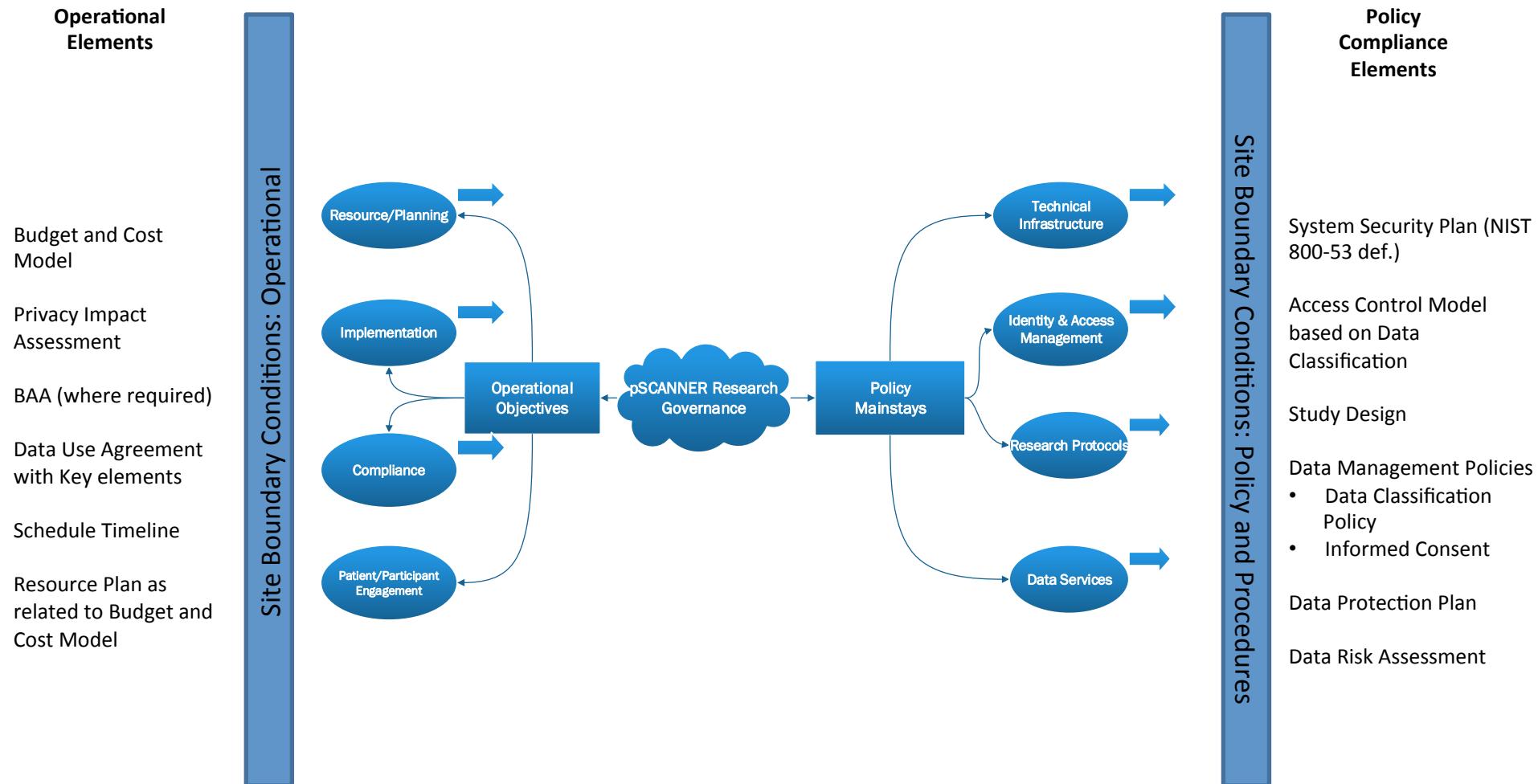


# Detail: Data Services

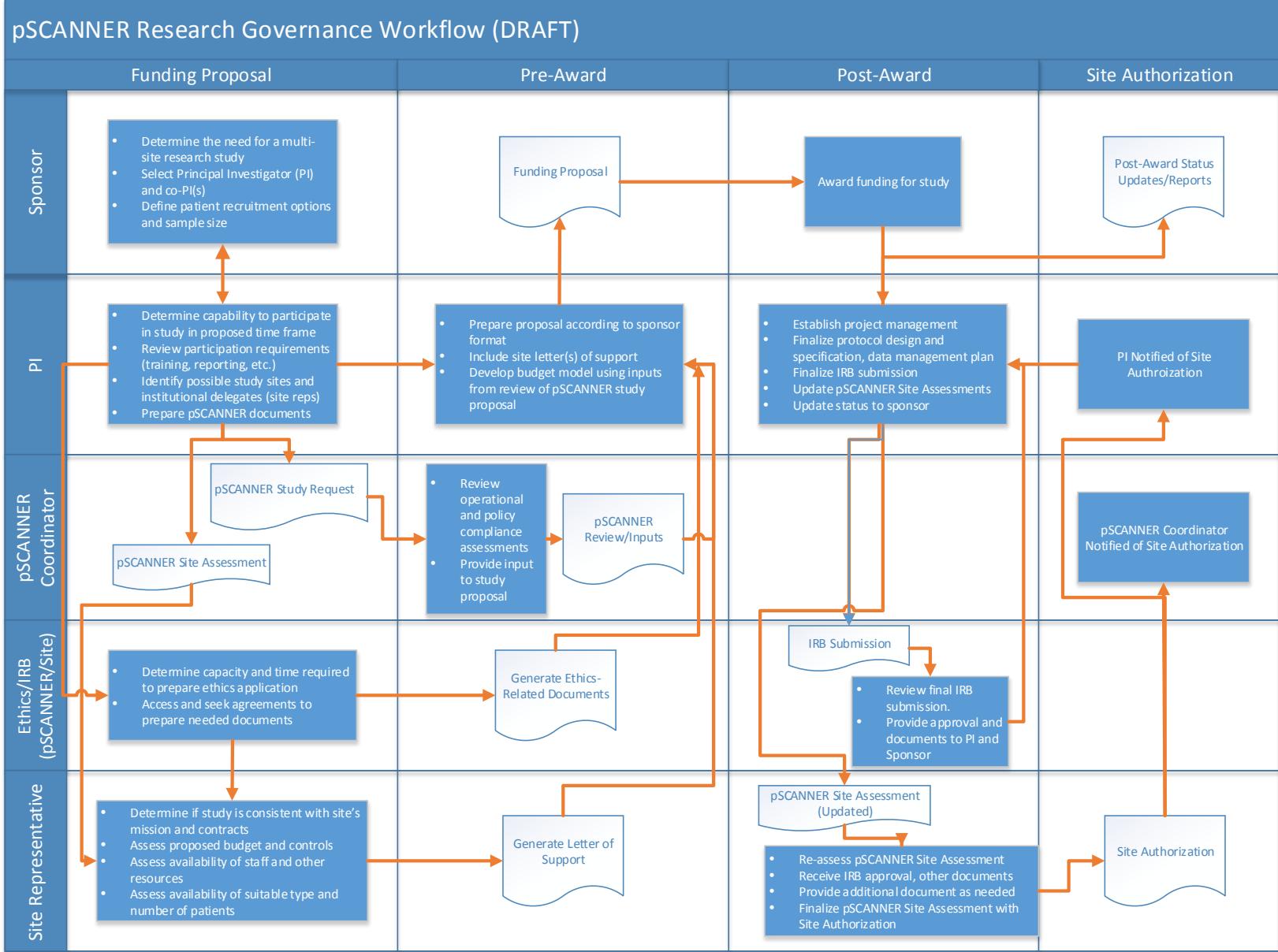


# Governance Framework

pSCANNER



# Study Initiation and Approval



# Site Assessment Example



Phase:	Pre-Award	Post-Award
Deliverable:		
<b>Harmonization</b> <ul style="list-style-type: none"> <li>• Study consistent with site mission and contracts?</li> <li>• Suitable types and number of patients available?</li> </ul>	Must be verified and committed to prior to letter of support	No change from pre-award analysis
<b>Resource/Planning</b> <ul style="list-style-type: none"> <li>• Budget</li> <li>• Schedule Timeline</li> <li>• Resource Availability</li> </ul>	Preliminary sizing estimates must be provided for study proposal to sponsor	Scope of work and final numbers must be agreed to before site authorization accepted by PI
<b>Implementation Metrics (Data-Related)</b> <ul style="list-style-type: none"> <li>• Schedule/Timeline</li> <li>• Level of Effort</li> <li>• Appropriate data model / data inputs</li> </ul>	Scope of work must be stated and consistent with resource/planning numbers provided	Same as above
<b>Compliance</b> <ul style="list-style-type: none"> <li>• Policy Alignment based on review of policies involving site research, privacy, data classification, and others as required <ul style="list-style-type: none"> <li>○ Did site undergo pSCANNER Policy Compliance Assessment?</li> <li>○ What were the findings?</li> </ul> </li> <li>• Agreements (Needed) <ul style="list-style-type: none"> <li>○ Participant Agreement</li> <li>○ BAA</li> <li>○ Data Use Agreement</li> </ul> </li> </ul>	Alignment on policies must be verified via pSCANNER taxonomy <u>OR</u> site must agree to undergo pSCANNER policy compliance assessment	All required agreements signed and executed by all parties
<b>Patient/Participant Engagement Required</b> <ul style="list-style-type: none"> <li>• Aggregate data being requested? (No direct patient engagement, data-sharing agreement)</li> <li>• DID or LDS being requested? (May need authorization, data sharing agreement)</li> <li>• Individually-identifiable data being provided? (Need to understand patient/participant engagement techniques, use of informed consent)</li> </ul>	Questions must be completed to determine need for actual patient contract	No change from pre-award analysis unless study protocol has been modified

# Governance Parallels



- HIE – 5 Domains
  - Stakeholder Engagement
  - Structure & Organization
  - Business & Finance
  - Privacy & Legal
  - Technology & Security
- CDRN -- Activities
  - Patient Engagement
  - Strategic Decision-Making
  - Contract Management
  - Policy and Procedure Management
  - IRB Coordination
  - Data Governance
  - Approval of Research Studies and Queries
  - Project Management



pSCANNER and HIE in CA

# HIE Readiness for Research?

- Overwhelming HIE focus on treatment today
  - › Pop health analytics emerging as secondary focus
- Research largely an unexplored domain
- Negative association of research with pharma and selling data, but...
- ... Emergence of CDRNs provides potential for large-scale, trusted partners

# Questions for Discussion

- What policy and technical work would be required to enable researchers in CDRNs to access HIE data in California?
- What would be needed to justify the business case for HIEs?
  - › Payment for study participation?
  - › Ability for HIE participants to initiate research studies / queries?
  - › Access to “research-grade” analytics platform for HIE users?
  - › Consolidated quality reporting?
- Should CTEN explore implementing a transaction pattern for research?

# Contact Information



Daniella Meeker, PhD  
Assistant Professor, USC Keck School of Medicine  
Director, Clinical Research Informatics  
Southern California Clinical Translational Sciences Institute  
[dmeeker@usc.edu](mailto:dmeeker@usc.edu)

Mark Elson, PhD  
Principal, Intrepid Ascent  
[mark@intrepidascent.com](mailto:mark@intrepidascent.com)

Barbara Filkins  
Principal, Syntax2Semantics  
[filkins@impulse.net](mailto:filkings@impulse.net)

pSCANNER website: <http://pscanner.ucsd.edu/>  
PCORnet website: <http://pcornet.org/>