

UF Health Integrated Data Repository (IDR) Research Data Services

Ben Staley, PharmD

Director, IDR Research Data Services

UF Health

IDR Research Team: irbdatarequest@ahc.ufl.edu

What is the Integrated Data Repository (IDR) Research Data Services?

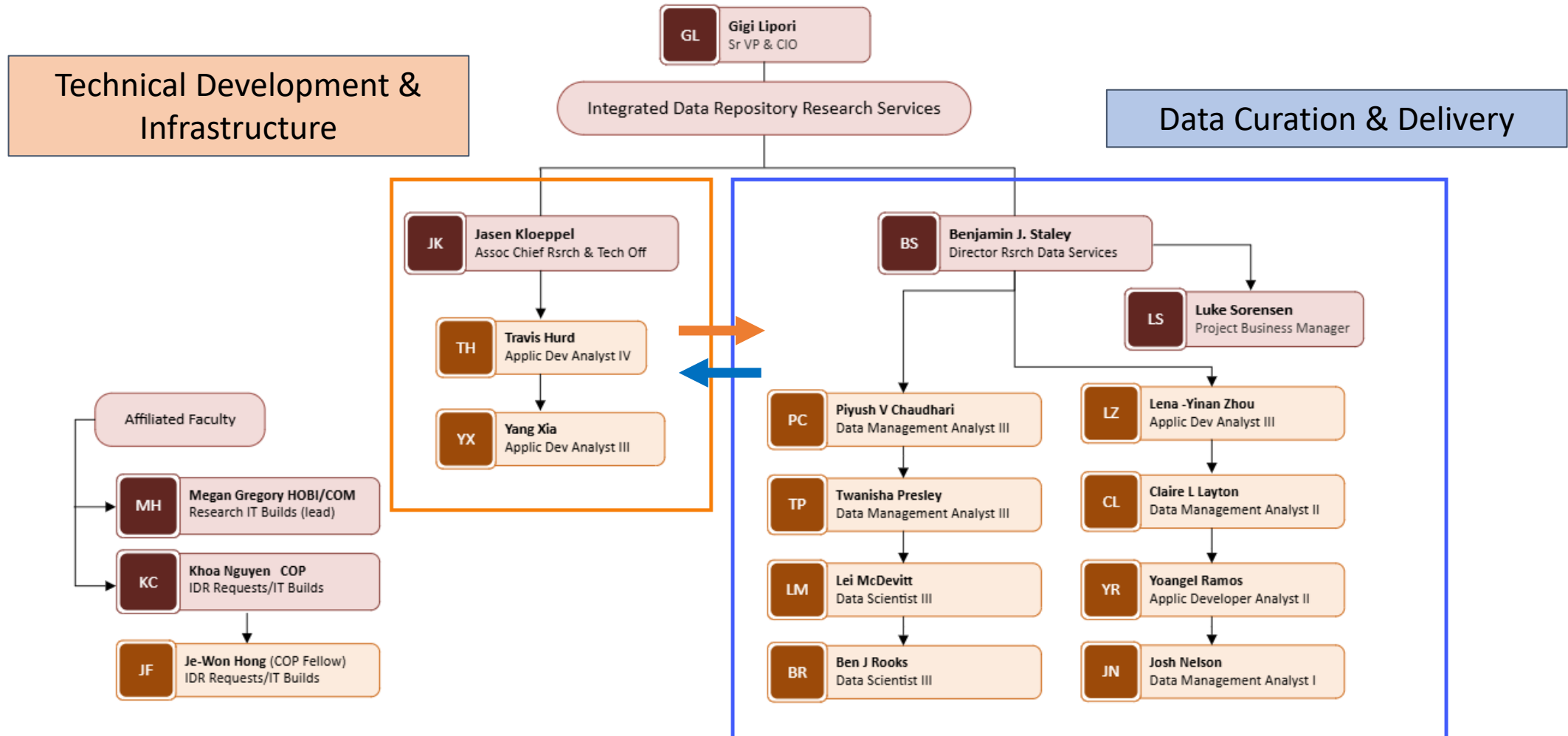
- Provides data support for researchers, clinicians, educators and leaders across UF and UF Health to **support research endeavors.**
- Researchers can obtain **datasets with rich details** about patients and patient care (demographics, diagnoses, vitals, labs, medications, imaging, clinical notes, etc.)
- Support for scientific **discoveries, grants, and publications.**
- Facilitate **cohort discovery** and study feasibility through **self-service data discovery tools**
- Assistance for **recruitment studies**
- Support **OneFlorida+** and **OMOP** common data models (CDMs)

Why an IDR for research?

- Clinical care generates massive amounts of data
- Data are entered & stored without much thought for research
- **People**, **Technology**, and **Process** needed to curate these data and deliver to researchers.



The People: ODSRI Org Chart






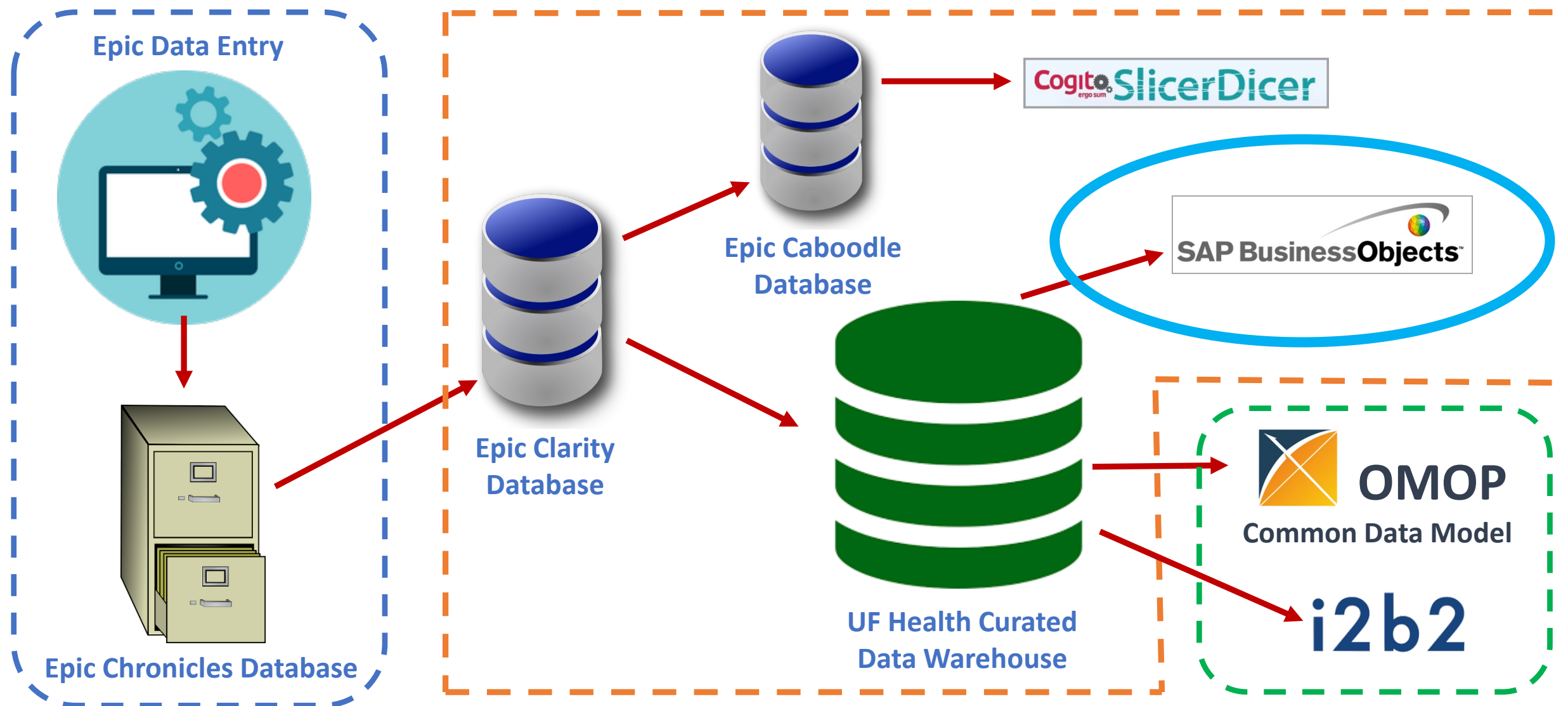
The Technology: UF Clinical Data Warehouse

- Large-scale clinical data warehouse (CDW)
- UF Health data
 - ~3 million patients
- Developed over decades by Shands and UF Health decision support services/IT analytics, and CTSI.
- Supports both Epic-generated and non-Epic generated data
- Supports clinical, education, and research missions



Data lineage

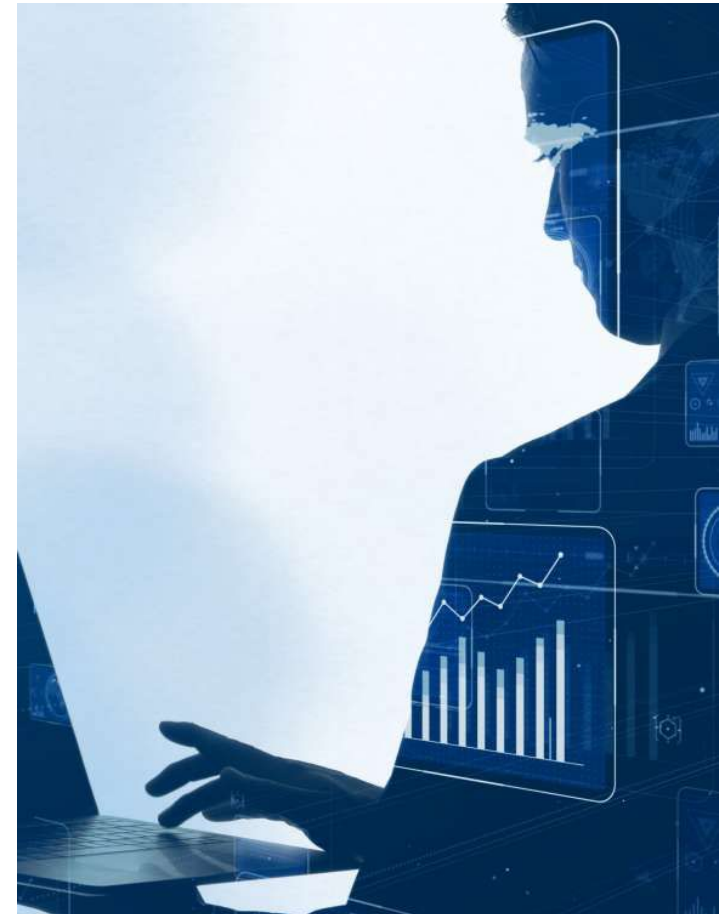
- Instant data load 
- Overnight data load 
- Quarterly data load 



The Process: IDR Research Services

1. Consultation
2. Feasibility and Cohort discovery
 - a) Self-service tools
3. Recruitment Support (C2S)
4. Research data

Fee For Service structure: 2 “free” hours of service with remaining hours billed at \$130/hr. Many requests funded through CTSI Voucher program



1. Consultation

- What is your research objective?
- What data are you hoping to collect?
- What types of data are available that the IDR can provide?

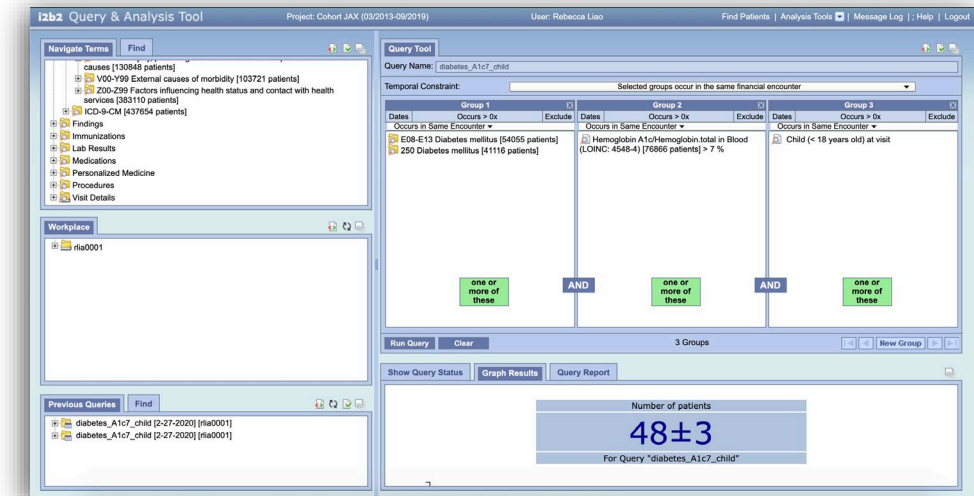


2. Feasibility and cohort discovery

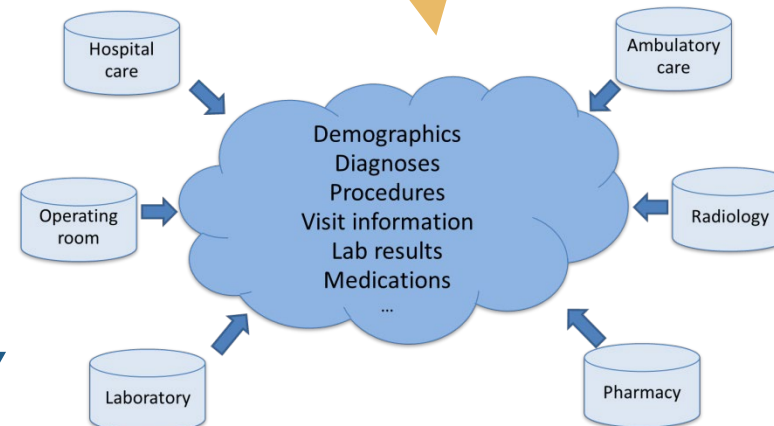
i2b2

How many children were diagnosed with diabetes and had a hemoglobin count > 7% in the same encounter?

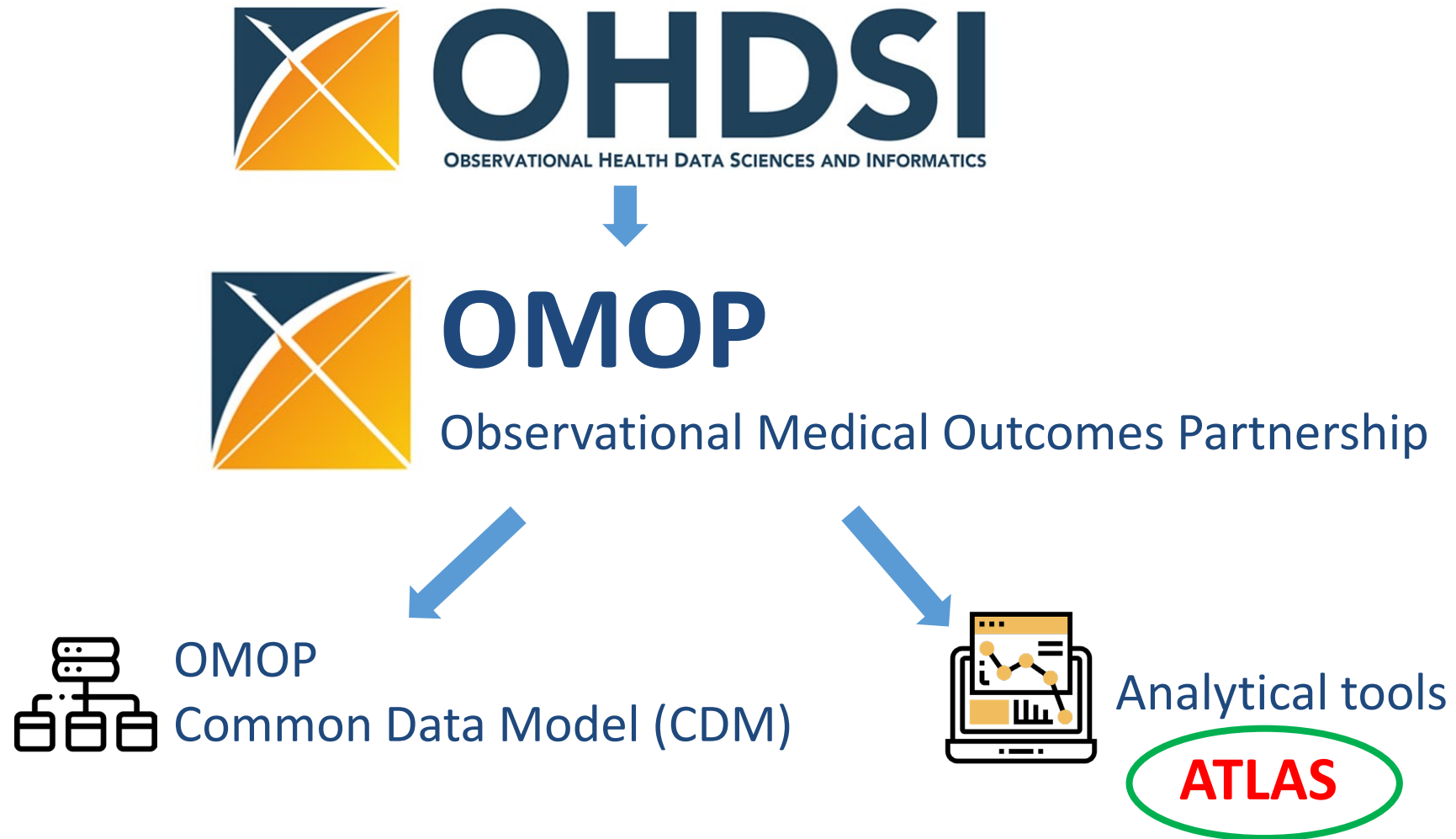
N = 48 patients



**Integrated
Data
Repository**



2. Feasibility and cohort discovery



What is ATLAS?

- ATLAS is a web-based tool that facilitates design and execution of analyses on standardized, patient-level, observational data in OMOP CDM format
- ATLAS is a free, publicly available web-based, open-source software application developed by the OHDSI community to support the design and execution of observational analyses to generate real world evidence from patient level observational data.

ATLAS Cohort Discovery (demo)

ATLAS

Home

Data Sources

Search

Concept Sets

Cohort Definitions

Characterizations

Cohort Pathways

Incidence Rates

Profiles

Estimation

Prediction

Reusables

Jobs

Configuration

Feedback

English

bstale

Cohort #13

created by bstale on 2023-08-14 13:19, modified by bstale on 2023-11-15 15:26

Warfarin in Afib

Definition

Concept Sets

Generation

Samples

Reporting

Export

Versions

Messages

Enter a cohort definition description here

Cohort Entry Events

Events having any of the following criteria:

a drug exposure of Warfarin

for the first time in the person's history

+ Add attribute...

Delete Criteria

with continuous observation of at least 365 days before and 0 days after event index date

Limit initial events to: earliest event per person.

Restrict initial events

Inclusion Criteria

New inclusion criteria

1. Age greater than/equal to 18

2. With prior non-valvular atrial fibrillation

3. Moderate to high risk of stroke

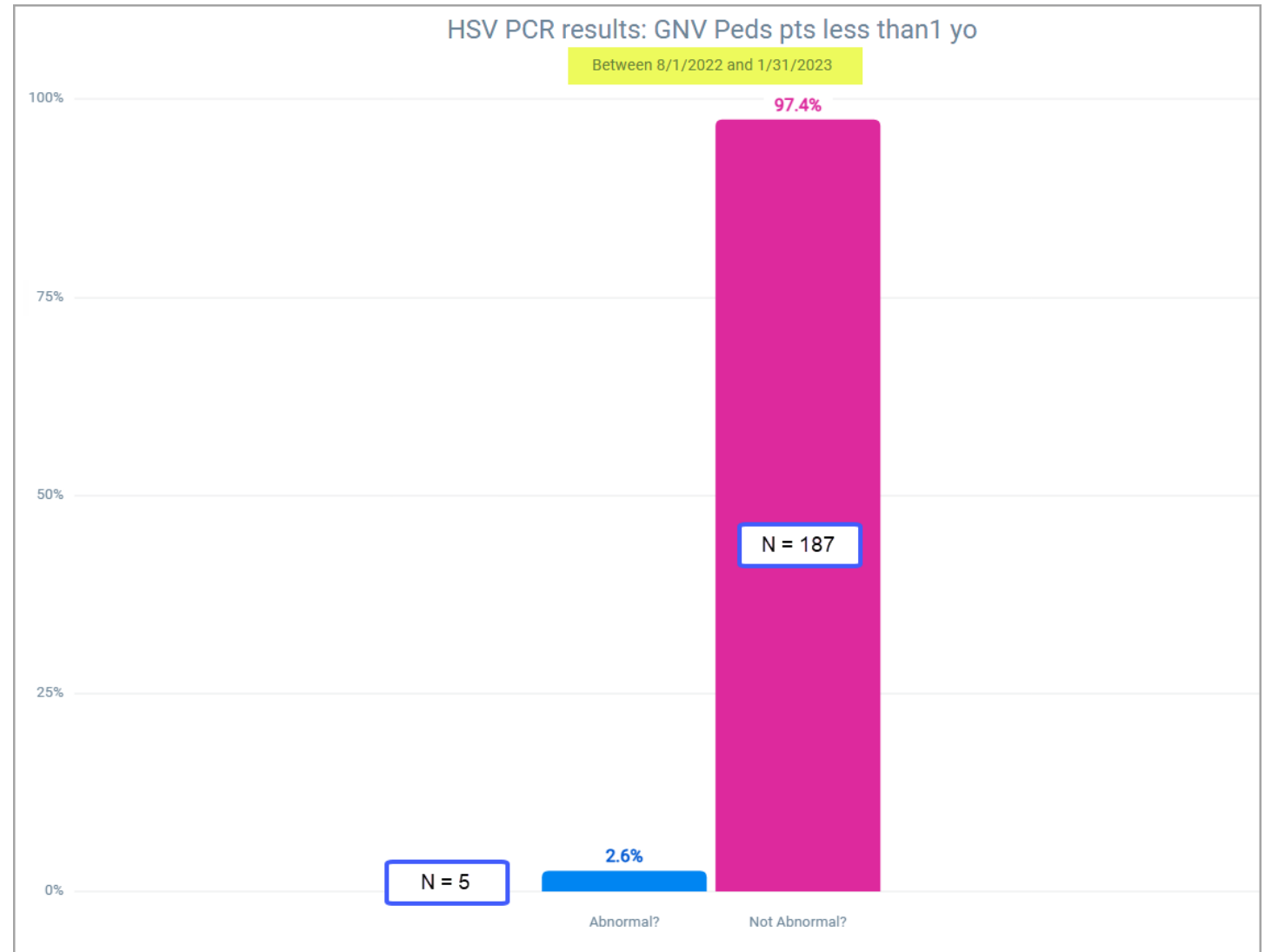
CHADS2 Score of at least 2

Limit qualifying events to: all events per person.

2. Feasibility and cohort discovery

Epic

Cogito  **SlicerDicer**



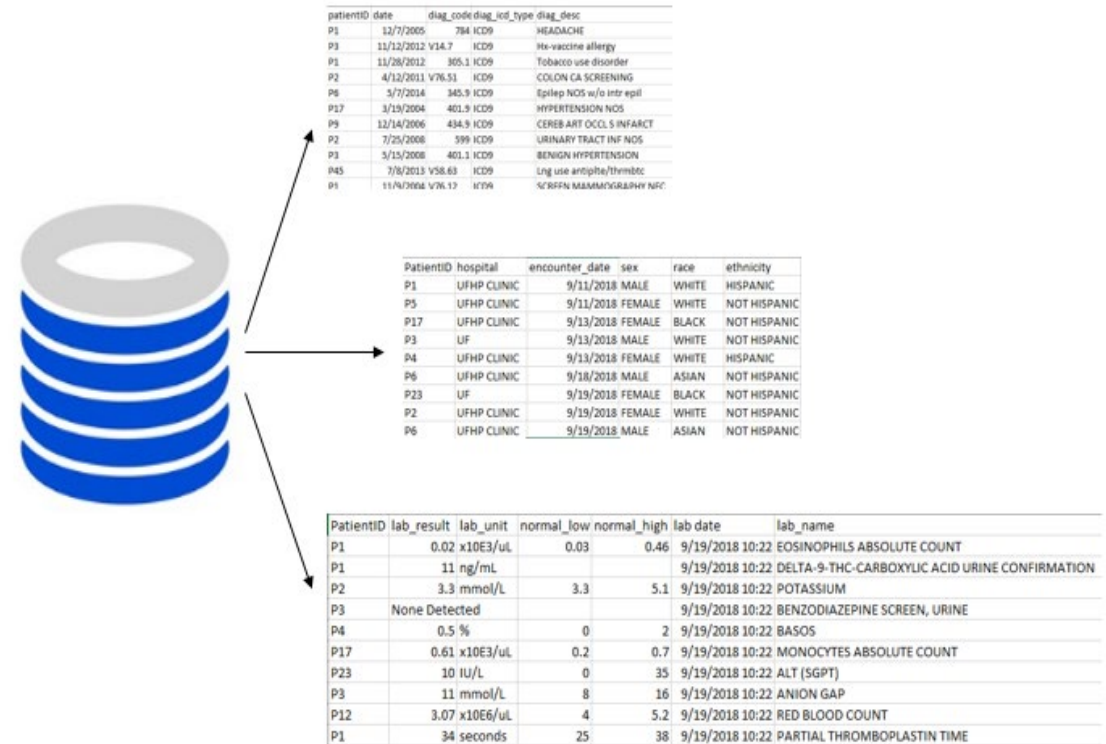
3. Recruitment support

- Consent2Share (C2S) Research Contact Registry
 - Voluntary database of patients interested in research opportunities
 - Must be approved as C2S study by IRB
 - In addition to C2S data requests, IRB research services manages deletions from C2S program.
- Lists of patients per provider “clinical relationship”
- Coordination with care teams for automated, real-time recruitment (MyChart messages)



4. Research data

- IRB approved or Non-Human (Fully De-Id)
- Line-level (individual-level) data
- Support retrospective observational studies
- May reduce chart review burden
- Wide variation in complexity and effort to complete



Submitting IDR Research Data Request

IDR Request Form

Request Type *

The initial 2 hours of services are provided at no charge, following that, the hourly rate of \$130/hr for analyst time applies. For more information regarding our research services please visit: <https://idr.ufhealth.org/research-services/>

- ☐ OMOP: ATLAS registration (summary statistics only, fully de-identified)
- ☐ OMOP: Line-level Data Elements based on ATLAS query (fully de-identified)
- ☐ OMOP: Prebuilt, Domain-specific Datasets (fully de-identified)
- ☐ Consultation
- ☐ i2b2 Registration
- ☐ Preparatory Research/Cohort Discovery
- ☐ IRB-Approved Consent2Share
- ☐ IRB-Approved MRN ONLY
- ☐ IRB-Approved Line-level Data Elements
- ☐ IRB-Approved IT Build
- ☐ IRB-Approved Images (if you need an image for immediate clinical care decision making, please contact Marcia McGriff (rodrmj@radiology.ufl.edu) and Naomi Oldham (oldham@shands.ufl.edu))
- ☐ Nonhuman with confidentiality agreement

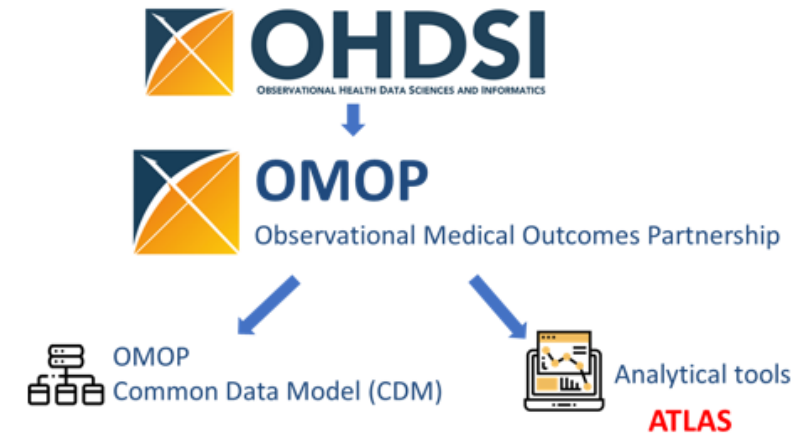
- Requests reviewed and assigned weekly
 - Scope of work outlining expected hours and associated costs will be provided upon analyst assignment
- Typically 3-4 week turnaround for standard requests

<https://idr.ufhealth.org/research-services/data-request-form/>

Multiple collaborations



OHDSI/OMOP Partner



Frequent Collaborators



Ongoing/Future initiatives

- **De-Id Images**
- **Cancer Data Commons**
- **NLP extracted variables**
- **Rapid De-ID note delivery**
- **OnCore Data in EDW**
- **Continued OMOP growth**
- **Genomic data (to include WGS)**
- **OB ultrasound data (Viewpoint)**
- **Expanded dental data (Axiom) in EDW**
- **Florida Digital Twin**

UF Health Integrated Data Repository (IDR) Research Data Services

Ben Staley, PharmD

Director, IDR Research Data Services

UF Health

IDR Research Team: irbdatarequest@ahc.ufl.edu