

# **Informatics Requirements and EHRs: Motivations to Participate**

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# EHRs and Precision Medicine

## Roles for EHRs in Precision Medicine Initiatives

- Facilitating Discovery
- Implementation

EHRs are more than provider entered data

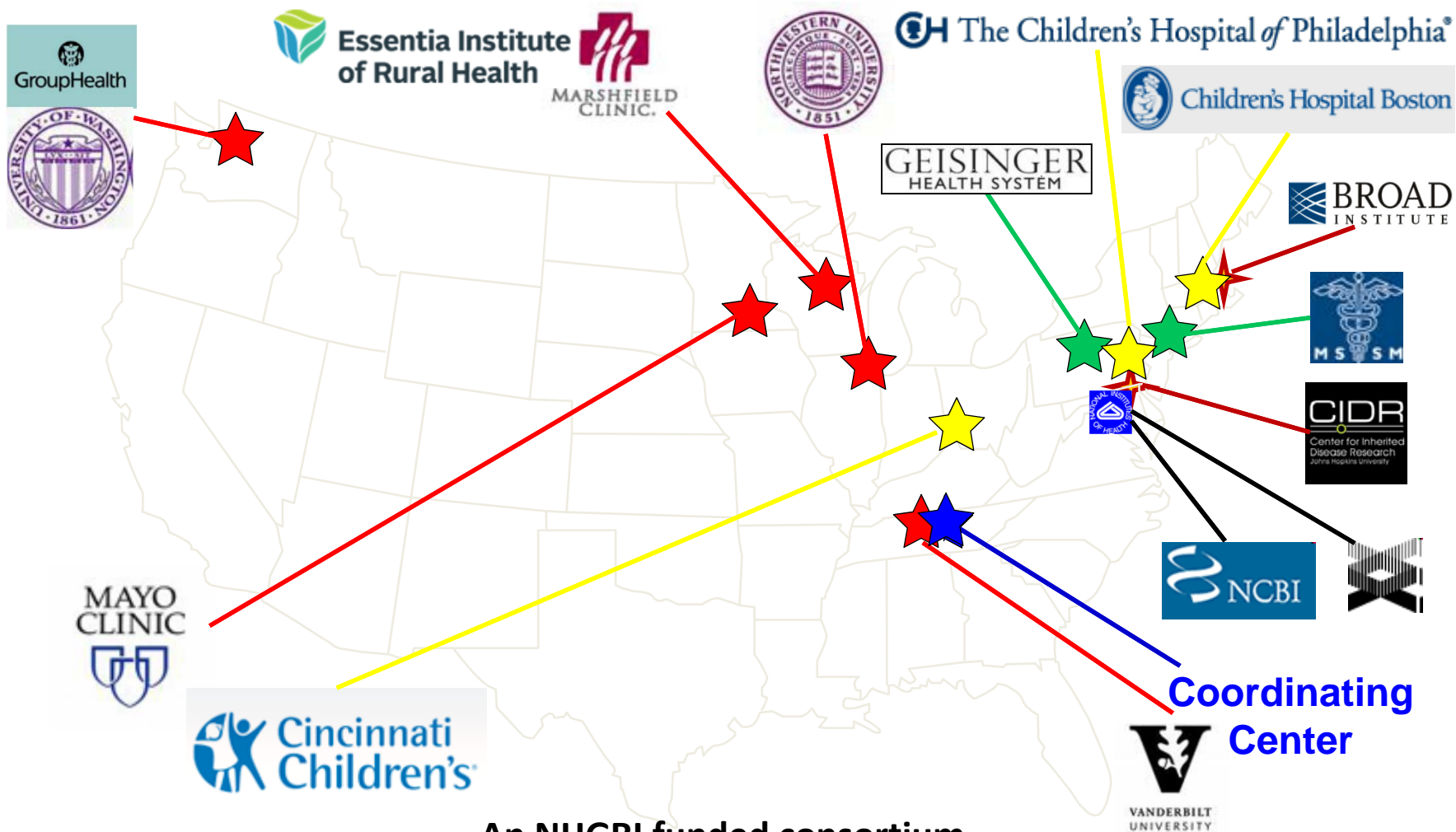
- Means to collect patient/participant entered information
- Access to research result (My Research Chart)

***EHR extracted information alone will not be sufficient to achieve our goals***

# The eMERGE Network

electronic Medical Records & Genomics

*A consortium of biorepositories linked to electronic medical records data for conducting genomic studies*



An NHGRI funded consortium

# Cohort of Cohorts

## Strengths

- Priority could be given to on-going data collection linked to EHR
- Potential for active engagement
- Wide scientific engagement

## Possible weakness

- Potential for limited data elements
- Status of consent

# Business case: Cohort of Cohorts

## Potential Barriers

- Loss of control of data
- Sustainability issues
- Reduced engagement by investigators who established

## Incentives

- Expanded data to add value to the original goals of the cohort
- More statistical power
- Expanded recruitment

# Clinical Providers able to provide extracts of EHR data

## Strengths

- Extensive and varied data
- “Unselected” Real-world data
- Can provide granular consenting mechanism
- Develop learning healthcare systems

## Weaknesses

- Sparse Matrix
- Requires additional consenting

# **Business case: Clinical Providers**

## **Potential Barriers**

- Loss of control of data
- Liability concerns
- Commitment of clinical IT units

## **Incentives**

- Return of data may benefit clinical care
- Potential marketing value
- Expanded recruitment
- May align with new payment models

# Volunteers utilizing "blue button" technology

## Strengths

- Engaged participants
- Clear mandate from community
- Solves the "ownership" problem

## Weaknesses

- Technology not yet mature
- Requires tool and method development to enable full utility



# **Business case: Blue Button Volunteers**

## **Potential Barriers**

- Need to develop strong educational programs
- Uneven levels of participation
- Study fatigue
- Complexity of data interpretation

## **Incentives**

- Return of data may benefit clinical care
- Improving their future health of family
- Engagement as a full partner

# Centralized vs Federated Organization

## Centralized:

- Efficient
- Potentially Unwieldy
- Need to develop “credit” mechanisms

## Federated:

- Maximizes broad participation
- Engages local experts with domain knowledge
- Reduces concern of loss of data control

# What Next??

- EHRs and the data they hold represent a critically important resource for this effort—and someone else is paying for that resource and collecting the data
- Explicitly consider incentives and disincentives to participate for all stakeholder groups in design—it will make a huge difference
- Incorporate planning for Implementation in the design considerations from the beginning