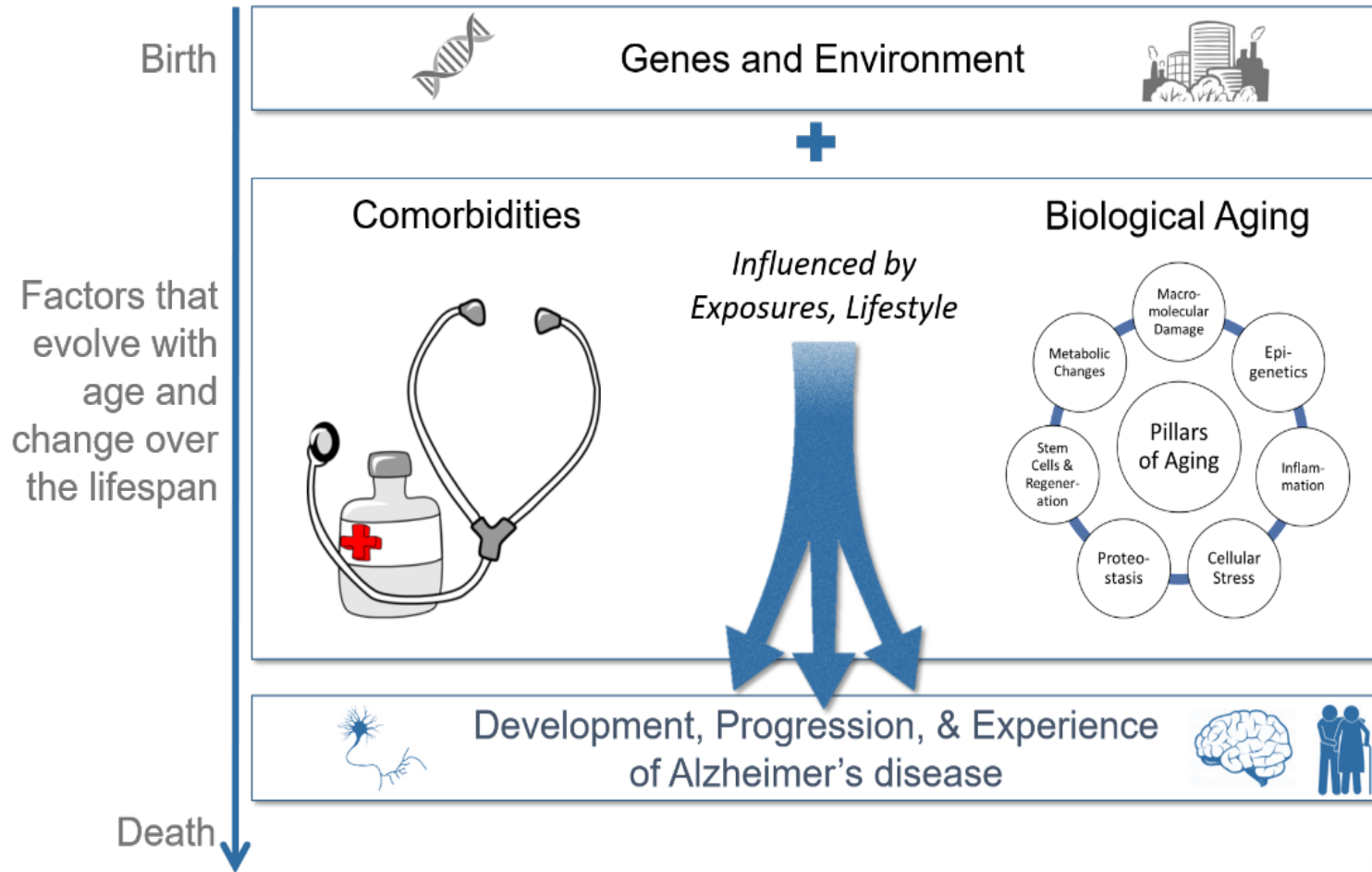


# Data Concierge: Making Center Data findable and available to the ADRD research ecosystem

**NACC Fall meeting**

Michael W. Lutz  
Duke/UNC ADRC

# Theme: Age-related factors across the lifespan



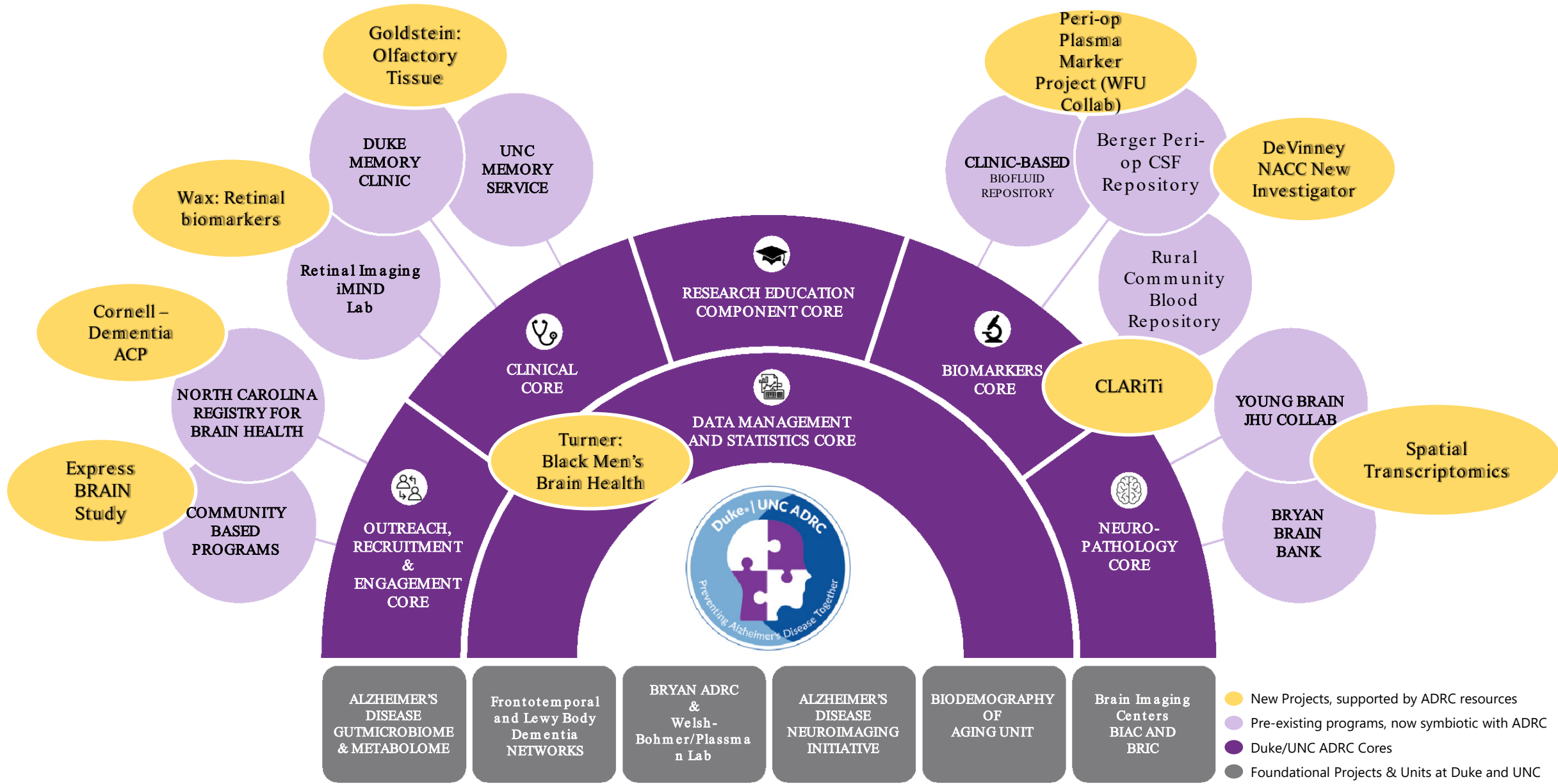
Apply geroscience frameworks to examine how age-related changes in key biological pathways are linked to AD risk and phenotypes.

Emphasis on cohort diversity

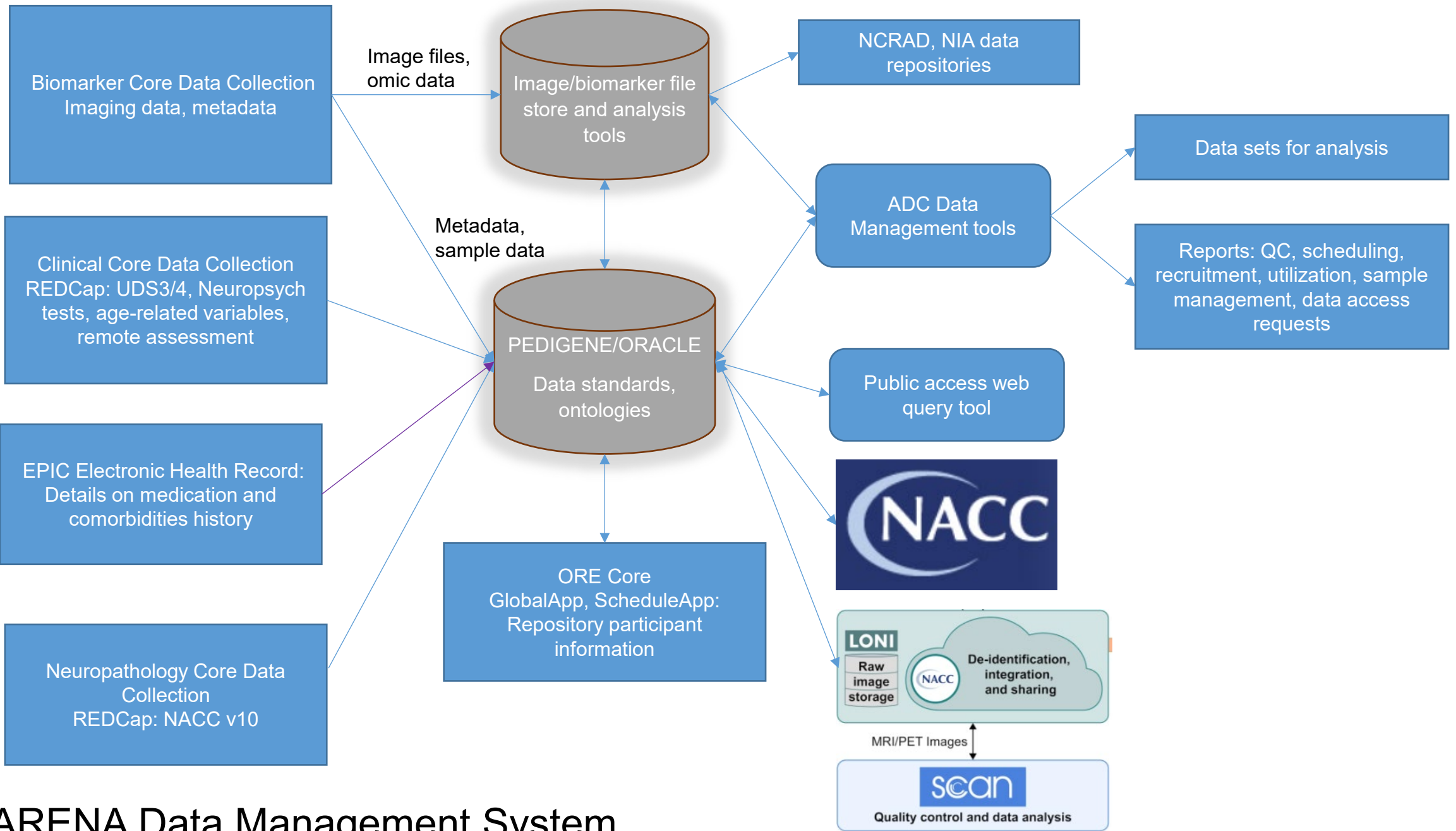
Includes “young cohort” (25-44 yr)

Slide courtesy Heather Whitson



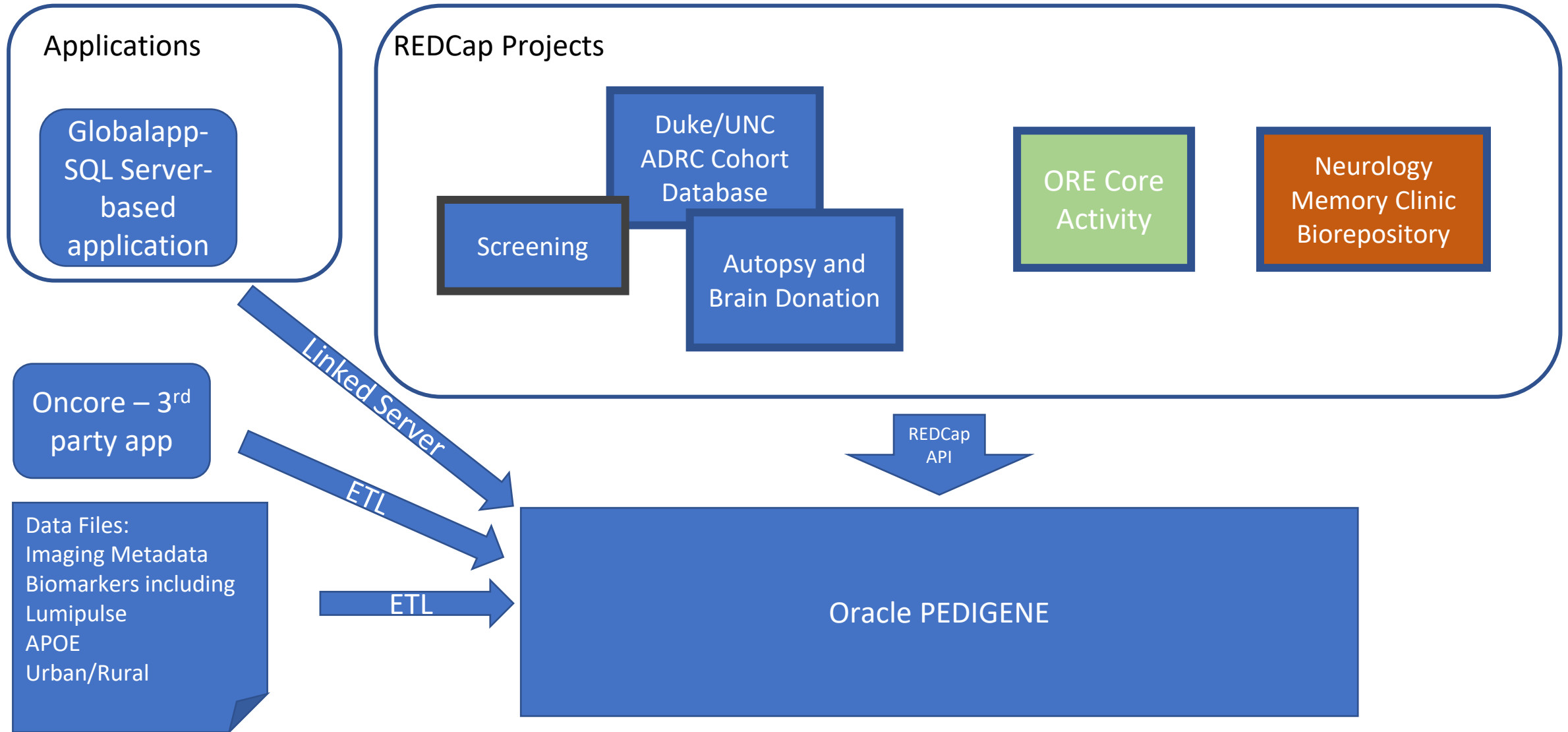


Slide courtesy Heather Whitson



# ARENA Data Management System

# Interfaces





- Familiarity with resources including “legacy” resources
- Showcase our resources in user-friendly way
- Engage with investigators and trainees who are interested in using the ADRC resources
- Help investigators write their requests for resources
- Keep information on resources current

What resources are available?

Resource library with Contact information

Can I obtain the sample needed?

ARENA Gateway, Statistical consult available

Easy to request the resources

Resource request system: approvals, documents, feedback, tracking

DUA, MTA, approvals, dialog

Updates as needed

# Data Resource Library: Details about each resource



<https://dukeuncadrc.org/data-resource-library/>

## Data Resource Library

The Duke/UNC ADRC curates resources from active protocols, with new data and samples being logged every day. Additionally, investigators in our Center have decades of experience in dementia-related studies that continue to be a rich resource for further research. Descriptions and contact information for each cohort and resource are provided below.

### Active protocols

The following resources are derived from active protocols, with ongoing enrollment and data collection:



### Duke-UNC Memory & Aging Study (MAS) and Young Cohort

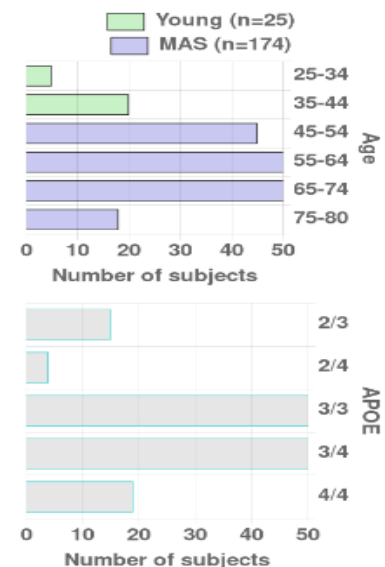
- UDS
- MRI
- Retinal Imaging
- Biosamples
- PET

The Duke/UNC ADRC oversees two cohorts, the Memory & Aging Study (MAS) (n=420 over five years) and the Young Cohort (n=120). Participants from both cohorts are recruited from the Triangle and Eastern North Carolina.

*See what data is available: ARENA Gateway: ADRC cohorts*

[More details on Duke-UNC ADRC Cohorts](#)

### Current recruitment:





## Data and Sample Collection

Each participant contributes **UDS**-based medical, neurologic, psychiatric, and neuropsychological evaluations.

We also collect **blood**, **urine**, and **cerebrospinal fluid** specimens.

During the baseline visit, we collect **motor-sensory assessments**, and **imaging**:

- **brain MRI** (T1, T2 FLAIR, diffusion-weighted, fMRI resting-state, susceptibility)
- **retinal imaging**

## Retinal Imaging Protocol

Zeiss Cirrus HD-5000 AngioPlex retinal and optic nerve imaging device



Optos California Scanning Laser Ophthalmoscopy Camera





# ARENA Gateway: interactive query tool for resources



Duke-UNC Memory & Aging Study (MAS) and Young Cohort

More info... ▾

Data source

Duke-UNC ADRC Coh... ▾

HELP

NEWS

Legend: ■ all data

Selector panel

Click this bar to query a subgroup of subjects ▾

Age at enrollment	
38	20 ≤ x < 45
155	45 ≤ x < 64
122	64 ≤ x < ∞
315	Total

Sex	
203	Female
119	Male
322	Total

Urban/Rural	
12	C
76	R
220	U
308	Total



Race	
4	Asian
54	Black or African American
11	More than one race
8	Unknown
246	White
323	Total

APOE	
23	2/3
9	2/4
107	3/3
101	3/4
28	4/4
268	Total

# The graphics are linked and interactive



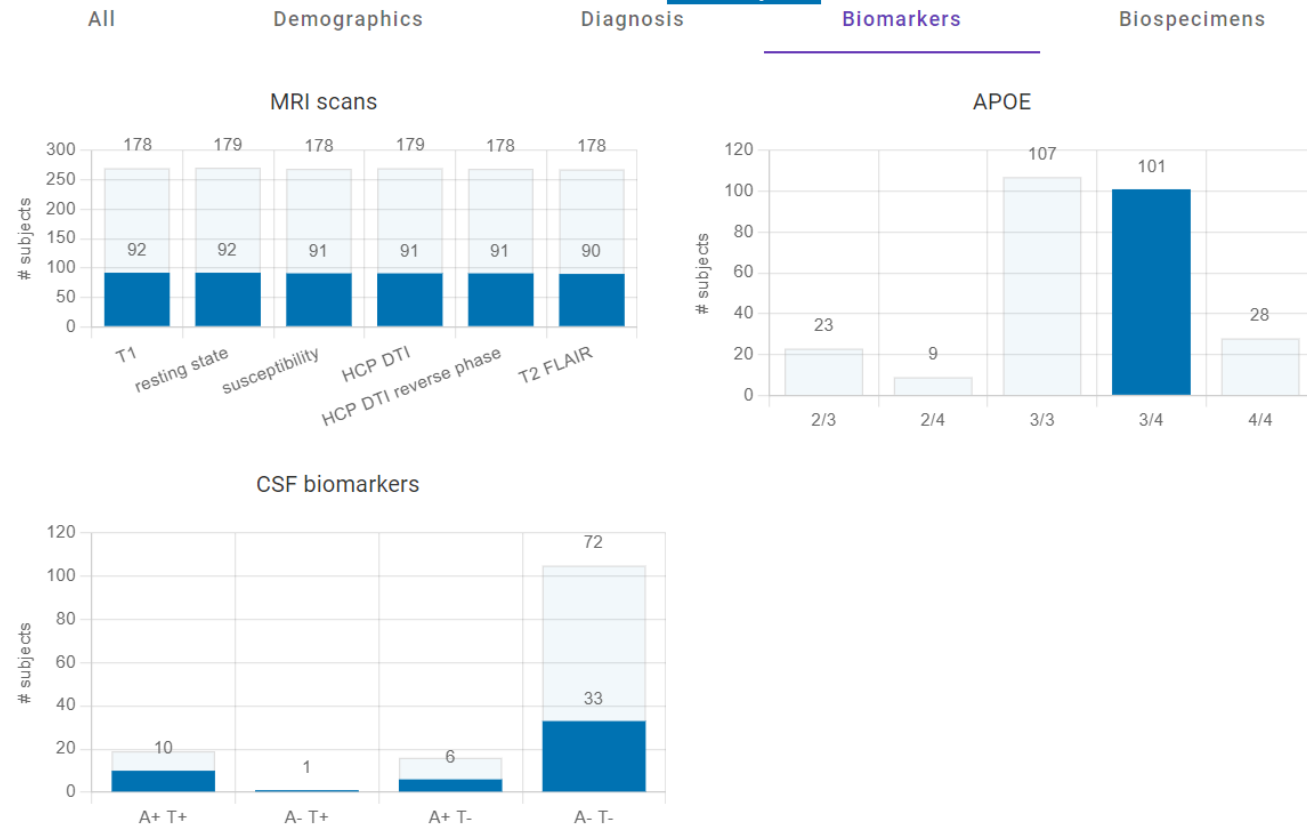
Duke-UNC Memory & Aging Study (MAS) and Young Cohort

More info... ▾

Data source  
Duke-UNC ADRC Coh... ▾

Legend: ■ all data ■ APOE is 3/4

38	12	20 <= x < 45
155	51	45 <= x < 64
122	38	64 <= x < ∞
315	101	Total
Sex		
203	75	Female
119	26	Male
322	101	Total
Urban/Rural		
12	4	C
76	18	R
220	79	U
308	101	Total



54	18	Black or African American
11	2	More than one race
8	0	Unknown
246	80	White
323	101	Total
APOE		
23	0	2/3
9	0	2/4
107	0	3/3
101	101	3/4
28	0	4/4
268	101	Total

# Building a query



Legend:  all data

## Selector panel

Click this bar to close

### Range selectors



Age at enrollment



Years of education



Unspun CSF available



Supernatant CSF available



Pellet CSF available



### Coded selectors

Sex

Female  Male

CSF available

No  Yes

Race

Asian  Black or African American

MCI type

Amnestic  Non-amnestic

# Biospecimens query



**ARENA**

Inquiries or questions: [andy.liu@duke.edu](mailto:andy.liu@duke.edu)

Legend:  all data

Data source  
Biospecimens Bank ▼

HELP

NEWS

*Age at specimen collection*

17	20 <= x < 50
92	50 <= x < 64
292	64 <= x < ∞
401	Total

*Race*

1	Unknown
8	Other
334	White
42	Black
2	Am. Ind./AL native
4	Asian
391	Total

Selector panel

Click this bar to query a subgroup of subjects

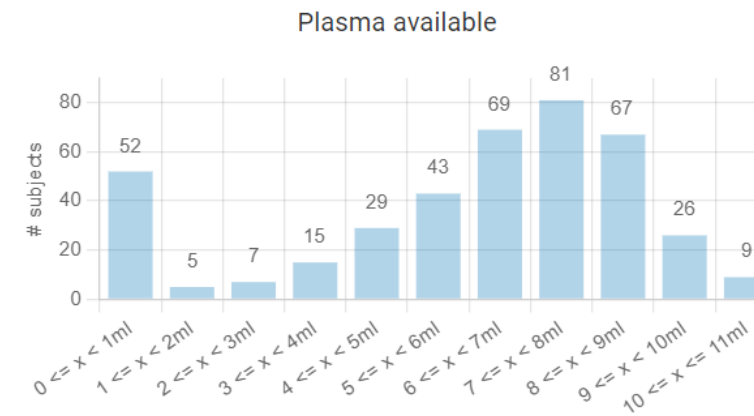
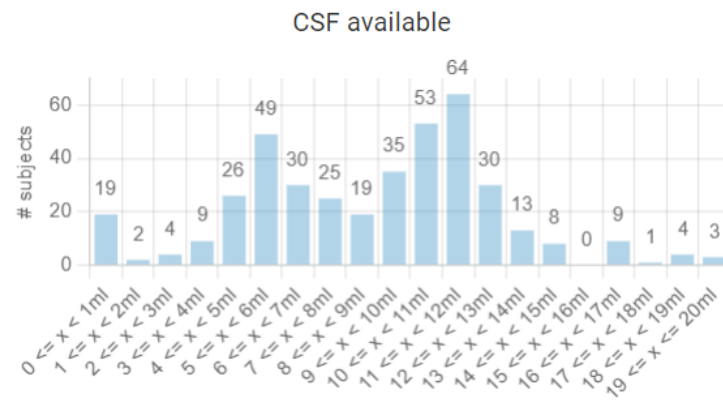
All

Demographics

Diagnosis

Biomarkers

**Biospecimens**



# Resource request



<b>Request ID</b>	28
<b>Are you a researcher?</b>	<input checked="" type="radio"/> Yes <input type="radio"/> No
<b>Researcher Interests</b>	
<b>What are you requesting? (check all that apply)</b>  <i>* must provide value</i>	<input type="checkbox"/> Letter of Support <input checked="" type="checkbox"/> Consultative meeting with a member of ADRC <input type="checkbox"/> Assistance with communication to the broader ADRC community <input checked="" type="checkbox"/> Assistance w/ participant recruitment <input type="checkbox"/> Pre-mortem Plasma, Serum, CSF <input type="checkbox"/> DNA <input type="checkbox"/> Clinical Data <input type="checkbox"/> Imaging Data <input type="checkbox"/> Post-mortem Brain tissue <input type="checkbox"/> Post-mortem CSF
<b>Consultation</b>	
<b>Purpose of meeting</b>  <i>* must provide value</i>	<input checked="" type="checkbox"/> Potential research collaboration <input type="checkbox"/> Feedback requested on grant proposal <input type="checkbox"/> Feedback on manuscript submission <input type="checkbox"/> Other
<b>Who would you like to meet with?</b>  <i>* must provide value</i>	<input type="checkbox"/> Specific Core <input checked="" type="checkbox"/> ADRC PIs (Whitson/Garden) <input type="checkbox"/> Not Sure (request will be triaged by Admin Core) <input type="checkbox"/> Other:



## Project Summary/Research Description

### Title of Project (if applicable)

\* must provide value

Name of the project associated with the resource request or NA

Please provide information about your project: project summary, specific aims, brief analytical plan including statistical power analysis, as well as biological or clinical justification for the effect size that the study is powered to detect.

Fill in the information in the boxes below or upload a file with this information. Choose:

- Enter project information in text boxes  
 Upload your own file

### Project summary (500 word max)

\* must provide value

Expand  
State the project's broad, long-term objectives.

### Specific aims (500 words max)

\* must provide value

Expand  
State concisely the goals of the proposed research and summarize the expected outcome(s).

### Brief analytical plan (500 words max)

\* must provide value

Expand

# Sample requests



## Pre-mortem Plasma, Serum, Whole Blood and CSF Requests

The Duke/UNC ADRC DMS Core is available to discuss your request and help with the analytical plan and power considerations. Would you like to meet with a statistician in the DMS Core to discuss your analytical plan?

Yes  
 No

\* must provide value

For pre-mortem serum, plasma and/or CSFs sample request, please indicate the number of samples and volume (mL) per individual patient sample from each patient group of each sample type (serum, plasma, CSF, other), that you are requesting.

	Serum (samples)	(vol)	Plasma (samples)	(vol)	CSF (samples)	(vol)	Other (samples)	(vol)
AD (dementia with positive biomarkers)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Non-AD dementia	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
MCI with AD pathology (positive biomarkers)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
MCI with unknown/non-AD pathology (negative biomarkers)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

# “Non researcher” requests



<b>Request ID</b>	9
<b>Are you a researcher?</b>	<input type="radio"/> Yes <input checked="" type="radio"/> No
<b>ADRC has many resources for the public. Are you:</b>	<input type="radio"/> Requesting a consultation with our Admin Core to discuss having an expert present on an Alzheimer's topic <input checked="" type="radio"/> Requesting a consultation with our Outreach Team (ORE Core) to discuss the creation of a community event or ADRC participation in a community event <input type="radio"/> A student looking for information on working on an Alzheimer's research project <input type="radio"/> Requesting information about how to participate in research on Alzheimer's disease and cognitive aging <input type="radio"/> Requesting information about how to participate in clinical trials for treatment of mild cognitive impairment and Alzheimer's disease <input type="radio"/> Other



# From start to finish



Request ID	Public Survey 1	New Adrc Resource Requests	Los Review	Prereview Form	Public Questions Review	Premortem Review	Postmortem Review	Clinical Data Review	Image Data Review	Advertising Review	Participant Recruitment Review	Consult Review
<a href="#">2</a>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<a href="#">3</a>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<a href="#">4</a>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<a href="#">9</a>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<a href="#">12</a>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<a href="#">17</a>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Resource request review



<b>Request ID</b>	30
<b>ADRC Core Reviewing Request</b> <small>* must provide value</small>	<input type="text" value="DMS Core"/>
<b>Resource request Core receipt date</b> <small>* must provide value</small>	<input type="text" value="06-03-2024"/> <input type="button" value="Today"/> M-D-Y <small>MM/DD/YYYY</small>
<b>Review</b>	
<b>Reviewer:</b> <input type="text" value="Mike Lutz"/>	<b>Review date:</b> <input type="text" value="06-03-2024"/> <input type="button" value="Today"/> M-D-Y
<b>Notes</b> <small>* must provide value</small>	<div style="border: 1px solid #ccc; padding: 5px;">This request was completed as per correspondence with requester.</div> <p style="text-align: right;"><a href="#">Expand</a></p>
<b>Decision</b>	
<b>Decision:</b> <input checked="" type="radio"/> Approved <input type="radio"/> Not Approved <input type="radio"/> Pending	<a href="#">reset</a>
<b>Decision date:</b> <input type="text" value="06-03-2024"/> <input type="button" value="Today"/> M-D-Y	
<b>Response for requestor</b> <small>* must provide value</small>	<input checked="" type="radio"/> Enter response in a text box <input type="radio"/> Upload your requestor response file
	<a href="#">reset</a>
<b>Please enter the final response file for the requestor</b> <small>* must provide value</small>	<div style="border: 1px solid #ccc; padding: 5px;">This request was completed.</div>

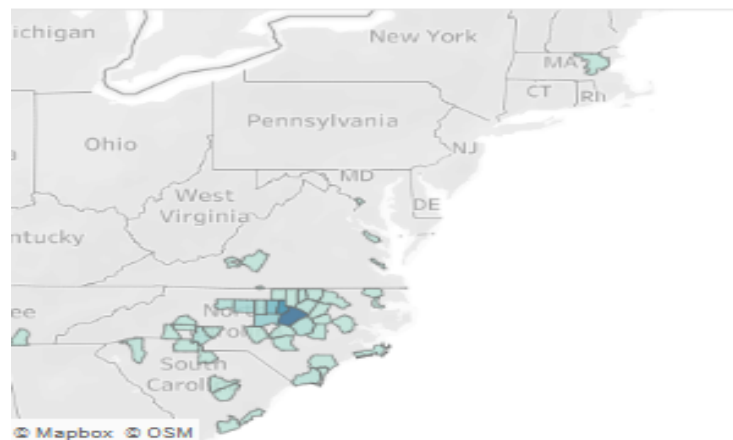
# Communication between Cores: Enrollment Report and Dashboards



## Status

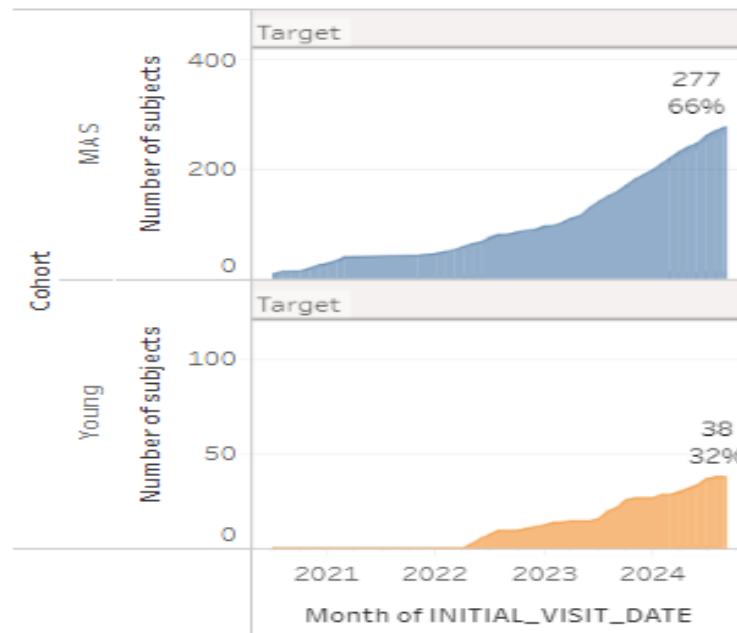
Active	293
Deceased	1
Discontinued (by ADC/PI)	1

## Enrollment by county



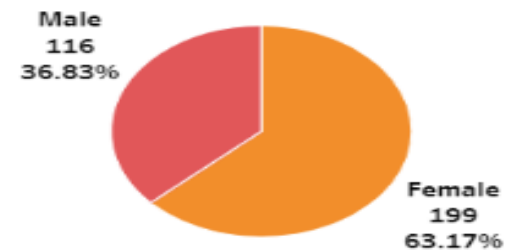
Data automatically updated 9/18/2024 5:00:59 AM

## Enrollment for date range: All

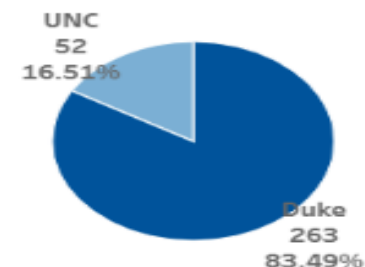


Data automatically updated 9/18/2024 5:00:59 AM

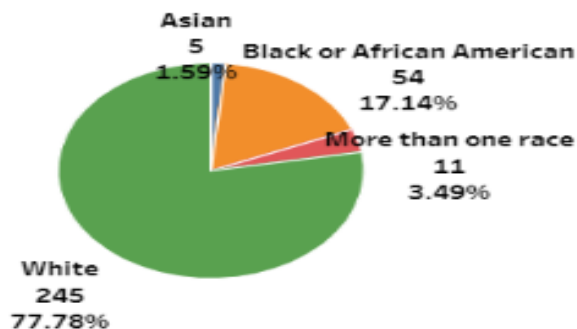
## Sex



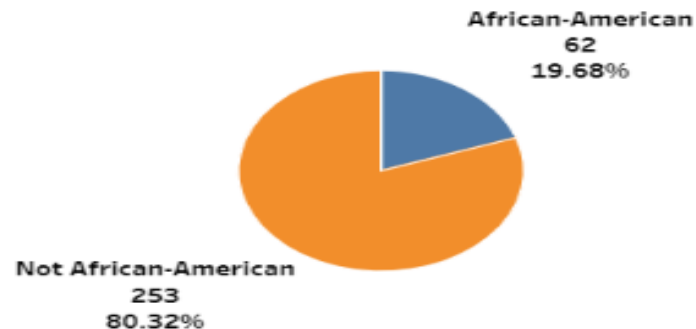
## Enrollment Site



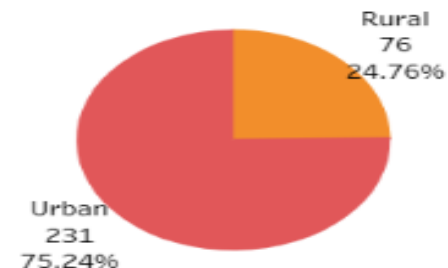
## Race



## African-American

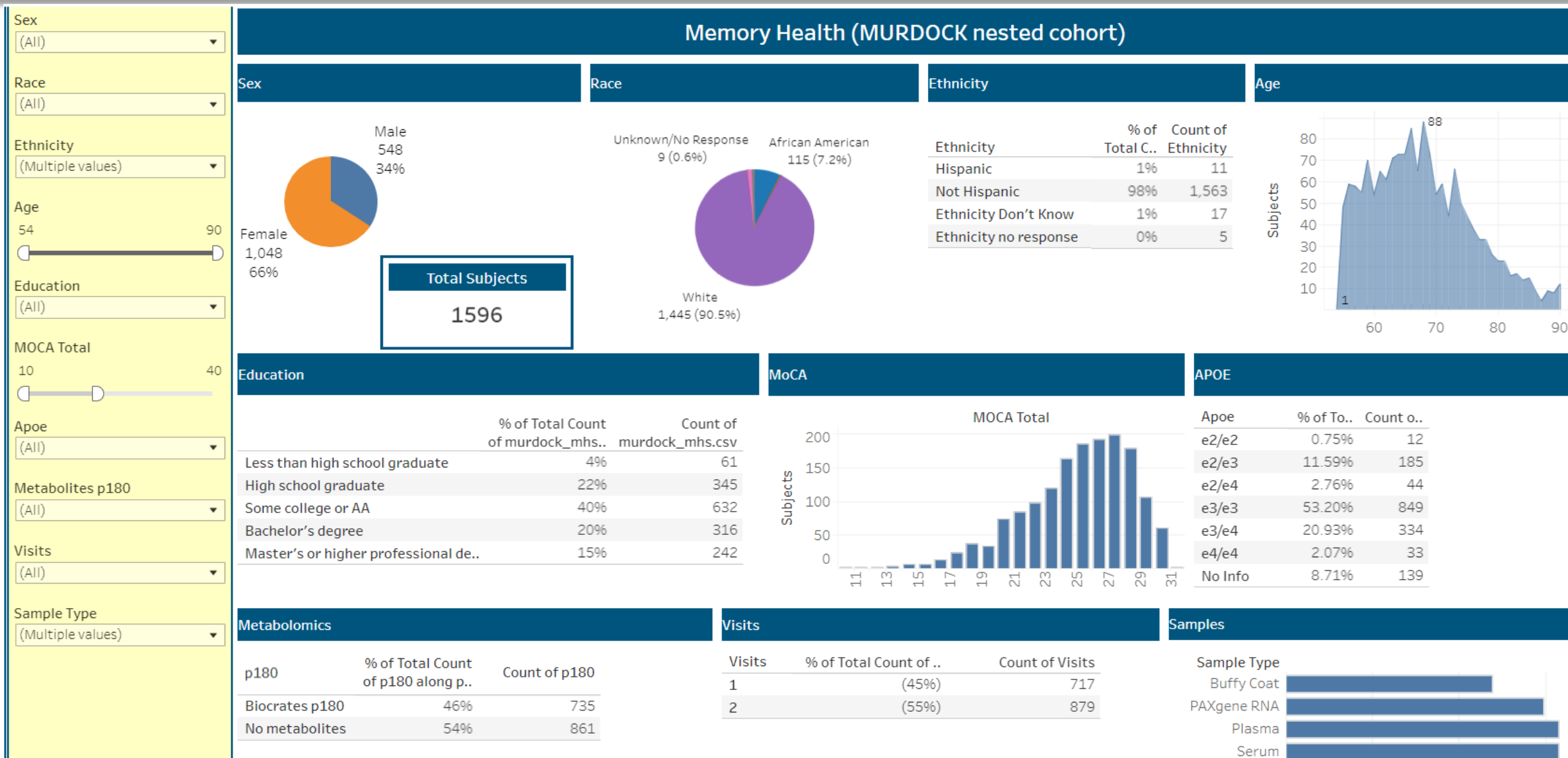


## Urban/Rural

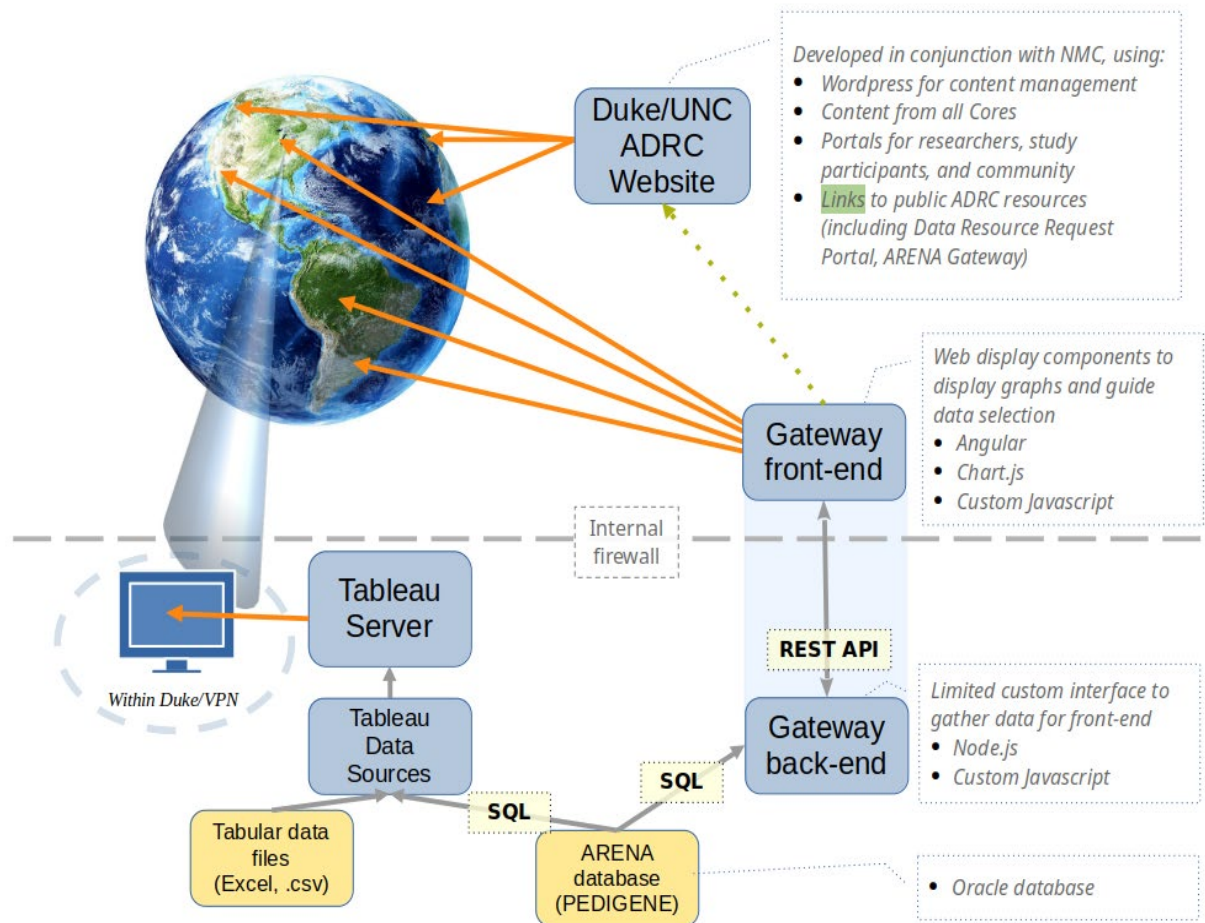


Data automatically updated 9/18/2024 5:00:59 AM

# Tableau report for resource in the ADRC ecosystem



# Development of Gateway and Tableau applications



- Chart.js - frequently used chart types, plugins, and customization options.
- Node.js - free, open-source, cross-platform JavaScript runtime environment that lets developers create servers, web apps, command line tools and scripts.
- Angular – platform and framework for building single-page client applications using HTML and TypeScript.



## Programming

- Requires learning programming environments
- Much easier to add new data sources to report (extensible)
- More control over report structure
- Free, open source software

## Tableau

- For “non programmers” easier to define a report but still a learning curve
- Would require each new visualization to be developed from start, many mouse clicks!
- Best for displays that “map” to business data visualization
- Requires computational infrastructure likely from an organization with technical support
- Costs – institutional and developer licenses

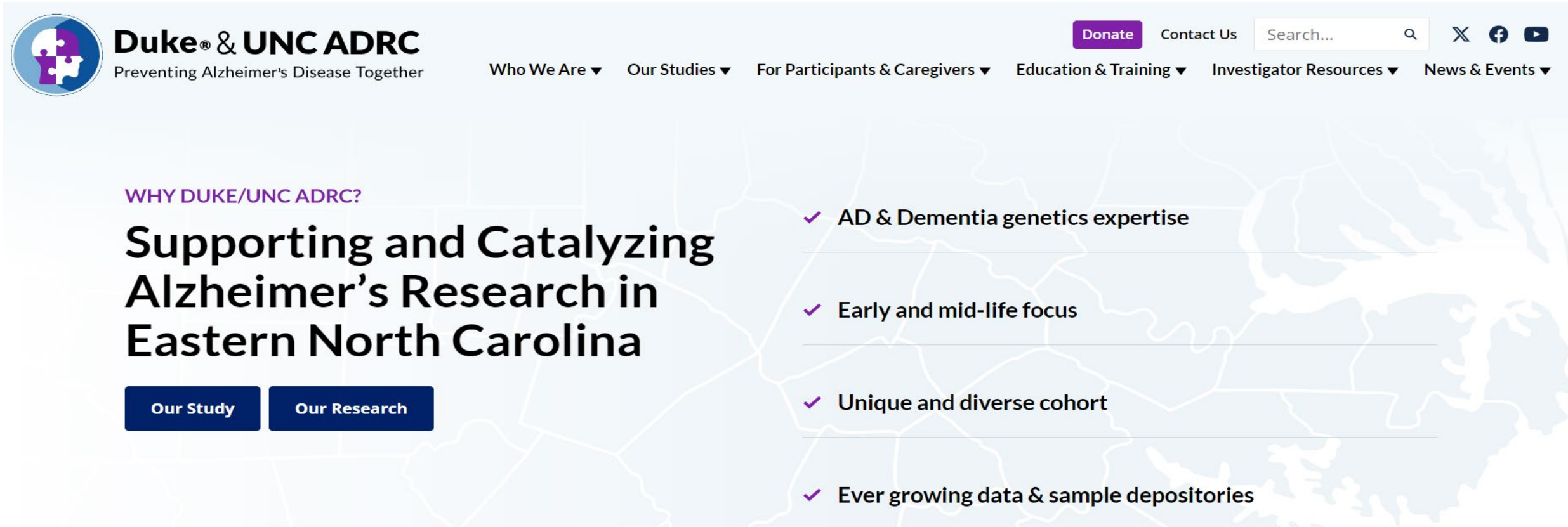


- Option to query completed resource requests to encourage collaboration/resource re-use (“R” in FAIR)
- Automatic generation of data use agreements (DUA) and MTAs from information submitted by investigator for resource request. Automatic routing of these documents for approval
- Expand, develop and publicize Investigator’s Resources page (ADRC 101)
- Implement participant tracking for individuals interested in participating in ADRD research with investigator interface for management.
- Information on additional resources (samples, data) added to the Center website as specific collaborative projects produce data.
- Curation and linkages to data from projects that utilized Center Resources

# See for yourself!



## Duke/UNC ADRC Website: <https://dukeuncadrc.org/>



The screenshot shows the homepage of the Duke & UNC ADRC website. The header includes the logo, the text "Duke® & UNC ADRC Preventing Alzheimer's Disease Together", and a navigation menu with items like "Who We Are", "Our Studies", "For Participants & Caregivers", "Education & Training", "Investigator Resources", and "News & Events". There is also a "Donate" button, a "Contact Us" link, and a search bar. The main content area features a map of the Eastern North Carolina region and a list of key features:

**WHY DUKE/UNC ADRC?**

### Supporting and Catalyzing Alzheimer's Research in Eastern North Carolina

[Our Study](#) [Our Research](#)

- ✓ AD & Dementia genetics expertise
- ✓ Early and mid-life focus
- ✓ Unique and diverse cohort
- ✓ Ever growing data & sample depositories

Contact: [Michael.lutz@duke.edu](mailto:Michael.lutz@duke.edu)



# Acknowledgments



Data Concierges: Colette Blach, Syam Gadde

ADRC Data Management team: Rodney Jones, Blair Chesnut, Scott Davis, Heather MacDonald, Colette Blach, Syam Gadde

Kansas ADRC: Suzanne Hunt, Russell Swerdlow

Wake Forest ADRC: Mark Espeland, Eric Fischer, Ramon Casanova

University of Washington ADRC: Robin Stillwell, Tung Le

Funding: [P30AG072958](#), Ruth K Broad Foundation

Duke/UNC Exec: Heather Whitson, Gwenn Garden, Sheng Luo, Sara Patillo, Brenda Plassman, Core leaders

Duke/UNC External Advisory Board



## Data Sources

### UDS Form – REDCap

Php wrapper calls REDCap API, inserted into PEDIGENE via scripts and Oracle functions.

Refreshed daily, Linux cron

40+ Tables

Transfer includes checks for REDCap format changes, cleaning for embedded line feeds

Reports to team on records requiring verification e.g. screening table records do not exist

Joins on a global identifier

### GlobalApp Consent information

SQL Server database, scheduled transfer of views/ Oracle materialized view

Refreshes Nightly

### Biomarkers

ETL as needed

### OnCore-Study Registration

ETL as needed

### Image metadata- Identifiers, key properties

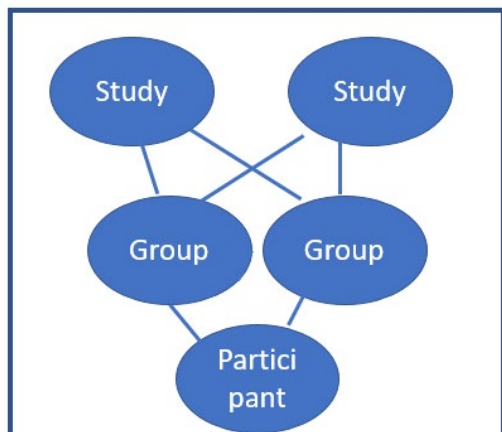
ETL

### Geocoding - ArcGIS Pro

ETL monthly Local Streetview data, census urban shapefile overlay

## PEDIGENE (Oracle 19, Linux Server)

Group and Demographics



Exams

Samples

Images

Security Database  
Database link,  
Context

## Data Reports and Tools

Arena Gateway and Locker Room

SQL and PEDIGENE Views

Enrollment Report

R, cron, refreshes daily

Sample Selection

One row per specimen,  
PEDIGENE Views

Operational Reports

Resource Request – monitoring and reporting

UDS Uploads – Consistency checks and QC

R, Oracle Views, SQL

Tableau view

One row per participant + queryable metadata  
Export to Tableau refreshes nightly

Slide courtesy Colette Blach