



JOHNS HOPKINS

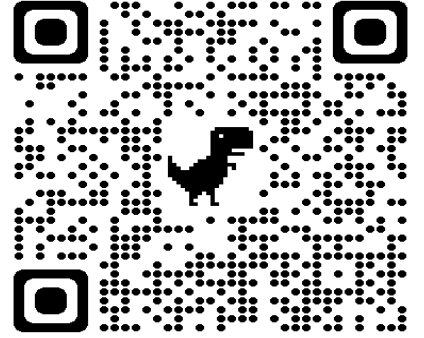
INSTITUTE *for* CLINICAL &  
TRANSLATIONAL RESEARCH

## Core Clinical Data Acquisition

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# CCDA

Core for **C**linical **R**esearch **D**ata **A**cquisition (CCDA) assists researchers with accessing clinical data for research



## Services we Provide

- Data Feasibility for Grant Applications
- Sample-Size Estimates
- Data navigator for PMAP
- MyChart Recruitment
- Research Data Extracts
- Data De-identification services
- Honest Broker services
- SlicerDicer & TriNetX tools assistance

## Data Sources we can Access

- Epic Clarity
- EDW
- PMAP
- OMOP
- CaseMix Datamart
- CRMS

# How to Request a CCDA Service?

<https://ictr.johnshopkins.edu/service/informatics/ccda/>

The screenshot shows the website for the Core for Clinical Research Data Acquisition (CCDA). At the top left is the Johns Hopkins logo and the text "JOHNS HOPKINS INSTITUTE for CLINICAL & TRANSLATIONAL RESEARCH". To the right is a search bar. Below the logo is a dark blue navigation bar with links: HOME, ABOUT, SERVICES & RESOURCES, FUNDING, EDUCATION & TRAINING, and COMMUNITY ENGAGEMENT. The main content area features a large banner with the text "CORE FOR CLINICAL RESEARCH DATA ACQUISITION (CCDA)" over a background of data visualizations. Below the banner is a breadcrumb trail: HOME > SERVICES AND RESOURCES > CLINICAL RESEARCH DATA/INFORMATICS > CORE FOR CLINICAL RESEARCH DATA ACQUISITION (CCDA). A quote from a user is displayed: "The Core for Clinical Research Data Acquisition (CCDA) assists researchers with accessing clinical data for research purposes. The CCDA is staffed with experienced data analysts who will assist you with access to data while also helping you comply with Data Trust privacy and security regulations." To the right of the quote is a blue button labeled "Make a Request" which is highlighted with a red border. Below the quote is a "Contacts" section listing Shipra Sachdeva, IT Manager, with the email address [shipra.sachdeva@jhu.edu](mailto:shipra.sachdeva@jhu.edu).

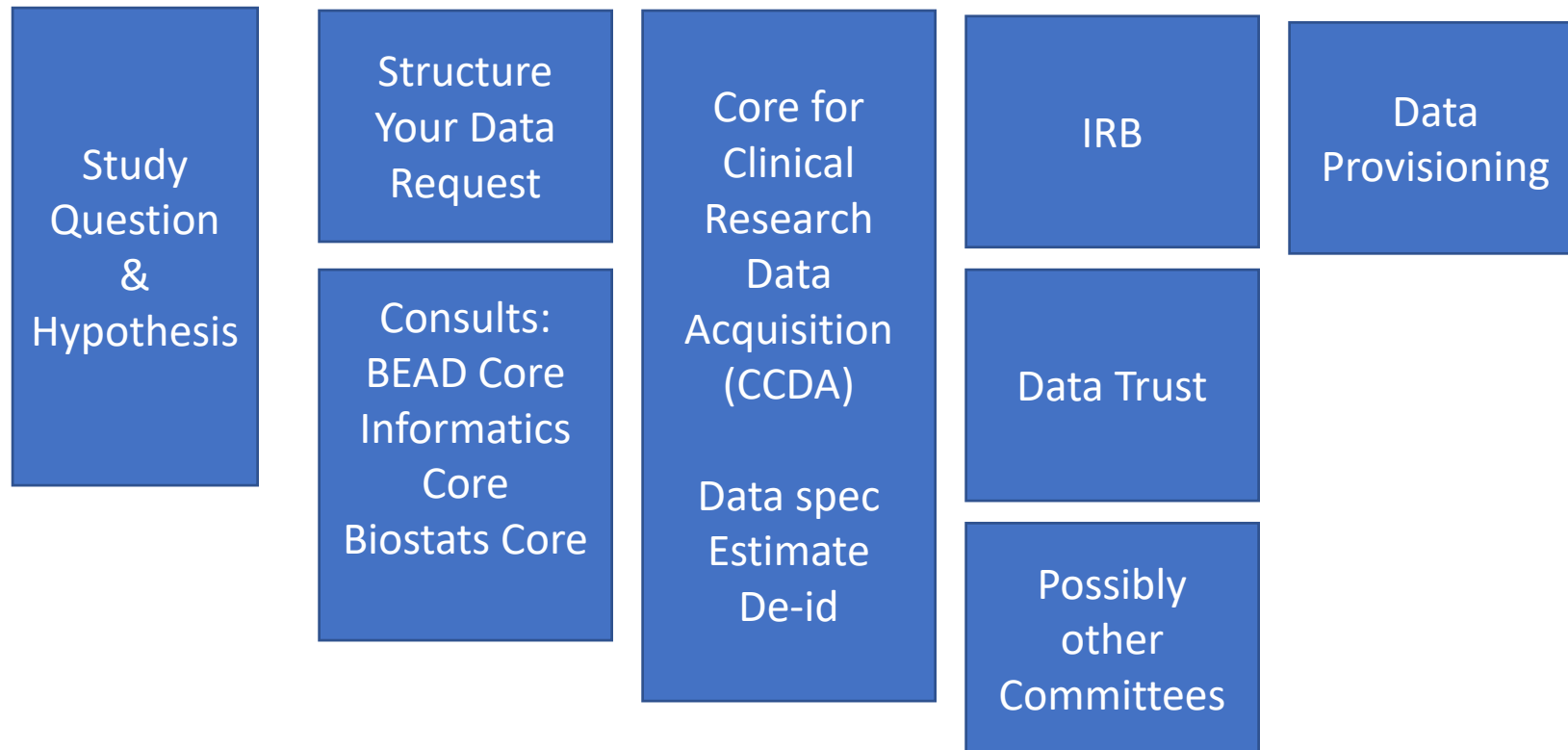
The screenshot shows a search results page for "Clinical Research Data/Informatics". The search bar at the top contains the text "Clinical Research Data/Informatics". Below the search bar is a yellow header with the text "Clinical Research Data/Informatics". The search results are listed below, with the first result selected (checked):

- Core for Clinical Research Data Acquisition (CCDA) Consulting Service - [Details](#)
- Consult for IRB submission (feasibility counts, specification documents, or general consult) - [Details](#)
- Data extraction for IRB-approved studies (Epic, PMAP, Casemix Datamart) - [Details](#)
- Patient list download from SlicerDicer or TriNetX for IRB-approved studies - [Details](#)
- New TriNetX account - [Details](#)
- OMOP ATLAS - Cohort Discovery - [Details](#)

A "reset" link is located at the bottom right of the search results area.

# *Requesting* and *Accessing* the Data

## Data Request Process



# *Finding* the Data – Common Sources

## Epic

- Manual chart review
- Epic Clarity
- Epic Data Warehouse
- SlicerDicer
- Reporting Workbench

## Precision Medicine (PMAP)

- Derived database tables
- OMOP CDM
- JH-Crown

## Hopkins Non-Epic

- Registries and Departmental Systems
- Datamart/CaseMix
- Legacy EMRs (rare)

## Cross-Institutional

- TriNetX
- PaTH
- CRISP
- N3C

## Self-Service

- TriNetX, SlicerDicer
- PaTH, ACT
- PMAP – LEAF or Atlas for OMOP
- REDCap/Epic documents

# Ways to Get Data from the Epic EMR

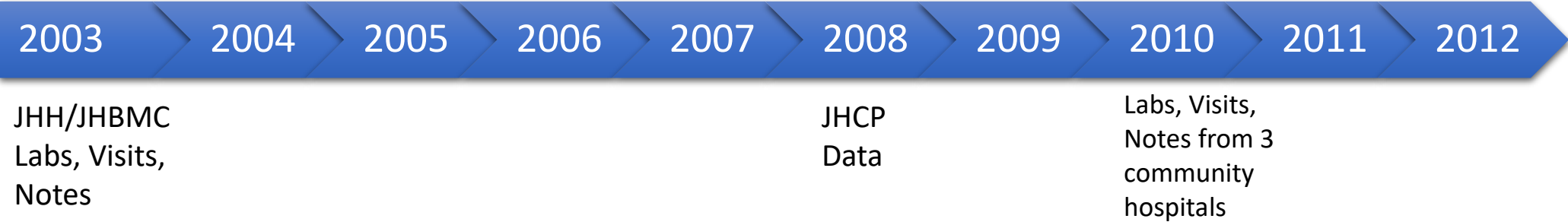
## Epic

- Manual chart review
- Epic Clarity
- Epic Data Warehouse
- SlicerDicer
- Reporting Workbench

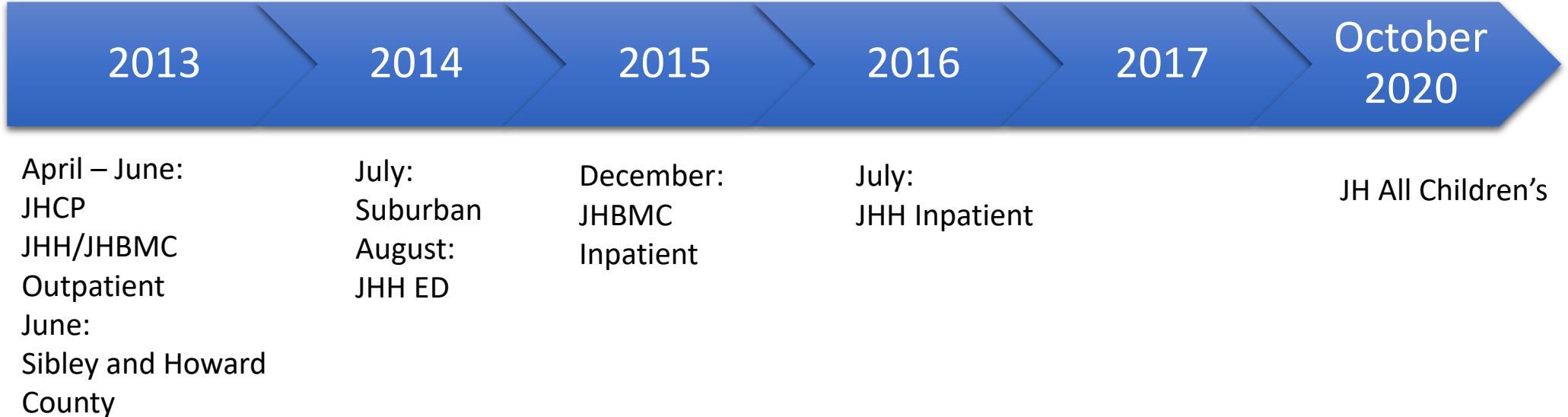
- **Must have IRB approval!**
- **Manual Chart abstraction**
  - Labor intensive
  - **IMPORTANT:** interview clinicians who enter data so you understand the workflow (and important caveats to consider when analyzing this data)
- **Epic Databases**
  - Clarity and Epic Data Warehouse
  - The Core for Clinical Research Data Acquisition (CCDA) can pull data for you (more about CCDA later)
- **Reporting Workbench** – Epic Research Request Review (R3) committee approval required
- **SlicerDicer** – self-service (next slide)

# Timeline of Data Available in Epic

## Historical data backloaded into Epic:



## Epic Go-Live Rollout:

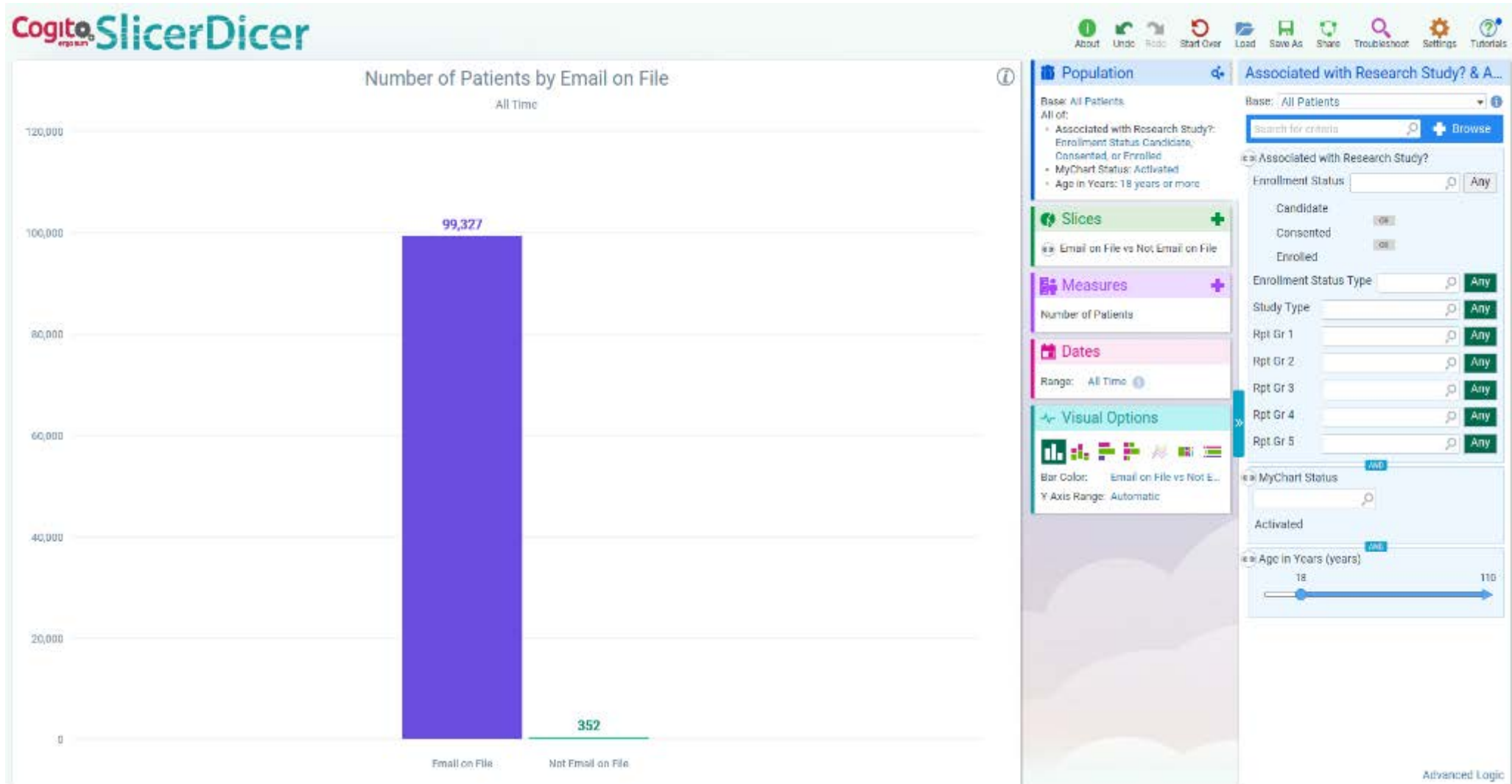


# Self-Service: Epic's SlicerDicer

## Epic

- Manual chart review
- Epic Clarity
- Epic Data Warehouse
- SlicerDicer
- Reporting Workbench

- Limited to Epic users
- De-identified patient counts (if under 10 patients, still shows a count of 10)
- Providers can see charts of patients for whom they have a care relationship
- With IRB approval, can obtain a patient list
- **IMPORTANT:** good for feasibility counts and basic chart review – has data quality issues that are not always obvious





# Precision Medicine Analytics Platform (PMAP)

## Precision Medicine (PMAP)

- Derived database tables
- OMOP CDM
- JH-Crown

## How it Works



**The Discovery Platform brings together data from different sources for you to analyze.**



### Epic

Electronic Medical Records, including patient demographics, encounters, notes, labs, flowsheets, and



### REDCap

Research registries



### Custom data sources

Research Access databases  
spreadsheets



### Vendor Neutral Archives

Radiology imaging



### Physiological monitors

Including critical care units

# Common PMAP Databases

## Precision Medicine (PMAP)

- Derived database tables
- OMOP CDM
- JH-Crown

- **Derived “foundation”** database tables – Epic data in a more organized, re-usable format; can be provisioned quickly
- **OMOP** – Epic data in a cross-institutional and multi-disciplinary Common Data Model - <https://ohdsi.org/>
- **JH-Crown** – COVID-19 research - <https://ictr.johnshopkins.edu/coronavirus/jh-crown/>  
**(Subsidies exist to support junior faculty!)**
- **Disease registries** - <https://www.hopkinsmedicine.org/inhealth/>
- **Biospecimens** – OpenSpecimen
- **Genomic data**
- **Clinical notes repository** for concept extraction

# *Finding* the Data – Hopkins Non-Epic

## Hopkins Non-Epic

- Registries and Departmental Systems
  - Datamart/CaseMix
  - Legacy EMRs (rare)
- **Claims data** from Johns Hopkins Healthcare or CMS
    - Requires special approvals to access
  - **CaseMix/Datamart** – HSCRC diagnoses, procedures, hospitalizations
  - **Death data** – National Death Index, MD Office of Vital Statistics
  - **Legacy EMRs** prior to Epic
  - **Departmental** systems
  - **Specialty** Research databases (REDCap)
  - **Genomic** data
  - **Tableau** dashboards
  - **National Registries** – Maryland Trauma Registry, Tumor Registry, UNOS Registry (transplants), NSQIP, many more...
  - **De-identified datasets** – Ask Welch Center or Sheridan librarians