

## Intro to BMI Data Services

May 19, 2016



## Agenda

- Overview of services
- Example collaborations
  - Maternal Infant Data Hub
  - IMPACT Study
- Q&A



## Our mission

To improve child health by facilitating investigator interactions with high-quality data in order to gain new, actionable knowledge.



## Key services

- Development of data collection/transfer tools
- Complex extraction of clinical data for research purposes
- Integration of data and transformation into standard/common models
- Implementation of reporting, visualization and discovery tools
- Data-in-once solutions



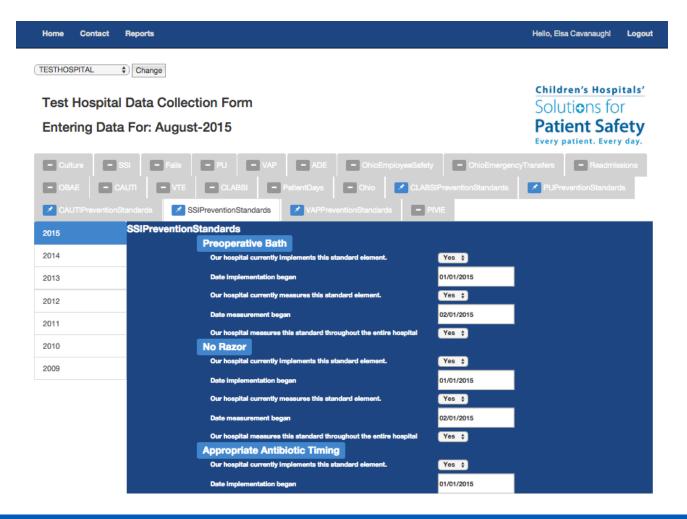
## Our impact (FY16)

- \$2.2M funded research collaborations
- 20+ active multi-center projects
- 100+ investigators in 30+ divisions supported
- 5000+ users at 300+ sites supported
- 120+ research data requests completed
- 300+ research data sets delivered

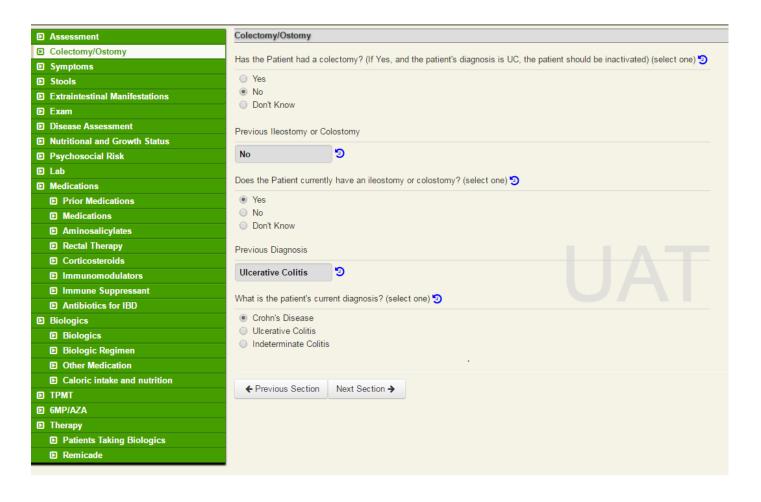


- Develop custom web/mobile applications
  - Complex workflows
  - Customized/personalized user interfaces
  - Integration w/ clinical and research information systems (e.g., Epic, Cerner)











- Develop/implement data transfer portals
  - Support for flat files and web services/APIs
- Leverage CCHMC research network environment for highly configurable, secure access control



## Data extraction

- Provide honest broker service for research data requests sourced from the CCHMC EHR and other clinical/research information systems
- One-time data sets and recurring reports/refreshes



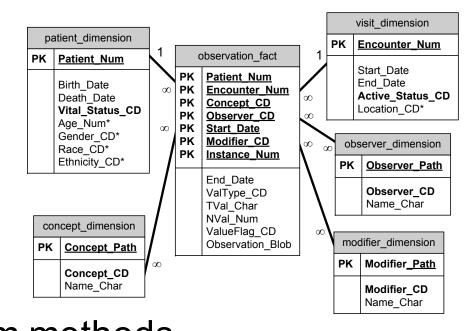
## Data extraction

- CCHMC central intake form
  - http://iportal.cchmc.org/sites/is/EpicDataRequest/ sitepages/datarequestmenu.aspx
- help-dataservices@bmi.cchmc.org



## Data integration/transformation

- Leverage common data models
  - o i2b2, OMOP, PCORnet
- Produce derived data sets/measures using standardized/
  reusable and custom methods



Collaboration with CCHMC Division of Biostatistics
 & Epidemiology



## Reporting/visualization/discovery

- Support CCHMC research data warehouse
- Implement/modify applications, reporting tools and analysis libraries that interact with common data models
- Develop and implement web-based data characterization tools
- Develop distributed, web-based reporting solutions

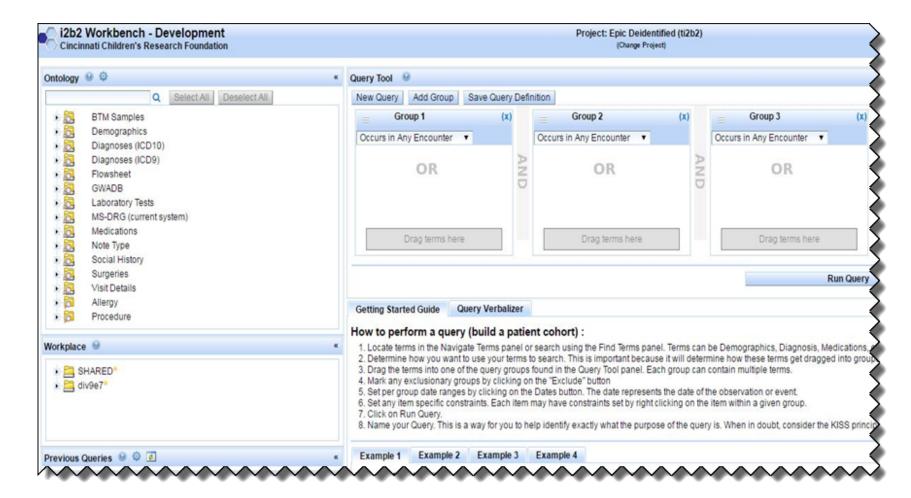


#### CCHMC research data warehouse

- Uses: cohort identification, hypothesis generation
- Limited data set including 1.2M patients, 26M encounters and 230M observations/facts:
  - Diagnoses
  - Vitals
  - Labs/medications
  - Allergies
  - Social history
  - Surgeries
  - Samples (Better Outcomes for Children)



#### CCHMC research data warehouse: workbench





#### Distributed research networks

#### Uses:

- Queries of patient populations across participating institutions
- Identification of cohorts/testing of hypotheses across institutional/geographic boundaries
- Currently supported networks:
  - PEDSnet (8 national pediatric hospitals)
  - ACT (21 national pediatric/adult hospitals)
  - OCTC (12 Ohio pediatric/adult hospitals)











## **Data-in-once solutions**

- Multi-use, "enhanced" registries: research + quality improvement + care management
- Primarily for learning networks/health systems
- Requires significant investment, collaboration with Anderson Center
   & Biostats/Epi at CCHMC







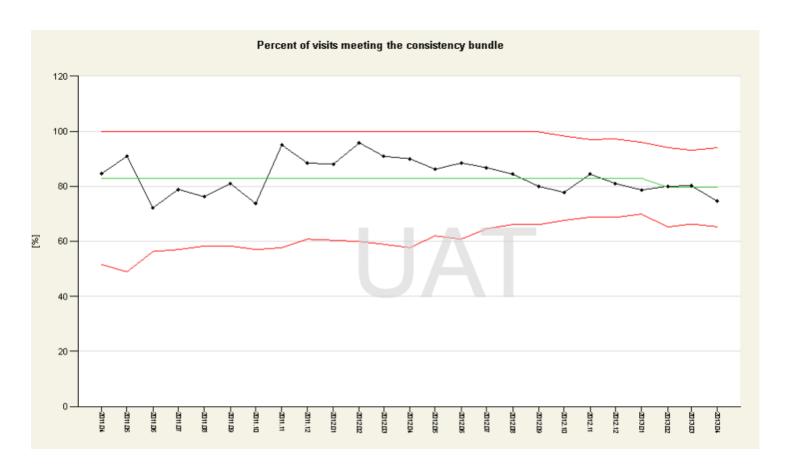




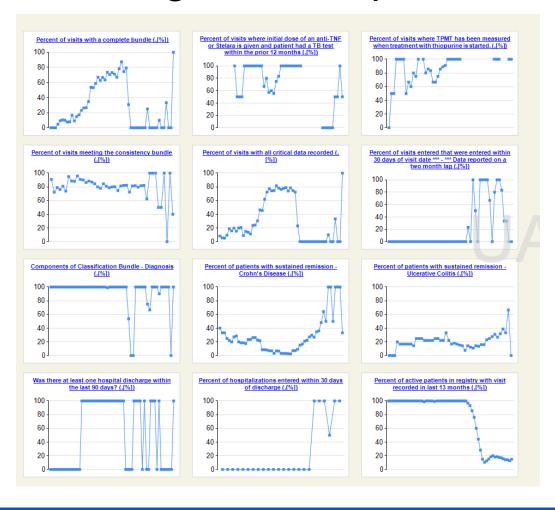
## Data-in-Once: Benefits

- Elimination of redundant data entry
- Integrated inbound and outbound data quality checks
- Identified and de-identified access layers
- Diverse, modular outputs
  - Reports
  - Data sets
  - Query abilities











Patient Name: Huxtable,Rudy /MRN:6005603 Patient Num: 5						Birth Date: 7/16/2002 Current Age: 12.0				Primary Provider: Secondary Provider:			
Diagnosis: Crohn's Disease - 5/2010						Last Visit: 3/7/2014				Last PPD & Date:			
Phenotype: Inflammatory, non-penetrating, non-stricturing						Wt (kg): 20.41				Negative 9/7/2012			
Lower: Ileal only						Ht (cm): 91.44				Last CXR:			
Upper Proximal: No						BSA: .72				Negative 9/10/2010			
Upper Distal: No						Date of last hospitalization:				Last Gold Test & Date:			
Perianal Phenotype: No						Not Recorded				Not Done			
>> Visits	: 0	01/15/2013	01/23/2013	02/26/201	3 04/	09/2013	05/21/2013	07/09/2013	08/19/2	013	03/07/2014	Age of Result	
PCDAI		0	20	0	10		0	10	25		50	Ť	
MGA		Quiescent	Quiescent	Quiescent	Quiescent		Quiescent	Quiescent	Quiescent	.	Mld		
Nutritional Status		Setisfactory	Satisfactory	Satisfactory	y At risk		Setisfectory	Setisfactory	Sotisfacto	ny	Setisfactory		
Growth Status		Setisfactory	Satisfactory	Satisfactory	y Satisfactory		Setisfectory	Setisfectory	Sotisfocto	7	Setisfactory		
Ubumin		4.5		43	4.5		4.3	4.4	4.3			12 mo ⊕	
RP		0.00		0.00	0.00	)	0.50	0.00				13 mo ⊕	
SR									7.0			12 mo Φ	
lematocrit		36.0		36.1		,	35.7	35.5	34.8			12 mo 🔱	
Result date	may differ f	rom visit date			a	Lab order	ing guidelines:	5-ASA:q6mo	6mp/AS	A/MTX	q3-4mo 8	iologics:q2-3mo	
Care Stra	atification	 n											
CS Score CSS Gr		COLLO		Month se Activity	BMI Z-	Score	Ht Velocity	Hosp Adm within 3 months		rently on Cortico last Cortico 12 months		Psychosocia Risk Factor:	







## **Future directions**

- Research data warehouse:
  - Workbench upgrades
  - Flowsheets, de-identified notes
- Learning health systems:
  - Modularly programmed, reusable measures
- Structured data capture pilot
  - Study forms embedded in the EHR



## Example collaborations

- Maternal Infant Data Hub
  - Study Team: Eric Hall, PhD; Jim Greenberg, MD
  - BMI Team: Janet Zahner, Jay Gholap, Parth Divekar, Diana Epperson
- IMPACT Study (Illness Management & Parental Adjustment to Cancer Treatment)
  - Study Team: Ahna Pai, PhD; Caroline Morrison
  - o BMI Team: Billy Shuman, Jeremy Nix



## Contact us

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help-dataservices@bmi.cchmc.org





Pai Lab and BMI Collaboration May 19, 2016



# **IMPACT Study**

- 15,780 Children are diagnosed with cancer every year in the United States (ACS, 2014)
- Uncertainty inherent to the cancer experience
  - Dramatically increases uncertainty experienced by patients and their caregivers
  - Parental Uncertainty is robustly related to psychological distress of BOTH parents and the child with cancer.
- Multi-site randomized control trial of IMPACT
  - Minimize and manage the uncertainty faced by families with a child diagnosed with cancer
  - Parents of children newly diagnosed with cancer



## Sources of Uncertainty

- Communication
- Social Support

Ambiguit\

- Symptoms
- Test results

Unpredictability

# Development of IMPACT Application

Lack of Information

- Illness
- Treatments
- Hospital

Complexity

- Large medical team
- Clinic schedule

# **IMPACT** Application

- Accessibility
  - Variety of device manufacturers- Apple, Android
  - Smartphone, Tablet, Computer
  - Login to secure health information
  - Easy to navigate
- Information about the Treatment Process
  - Content designed based on family interviews
  - Integrate content from trusted sources
- Personalized information integration
  - Laboratory results
  - Healthcare provider contact information
  - Calendar of medical appointments
- Interactive Uncertainty Management navigation



# Accessibility

#### Needs

- Variety of device manufacturers- Apple, Android
- Smartphone, Tablet, Computer
- Login to secure health information
- Easy to Navigate

#### Solutions

- Mobile centric website
- MyChart authentication

### Information about the Treatment Process

#### Needs

- Content designed based on family interviews & existing literature
- Integrate content from trusted sources

#### **Solutions**

- Live Well Collaborative for design
- Information pulled directly from National Cancer Institute

## Personalized Information Integration

#### Needs

- Laboratory results
- Healthcare provider contact information
- Calendar of appointments

#### **Solutions**

- Centerlink pull for provider contact information
- EPIC data pull for laboratory results and calendar appointments



## Interactive Uncertainty Management Component

#### Need

- Interactive Uncertainty Management navigation

#### Solution

- Interactive navigation
- Editing capabilities
- Stored history



# Responsive Design





# Technology

- Latest Web Technologies
  - HTML5, CSS3, JavaScript Frameworks

- Full-text searching
  - Rebuilt nightly

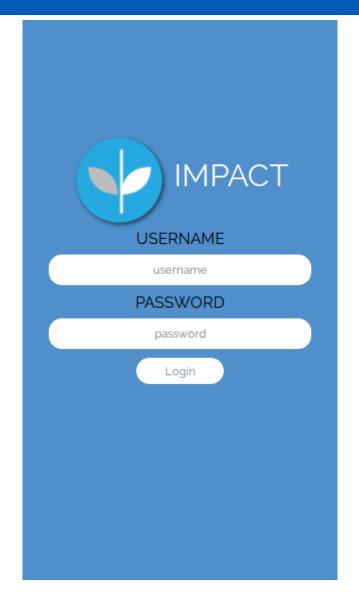


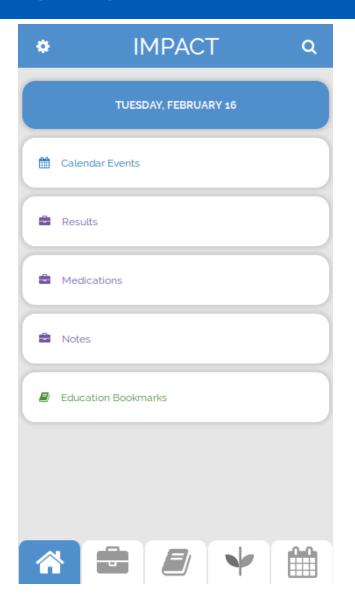
Not a traditional mobile application

## Data

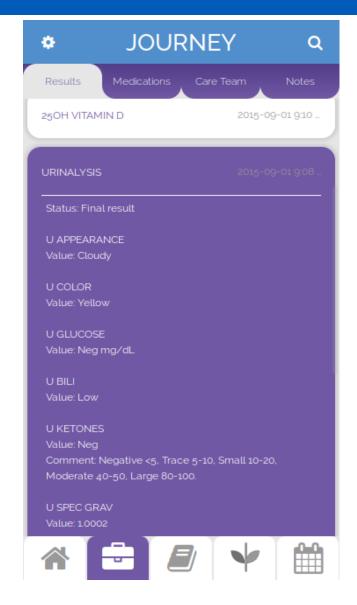
- Epic web services (MyChart)
- National Cancer Institute (cancer.gov)
- National Library of Medicine
  - MedlinePlus (medications)
- Organization handouts (CCHMC)





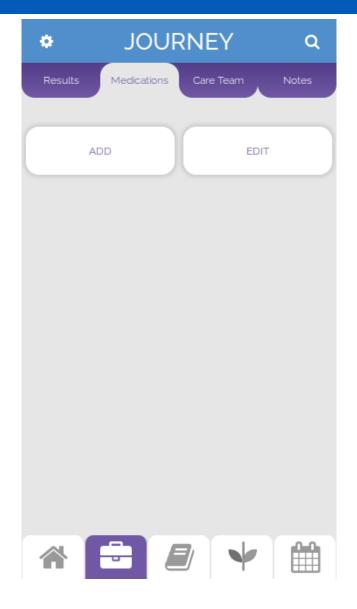


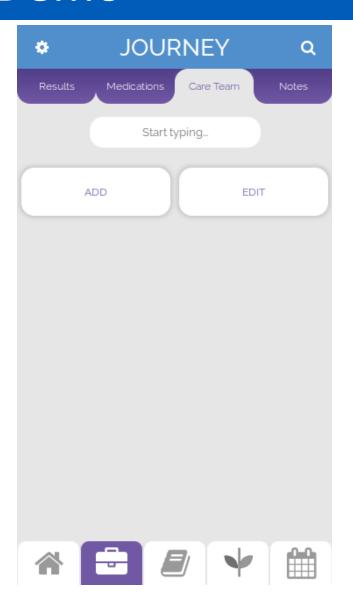




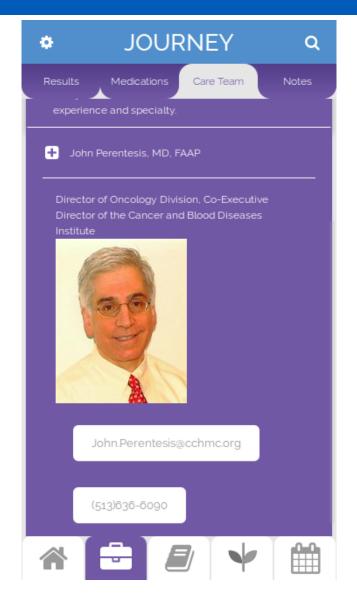


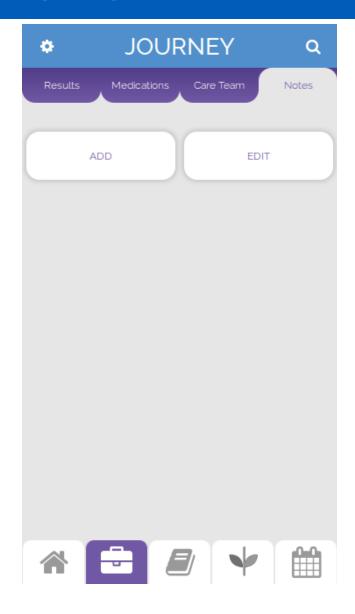




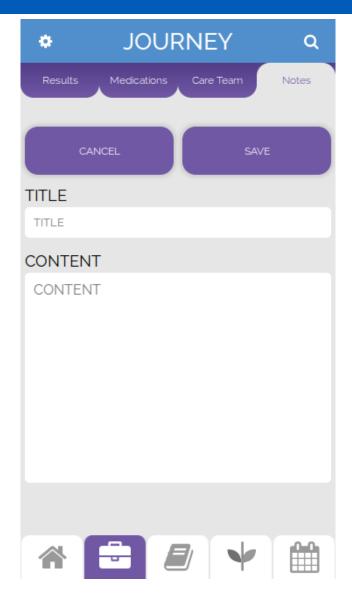


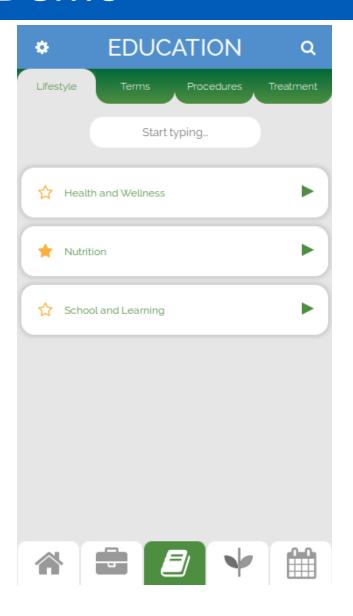






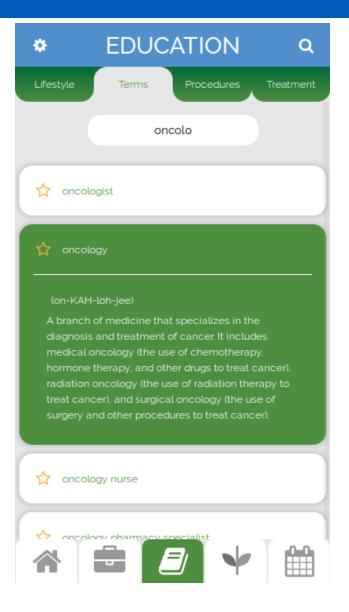




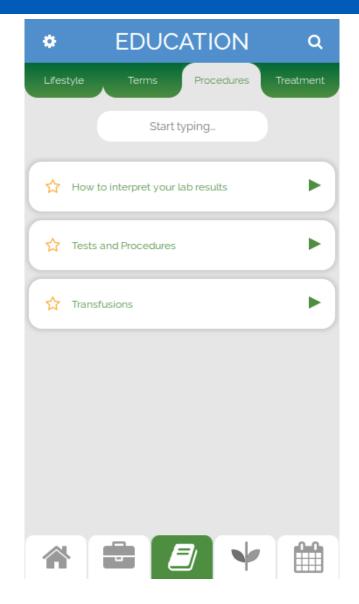


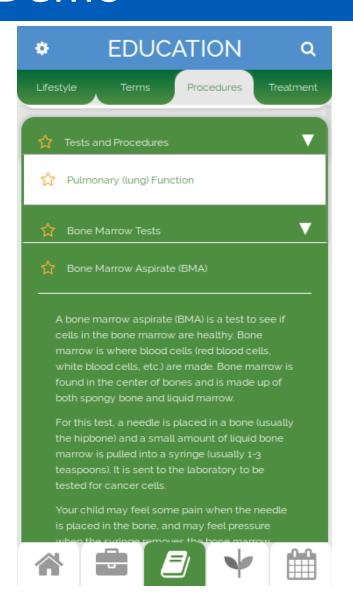




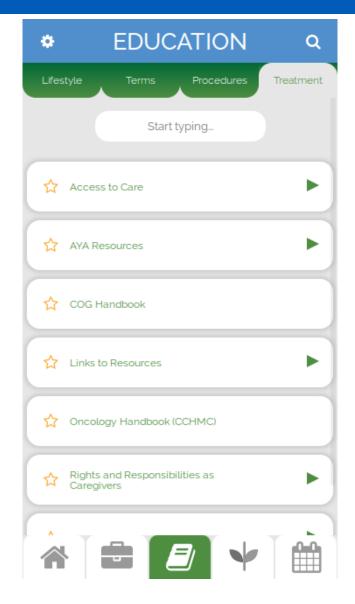


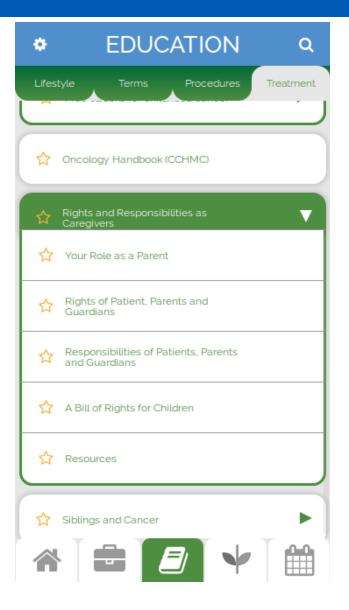






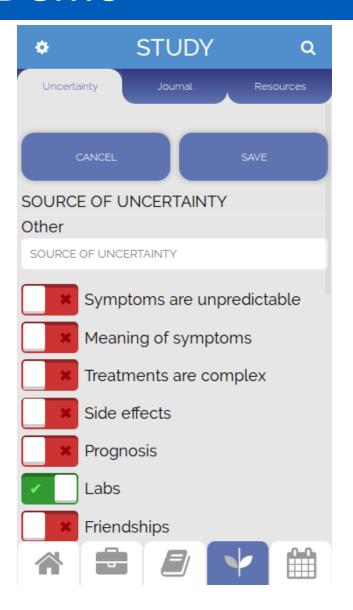






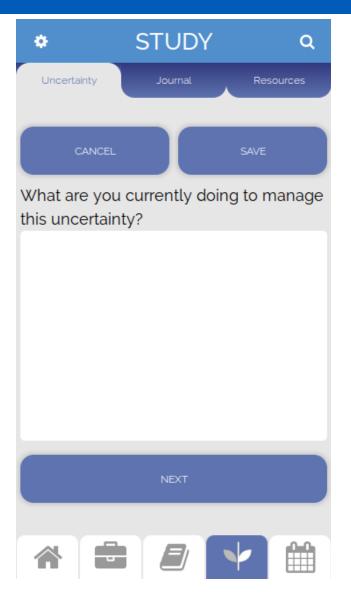










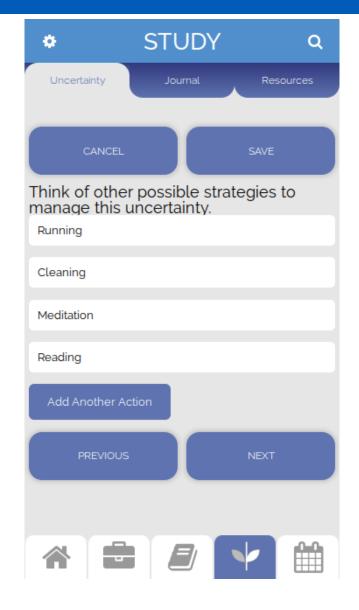


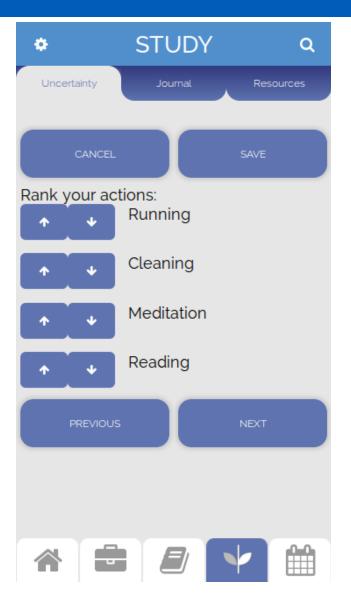




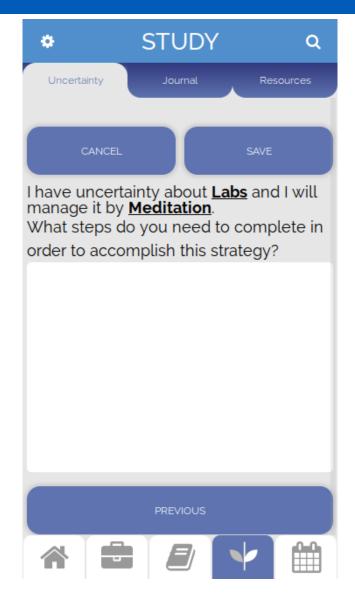






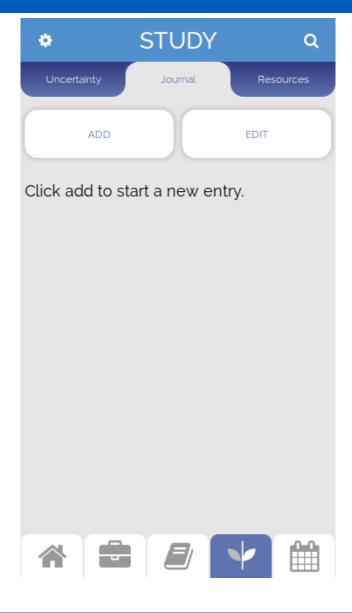


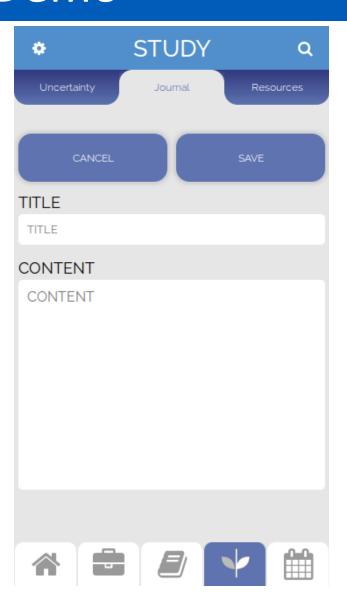




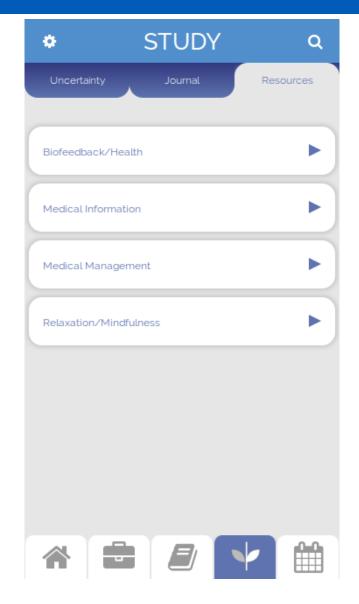


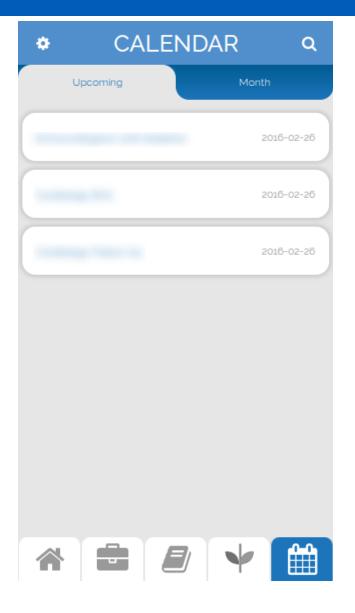




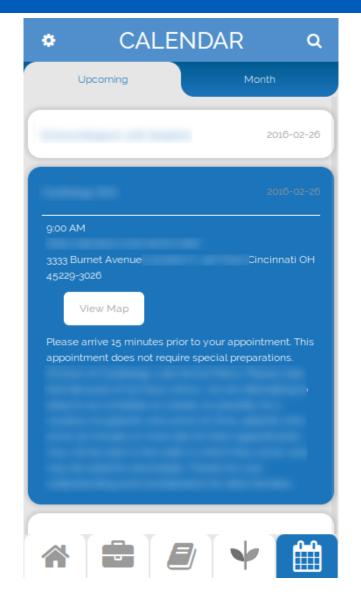


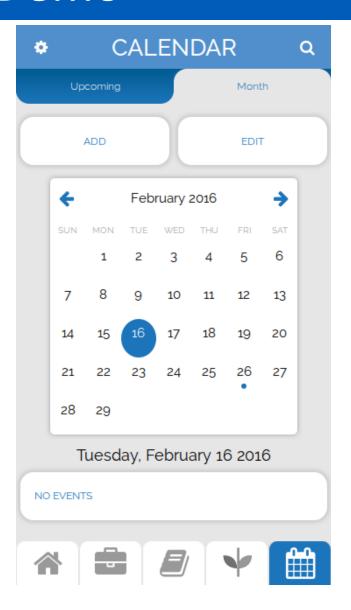










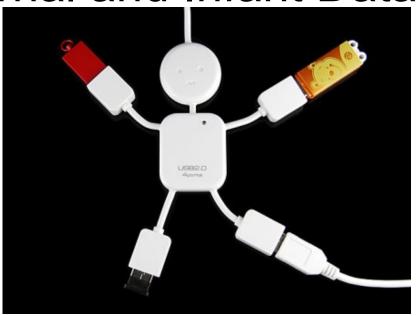




# Questions?



# Lifespan Data Integration Module: Maternal and Infant Data Hub



## Children's Maternal-Child Health Research

- Measures of community maternal and infant health are instrumental for
  - Planning
  - Allocation of key resources
  - Testing of relevant hypotheses
  - Effective operation of healthcare and community-based programs
- Focus on reduction of infant mortality

# Children's What is an Infant Mortality Rate?

 The number of deaths in children under 1 year of age per 1000 live births in the same timeframe

$$\frac{\#\ infant\ deaths}{\#\ live\ births}*1,000$$

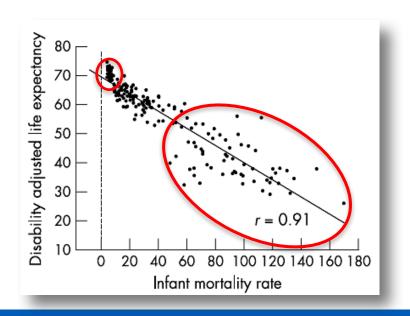
Hamilton County IMR (2011-15)

$$\frac{508}{54,805}$$
 \* 1,000 = 9.3



# Children's Why Focus on Infant Mortality Rate

- A highly sensitive proxy measure of population health
- Early warning signal



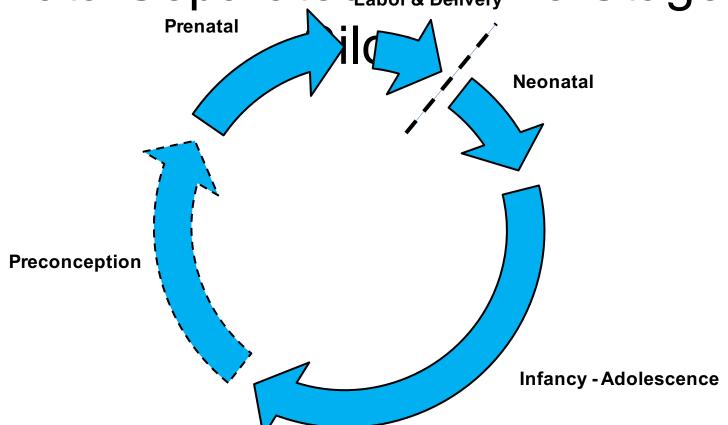


# Children's Local Causes of Infant Mortality

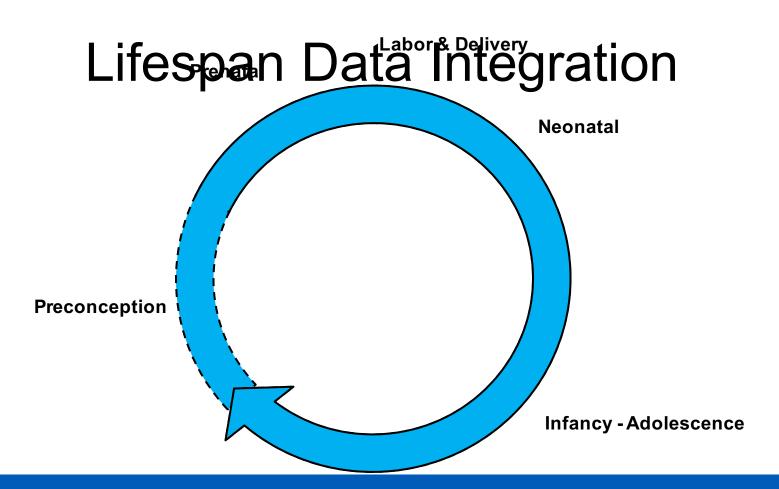
- Preterm birth ≈ 60%
- Congenital Anomalies ≈ 15%
- Sudden Unexpected Infant Death (SUID/SIDS) or Sleep Related Deaths ≈ 14%



# Data Separated into Life Stage





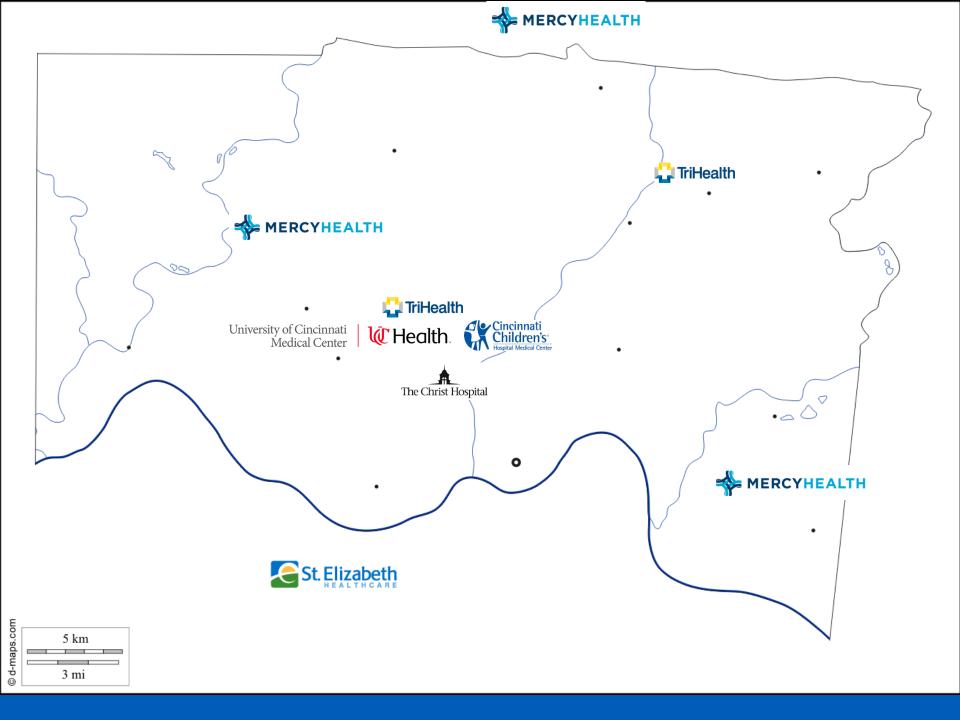


# Children's Challenges

- Data reside in silos without interoperability
- Questions of data ownership
- Regulatory barriers
- Appropriate privacy concerns
- Lack of sustainability of funding
- Two classes of individuals mother and baby

# Cincinnati Children's CCHMC Neonatology

- Manages nurseries throughout Greater Cincinnati
  - Approximately 90% of all newborns
  - Nearly all Medicaid insured or high-risk babies
  - 100% of Neonatal Intensive Care @5 NICUs
- Program Structure
  - Centralized billing
  - Standardization of care



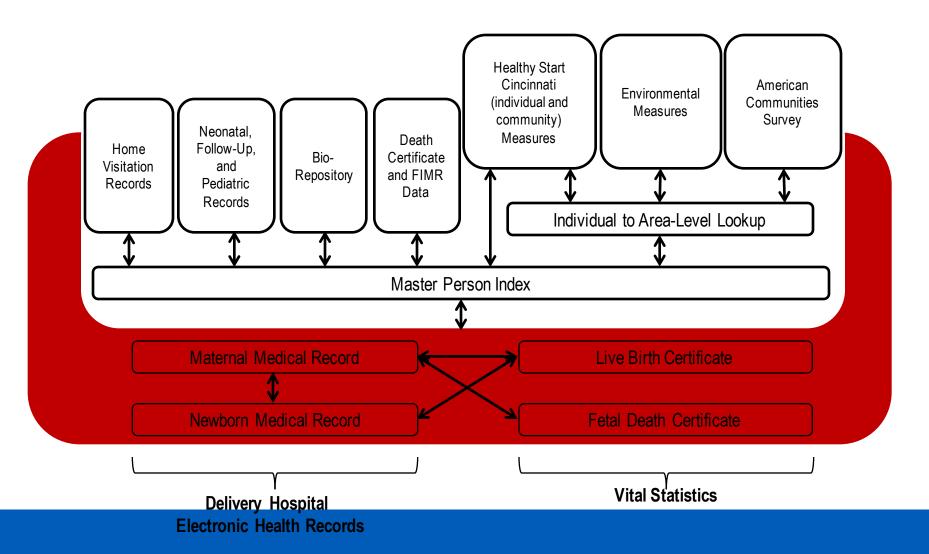
# Children's An Opportunity

- CCHMC neonatal billing provides a near population-based definition of regional births
- Usable as a hub for additional record linkage
  - Regional EHRs
  - Home visitation records
  - Vital statistics
  - Regional demographic and environmental measures
- Pilot Support from the CCTST and CCHMC Academic and Research Committee

 Support seamless integration of maternal, neonatal, and pediatric records to establish a population-based, clinically focused, regional research data repository, or data hub.



### **Maternal and Infant Data Hub**



- University of Cincinnati Medical Center EHR
  - Maternal Prenatal and Labor and Delivery and Infant
    - Medications, Procedures, Diagnoses
- CCHMC EHR
  - NICU and Pediatric
    - Medications, Procedures, Diagnoses, Growth and Developmental Measures
- Every Child Succeeds
  - Home visiting
    - Maternal mental health and substance use

## Children's Data Hub Utilization

- Aggregates and links data containing identifiers
  - Ongoing IRB approval
  - Honest broker model
- De-identified data sets may be requested without additional IRB approval
- Identified data sets may be obtained with study specific IRB approval

## Cincinnati Children's Data Hub Utilization

- Envisioned as a core resource for
  - Maternal and child health providers, policymakers epidemiologists, community agencies. researchers
- Supporting
  - Cohort identification
  - Hypothesis generation
  - Hypothesis-driven research
  - Monitoring of time-related changes in neonatal and maternity care and outcomes
  - Benchmarking of neonatal & developmental outcomes

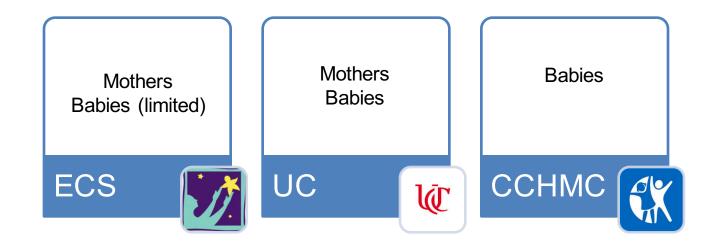


## **MIDH**

Maternal infant data hub
Common data model presentation
5/19/2016



# Cincinnati Current Setup



# Children's Current Setup - Duplications

ECS	UC	ССНМС
Baby:	Baby:	Baby:
• Beth I. 6/10/2015 (no ID)	• Beth I. 6/10/2015 (MRN 11223344)	<ul> <li>Beth I. 6/10/2015 (MRN 31415926)</li> <li>Beth I. 6/10/2015 (MRN 0112358)</li> </ul>
Mother:	Mother:	Mother:
<ul> <li>Michelle G. (no DOB) (screening ID 01234567)</li> </ul>	<ul> <li>Michelle G. 9/20/1990 (MRN 98765432)</li> </ul>	

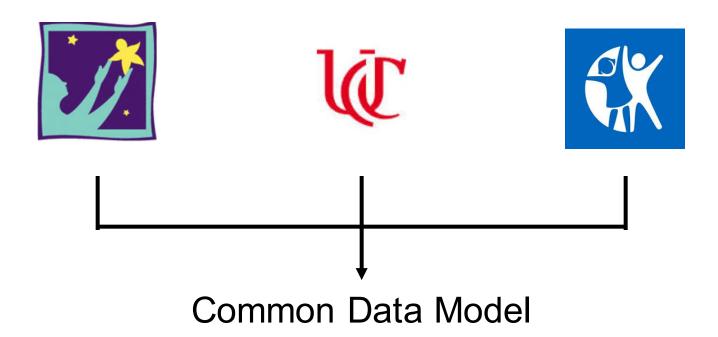


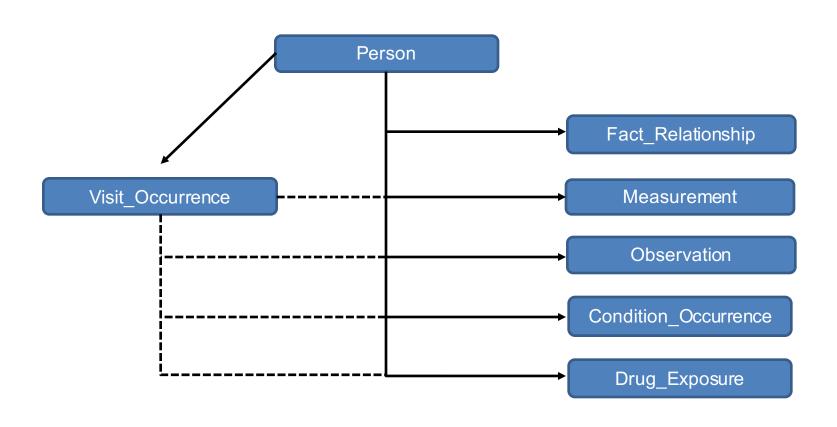
# Children's Current Setup – Data Limitations

ECS	UC	ССНМС	
<ul> <li>Primary mother's data</li> <li>Baby's name, gender, and DOB are available</li> <li>Home Visits</li> <li>Surveys/Questionnaires</li> </ul>	<ul> <li>Data about baby and mother</li> <li>Medications</li> <li>Labs</li> <li>Diagnoses</li> <li>Demographics</li> </ul>	<ul> <li>Only baby's data</li> <li>All clinical data available in Epic</li> </ul>	



# Children's Leveraging data





# CDM – Fact Relationship table

- Baby -> mother
- Mother -> baby
- Grandmother -> mom -> baby
- siblings

## CDM — Person Consolidation

MIDH ID	ID NUM	PERSON TYPE	FIRST NAME	LAST NAME	BIRTH DATE	GENDER
29739	1234567	ECS - mom	Michelle	G		F
29739	98765432	UC - mom	Michelle	G	9/20/1990	F
40097	31415926	CCHMC - baby	Beth	ı	6/10/2015	F
40097	112358	CCHMC - baby	Beth	ı	6/10/2015	F
40097		ECS - baby	Beth	ı	6/10/2015	F
40097	11223344	UC - baby	Beth	I	6/10/2015	F



Person ID: 29739

- 23 Home Visits (5/11/2015 11/12/2015)
- No recorded diagnoses
- 260 distinct lab results
- 1 recorded ECS family assessment

# Children's CDM— Baby's Results

Person ID: 40097

- 1 recorded diagnosis (774.6 Unspecified fetal and neonatal jaundice)
- 3 distinct lab results

#### Cincinnati CDM — Person Consolidation Children's CDM — Person Consolidation

#### Matching and Consolidation Techniques

- Compare first name, last name, birth date, and gender
- Remove non-alpha characters (spaces, hyphens, apostrophes, etc.) from first and last names before comparing
- Birth Dates must match
- Genders must match or be blank (Gender is often not recorded in ECS)



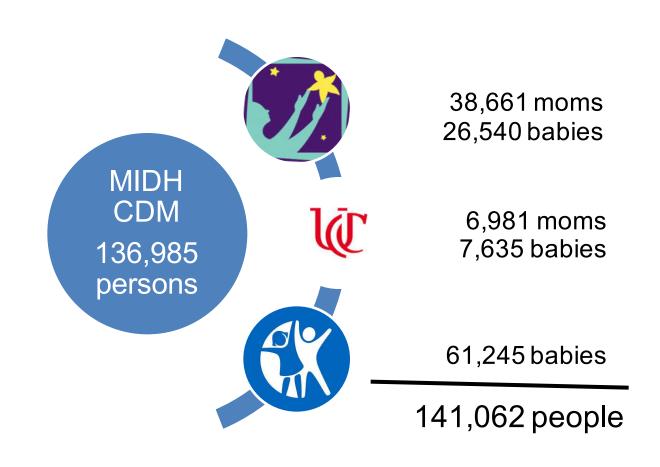
#### Children's CDM — Person Consolidation

#### **Edit Distance**

- A technique used for "fuzzy matching" when comparing first and last names
- Allows us to identify matches even when first and/or last names are not a perfect match in various source systems
- Also known as "Levenshtein Distance "(named after the Russian scientist Vladimir Levenshtein, who devised the algorithm in 1965), is a measure of Similarity between two strings, s1 and s2. The distance is the number of insertions, deletions or substitutions required to transform s1 to s2.
- Ex: Edit Distance between "shackleford" and "shackelford" = 2



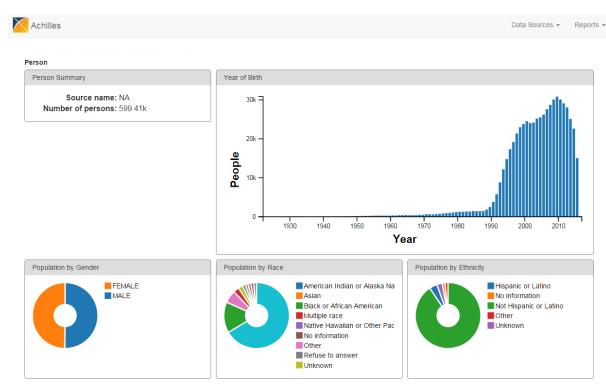
#### Children's CDM — Person Consolidation



- CONCEPTS table includes standard vocabularies (ICD-9, CPT, SNOMED, LOINC, etc)
- CONCEPTS table can also hold custom vocabularies (ex: ECS assessment types)

#### Children's Presentation Tool - Achilles

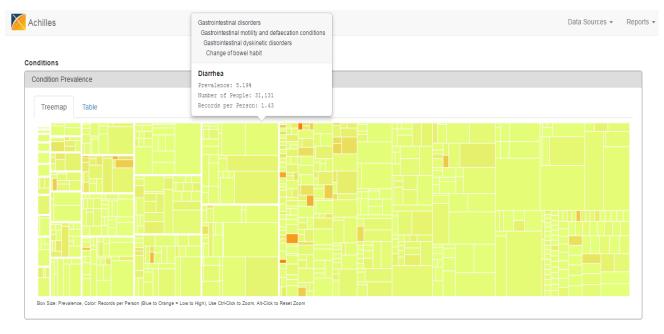
- Designed to work with this CDM
- Presents high level counts and groupings



\* not MIDH data

## Children's Presentation Tool - Achilles

 Density charts for prevalence



\* not MIDH data



## Children's Presentation Tool - Achilles

Person and Record counts per condition, drug, lab

