

Strategies for Enhancing the Value and Utility of Electronic Health Record Research

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What are Electronic Health Records?

- A digital version of a patient's paper chart
- Record of tests, diagnoses



A Key to Discovery

- We collect a tremendous amount of information about health and disease through **electronic health records (EHR)**
 - Diagnoses
 - Information about patient such as BMI
 - Clinical Lab Measurements
 - Medications
- We can integrate and learn from these information to help inform better patient treatment



Image: http://www.brimg.net/images/doctor-using-mobile-chart-checking-patient-corbis_573x300.jpg

Image: <http://ihealthtran.com/wordpress/wp-content/uploads/2012/11/EHR-Health-IT.jpg>

A Key to Discovery

- EHR data is being collected across the lifespan now
- These data, covering both primary and specialty care, provide important information across health and disease
- Can be used for research and discovery



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<http://ihealthtran.com/wordpress/wp-content/uploads/2012/11/EHR-Health-IT.jpg>

Geisinger Health System

A network of ~78 primary and specialty clinic sites including 41 community-based primary care clinics

Stable population

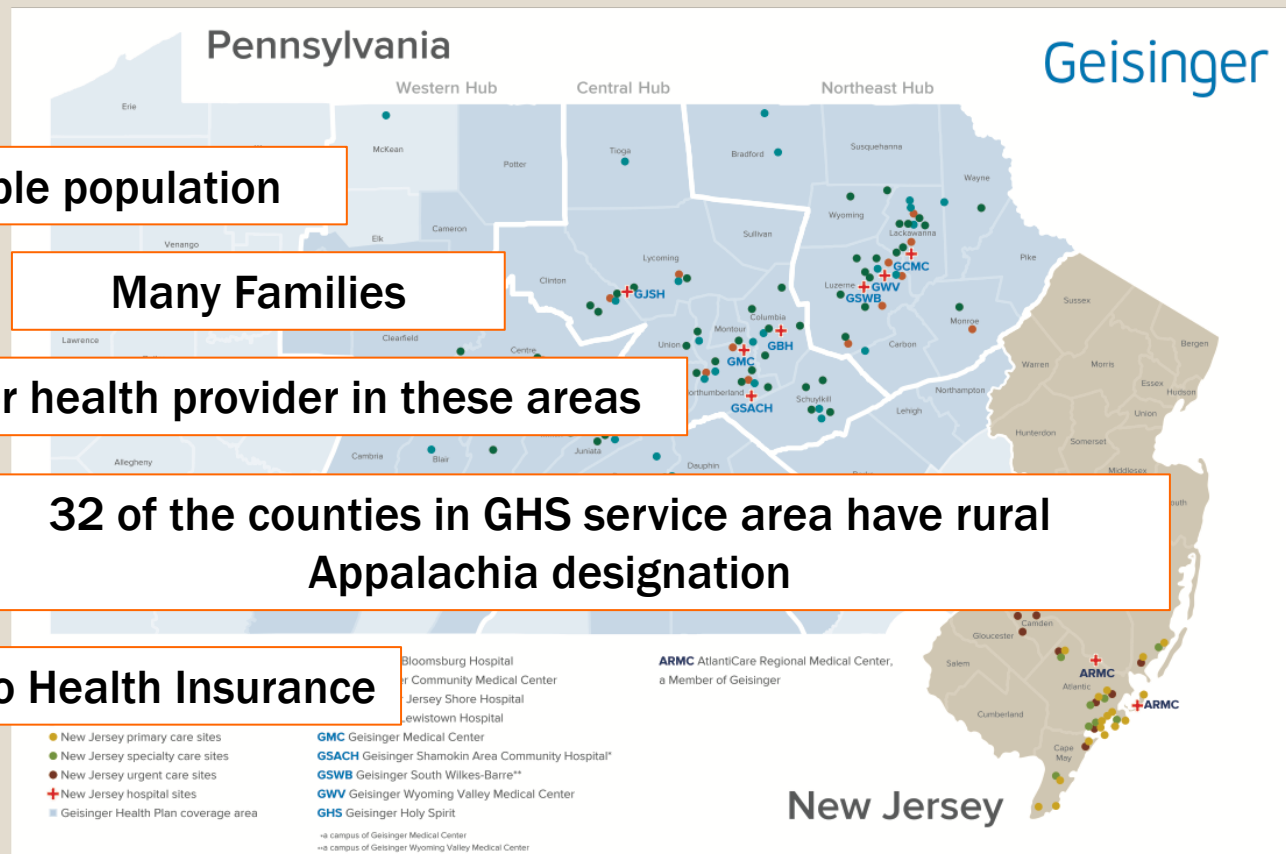
Many Families

Major health provider in these areas

32 of the counties in GHS service area have rural Appalachia designation

Also Health Insurance

~20 years
of EHR data



Electronic Health Records and Beyond

- Ambulatory (Outpatient)
- Inpatient (Hospital Admissions)
- Diagnosis information
- Emergency Department
- Surgery
- Medication Orders
- Clinical Lab Measurements (Orders and Results)
- Imaging Orders
- Procedures
- Demographics
- Patient History (Social, Surgical, Medical, etc.)
- Problem List

Longitudinal

Electronic Health Records and Beyond

- Cardiology Databases Cardiovascular Imaging (MR/CT)
 - Electrocardiogram
 - Echocardiogram
 - Surgical and Catheterization
- Radiology Pre-procedure questions
 - Radiology Reports
- DEXA
- Insurance Claims
 - Membership
 - Medical
 - Pharmacy
- Pathology
- Pulmonary Function
- Tumor Registry

EHR To Improve Care?

- For specific diseases and medical decisions
 - Certain data used over and over again depending on the disease, condition, or medication
 - We can algorithmically link together that information faster for clinicians
 - Can monitor if this provided information improves clinician and patient treatment, intervention, and experience
- For challenging ongoing health conditions without clear cut diagnoses or treatment, or resistant treatment
 - We can integrate data to improve the ability for clinicians to engage in decision making
- Are there data existing in the EHR that can inform other important diseases or outcomes?
 - Using more of the data in creative ways
 - Radiology identifying other important features for other diseases

Linking EHR to Genetic Data

- We collect a growing amount of genetic and -omic data
 - Whole Genome Sequencing (WGS)
 - Whole Exome Sequencing (WES)
 - Other -omic data
 - The cost of these technologies is falling fast
- We can link these data to EHR
 - Growing number of biorepositories for EHR and genetic association research
- Success in research discovery with de-identified patient electronic health records (EHR) linked to de-identified genetic data
 - Identification of novel genetic associations
 - Common disease
 - Pharmacogenomics



What Are Some of the Challenges?

- EHR were not designed for research
- Where is the data we seek for a specific project?

Social and behavioral determinants

Factors that contribute to a persons state of health and health risk

- What does the absence of data mean?
 - Do we just not have it recorded?
- What about errors or lack of clarity throughout a patients medical history?
 - Autoimmune disease recorded as other autoimmune disease until MS diagnosed
 - Medical record can seem to indicate a patient has multiple autoimmune disease

Social and Behavioral Determinants

- Social and behavioral determinants of health are critical information for health
 - Key factors that relate to health risk and comorbidities
 - **Many are not regularly collected in the clinical record**
 - Important for learning health care systems, important for research
- Example:
 - In genetic epidemiology, controlling for the impact of social and behavioral determinants isolates what is genetic impact
 - A patient can be taking regular medications for a condition, but not taking into account social and behavioral determinants may miss key risk factors related to not improving
- Sex, age, alcohol use, smoking, social environment including discrimination and income, where you live, access to health care...

Social and Behavioral Determinants

■ Race

- Often used in biomedical research
 - Black or African American
 - White
 - Asian
 - Native Hawaiian or other Pacific Islander
 - American Indian or Alaska native

■ Ancestry

- Global family history
- Far more distinctions than five categories
- History, human migrations, relationships

■ Ethnicity

- Cultures, customs, lifestyle
- Broader construct that takes into consideration cultural tradition, common history, religion, and often a shared genetic heritage

- These are not acting alone, these intersect in various ways
- Racial disparities resulting in impacts on health
- Genetic variability across ancestry that impacts health



Social and Behavioral Determinants

- Environmental exposures
- Diet
- Smoking



Social and Behavioral Determinants

- Where you live
 - Environmental exposures
 - Food choice
 - Education access



Social and Behavioral Determinants

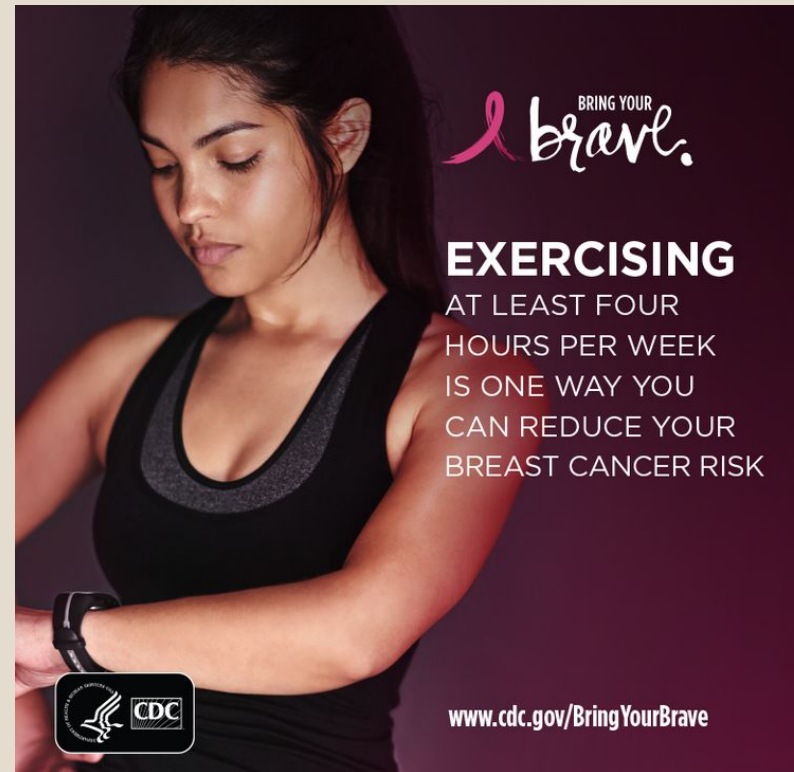
- Mental health
 - Depression
 - Social isolation
 - Anxiety



Social and Behavioral Determinants

■ Exercise

- Think about how behavioral and social determinants also impact exercise
- Education, income, gender, location, race/ancestry/ethnicity, childhood exposure to regular exercise
- Physical activity can be used to treat as well as prevent disease
- Physical activity can improve learning



Social and Behavioral Determinants

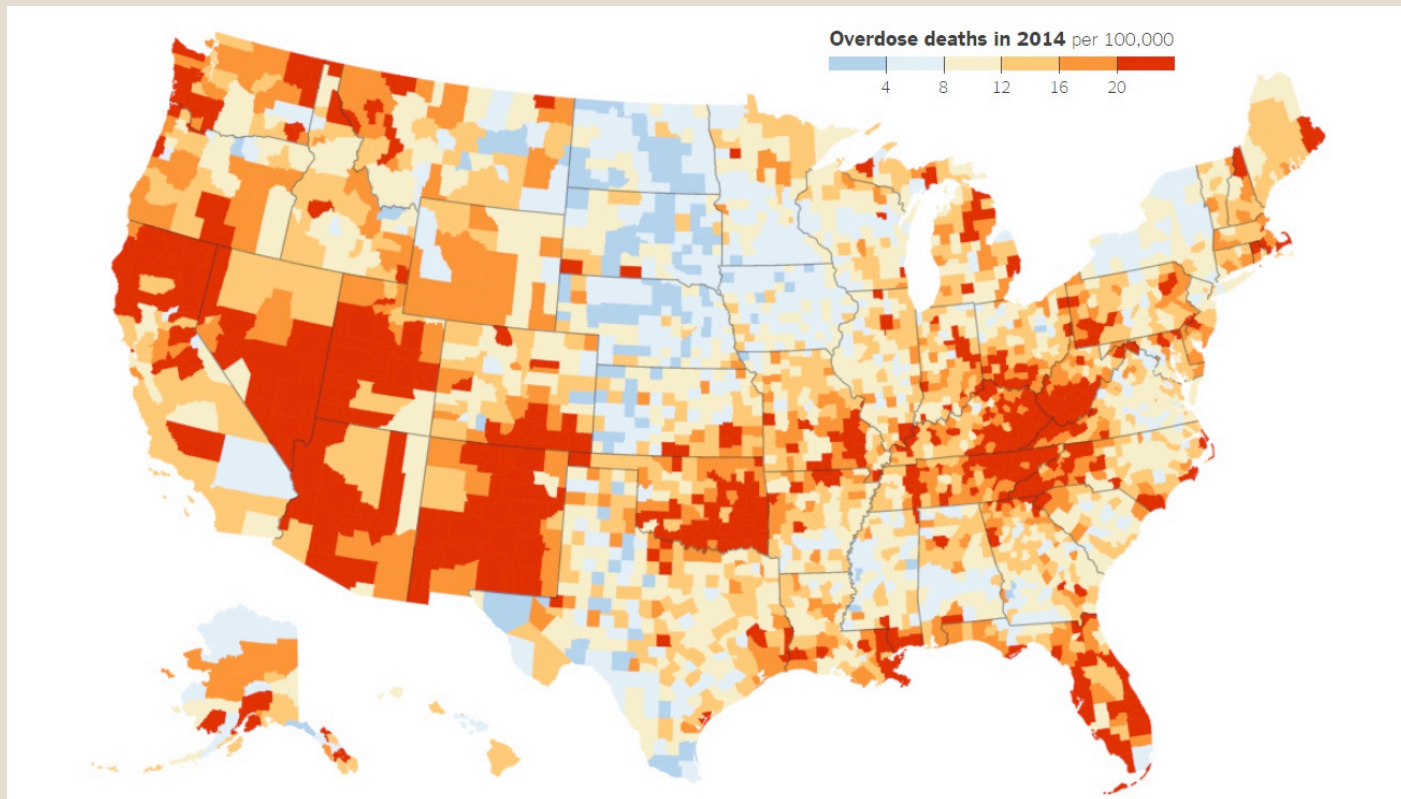
■ Stress

- Not all stress is bad
- Chronic stress can have negative health impacts
- As well as how stress is navigated
 - Alcohol
 - Food
 - Other behaviors that can negatively effect health
- Seventy-five percent to 90% of all doctor's office visits are for stress-related ailments and complaints



Social and Behavioral Determinants

- Alcohol
- Drug use
 - Prescription
 - Non-prescription



EHR for Determinant Identification

- Sometimes some of these are recorded in the EHR
 - But in free text
- Phenotypic algorithms
 - Combining multiple pieces of data from the EHR to obtain high quality information
 - Example: T2D algorithm that well defines cases and controls
 - Using expert knowledge
 - Careful evaluation of how well it identifies and misses patients
 - Can be deployed as the EHR continues to grow to obtain that key information over and over again

EHR for Determinant Identification

- How can the EHR be used to identify behavioral and social determinants?
 - Socioeconomic status
 - At Vanderbilt there is social history information
 - Can use this to get at socioeconomic status
 - Economic and social position in relation to others, based on income, education, and occupation

Subject Status: ☐ Included ☐ Excluded ☐ Undetermined ☒ Not R

Select tabs to display ▼

Documents × Medications × Labs × ICD9 Codes × Cor

Open Filters Open Highlight

High Value Documents Other Documents Problem Lists

- Synthroid 0.15 mg qd

ALLERGIES:

- NKDA

FAMILY MEDICAL HISTORY:

- Mother(70): Deceased, CHF, hypertension

- Father(40): Deceased, stomach ulcers, colitis

- Siblings(x10): Four deceased, diabetes, CAD, MI, hypertension

- Daughter(39): Unknown blood disorder

SOCIAL HISTORY:

- Marital status: Single

- Education: Completed 8th grade

- Unemployed: Disability/SSI

- Tobacco: None

- Alcohol: No history

- Illicit drug use: No history

EXAMINATION

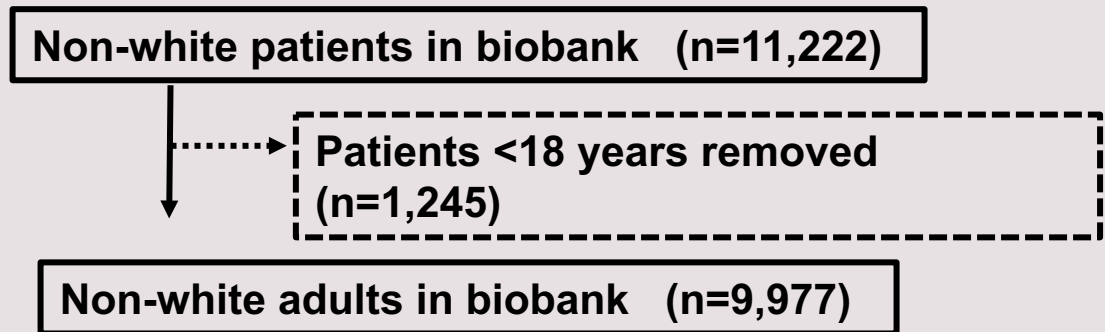
VITALS: P: 64 BPM BP: 170/50 mm Hg Wt: 165 lb Ht: 63.0

GENERAL: well developed; well nourished; no acute distress.

PRESENT

TEXT MINING FOR SES

Algorithms
developed and
evaluated in an
adult minority
patient population



Brittany Hollister, PhD

Process for Extraction

Sample Selection

Non-white patients in biobank (n=11,222)

Patients <18 years removed
(n=1,245)

Non-white adults in biobank (n=9,977)

1. Development

200 records

Manual review of EHRs

Semantic Categories

Occupation

Education

Insurance Status

Homelessness

Identification of semantic tags

Refine algorithms

2. Evaluation

50 records

Manual review to establish gold standard

Comparison of manual review with algorithms

3. Application

9,977 records

Occupation, unemployment, retirement,
education level, lack of insurance,
Medicaid, homelessness

SUMMARY AND MAJOR CHALLENGES

- **Effective for**
 - Uninsured
 - Unemployment
 - Occupation
 - Medicaid
 - Education level

- **Less Effective**
 - Retirement
 - Homelessness

Missing data

Inconsistencies in recording by providers

Capturing changes over time



Patient Reported Information

- Survey information and feedback
 - Pain management
 - Drug use
 - Alcohol use
 - Surveys for depression and stress
 - Surveys for asthma control
- Standardized surveys
 - PhenX (<https://www.phenxtoolkit.org/>)
- Activity



What else do we need to bring in?

- Family health and history



<http://www.tanfamilychronicles.com/2013/09/the-extended-tan-family-photoshoot-with.html>

http://www.sliderobes.com/media/Three_Generation_Family.171224921_std.jpg

What else do we need to bring in?

- Family health and history
 - <http://www.healthheritage.org/>
- You control who sees your data
- Choose to send a copy of your disease risk assessment to your doctors
- Share information with family members and collect their medical histories to make your family medical history more complete.



Patient-Provided Data

Advantages

- Convenient
- Structured
- Relatively inexpensive

Disadvantages

- Self-reported
- Response bias
- Unequal access to technology

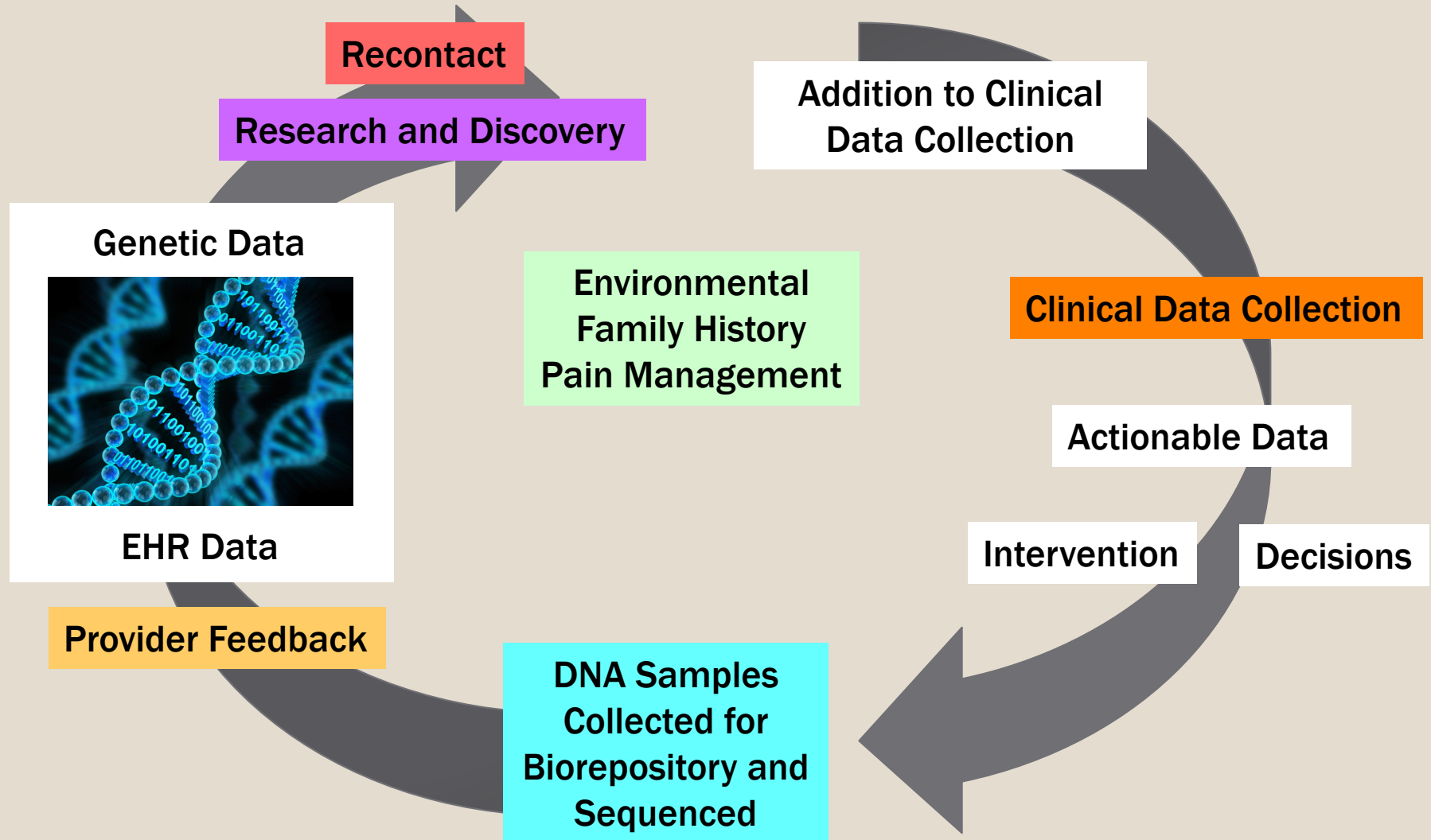
What Do We Also Do?

- This is where learning health care systems and research could help
 - Research coming back to the clinic to highlight issues and inconsistencies
 - With more and more deployment of EHR, more and more compatibility between EHRs

What is a Learning Health Care System?

Use Patterns and Knowledge Recorded to Improve Clinician and Patient Experience

- Life cycle of the data – an opportunity



- Geisinger Health System
 - Biomedical and Translational Informatics Institute
 - Geisinger Precision Health Center

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