Core Clinical Data Acquisition
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CCDA
Core for Clinical Research Data Acquisition (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 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.

Contacts

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Requesting and Accessing the Data

Data Request Process

- Study Question & Hypothesis
- Structure Your Data Request
- Consults: BEAD Core Informatics Core Biostats Core
- Core for Clinical Research Data Acquisition (CCDA)
- Data spec
- Estimate
- De-id
- IRB
- Data Trust
- Possibly other Committees
- Data Provisioning
### Finding the Data – Common Sources

<table>
<thead>
<tr>
<th>Epic</th>
<th>Precision Medicine (PMAP)</th>
<th>Hopkins Non-Epic</th>
<th>Cross-Institutional</th>
<th>Self-Service</th>
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</table>
| • Manual chart review  
• Epic Clarity  
• Epic Data Warehouse  
• SlicerDicer  
• Reporting Workbench | • Derived database tables  
• OMOP CDM  
• JH-Crown | • Registries and Departmental Systems  
• Datamart/CaseMix  
• Legacy EMRs (rare) | • TriNetX  
• PaTH  
• CRISP  
• N3C | • TriNetX, SlicerDicer  
• PaTH, ACT  
• PMAP – LEAF or Atlas for OMOP  
• REDCap/Epic documents |
Ways to Get Data from the Epic EMR

- **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:

- **2003 - 2012**
  - JHH/JHBMC Labs, Visits, Notes
  - JHCP Data
  - Labs, Visits, Notes from 3 community hospitals

Epic Go-Live Rollout:

- **2013 - October 2020**
  - April – June: JHCP
  - JHH/JHBMC Outpatient
  - June: Sibley and Howard County
  - July: Suburban
  - August: JHH ED
  - December: JHBMC Inpatient
  - July: JHH Inpatient
  - JH All Children’s
Self-Service: Epic’s SlicerDicer

- 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)

**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

- **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/](https://ohdsi.org/)
  (Subsidies exist to support junior faculty!)
- **Disease registries** - [https://www.hopkinsmedicine.org/inhealth/](https://www.hopkinsmedicine.org/inhealth/)
- **Biospecimens** – OpenSpecimen
- **Genomic data**
- **Clinical notes repository** for concept extraction
**Finding the Data – Hopkins Non-Epic**

- **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