Aligning care and research to reduce burdens / improve integration

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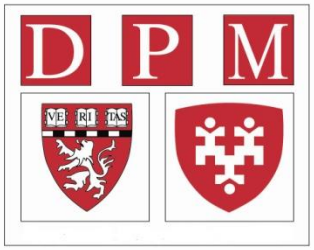

Starting points

- Don’t interfere with normal workflow
- EHRs are useful
- Consortia are often required

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  - Trials require someone to change something
- EHRs are useful, but…
  - Difficult to use for research
  - Rarely sufficient
- Consortia are often required, but…
  - Expensive to build and maintain
  - Barriers to data sharing
  - Governance challenges

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Minimize interference with operations

- Managerial time and systems support are required to avoid impact on front line personnel
- E.g.,
  VP for Clinical Operations,
  Chief Nursing Officer,
  Quality Improvement staff,
  Infection Prevention team,
  ICU directors,
  Pharmacy staff,
  Supply chain management,
  IT department

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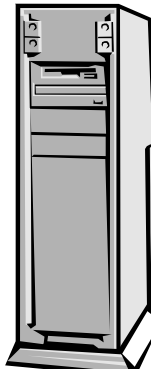
Getting Data from EHRs: EHR Support for Public Health (ESP)

Practice EHR

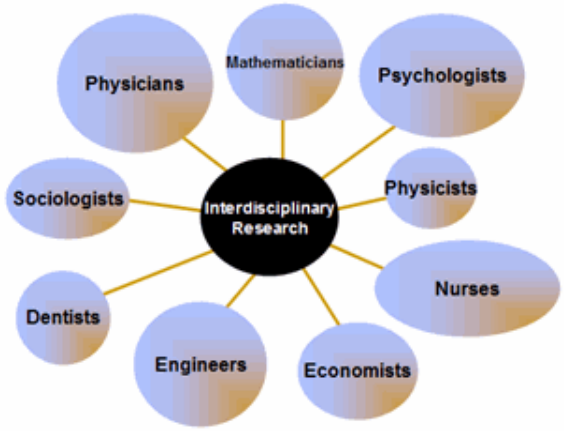
- diagnoses
- lab results
- meds
- vital signs
- demographics

ESP Server



HL7 electronic line lists or aggregate summaries

Research team



JAMIA 2009;16:18-24
Am J Prev Med 2012;42:S154-162

Sending data to an EHR

- Capability to send information to EHR
  e.g., a structured query asking if a patient is eligible to be approached to participate in a trial

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Administrative data

- Covers care across locations
- Available for large populations
- Better standardized than EHRs
- Most useful when linked to EHRs

FDA Mini-Sentinel's Common Data Model

- Administrative data
  - Enrollment
  - Demographics
  - Outpatient pharmacy dispensing
  - Utilization (encounters, diagnoses, procedures)
- Electronic Health Record data
  - Height, weight, blood pressure, temperature
  - Laboratory test results (selected tests)
- Registries
  - Immunization
  - Birth and Death

Mini-Sentinel Distributed Database

- Populations with well-defined person-time for which most medically-attended events are known
- 126 million individuals*
  - 345 million person-years of observation time
- 3 billion dispensings
- 2.4 billion unique encounters
  - 40 million acute inpatient stays
- 13 million people with laboratory test results

*As of 12 December 2011. The potential for double-counting exists if individuals moved between data partner health plans.

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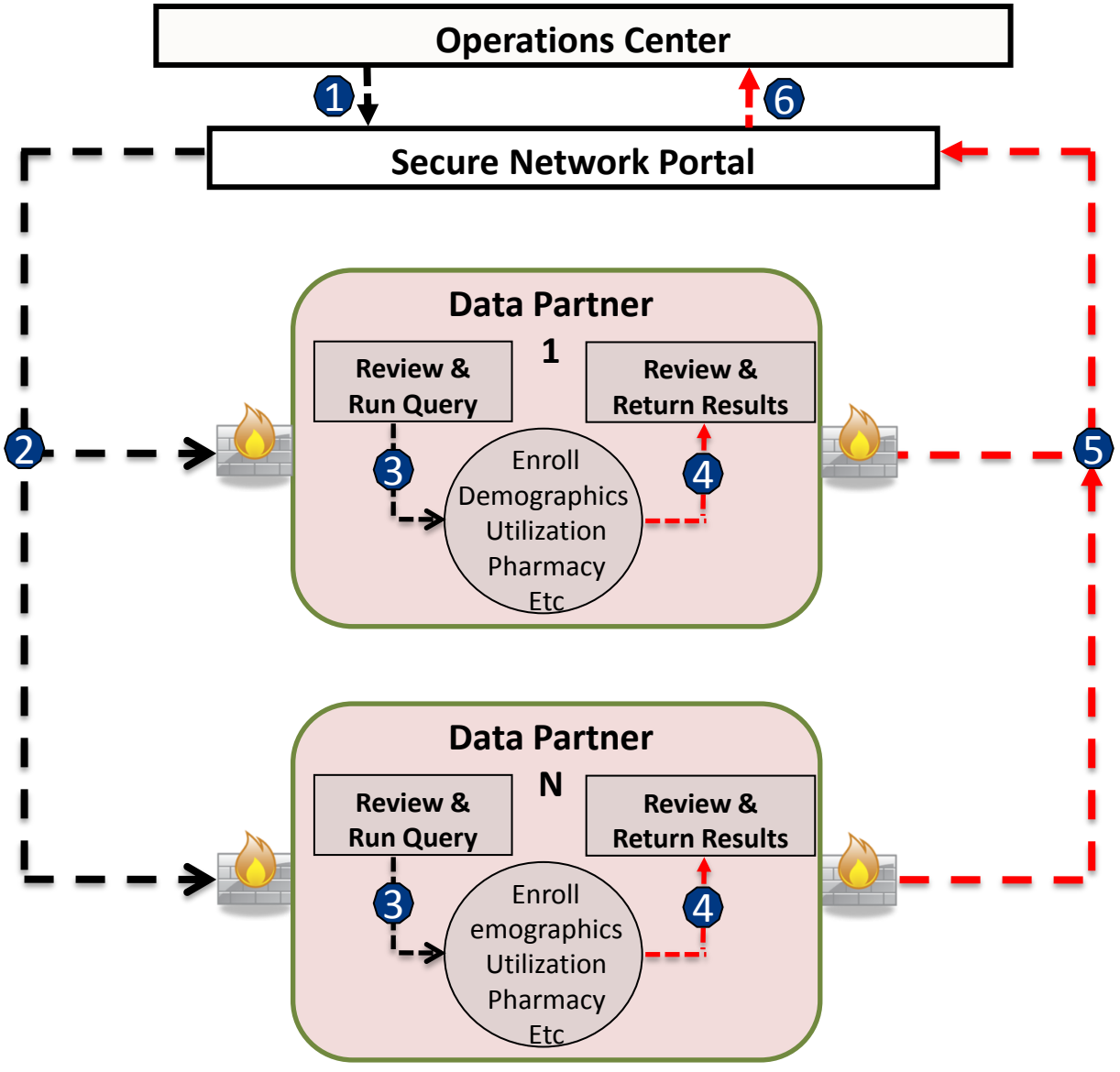
The Office of the National Coordinator for Health Information Technology

Query Health: Distributed Population Queries

"Send questions to the data!"

Putting the I in HealthIT℠
www.HealthIT.gov

Distributed analysis schema



1- User creates and submits query (a computer program)

2- Data partners retrieve query

3- Data partners review and run query against their local data

4- Data partners review results

5- Data partners return results via secure network

6 Results are aggregated

Rationale for Distributed Networks

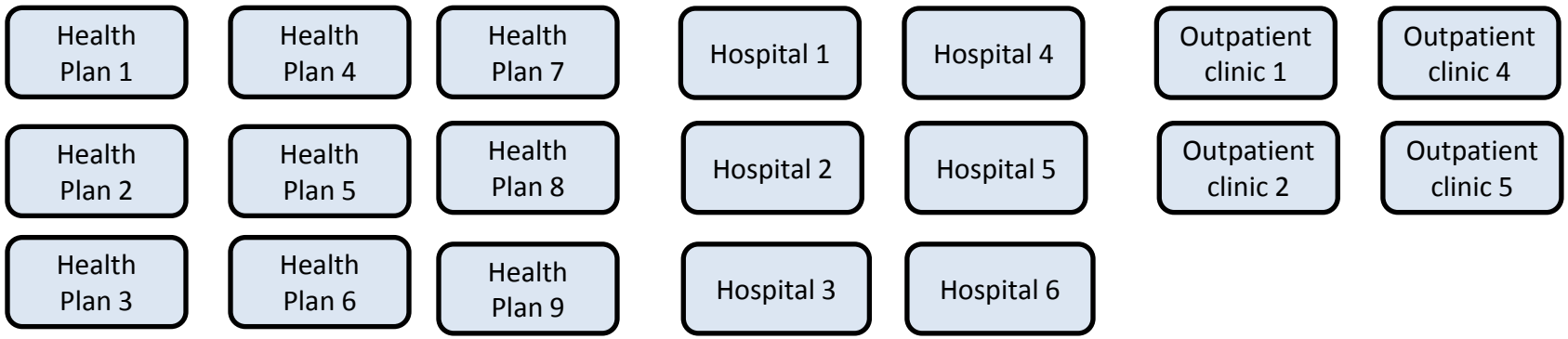
- Minimizes sharing of confidential information
  - Protected Health Information
  - Proprietary data
- Data holders retain control over the users and uses of their data

Contact: Jeff_brown@hphc.org

Distributed network examples

- FDA Mini-Sentinel
- NIH
  - Cancer Research Network
- AHRQ
  - SPAN (Scalable PArtnering Network for CER)
  - PEAL (Population based Effectiveness for Asthma and Lung Disease)
- HMO Research Network

Multiple Networks Sharing Infrastructure



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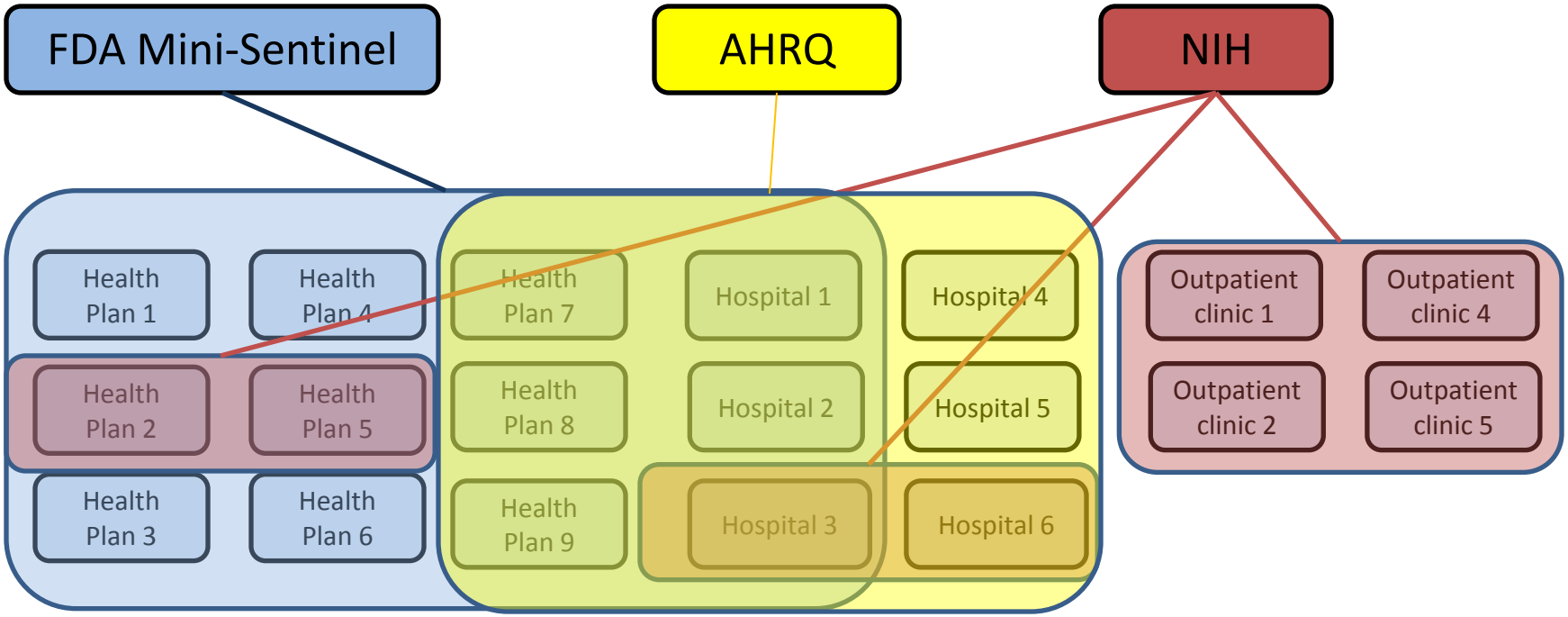
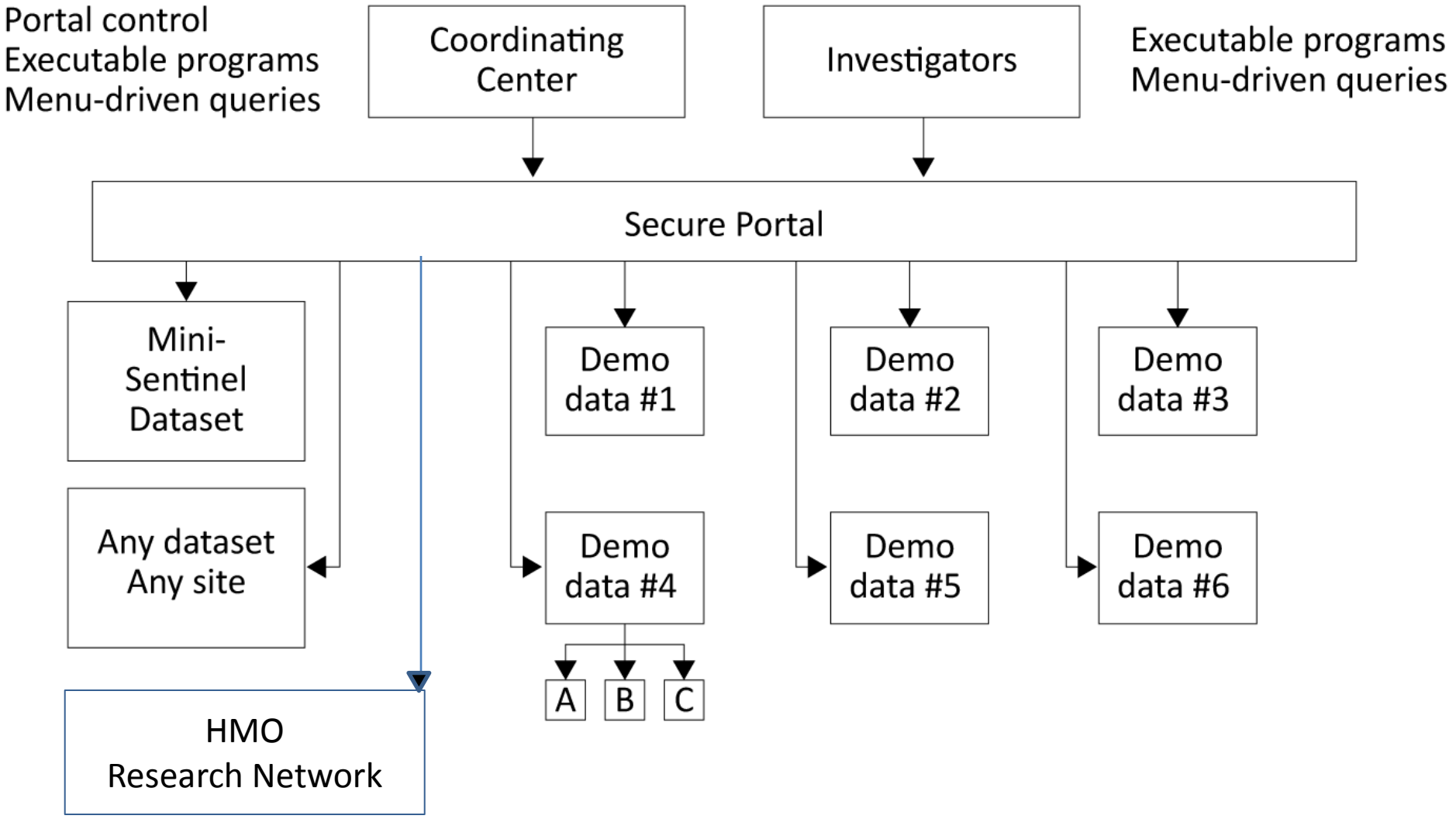


- Each organization can choose to participate in multiple networks
- Each network controls its governance and coordination
- **Networks share infrastructure, data curation, analytics, lessons, security, software development**

NIH Distributed Research Network

of the Health Care Systems Research Collaboratory



Thank you!