

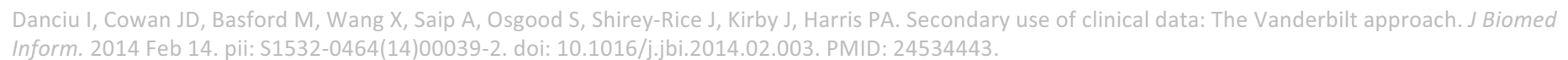


# DATA DEMOCRATIZATION

*Designing Platforms and Service Models  
To Support Research Teams*

Paul Harris, PhD  
Director, Office of Research Informatics  
Professor, Biomedical Informatics & Biomedical Engineering



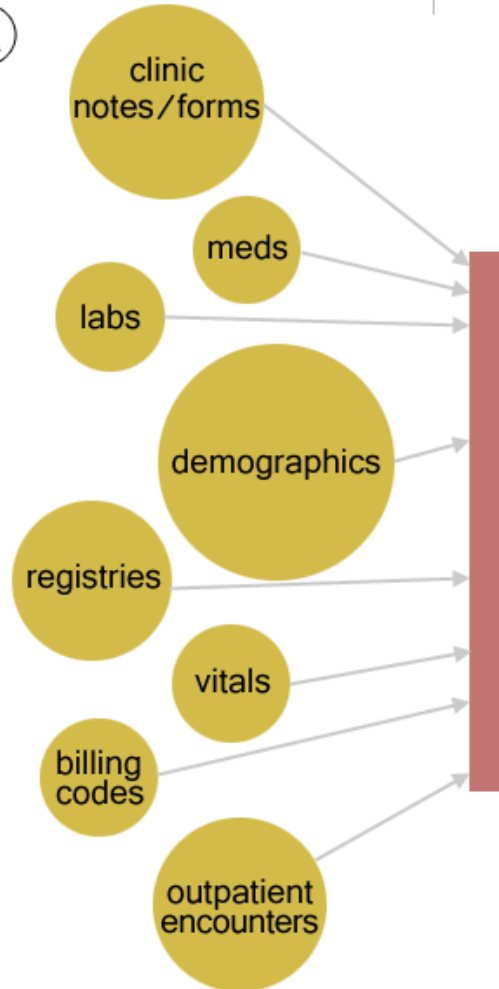






## CLINICAL ENTERPRISE

(A)

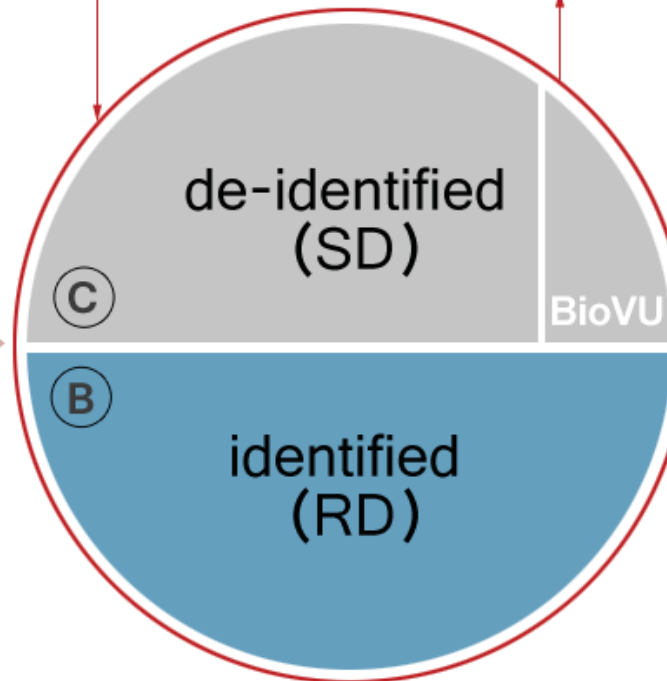


(E)

## INFORMATICS METHODS DEVELOPMENT

(D)

Examples: Natural Language Processing  
Pattern Recognition  
Automated Phenotyping  
Automated Study Recruitment Eligibility  
End User Research Integration Methods  
Anonymization and Reidentifiability

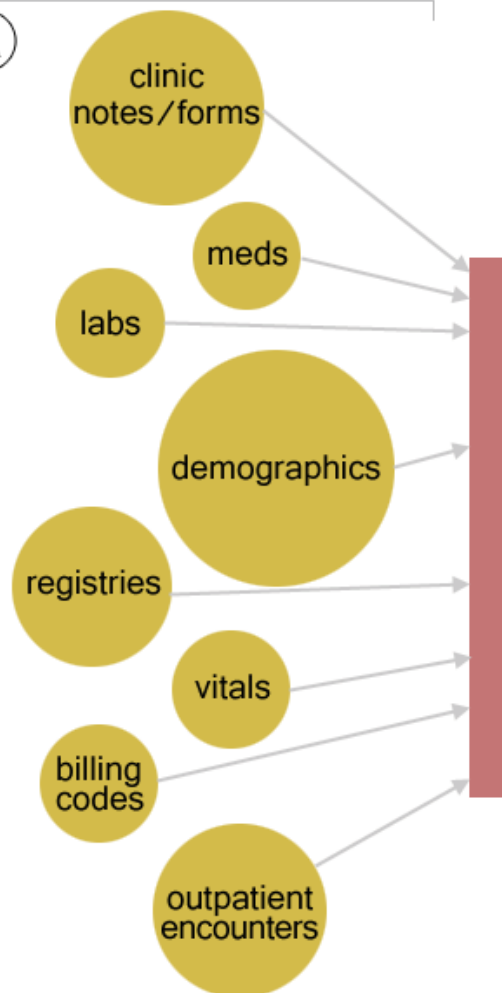


## RESEARCH DATA WAREHOUSE



## CLINICAL ENTERPRISE

(A)

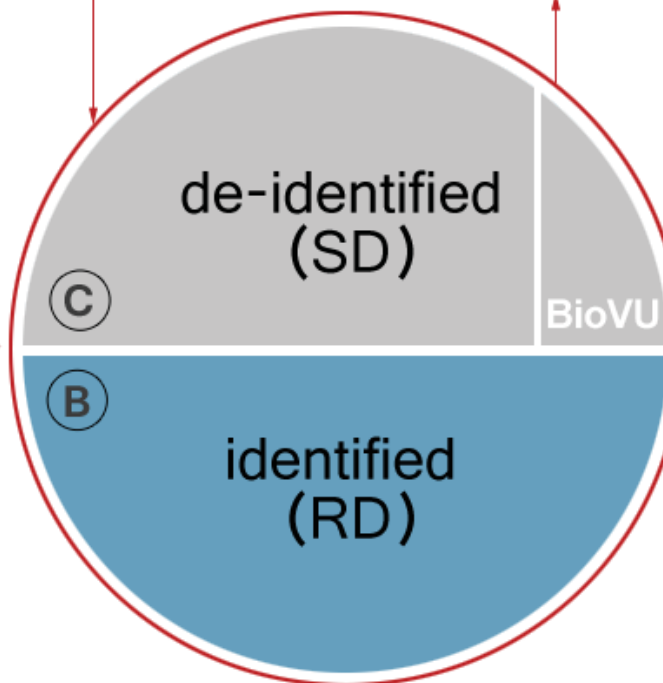


(E)

## INFORMATICS METHODS DEVELOPMENT

(D)

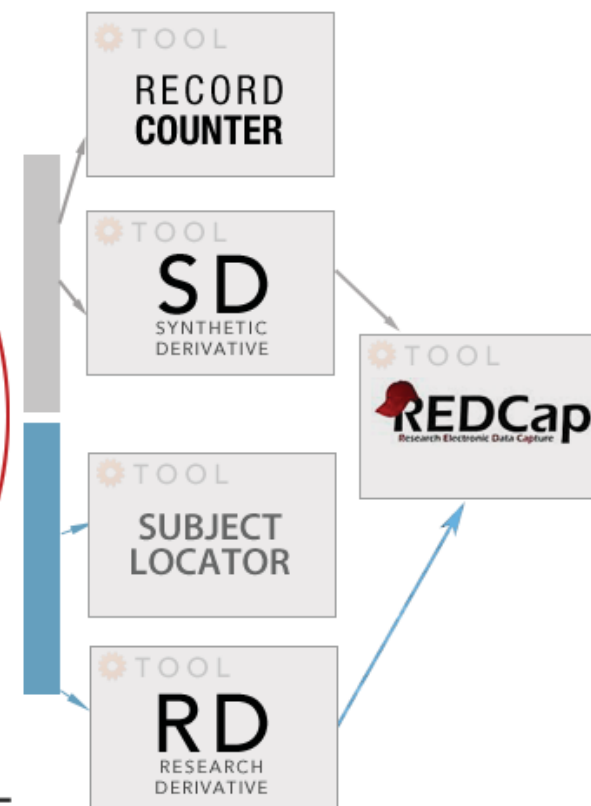
Examples: Natural Language Processing  
Pattern Recognition  
Automated Phenotyping  
Automated Study Recruitment Eligibility  
End User Research Integration Methods  
Anonymization and Reidentifiability



## RESEARCH DATA WAREHOUSE

## RESEARCH ENTERPRISE

(F)



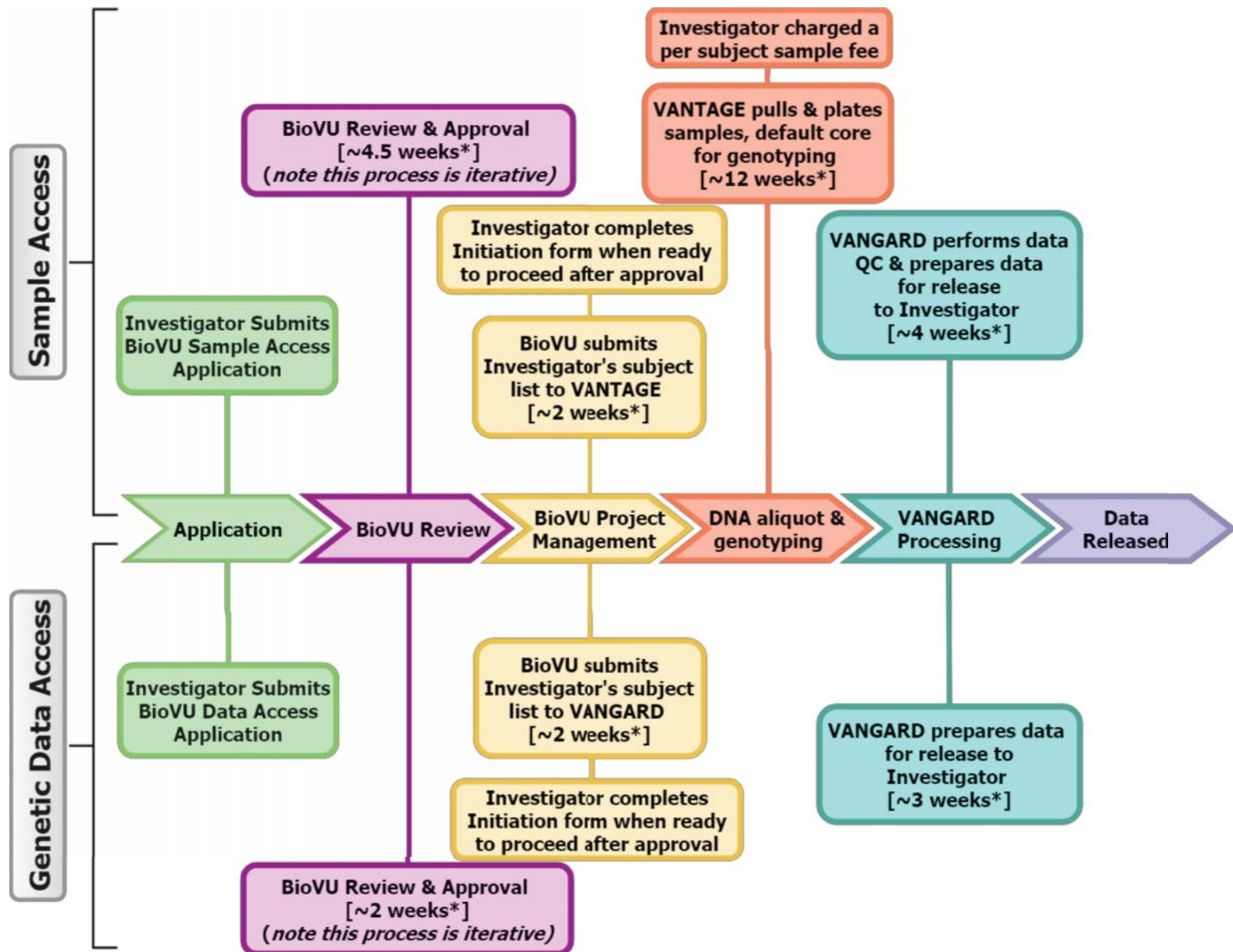




# ACCESS TO THE PEOPLE

BioVU

Democratization of Assets (sample/data)  
Requires Coordination

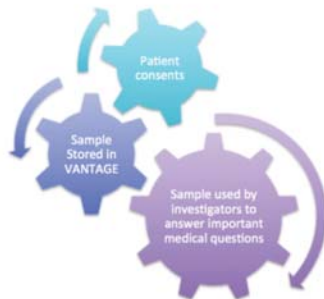


\*the times provided above are estimates that are subject to change

# ACCESS TO THE PEOPLE

BioVU

BioVU is Vanderbilt's biobank of DNA extracted from leftover and otherwise discarded clinical blood specimens. BioVU operates as a consented biorepository; all individuals must sign the BioVU consent form ([click here](#)) in order to donate future specimens. BioVU subjects are de-identified and linked to the Synthetic Derivative (SD, [click here](#)) enabling researchers to access genetic data/DNA material as well as dense, longitudinal electronic medical record (EMR) information.



## FY19 Rates for BioVU Projects

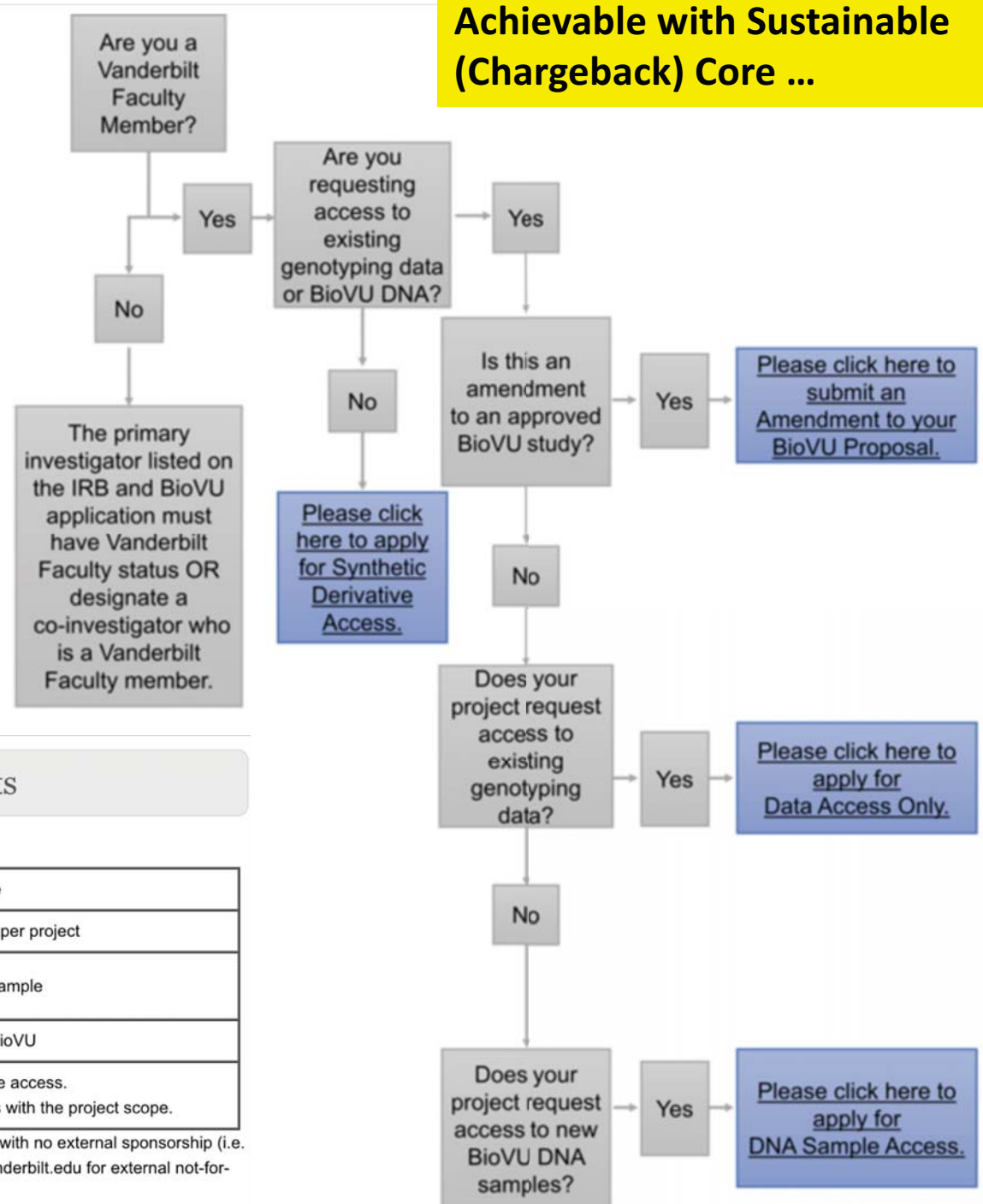
Core Services	Rate
Existing Genetic Data Access	\$0.32 / subject per project
DNA Sample Access for generation of new data	\$22.00 / sample
Plasma Sample Access	contact BioVU

\*Access to the Synthetic Derivative (SD) is automatically included with data and sample access.

\*\*All access for BioVU resources are per project and require IRB agreement that aligns with the project scope.

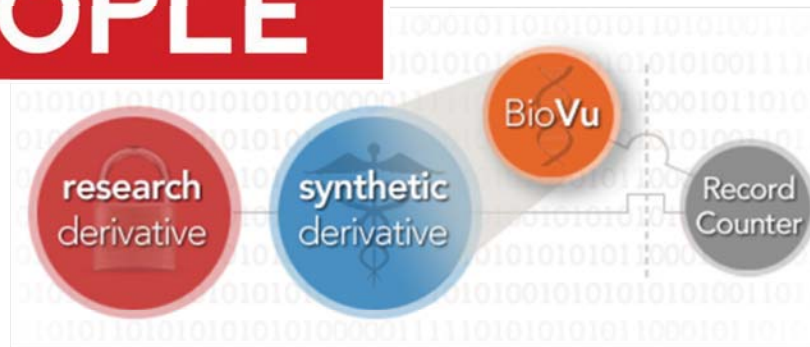
BioVU data access fees will be subsidized by ~90% for internal investigator-led research with no external sponsorship (i.e. ~\$0.03/subject/project). These rates reflect costs for internal payers. Contact [BioVU@vanderbilt.edu](mailto:BioVU@vanderbilt.edu) for external not-for-profit and for-profit payer rates.

Saying 'Yes' to Everyone Is Only Achievable with Sustainable (Chargeback) Core ...





# DATA TO THE PEOPLE



## BioVU

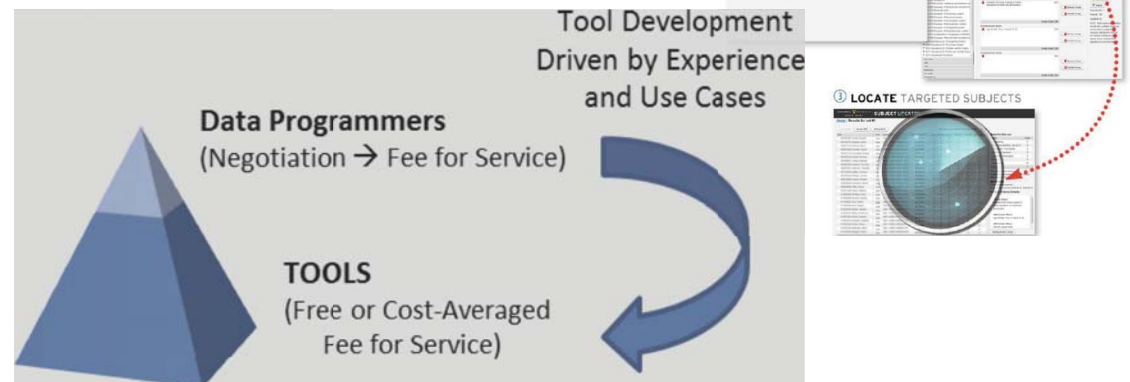
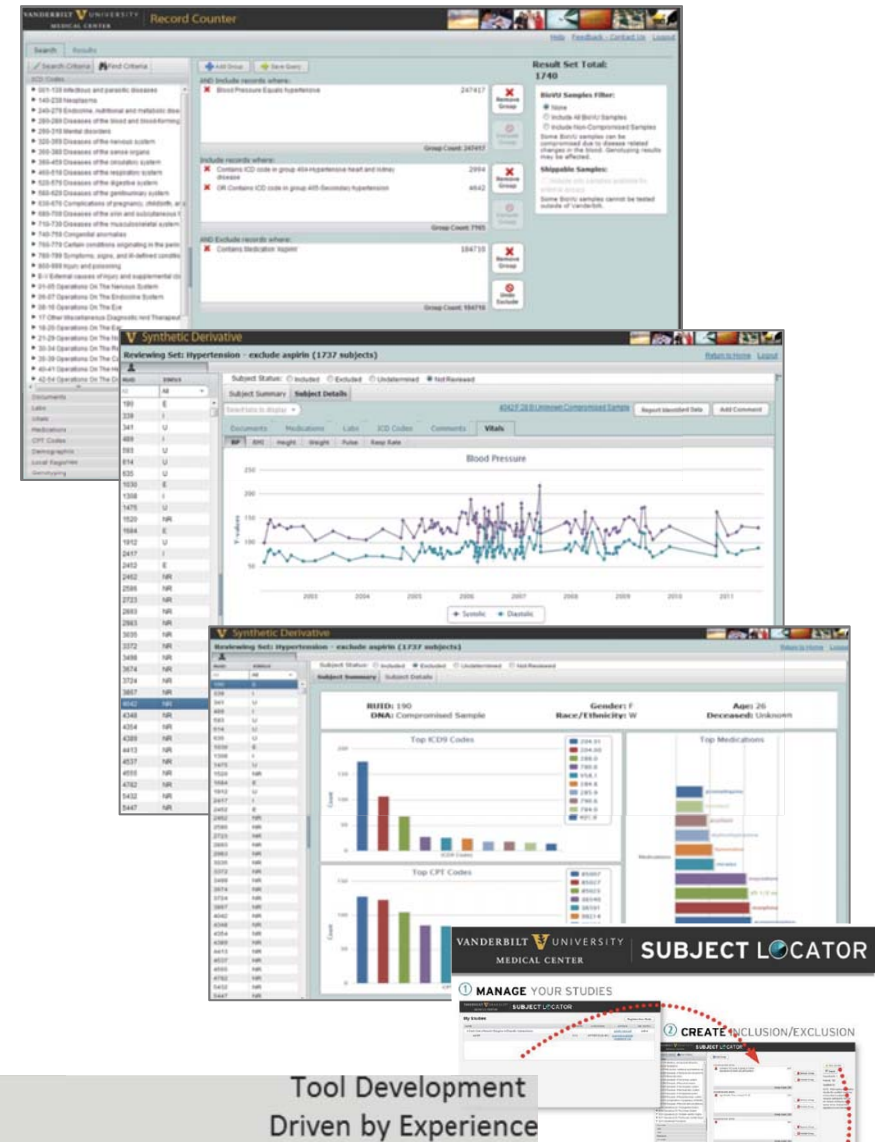
- Links DNA extracted from discarded blood samples to de-identified EMR
- ~245k DNA samples, ~30k pediatric
- 164 Current/Ongoing BioVU projects

## Synthetic Derivative

- Research tool to enable studies with de-identified clinical data
- Contains 2.8 million records; highly detailed longitudinal clinical data for ~1 million

## Research Derivative

- Identified clinical data warehouse
- Tools (e.g. Subject Locator)
- Services (Fee for Service)
- REDCap extraction toolkit



# DATA TO THE PEOPLE

## How to Use the Vanderbilt Synthetic Derivative Discover Tool

## Self-Service Tools – Require Outreach / Education

**Vanderbilt University Medical Center Synthetic Derivative**

### How to build Search Criteria

**VSD Discover** Dashboard Search Review Help Logout

Switch Study: Currently in Test Study

Select Criteria: Search for Criteria

Demographics: ICD9 Codes, ICD10 Codes, PhenX Codes, CPT Codes, Medications, Labs, Documents, Vitals, Blood Pressure, BMI, Weight

Include records where:

- Contains CPT code 0500F
- OR Contains CPT code 0503F

Group Count: 21976

AND Include records where:

- Blood Pressure is Normal (Systolic < 120 / Diastolic < 80)

Group Count: 840110

AND Include records where:

- Weight is Any Value - Vitals Exists

Group Count: 1352288

Result Set Total: 21449 (Save limit = 10,000)

Limit By: Time, Remove Group, Exclude Group

BioVU Samples Filter:

- None
- Include All BioVU Samples
- Include Non-Compromised Samples

Shippable Samples:

Some BioVU samples can be compromised due to disease related changes in the blood. Genotyping results may be affected.

Some BioVU samples cannot be tested outside of Vanderbilt.

To create complex search queries:

- To search for records containing one or more data items, place the items in the same group box. For example, to search for records with CPT code 0500F OR records with CPT code 0503F place both codes in the same box.
- For records that contain two or more data points, add a new box for each additional data point by clicking on the "Add Group" button. For example, searching for CPT code 0500F or CPT code 0503F (Box 1) AND Blood Pressure (Box 2).
- To exclude a criteria, click on the "Exclude Group" button beside the group box. In the example pictured, records that contain weight can be excluded from the search by clicking the "Exclude Group" button.

**Vanderbilt University Medical Center Synthetic Derivative**

### Once you have logged in...

**VSD Discover** Dashboard Search Review Help Logout

Welcome to the Synthetic Derivative -- Select a study to begin:

STUDIES AND SETS

- Recently Viewed Sets
- Development of the Smoking Algorithm
- Plasma Pilot Testing
- Psychiatric GWAS Consortium
- Test Study

What's new with SD Discover? [Check SD office hours](#)

SD Discover is an official name of the user interface application. This better distinguishes the application from the SD database, which is also referred to as "the SD".

Easy switch between Studies/Sets using the header toolbar "switch" button in Search and Review. The header toolbar displays which study/set you are currently working in. The button pops open a selector window to change your study/set. You no longer need to go through the Dashboard page.

Easy navigation between pages of the application using the header toolbar links on all pages. You no longer need to go through the Dashboard page to navigate between Search and Review.

Synthetic Derivative BioVU

Synthetic Derivative Population (2554132)

Count

1000k

800k

600k

400k

200k

0k

Under 2 2 to 5 6 to 12 13 to 17 18 to 44 45 to 64 65 and Older

AFRICAN AMERICAN (233880)

ASIAN (24644)

CAUCASIAN (1406452)

LATINO (54232)

NATIVE (2583)

OTHER (15483)

UNKNOWN (807048)

Studies are listed on the left side. Click on the arrow to see sets in the study. Notifications are in the top right for new features, etc. The lower right dashboard shows the population for the SD and BioVU.

**Vanderbilt University Medical Center Synthetic Derivative**

### Starting your Review

**VSD Discover** Dashboard Search Review Help Logout

Switch Set: 10272016 (100)

Subject Detail Data

Subject Status: Included, Excluded, Undetermined, Not Reviewed

Report Identified Data Add Comment

Documents Problem Lists Medications Labs ICD Codes Comments Summary

Open Filters Open Highlight

High Value Documents Other Documents

2004-09-17 12:01:01.0 [Doc type: HP]

LETTER

\*\*DATE(Sep 17 2004)

\*\*NAME(DOX M. WYN) M.D.

Create a Set Annotation:

Enter the annotation label

Create Edit Annotations

Findings for RUID 3856:

The "Subject Status" options refer to the review status of each subject. This is included to keep track of certain subjects you may need to refer to later.

When reviewing a data set, the list of subjects are found on the left under "Subject Detail Data" (circled in red).

# DATA TO THE PEOPLE

**Saying Yes to Everyone  
Is Only Achievable with  
Chargeback Core ...**

## Pricing

RD Discover access including cohort creation and data export is free.

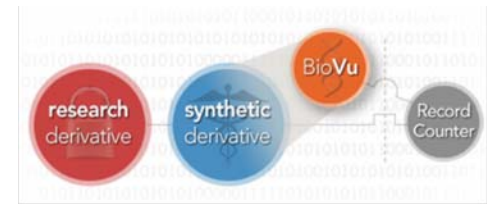
Custom programming is billable through the IDASC Core at a rate of \$125/Programming hour and \$67/Project Management hour. Cost estimates may be provided prior to initiating billable work.

## Application





# Guiding Principles and Lessons Learned



## #1 – Engage Human Subjects, Privacy and Ethics Boards Early

Communicate --- get comfortable and stay comfortable

## #2 – Build Last-Mile Utilization Methods

Data warehouses are useless unless utilized

## #3 – Promote Awareness

Data warehouses are useless unless utilized

## #4 – Low- or No-Cost Tools Can Help Democratize Access

Hypothesis generation + Pilot data for grants

## #5 – Consider Human (Non-Technical) Models

Prioritization is critical

Build in cost-function for iterations

Listen for gaps and use to inform new tool development

## #6 – Evaluate Institutional Impact

Publications

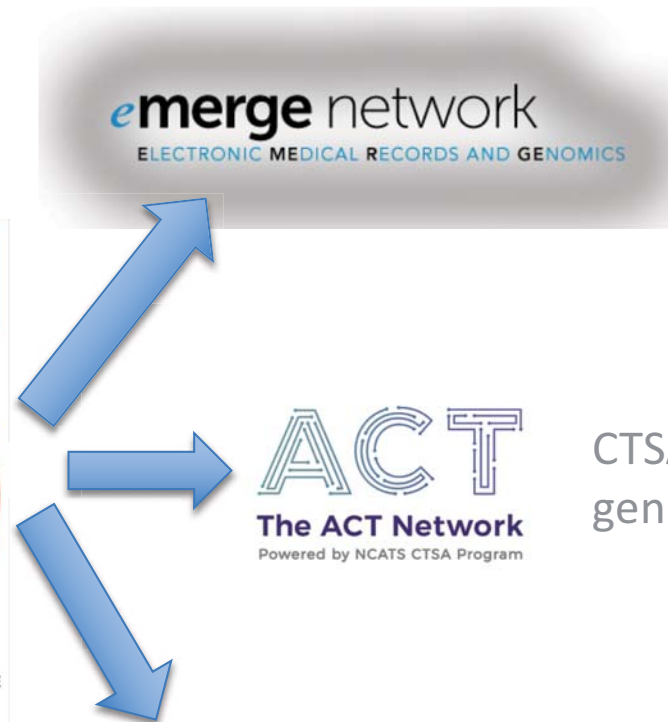
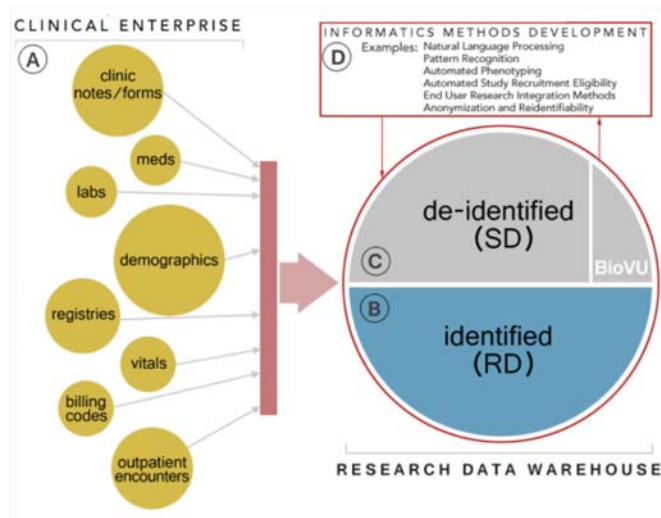
Grants (indirects supply return on institutional investment)

Researcher Diversity (use case, department, faculty level)





Data may also be leveraged to join/participate/lead research networks



Multi-site research network focused on genomic medicine.

CTSA Network – hypothesis generation and site selection

Network-based pragmatic research using health data and patient partnerships

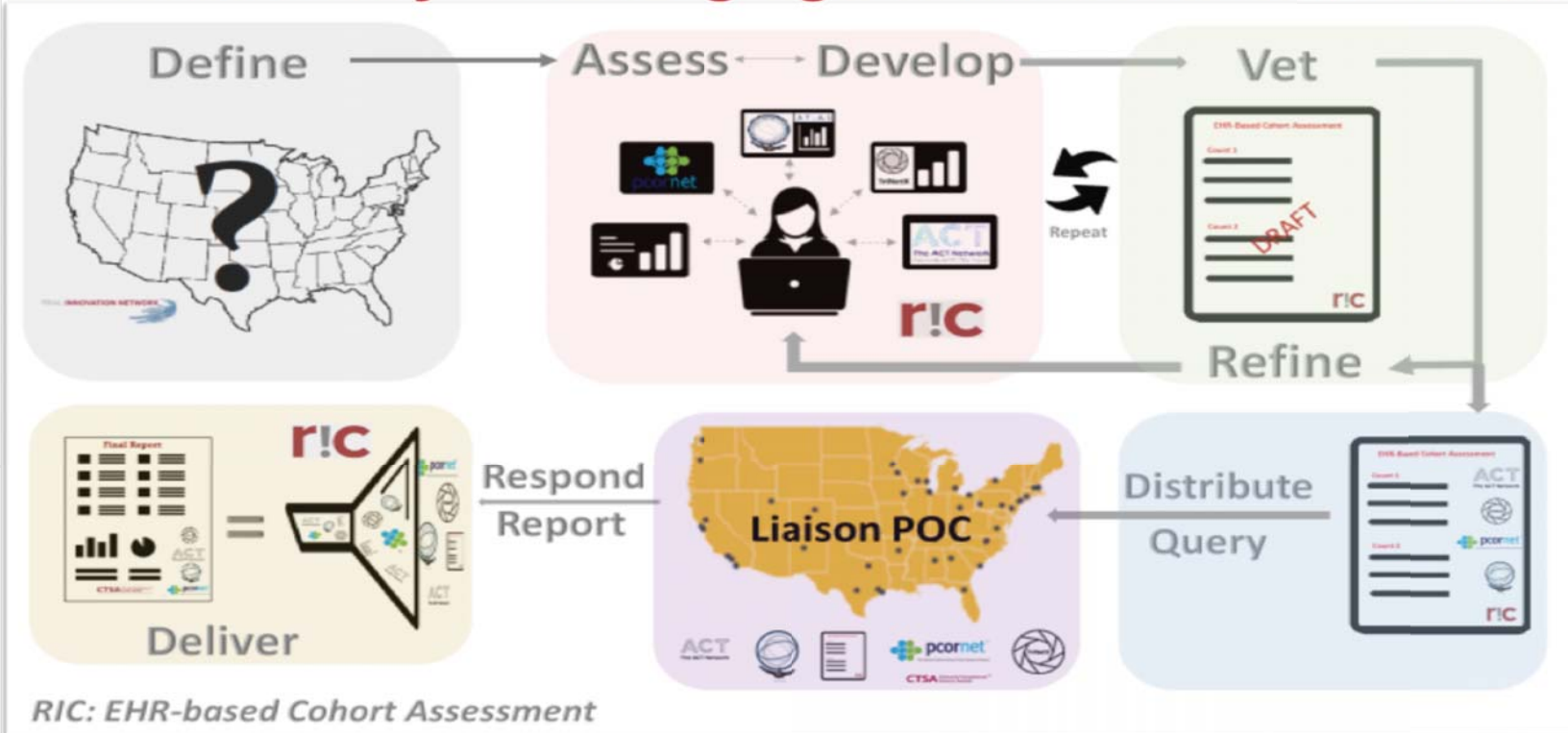




Data may also be leveraged to join/participate/lead research networks



## Site Feasibility: Leveraging CTSA Informatics Teams



# Tools and Methods development may also be leveraged



## All of Us

### A unique participant community...

The *All of Us* Research Program aims to engage a community of one million or more volunteers who reflect the diversity of America, including many people who haven't taken part in medical research before. We welcome participants both healthy and sick, of all backgrounds and walks of life, from all regions across the country.

Participants answer surveys about their health, lifestyle, and environment. Some participants will also contribute physical measurements, biosamples (blood and urine), their Electronic Health Record (EHR), and more. Taken together, these data give the program the scale and scope to enable research for most common diseases, as well as many rare conditions, and may help increase our understanding of healthy states.

[Learn more about the \*All of Us\* Research Program protocol >](#)



**Biosamples**



**Electronic Health Records**



**Measurements**



**Mobile Health Data**



**Surveys**



...meets a unique  
research community...

...to transform research...

We believe researchers and participants should have broad access to data. We encourage researchers to sign up as *All of Us* participants, too. And we are committed to building meaningful partnerships with our participants, ensuring that the program reflects the needs and values of researchers and participants alike. This includes making participants' information available to them, so they can learn more about their health and *All of Us* discoveries over time.

[Learn more about the \*All of Us\* Research Program's Core Values >](#)

A data resource  
for *All of Us*

Broad access  
to data

Partners, not  
subjects

Safe, open  
research

Privacy first,  
privacy always





# Guiding Principles and Lessons Learned



**#1 – There are no ‘perfect’ data models, ontologies or standards ... make an informed choice and move on** (we recently reworked our back-end data model to OMOP to allow methods development teams to remain consistent across VUMC and AoU systems)

**#2 – Build to Evolve**

**#3 – Recognize Data May Open Doors For Collaboration**

**#4 – Recognize Benefits and Costs (extra storage / managers) For Data Stores**

**#5 – Change Control Is Crucial When Working With Multiple Data Stores**



## Prospective Data Collection / Management





**We have a very large and  
active community of users  
for an electronic data  
capture system called**



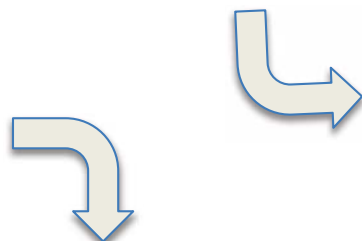


Local @ VU

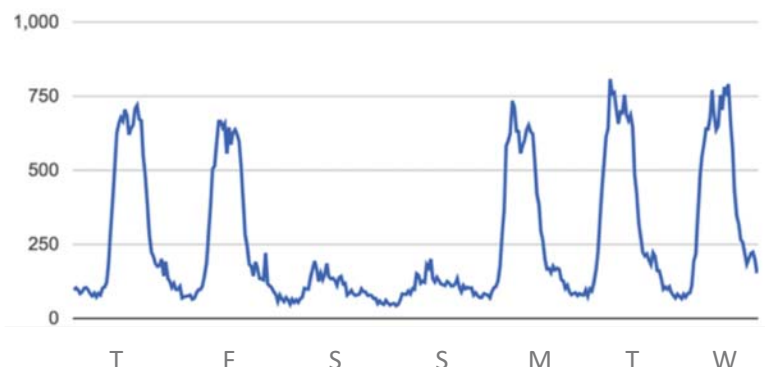


Overall

Typical Week



**Concurrent Users** (Past Week)



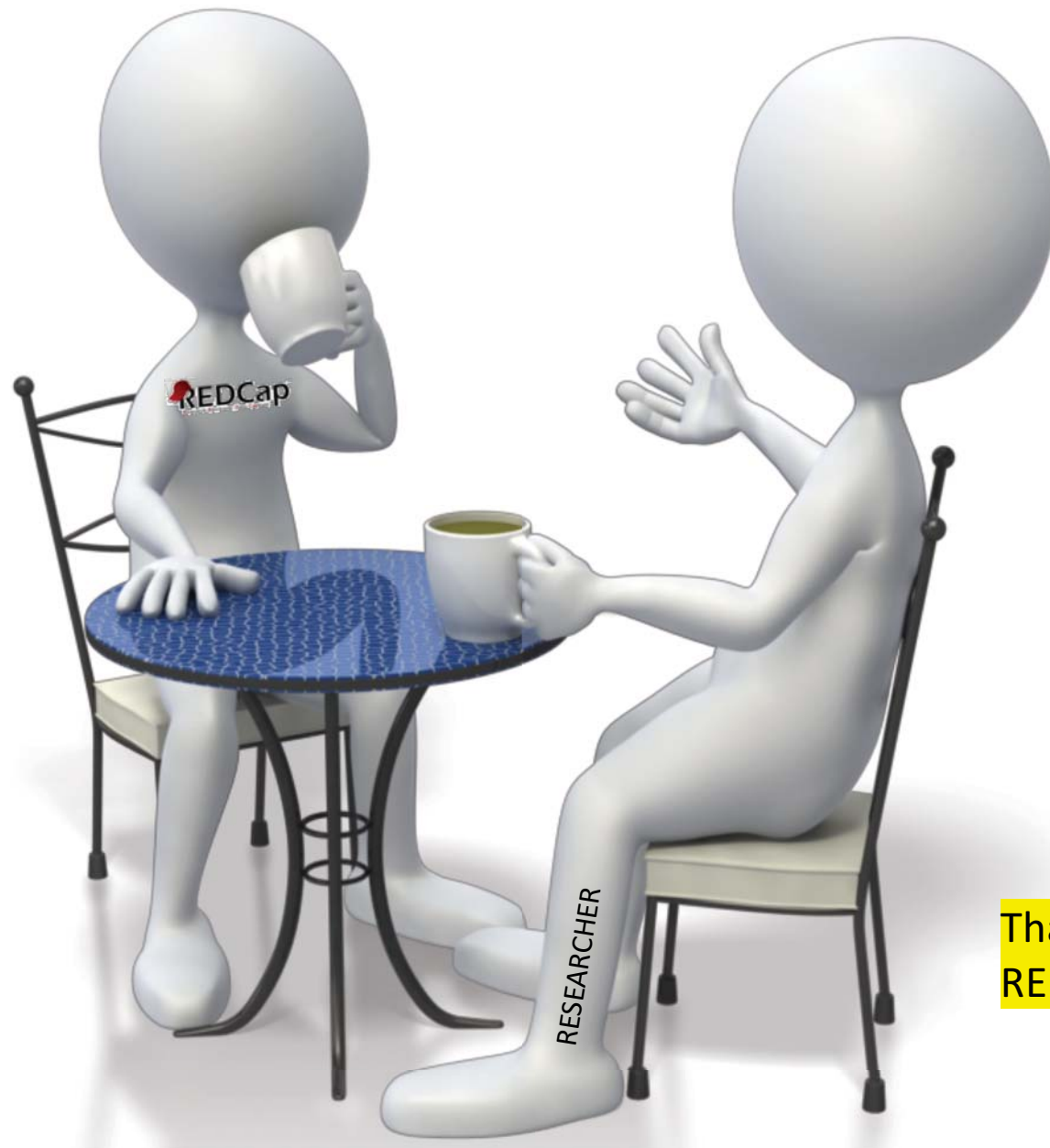
**Locations of users accessing REDCap in the past week**



## System Statistics

<b>Total projects</b> (excludes 'practice' projects)	56,047
• Project status	
- Production <a href="#">view types</a>	21,070
- Projects not containing surveys	5349
- Projects containing surveys	15721
- Development <a href="#">view types</a>	22,872
- Inactive <a href="#">view types</a>	2,813
- Archived <a href="#">view types</a>	9,292
• Project types	
- Projects not containing surveys	14,229
- Projects containing surveys	41,818
• Project purpose	
- Research <a href="#">view subcategories</a>	15,242
- Basic or bench research	2138
- Clinical research study or trial	5724
- Translational research 1 (applying discoveries to the development	780
- Translational research 2 (enhancing adoption of research findings	656
- Behavioral or psychosocial research study	3861
- Epidemiology	1019
- Repository (developing a data or specimen repository for future u	719
- Other	1433
- [Subcategory not selected]	927
- Operational Support	16,385
- Quality Improvement	17,376
- Other	6,460
• Total user accounts	39,407
- Active users [?]	26,436

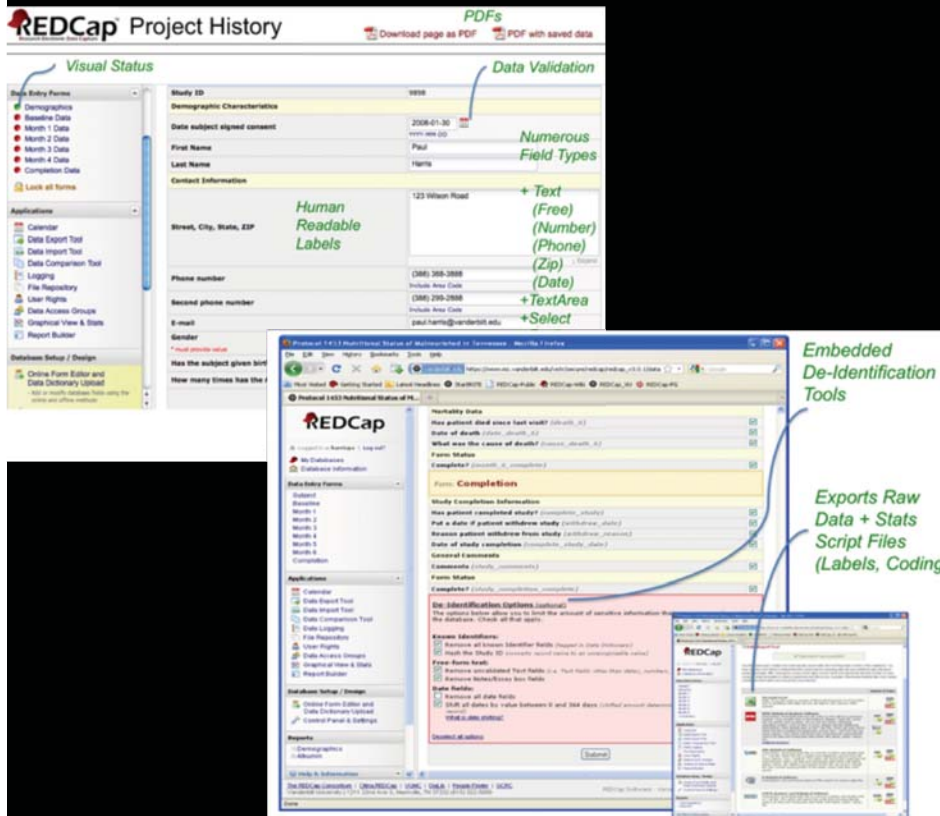
Empowerment is bi-directional (used systems get better)



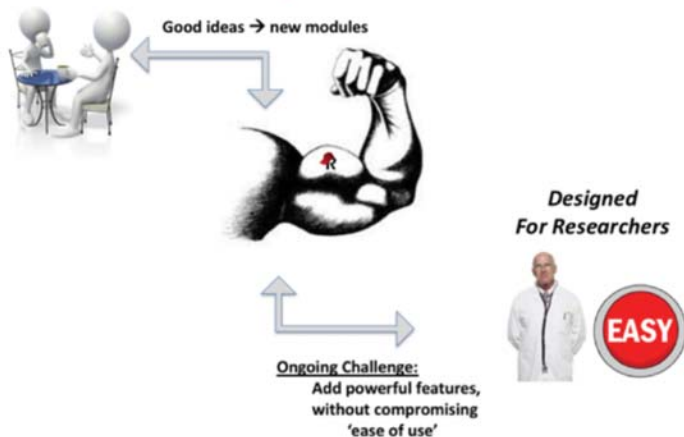
That's great, but will  
REDCap do ... ?

## Summary:

- Data Planning ('easy way to do the right thing' with data capture, management, audits, security)
- Data Collection (researcher, provider, participant, patient)
- Data Export (all major statistical packages)
- Data Import (file or via API)
- Data Integration (API services)
- Consortium-wide REDCap library of shared instruments (e.g. validated scales, PROs)
- Off-Line App Version (iOS, Android)
- Text/Audio/Video capabilities
- Multi-modal (web, SMS, phone)
- RCT features – randomization, data query workflow
- Document Repository
- E-consent (new)
- MyCap Integration (new)
- **EHR Interoperability - via FHIR (new)**



### User-Driven Development/Prioritization





Available at no cost to academic, government, non-profit partners



Institutions	Countries	Projects	Articles
3178	128	614k	6093

## Map of REDCap Consortium Partners

[View fullscreen map](#)





**Any chance  
you could  
integrate in  
some way  
with our EHR?**  
*e.g. so we don't  
have to  
copy/paste?*



# Why is this hard?



**Direct Connection is usually prohibited**  
(performance, security)

**Mapping is non-trivial**  
(which EHR glucose – type?/time?)

**Transformations may be required**  
(gender = m/f, 0/1, 1/0, Male/Female)

**Lack of true standards across EHR**  
implementations (seen one, seen one)

**EHR teams are typically busy**  
(clinical priorities)

**PHI concerns Privacy Offices**  
(breaches are more expensive than  
data entry personnel)

# Collaboratory



1

**Epic**



**REDCap**  
Research Electronic Data Capture



*Precision Use of REDCap Forms  
(the right form(s) for right  
patient for right user  
at the right time)*

2

**MyChart**



**REDCap**  
Research Electronic Data Capture



*Embedding Surveys  
(e.g. Pre-Screening)*

3

**Epic**



**REDCap**  
Research Electronic Data Capture

A screenshot of the REDCap interface showing a table with columns for patient ID, date, and various data points. The table is titled 'Patient Data for Study 01' and shows data for multiple patients.

*Dynamic Data Pull  
Real-time (Demography, CCD) +  
Harvesting (e.g. Labs/Vitals)*

## Setting up REDCap DDP on FHIR



**Coming soon to AppOrchard ...**

For now, just contact me directly and we can connect you to Epic Engineers for credentialing

REDCap

HomeMy ProjectsNew ProjectSend-ItMessengerControl Center

My ProfileLog out

Control Center Home

Notifications & Reporting

To-Do List 6

Dashboard

System Statistics

Activity Log

Activity Graphs

Map of Users

Projects

Browse Projects

Edit a Project's Settings

Users

Browse Users

Add Users (Table-based Only)

User Whitelist

Email Users

API Tokens

Administrators & Acct Managers

Technical / Developer Tools

External Modules

API Documentation

Plugin, Hook, & External Module Documentation

MySQL Dashboard

MySQL Simple Admin

Miscellaneous Modules

Dynamic Data Pull (DDP) - Custom

DDP on FHIR with EHR Launch

Custom Application Links

Publication Matching

Find Calculation Errors in Projects

System Configuration

Configuration Check

General Configuration

Security & Authentication

User Settings

File Upload Settings

Modules/Services Configuration

Field Validation Types

Home Page Settings

Project Templates

Default Project Settings


Footer Settings (All Projects)

Cron Jobs

External Modules

Admin Dashboard

DDP on FHIR with EHR Launch



REDCap can communicate with any EHR (electronic health record system) that has implemented 'SMART on FHIR' web services that allow for interoperability and data extraction from the EHR. In this way, REDCap can be embedded inside and launched within an EHR user interface (e.g., Cerner, Epic Hyperspace), which allows REDCap users to easily add patients to their projects and/or to access patient data inside a REDCap project. In addition to launching REDCap inside the EHR, REDCap can also extract data from the EHR to import clinical data into a REDCap project by using a feature called 'DDP on FHIR' (Dynamic Data Pull using SMART on FHIR). DDP on FHIR provides an adjudication process whereby REDCap users can approve all incoming data from the EHR before the data is officially saved in their REDCap project.

Before 'DDP on FHIR with EHR Launch' can be used by REDCap users, it must first be set up and enabled on this page. To get started, download the ZIP file linked below, and follow the instructions contained therein. There may be instructions for your particular EHR, but if not, then you may use the 'Instructions - General' file. After you have followed the setup procedures, all REDCap users who wish to use this feature must first launch REDCap from within the EHR user interface. That step is the starting point for all users and is mandatory for REDCap to determine that the user truly has access to the EHR. Once that step has been completed, the REDCap user may use DDP on FHIR solely from the REDCap side (without being inside the EHR), if they wish, for any projects that have DDP on FHIR enabled, or they can utilize REDCap as launched from within the EHR as well.

[Setup instructions and technical specifications \(ZIP\)](#)

[Informational page on how to use DDP \(for providing to users\)](#)

Enable 'DDP on FHIR with EHR Launch'

Enabled

Once DDP on FHIR is enabled for the system, it can then be enabled for a given project by an Administrator on the project's Project Setup page (in the 'optional modules and customizations' section). Also, users that launch REDCap from inside the EHR system will be able to access their DDP on FHIR projects from the EHR interface.

Custom name for the EHR system

Epic

This will be the name of the EHR system as it is displayed for the user. If left blank, it will simply say 'EHR' in its place.

e.g., Epic, Cerner, EMR, EDW

Redirect URL (to add to your FHIR client for REDCap)

Copy and paste the Redirect URL below and provide it to your EHR technical team to be added to your FHIR client.

Redirect URL (read-only):

EHR-specific and FHIR-specific settings

Client ID and Client Secret for the FHIR app/client created for REDCap in the EHR

These are essentially a username and API key that REDCap will use to communicate with your EHR using the SMART on FHIR services. These client values will likely need to be generated for you by your EHR's technical team.

Client ID:

Client Secret:

.....

Show secret

(Make sure that the Client Secret is the secret value itself and not the stored hashed value of the secret.)

SMART on FHIR web service URL:

## DDP on FHIR setup page in REDCap



# Project-Level Mapping EHR→REDCap

Number of fields selected: 31
Map the fields selected below
Cancel

Source Fields List
Filter: Search source fields by keyword

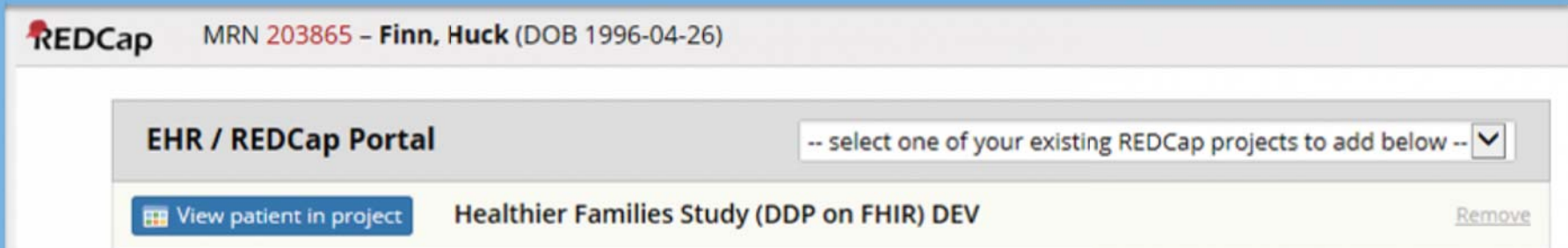
☒ **id (Medical record number)** ?  
☐ **Demographics** select all | deselect all  
☒ birthDate (Date of birth) ?  
☒ gender (Sex) ?  
☒ name-family (Last name) ?  
☒ name-given (First name) ?  
☒ address-line (Address (street)) ?  
☒ address-city (Address (city)) ?  
☒ address-state (Address (state)) ?  
☒ address-postalCode (Address (postal code)) ?  
☒ address-country (Address (country)) ?  
☒ phone-home (Phone number (home)) ?  
☒ phone-mobile (Phone number (mobile)) ?  
☒ email (Email address) ?  
☐ **Condition** select all | deselect all  
☒ problem-list (Problem List and health concerns) ?  
☐ **Medications** select all | deselect all  
☒ active-medications-list (Active medications list) ?  
☐ **Vital Signs** select all | deselect all  
☒ 8480-6 (Systolic blood pressure) ?  
☒ 8462-4 (Diastolic blood pressure) ?  
☒ 8310-5 (Body temperature) ?  
☒ 8867-4 (Heart rate) ?  
☒ 9279-1 (Respiratory rate) ?  
☒ 8302-2 (Body height) ?  
☒ 3141-9 (Body weight) ?  
☐ **Labs**

**MAP SOURCE FIELDS TO REDCAP FIELDS**

External Source Field (StarPanel)	Map to REDCap Field	Map to REDCap date/time field <small>(Date/time value is used with day offset to construct window of time when searching for source data)</small>	Remove mapping?
<b>mrn</b> "Medical Record Number" ★ Source Identifier Field	mrn "Medical record number"		
<b>Demographics</b>			
<b>dob</b> "Date of Birth"	dob "Date of birth"		✗
<b>ethnicity</b> "Ethnicity"	ethnicity "Ethnicity"		✗
<b>firstName</b> "First Name"	first_name "First Name"		✗
<b>gender</b> "Gender"	sex "Gender"		✗
<b>lastName</b> "Last Name"	last_name "Last Name"		✗
<b>race</b> "Race"	race "Race"		✗
<b>Labs</b>			
<b>AN-GAP</b> "ANION GAP" ⚡ Use same mapping for other source field	angap "Anion gap (AN-GAP)" ⚡ Map other REDCap field	Date/time field: visit_date "Visit date" Preselect a value (optional): -- none --	✗
<b>BUN</b> "UREA NITROGEN BLOOD" ⚡ Use same mapping for other source field	bun "Urea nitrogen blood (BUN)" ⚡ Map other REDCap field	Date/time field: visit_date "Visit date" Preselect a value (optional): -- none --	✗
<b>CO2</b> "CARBON DIOXIDE BLOOD" ⚡ Use same mapping for other source field	co2 "Carbon dioxide blood (CO2)" ⚡ Map other REDCap field	Date/time field: visit_date "Visit date" Preselect a value (optional): -- none --	✗
<b>Ca</b> "CALCIUM BLOOD"	ca "Calcium blood (Ca)"	Date/time field: visit_date "Visit date"	✗



## EPIC Content Screen Details Removed by Request



REDCap MRN 203865 – Finn, Huck (DOB 1996-04-26)

**EHR / REDCap Portal** -- select one of your existing REDCap projects to add below --

[View patient in project](#) Healthier Families Study (DDP on FHIR) DEV [Remove](#)

An Epic-specific REDCap window is opened within Hyperspace to display the Epic user's REDCap projects.

REDCap login needed only once – afterwards, Epic Provider + REDCap user mapping maintained.

Quick view of patient-in-context status on REDCap project(s) – View –or Add options

## EPIC Content Screen Details Removed by Request

REDCap MRN 203865 – Finn, Huck (DOB 1996-04-26)  
My Projects Project: Healthier Families Study (DDP on FHIR) DEV

### Adjudicate data from Epic

[View DDP adjudication instructions](#)

Fetching data for Study ID "1" using  $\pm 365$  days

New items: 12 Time of last data fetch: 21 days ago

REDCap Field	REDCap Date/Time	Epic Source Date/Time	REDCap Current Value	Epic Source Value	Import? ↓
<b>Demography</b>					
first_name "First Name"	-	-		Huck	<input checked="" type="radio"/> reset
last_name "Last Name"	-	-		Finn	<input checked="" type="radio"/> reset
sex "Gender"	-	-		Male (1)	<input checked="" type="radio"/> reset
ethnicity "Ethnicity"	-	-		NOT Hispanic or Latino (1)	<input checked="" type="radio"/> reset
race "Race"	-	-		Other (9)	<input checked="" type="radio"/> reset
dob "Date of birth"	-	-		1996-04-26	<input checked="" type="radio"/> reset
address_city "Address (city)"	-	-		MADISON	<input checked="" type="radio"/> reset
phone_number_home "Phone number (home)"	-	-		608-445-7733	<input checked="" type="radio"/> reset
problem_list "Problem list"	-	-		- active	<input checked="" type="radio"/> reset

Save

Cancel

View the current patient record inside a REDCap project to do data entry or DDP adjudication (i.e., importing data into REDCap from Epic).

This is a non-temporal data use case

## EPIC Content Screen Details Removed by Request

REDCap MRN 203865 - Finn, Huck (DOB 1996-04-26)  
My Projects Project: Healthier Families Study (DDP on FHIR) DEV

### Record Home Page

#### Adjudicate data from StarPanel

Displayed below is the data fetched from the external source system. It will be imported into REDCap, select the source value by clicking the radio button for the data with the most correct value. Once you made all your selections, press the Save button.

Fetching data for Study ID "50" using ±30 days

Refresh data from StarPanel using ± 30 days from date AND time  
min: 0.01 days (15 minutes), max: 365 days

New items: 9

Time of last data fetch: just now

- ☒ Display all items (all forms)  
☐ Display only this form's items

View 6 hidden items (existing values)

REDCap Field	REDCap Date/Time	StarPanel Source Date/Time	REDCap Current Value	StarPanel Source Value	Import?
na "Sodium blood (Na)"	2008-08-14 (00:00)	2008-08-14 11:06		140	<input type="radio"/> reset
		2008-08-14 11:16		135	<input checked="" type="radio"/> reset
		2008-08-14 13:39		140	<input type="radio"/> reset
k "Potassium blood (K)"	2008-08-14 (00:00)	2008-08-14 11:06		4.0	<input type="radio"/> reset
		2008-08-14 11:16		3.5	<input checked="" type="radio"/> reset
		2008-08-14 13:39		4.0	<input type="radio"/> reset
cl "Chloride blood (Cl)"	2008-08-14 (00:00)	2008-08-14 11:06		104	<input type="radio"/> reset
		2008-08-14 11:16		105	<input checked="" type="radio"/> reset
		2008-08-14 13:39		104	<input type="radio"/> reset
co2 "Carbon dioxide blood (CO2)"	2008-08-14 (00:00)	2008-08-14 11:06		24	<input checked="" type="radio"/> reset
		2008-08-14 11:16		25	<input type="radio"/> reset

Save Cancel

View the current patient record inside a REDCap project to do data entry or DDP adjudication (i.e., importing data into REDCap from Epic).

This is a temporal data use case (key off visit)

# REDCap + Epic Interoperability Update



1



Methods  
(Need Reg Process)

2



Creating Secure  
Data Marts

3



Streamlining  
MyChart Use  
Cases



+ Recruitment  
+ eConsent  
+ JIT Research PROs



Huge Interest  
+ New Collaborators

Number of fields selected: 31 Map the fields selected below

Source Fields List

Filter: Search source fields by keyword

Demographics

Condition

Medications

Vital Signs

Links

MAP SOURCE FIELDS TO REDCAP FIELDS

External Source Field (Star/Panel)

Map to REDCap Field

Demographics

Condition

Medications

Vital Signs

Links

Select patient and then choose REDCap menu option



REDCap

EHR - REDCap Portal

An Epic-specific REDCap window  
Epic user's REDCap projects that  
OR to add that patient to study



Hyperspace Workflow  
+ Adjudicated Data Flow  
-- Launched @ VU + Consortium

Create an empty project (blank slate)  
Upload a REDCap project XML file (CDISC ODM format)  
Use a template (choose one below)  
Data Mart: Create a pre-populated project with medical records from eStar

STEP 1) Enter medical record numbers of patients to import from eStar (one per line)

STEP 2) If pulling time-based data, select the range of time from which to pull data (optional)

Pull data from [start date] to [end date]

STEP 3) Choose fields in EHR for which to pull data

Source Fields List

Filter: Search source fields by keyword

☒ Id (Medical record number)

☒ Demographics

☒ Condition

☒ Medications

☒ Allergy Intolerance

☒ Vital Signs

8302-2 (Body height)

8310-5 (Body temperature)

3141-9 (Body weight)

8462-4 (Diastolic blood pressure)

8867-4 (Heart rate)

9279-1 (Respiratory rate)

8480-6 (Systolic blood pressure)

Oxygen saturation | MFR | Pt

Body weight | Mass | Pt | ^Patient

Body height | Len | Pt | ^Patient

Body temperature | Temp | Pt

Breaths | NRat | Pt

Circumference, occipital-frontal | Len | Pt | Head

Heart rate | NRat | Pt



1

NIH U.S. National Library of Medicine

ClinicalTrials.gov


**STeroids to REduce Systemic Inflammation  
After Neonatal Heart Surgery (STRESS)**

VUMC

Data Mapped / **Launched**

Then Shared With Another Site

UTSouthwestern  
Medical Center

Mappings   
Transferred!

NIH U.S. National Library of Medicine

ClinicalTrials.gov

**Study of Anti-Malarials in Incomplete Lupus  
Erythematosus (SMILE)**

UTSouthwestern  
Medical Center

AMIA  
INFORMATICS PROFESSIONALS. LEADING THE WAY.

EHR-REDCap Integration via FHIR for Research Electronic Data Capture

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**Abstract**

*The near-ubiquitous use of EHRs creates expanding opportunities for pragmatic clinical research. Enterprise EHR platforms collect certain data useful for clinical-translational research, and can be configured for additional research electronic data capture (EDC). But specific EDC platforms, in particular REDCap, afford major advantages to clinical researchers. REDCap can now integrate with the EHR via a Fast Healthcare Interoperability Resource (FHIR) interface. We report the first application of this EHR-REDCap FHIR interface for an active clinical study.*

**Introduction**


When on a robust, integrated enterprise EHR platform, how should electronic data capture (EDC) for pragmatic clinical-translational research optimally be performed? As the day-to-day tool for clinicians and their staffs, one advantage of using an EHR for research EDC is being naturally embedded within normal clinical workflows. And employing the EHR can reduce the need for duplicative data entry of the same patient information with its accompanying need for data reconciliation. On the other hand, use of the dedicated research EDC application REDCap confers major advantages: constructing new EDC tools is simplified and can be performed by more staff; a large academic user base has helped create a library of over 2000 pre-built forms, and facilitates multi-institutional research projects; the EDC tools are EHR-agnostic; and data retrieval for subsequent analysis is streamlined<sup>1</sup>.

So this begs the question—can we leverage the best of both approaches? To do so would require interfacing with each EHR, which traditionally proves a daunting task. More recently, the Fast Healthcare Interoperability Resources (FHIR) specification from HL7 has emerged as a standard for real-time integration between EHRs and other applications<sup>2</sup>. The REDCap team thus has developed FHIR data interchange with EHRs for supporting clinical-translational research. EHR vendors currently provide FHIR “read” APIs, though “write” functions will be coming. In this project, we set out to demonstrate feasibility of EHR-to-REDCap integration via FHIR for combined EDC leveraging both the EHR and REDCap, to streamline conduct of a clinical-translational research study. We report here on the first instance in a production EHR of Epic-REDCap integration via FHIR for an active clinical study.

2

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ClinicalTrials.gov

Recruitment  
Status : Not yet  
recruiting

**PROCLAIM -- Misoprostol in the Prevention of  
Recurrent CDI Prevent Recurrence of Clostridium  
Difficile Infection With Misoprostol (PROCLAIM)**

VUMC



Washington  
University  
in St. Louis



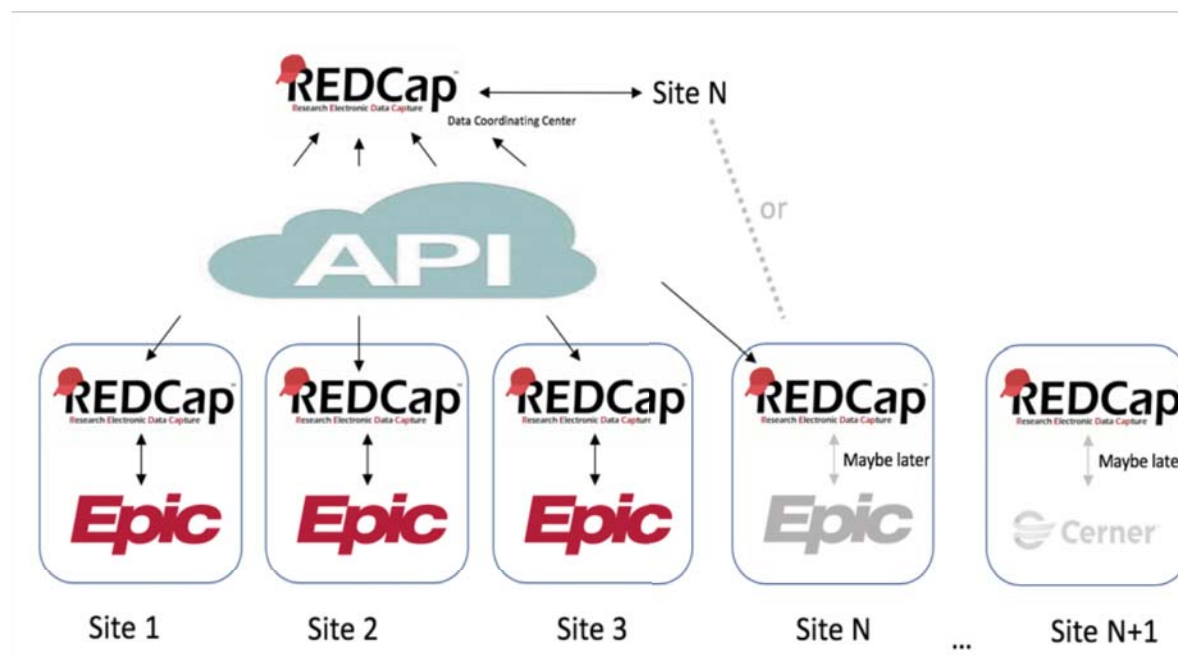
UNC  
HEALTH CARE



3

Early  
Impact

*Democratizing EHR extraction methods should  
Improve efficiency in multi-site data collection*



# Thank You!

## Q/A & Discussion



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