



Health Care Systems Research Collaboratory

# NIH Collaboratory Distributed Research Network

Millions of people. Strong collaborations. Privacy first.



# NIH Collaboratory

Health Care Systems Research Collaboratory



DESIGN



CONDUCT



DISSEMINATION

## NIH Collaboratory Distributed Research Network (DRN)

Millions of people. Strong collaborations. Privacy first.

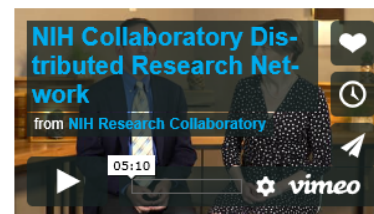
**Co-Chairs:** Jeffrey Brown, Richard Platt, and Lesley Curtis

**Project Manager:** Beth Syat

[Publications and Supplementary Material](#) | [Presentations](#)

Established by the [Electronic Health Records \(EHR\) Core](#), the NIH Collaboratory Distributed Research Network (DRN) enables investigators to collaborate with each other in the use of electronic health data, while also safeguarding protected health information and proprietary data. It supports both single- and multisite research programs.

The network's querying capabilities reduce the need to share confidential or proprietary data by enabling authorized researchers to send queries to collaborators holding data (i.e., Data Partners). In



Drs. Jeffrey Brown and Lesley Curtis explain the NIH Collaboratory Distributed Research Network.

### RESOURCES

[DRN Governance](#)

[Video: Uses of the NIH Collaboratory DRN](#)

# Data Partners & Available Data

- Data for more than 90 million lives
- Billions of medical encounters and filled outpatient prescriptions
- Variety of health plans



Kaiser Permanente Washington  
Health Research Institute



The **Meyers** Primary Care Institute



# Network Objective & Features

Support multisite studies funded by NIH and other not-for-profit sponsors through use of secure networking capabilities and analysis tools.

- Advantages
  - Analysis-ready data sets using a common data model
  - All activities audited and secure
  - Validated analytic tools
  - Efficient multisite studies
- Operating model
  - Data Partners keep and analyze their own data
  - Rapid-response querying
  - Network provides results, not data, to the requestor



# Uses of the Network

## Clinical trial planning

- Assess background rates of conditions, treatments, and outcomes in potential study populations
- Identify potential treatment sites
- Potential for direct outreach to members and clinicians

## Observational studies

- Principal strength in retrospective studies
- Prospective studies possible
- Capability to link to other data sources, such as registries



# Data Elements

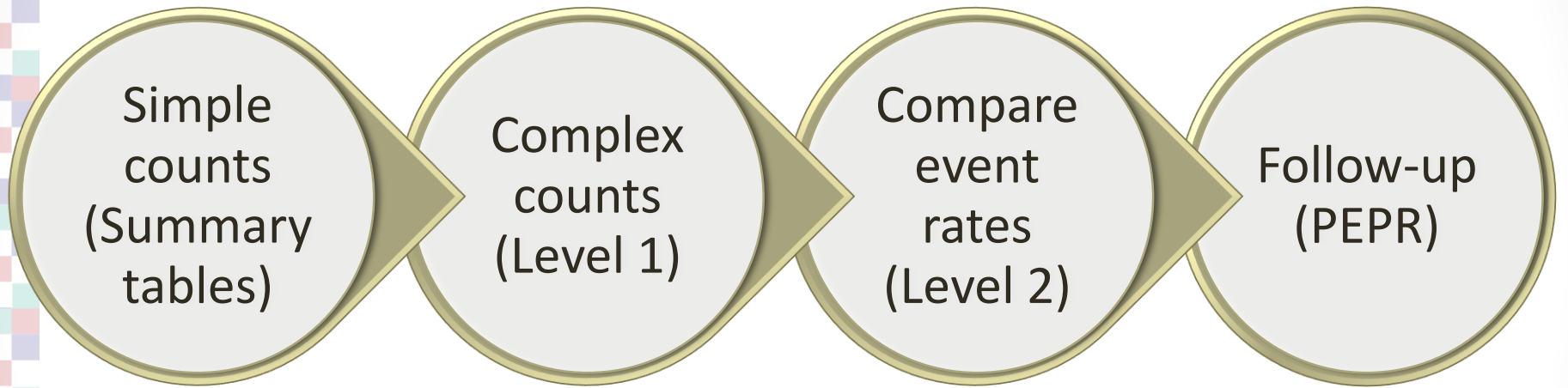
## Available or possible

- Ambulatory care diagnoses and procedures
- Outpatient pharmacy dispensing
- Laboratory test orders and selected test results
- Inpatient diagnoses, treatments, and procedures itemized in hospital bills
- Ability to contact providers and members

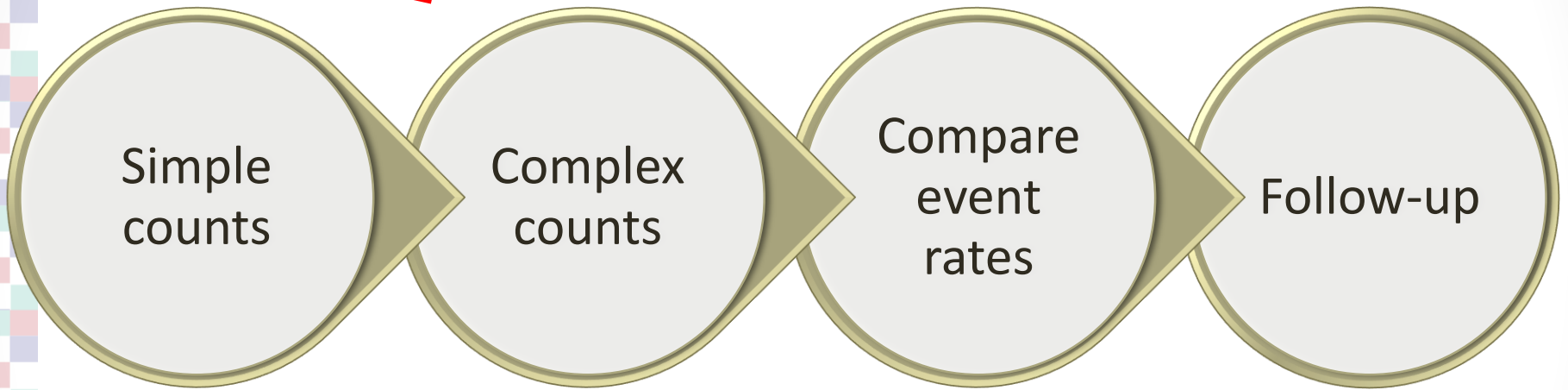
## Unavailable

- Out-of-hospital deaths
- Over-the-counter medications
- Community-based immunizations

# Rapid analysis querying sequence



# Querying sequence





# Completed Queries

- **Follow-up of abnormal cancer screening test results**
- **Temporal trends in pediatric antibiotic prescribing**
- **Chemotherapy-induced peripheral neuropathy**
- Hepatocellular carcinoma among new users of oral direct-acting antivirals for hepatitis C
- Feasibility of recruitment to replicate the Trial to Assess Chelation Therapy
- Characteristics of statin users older than 75 years
- Rates of opioid use and diagnoses of opioid use disorder and overdose
- Prevalence of long-term bisphosphonate use

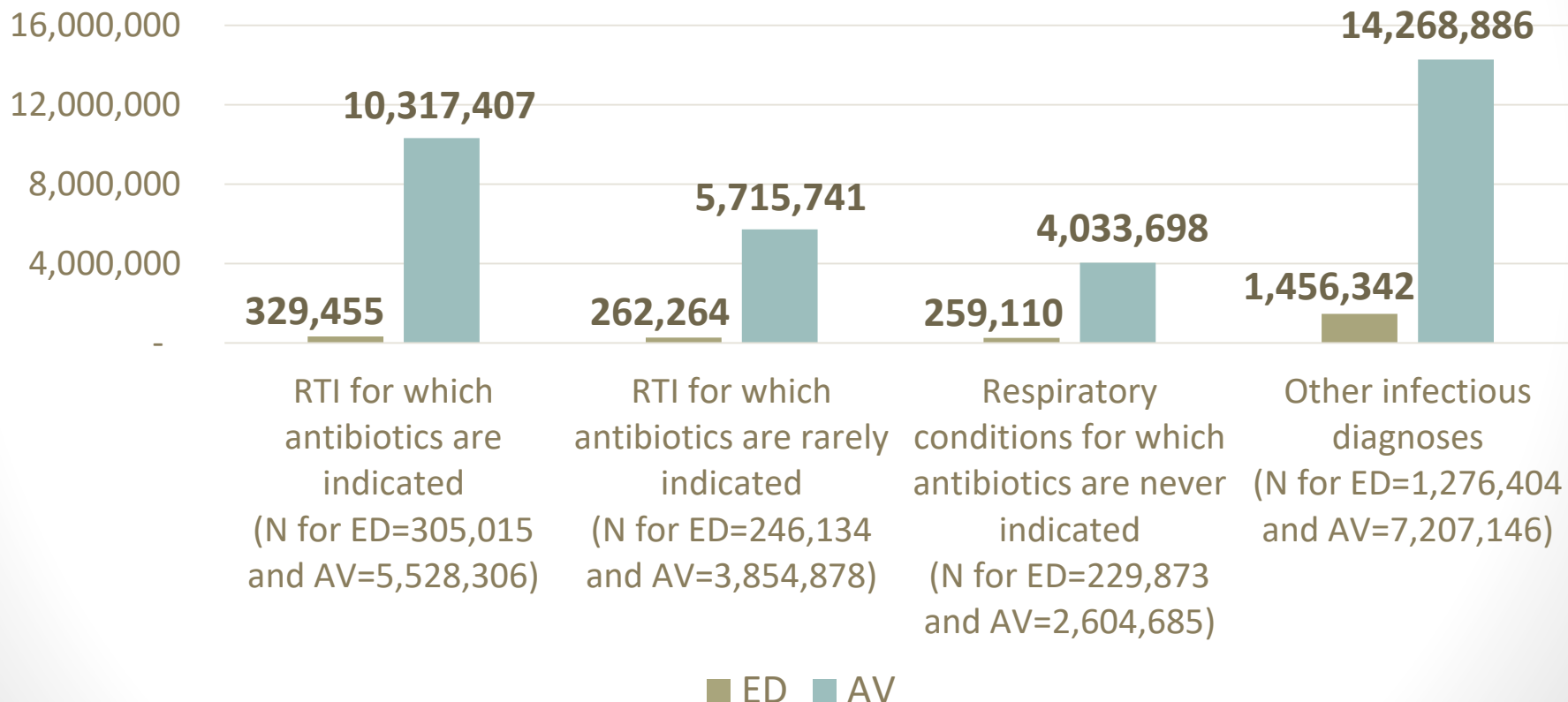


# Completed Query: Pediatric Antibiotic Use

- **Objective:** Examine recent trends in pediatric antibiotic prescribing, 2006-2016.
- **Design:** Retrospective study of temporal trends in pediatric antibiotic dispensing in emergency departments and ambulatory settings.

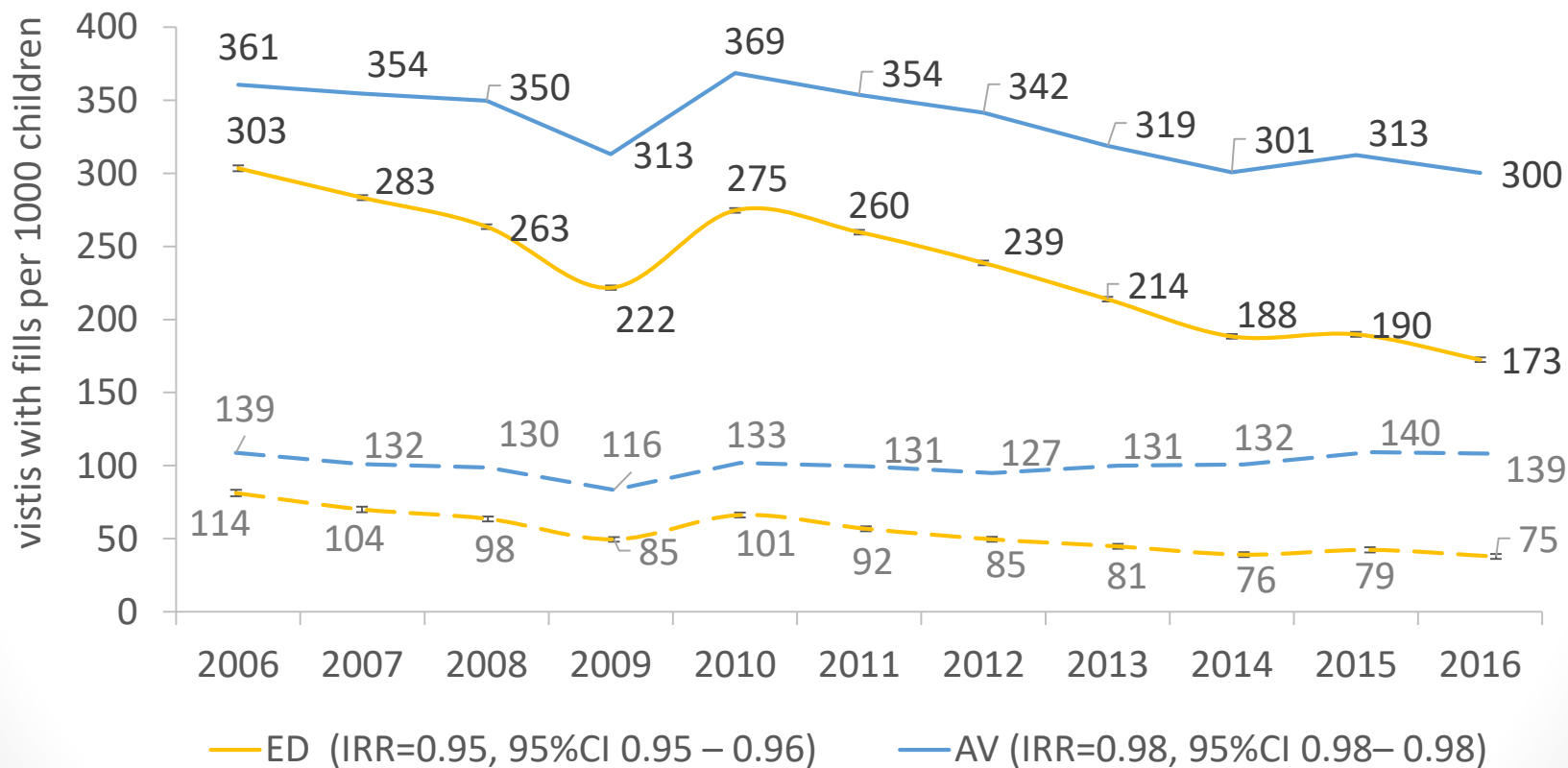
# Completed Query: Pediatric Antibiotic Use

Total Number of Antibiotic Fills



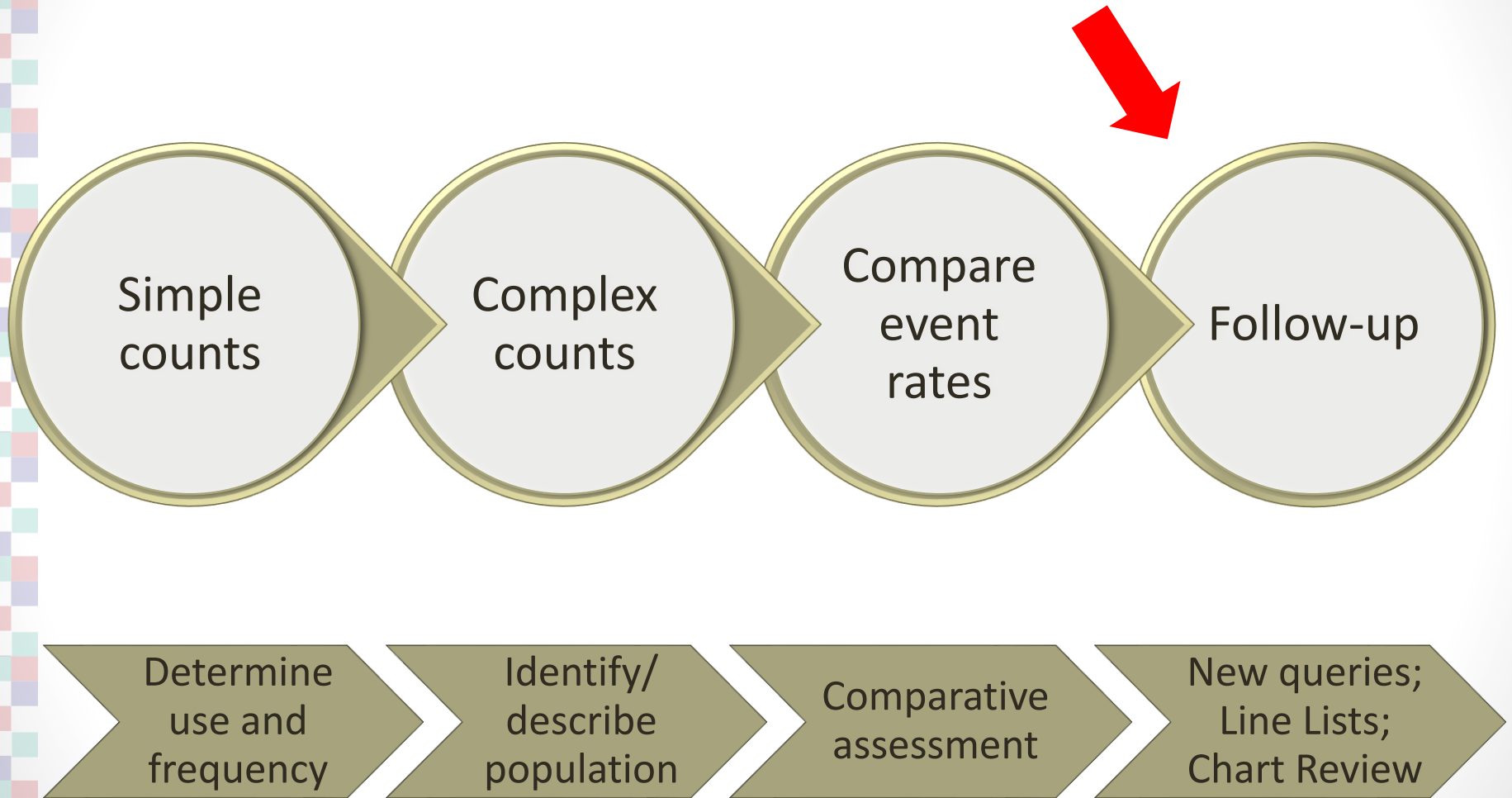
# Completed Query: Pediatric Antibiotic Use

Adjusted number of visits with **any** fills per 1000 children with RTI for which antibiotics are **rarely indicated**



Dotted line is broad-spectrum fills – ED (IRR=0.96, 95%CI 0.96-0.97 ) and AV (IRR=1.01, 95%CI, 1.01=1.01)

# Querying sequence



# Patient Episode Profile Retrieval (PEPR)

Episode Detail						^ Incidence: F = first observed; I = incident; blank = prevalent # Primary Dx: P = primary; S = secondary; X = N/A ~ Med enroll segment containing the admission date of the encounter or the drug enroll segment containing the dispensing date									
Days from expos	Enc type	L O S	Clinical code			Code description	Incidence^	P Dx#	Node (Y/N)	Main expos (Y/N)	Any vacc (Y/N)	Rx days supp	Rx amt	Cov start~	Cov end~
			Cat	Type	Code										
0	AV		DX	09	V0382	Need Proph Vacc Agnst Strep Pne				1			-386	1260	
0	AV		DX	09	V068	Need Proph Vacc Against Oth Comb Dz	F			1			-386	1260	
0	AV		DX	09	V202	Routine Infant/Child Health Check							-386	1260	
0	AV		PX	C4	90471	Immunization Admin	F			1			-386	1260	
0	AV		PX	C4	90472	Immunization Admin Each Add	F			1			-386	1260	
0	AV		PX	C4	90669	PCV7 Vaccine Im				1			-386	1260	
0	AV		PX	C4	90710	MMRV Vaccine Sc	F		1	1			-386	1260	
0	AV		PX	C4	99392	Prev Visit Est Age 1-4	F						-386	1260	
4	AV		DX	09	0090	Inf Colitis Enterit & Gastroenterit	F						-386	1260	
4	AV		PX	C4	99213	Office/Outpatient Visit Est	F						-386	1260	
7	IP	1	DX	09	27651	Dehydration	I	P					-386	1260	
7	IP	1	DX	09	53550	Uns Gastrit & Gastroduodit No Hemorr	I	X					-386	1260	
7	IP	1	DX	09	7862	Cough	I	X					-386	1260	
7	IP	1	DX	09	78703	Vomiting Alone	I	S	1				-386	1260	
7	IP	1	PX	C4	71020	Chest X-Ray 2Vw Frontal & Latl	F						-386	1260	
7	IP	1	PX	C4	74000	X-Ray Exam Of Abdomen	F						-386	1260	

Day 0, office visit  
Routine health check  
Immunization

Day 4, office visit  
Gastroenteritis

Day 7, hospitalized  
Vomiting / cough  
Dehydration  
Gastroenteritis



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FDA My Studies:

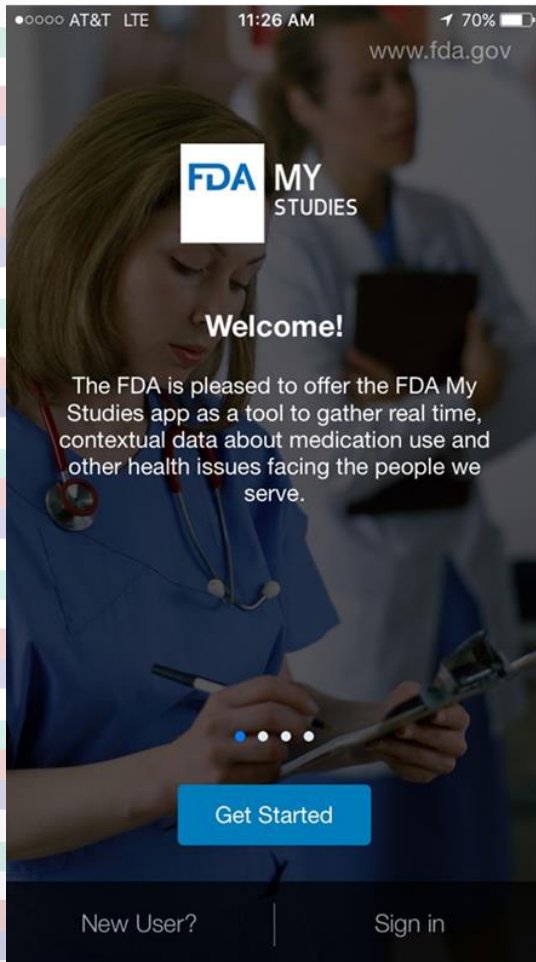
A Generalizable Mobile App for  
Distributed Research

# Rationale

- Link primary data from patients (or other reporters such as healthcare professionals) to secondary electronic health data
- Complements existing national infrastructure but may also be linked to studies outside of FDA Sentinel, the NIH Collaboratory, and PCORnet
- Potential uses
  - Distributed Pragmatic Trials
    - Consent
    - Patient Reported Outcomes
  - Observational Studies (e.g., virtual registries for rare diseases)



# Collecting Patient-Reported Data



- Mobile App
  - iOS and Android versions
  - Configuration portal for questions
- Secure storage environment
  - FISMA compliant
  - Partitioned for scalable distributed research
- Linkage to distributed electronic health data



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## More about the NIH Collaboratory DRN

What does the NIH Collaboratory Distributed Research Network (DRN) do?	+
How does the network operate?	+
Network Features	+
Who can submit a query/data request?	+
How do I submit a query/data request?	+
What datasets are available in the NIH Collaboratory Distributed Research Network?	+
How can my organization/network become a data partner?	+
What data software platform does the network use?	+
What are the confidentiality and nondisclosure rules for data partners and DRN Coordinating Center staff?	+



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**Thank you**