

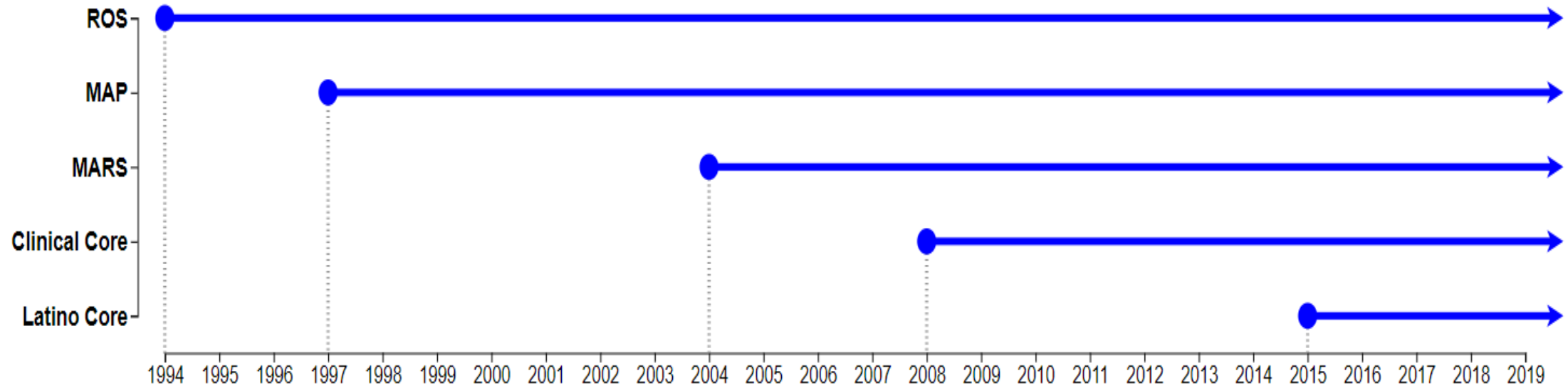
Spring ADC Meeting 2019

Data and Specimen Sharing
Tracking and Documentation

John Gibbons, MS

Data Manager / Manager Information System
Rush Alzheimer's Disease Center

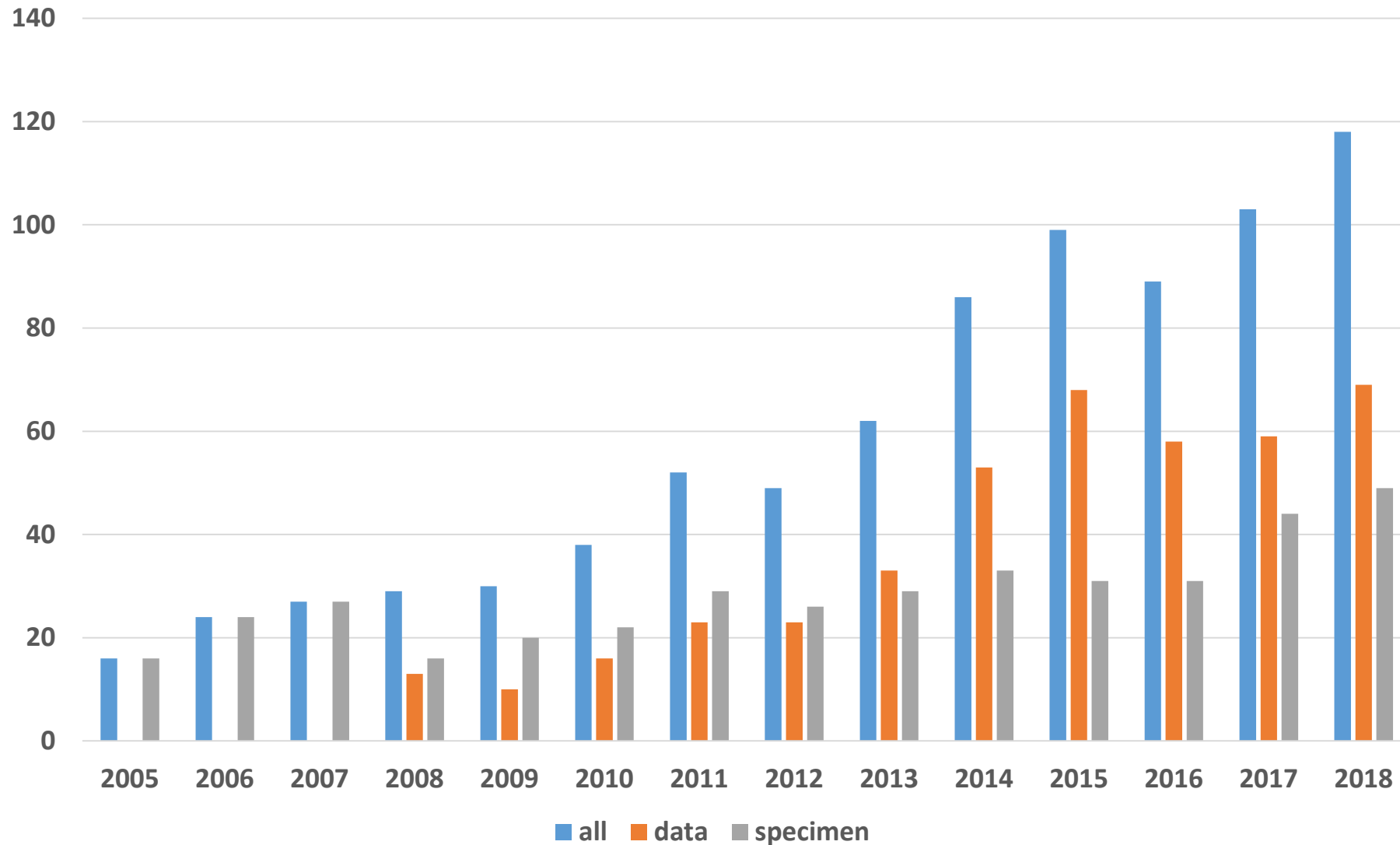
RADC Cohort Studies



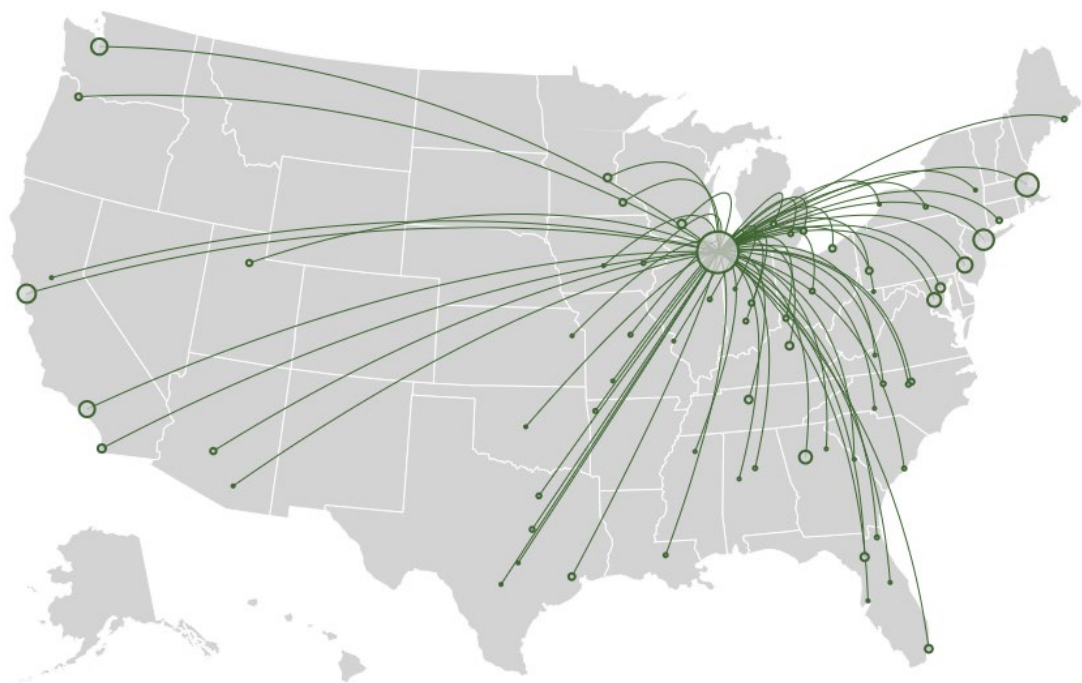
Data & Specimens

Study	Enrollment	Autopsy
ROS	1460	777
MAP	2159	828
MARS	758	27
Clinical Core	373	67
Latino Core	221	1
Total	4,971	1,700

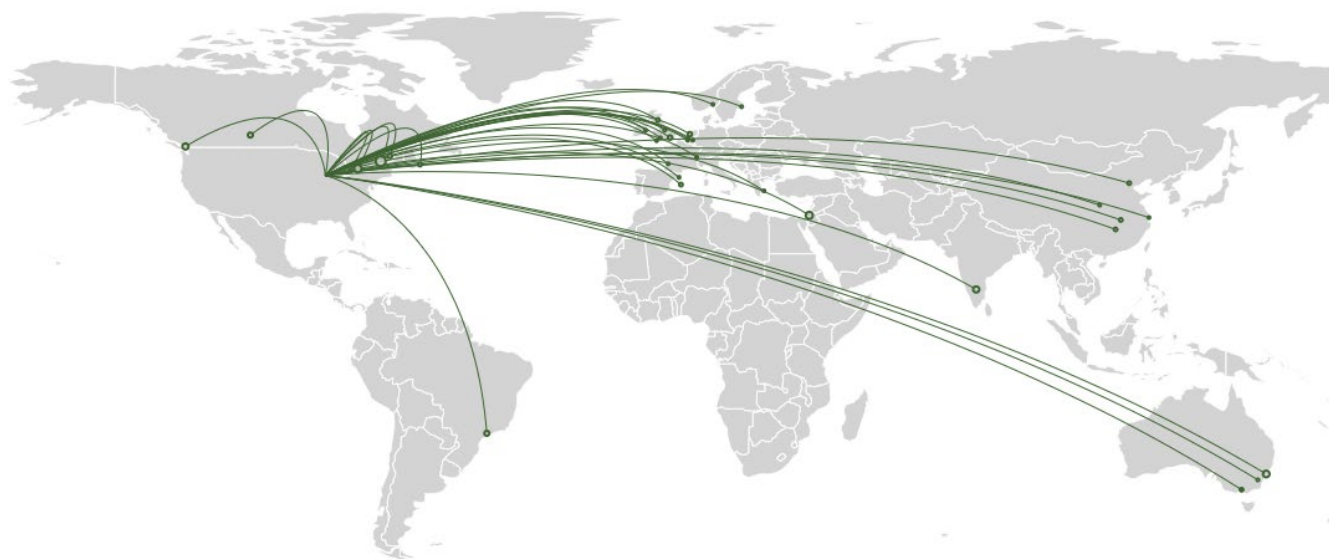
Data and Specimen Requests by year



National



International



Intake of
Requests



Fulfillment



Reporting

- Resource Sharing Hub
- Request Review Process
- DUA & MTA Tracking
- Specimen Selection

- Specimen Distributions
- Plating of Aliquots
- Generation of Data Sets and Codebooks

- Project States
- Tracking Shipments
- Tracking Specimen Distribution

Central Relational Database – SQL



- Participant information
 - Unique identifier
 - Consent to studies and repositories
- Research data
 - Cognitive, interview, device, MRI, -omics
- Computed variables
 - Documented
 - Processed from item-level data
 - Evolve over time
- External Requests for data, specimens
- Biospecimen inventory
- Aggregated data for analytics

Central Relational Database – SQL

Intake of Outside Requests



Laboratory Processes and Specimen Shipping



Compute Variables /
Aggregate Data



Study Data Collection

- Laptops – computer assisted interviewing forms
- Web-based forms

Internal Website



Research Resource Sharing Hub - www.radc.rush.edu

- Documentations
 - Studies / Sub-studies
 - Variables
 - -omics
 - Imaging
- Data Availability Reports
- Requests
 - Biospecimens
 - Limited Data Sets
 - Subject Recruitment

RADC Research Resource Sharing Hub [Log In](#)

Your vision

Our data

The **Rush Alzheimer's Disease Center (RADC)**, one of 29 Alzheimer's disease (AD) Research Centers across the country designated and funded by the **National Institute on Aging (NIA)**, is dedicated to supporting research about the cause, treatment, and prevention of AD, other dementias, and a range of other common chronic conditions of aging. The many RADC studies generate an enormous variety of unique data and biospecimens to support this effort. RADC faculty and staff are committed to sharing these resources with the wider aging and AD research community to accelerate the pace at which new knowledge is created for the treatment and prevention of dementia and other age-related chronic neurologic conditions, and have distributed data **across the United States and the world**.

The **RADC Research Resource Sharing Hub** was specifically designed to help you, the non-RADC investigator, navigate the complex data and biospecimens available for sharing, and to assist you in identifying data and biospecimens that you can use to support your own projects. We invite you to explore the site, see what is available, and submit your data and/or biospecimen request.

—David A. Bennett, MD, Director of RADC

Browse Documentation
Learn about RADC cohort studies through enrollment and autopsy timelines, and study design papers. Explore organized categories of available data such as omics, cognitive assessments, and neuropathology. Search documentation of variables and data collection procedures.





Query Frequency Reports
Generate reports on participant frequency for selected criteria, broken down by demographics. Use the Data Availability Report to examine RADC data and biospecimen availability and determine how available resources match a project's requirements. Use the Longitudinal Report to examine participant frequency across multiple waves of assessments.


Request Data/Specimens
Submit a request for data, biospecimens, or personal identifiers. Learn about the request submission, review, and distribution processes including requirements for material transfer and data use agreements.

Request Form

1. Principal Investigator
2. Co-Investigators
3. Study Information
4. Specimen
5. Experimental Plan
6. Other Information
7. Upload Documents
8. Review and Submit

Co-Investigators

	Name	Institution	Will receive the specimens?
 Update  Remove	Marie Curie	University of Paris	YES
 Update  Remove	Albert Einstein	Institute for Advanced Study	YES

 Add Investigator

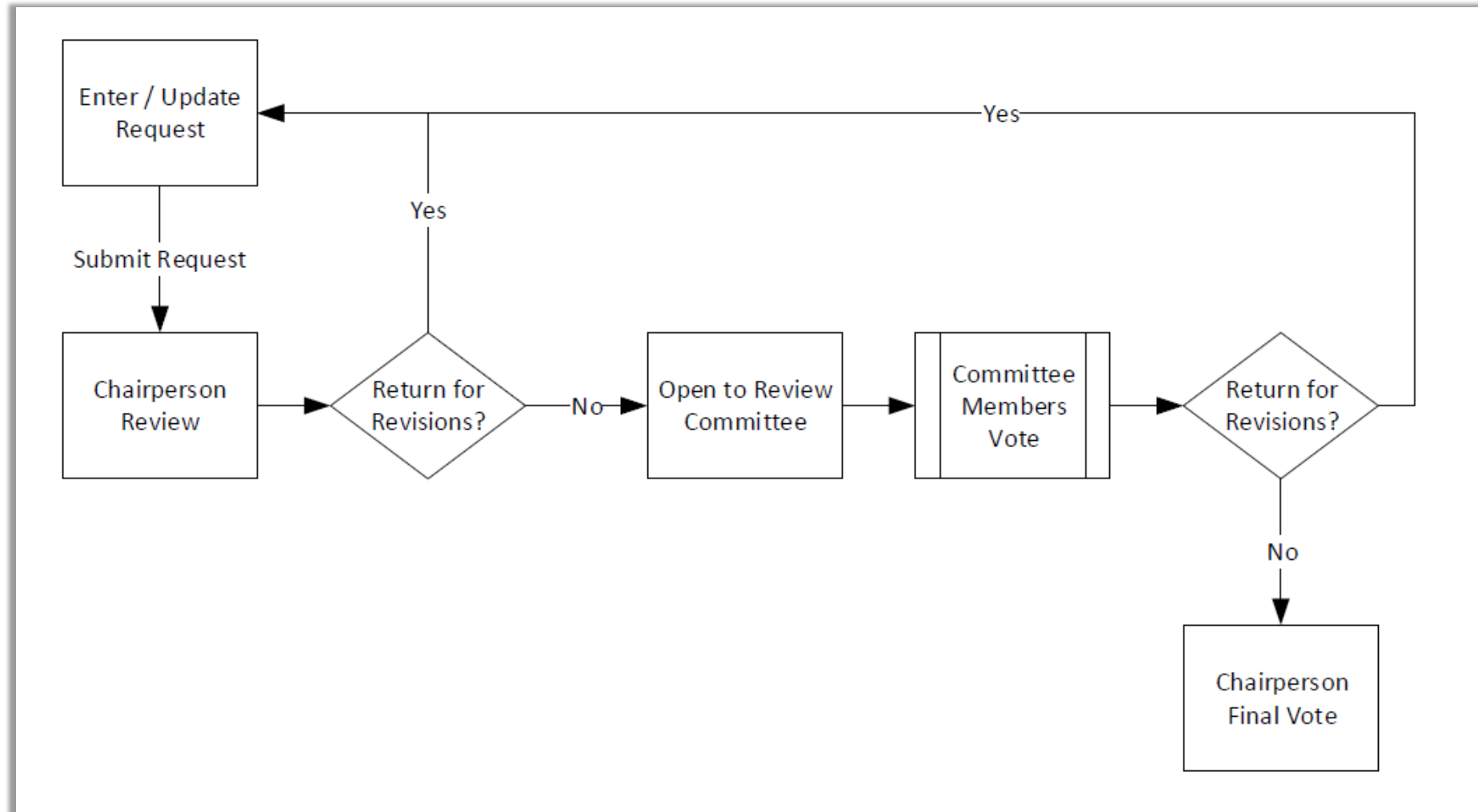
Specimen

Specimen requested

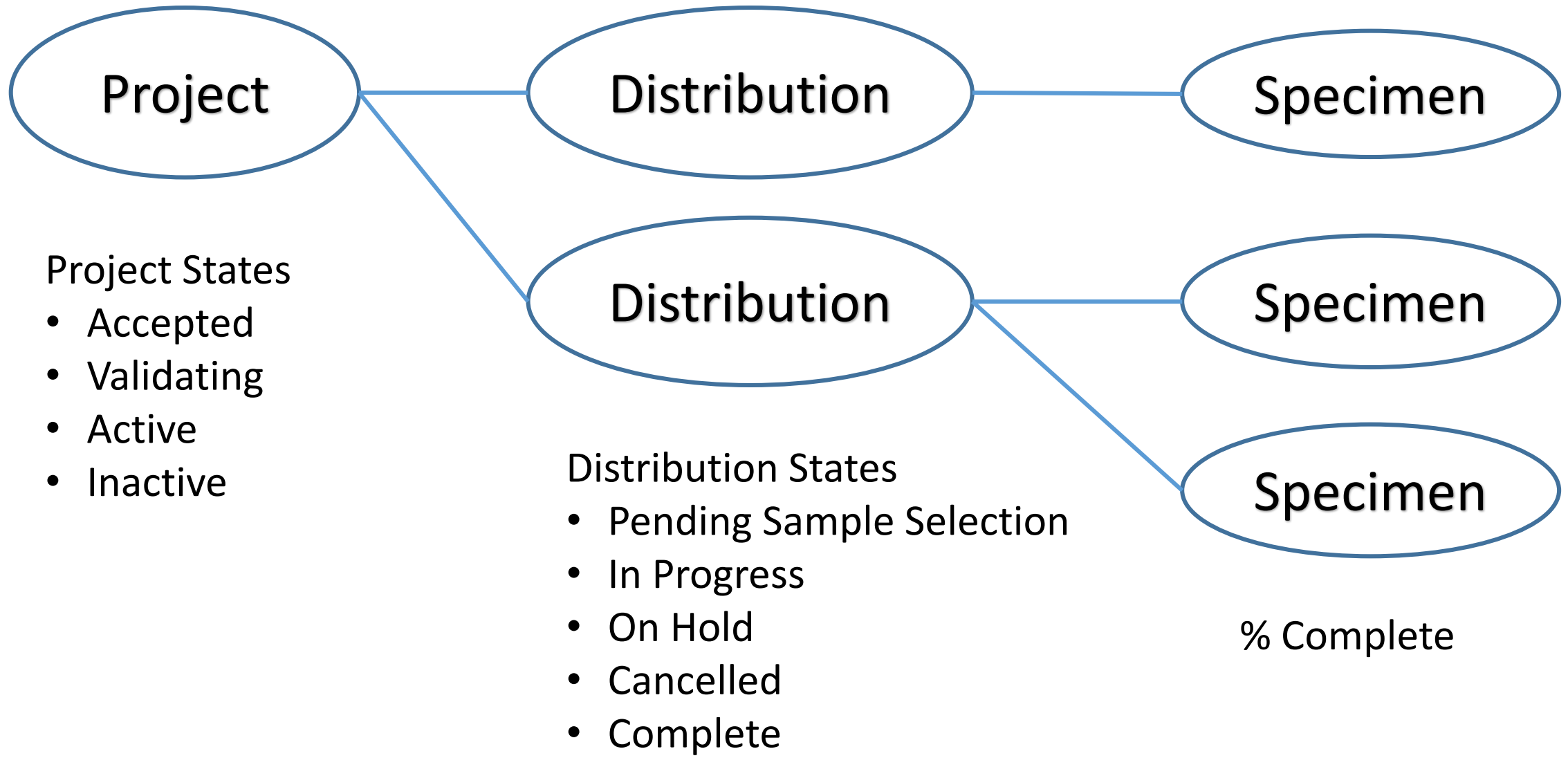
Procedures to be done on specimen

Specify number of cases and clinical diagnoses

Request Committee Review Process



Accepted External Request = Internal Project



Internal Tracking – MTA & DUA, Distributions

Project	(649) Neurobiologic Study or Cognitive Decline	Submitted	09/06/2012
Type	Specimen	Project State	VALIDATING
Institution	Rush	Status	Accepted - Active
PI	John Gibbons	Duration	Normal
Co-Investigators	Alec Burgess - Rush Yan Li - University of Southern California		
RADC Collaborator	David Bennett		

Jump to: [Project Summary](#) | [MTA](#) | [Voting History](#) | [Addendums](#) | [Documents](#) | [External Documents](#) | [Datasets](#) | [Discussion](#)

Distributions

	Current State	Distribution # - Name ↓	Created By - On	Last Distributed On	Distribution Completion (%)	Selection Completion
Display	PENDING_SAMPLE_SELECTION	100549 - Serum May 2016	John Gibbons - 04/12/2019		0	Incomplete

MTA Status

	Investigator Name	MTA Required	MTA Submitted	MTA On File	Date Submitted	Staff
Add MTA	John Gibbons (PI)	Yes	No	No		
Update MTA	Alec Burgess	Yes		No		
Update MTA	Yan Li	Yes		No		

Project Actions

[✎ Modify the project](#)

[📁 Upload project document](#)

[📄 Edit external documents](#)

[+ Add a new distribution](#)

[⚙ Set as inactive](#)

[🔄 Set as ongoing project](#)

[📊 Recalculate completion](#)

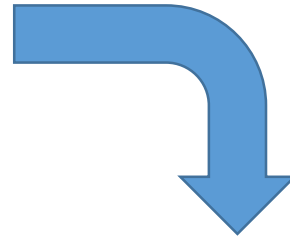
[🖨 Printable Project Summary](#)

[View Specimen Source Form](#)

Internal Tracking - Specification of Specimens

Specimen

Specimen requested



Specimen	Brain ▼	Total Distributions Requested	60
Fixation	Frozen block / pieces ▼	Completion Tracking Method	Algorithm ▼
Region Code	1101 - pre-frontal cortex (include brodmann areas 10-12, 32) ▼		
Samples / Cases	20 NCI / 20 MCI / 20 AD		
Sample size	5 grams		
Neuroanatomic location	DLPFC		
<input type="button" value="Save Changes"/> <input type="button" value="Cancel"/>			

Internal Tracking – Specimen/Participant Selection

Many factors to consider:

- Requested inclusion/exclusion criteria
- Protection of “high value” samples
 - Baseline
 - Proximate to death
 - Last collected
- Is there statistical sampling?
- Are there multiple of clinical and pathological diagnoses to consider?

Support team:

- Data Sharing Coordinator
- Data Management Team
- Statistics Team
- Rush ADC Collaborator

Intake of
Requests



Fulfillment



Reporting

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Fulfillment > Aliquot Selection

Serum and Plasma are relatively simple – single aliquots are shared

DNA is more complex

- Amount in aliquots varies
- Concentration and purity need to be QC'd
- May need extraction from frozen brain, sediment, or lymphocytes

DNA-specific aliquot workflows

- Pull to QC → Sub-aliquot
- Pooling → QC → Sub-aliquot
- Extraction (frozen brain or PBMC) → QC → Sub-aliquot

Fulfillment > Aliquot Selection

Workflows

Aliquot Selection

Extraction

Web / Excel

Pooling

Web / Excel

Sub-aliquoting

Web / Excel

Actions

Project Settings

DNA Selection Tool

Add Projid

Listings

Samples by Projid

Omitted Projids

Virtual Freezer Samples

Transaction Samples

Home > Lab Home > [Plating Projects List](#) > DNA for Project #100 / Dist. # 321

DNA for Project #100 / Dist. #321

Transaction Name : req_100542

Distribution Sample : DNA

Sample Types in Project : DNA, BTDNA, PBMC, PBMCd, Brain

Projid Source : DEFINED_LIST

Previously failed QC

Previously failed extraction

Aliquot from being pooled

Aliquot from being extracted

Not Selected **250**

The participants below have not had any aliquots selected for extraction, pooling, or sub-aliquoting.

1

0123456

DNA Source and Current Amounts

BTDNA + DNA: 0.00

DNA Samples/Sources

PBMC 5.57 (2)

Studies & Active Status

MAP: Active

Actions

Omit from project

	Aliquot ID	Sample Type	Sample Date	Visit	Ali. Cur. Amt.	DNA Conc.	DNA Purity	DNA Extract Date	Freezer Section	Loc1	Loc2	Loc3	Loc4
<div></div>	1468706	PBMC	01-15-2016	00	2.786				CRYO 6	Subdivision 1	RACK 2	BOX 7	Position 53
<div></div>	1468707	PBMC	01-15-2016	00	2.786				CRYO 6	Subdivision 1	RACK 2	BOX 7	Position 54

2

10123456

DNA Source and Current Amounts

BTDNA + DNA: 0.00

DNA Samples/Sources

PBMC 2.06 (1)

Studies & Active Status

MAP: Active

Actions

Omit from project

	Aliquot ID	Sample Type	Sample Date	Visit	Ali. Cur. Amt.	DNA Conc.	DNA Purity	DNA Extract Date	Freezer Section	Loc1	Loc2	Loc3	Loc4
<div></div>	1422304	PBMC	03-22-2018	00	2.064				CRYO 5	RACK 26	BOX 3	Position 59	0

Fulfillment > Tracking Distributions

1.



Tracks lab activities

- Tags aliquots for shipment
- Sub-aliquot process
- Create shipping manifest

2.

Web-based form...

- slides
- Paraffin embedded blocks



Laboratory Processes and Specimen Shipping



Web Services
API

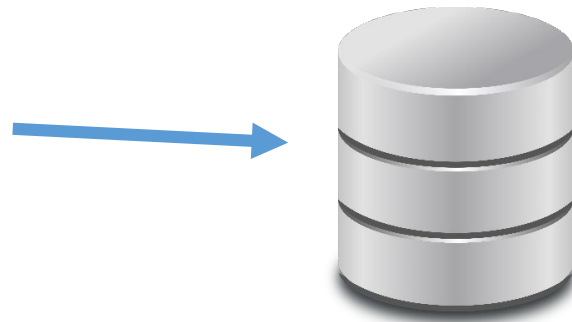
Aliquots Processes

Aliquot ID	Sample Type	Sample Date	Vial	Aliq. Amt.	DNA Conc.	DNA Purity	DNA Extract Date	Freezer Section	Location
001486	DNA	05-26-2014	01	0.8	1.524	1.85	08-02-2017	UF 35	Shelf 1 RACK 3 BOX 5 Position 26
001486	DNA	05-26-2014	02	0.8	1.524	1.85	08-02-2017	UF 35	Shelf 1 RACK 3 BOX 5 Position 26
107159	PSMAC	05-26-1994	00	3.3				CRTD_LNH	RACK 1 BOX 4 Position 29
987510	MTDNA	11-08-2008	06	2.4	0.1	1.87	10-09-2014	UF 35	Shelf 3 RACK 4 BOX 28 Position 06

Fulfillment Data > Computed Variables System

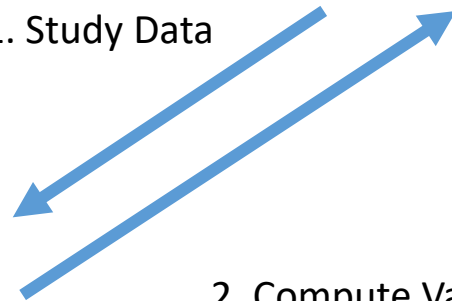
Study Data Collection

- Laptops – computer assisted interviewing forms
- Web-based forms



1. Study Data

Nightly Processing



2. Compute Variables

Central system to document computed variables that are updated nightly.

- 72 database tables
 - 35 longitudinal tables
 - 13 scaled tables
 - 15 table containing special forms of longitudinal variables
 - Baseline
 - Ever
 - Last valid

Fulfillment Data > Computed Variable

Episodic Memory

Property	Value
Name	cogn_ep
External Label	Episodic Memory
Category	Cognition / Domains
Availability	DUA / Hub / External
Type	Longitudinal / Scaled
Short Description	Episodic memory domain – Average or 7 tests
Long Description	See the hub!

Scaled to individual and combinations of studies.

“Cross sectional” in forms:

- Baseline
- Ever
- Last valid
- Cumulative

Fulfillment Data > **Data Sets** of Computed Variables

A custom data set is created for each project linked to each project.

1. Collection of Participants by:

- Study, Studies, or Substudy
- Data Criteria
 - Device data
 - Neuropath approved
 - In-vivo MRI
 - Ex-vivo MRI
- Specific list of identifiers

Linked to a specific project

Automatic generation of a custom codebook in a web-based single page format.

Data sets automatically generated as Excel and CSV

2. Collection of Variables

Distributions tracked by:

1. Date
2. Participant identifiers
3. List of included variables

Fulfillment Data > Data Sets of Computed Variables

RADC

Computed Variables

Variables ▾

Data Sets ▾

Stat ▾

Admin ▾

Search

John ▾

#893 — Gibbons P9871

ID745

NameGibbons P9871

StudyROS

Restriction TypeDATA_USE_AGREEMENT

PurposeDATA

Description

Data Set

Summary

Download Data and Codebooks

+ Scaled Variables

+ Nonscaled Variables

+ Add List of Variables

Admin Actions

☒ ID inclusion criteria

Settings

Data Set Overview

Categories

Characteristics

Alzheimer's disease : 4

ApoE : 1

Autopsy - General : 1

Beta-Amyloid : 3

Demographics : 5

Final consensus diagnosis : 1

Hippocampal sclerosis : 1

Lewy body/PD : 1

PHF tau tangles : 2

TDP-43 : 1

Vascular - General measures : 3

Vascular - Infarcts (Presence of) : 2

Cross-sectional: 25

Longitudinal: 0

Scaled: 4

Not Scaled: 21

Special Forms: 0

Normal: 25

Intake of
Requests



Fulfillment



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Project States Report

Project ID	Project State	Primary Investigator	Distribution ID	Distribution State	Sample types
649	VALIDATING	John Gibbons	100549	PENDING	
122	ACTIVE	Yan Li	100188	ON_HOLD	BRAIN [FROZEN BLOCK PIECE] — All MAP frozen brain x 6 regions <ul style="list-style-type: none"> ◦ VMC: 50 mg ◦ PPUT: 50 mg ◦ MF (BA9/46): 500 mg ◦ IT (BA20): 500 mg ◦ HIP, mid: 500 mg (full cross section) ◦ CALC (BA17): 500 mg
122	ACTIVE	Alec Burgess	100266	ON_HOLD	BRAIN [FROZEN BLOCK PIECE] — All ROSMAP frozen brain <ul style="list-style-type: none"> ◦ MF (BA9/46) - Region code 1100: 10 mg (2mm punch) x 3
567	VALIDATING	Maylene Liang	100526	PENDING	BRAIN [FROZEN BLOCK PIECE] — 45 (with frq) - Check in May 2019 for availability <ul style="list-style-type: none"> ◦ MT (21): 1 gram ◦ MF (9/46): 1 gram ◦ AWS: 1 gram ◦ CBM: 1 gram
1042	ACTIVE	John Gibbons	100300	IN_PROGRESS	BRAIN [FRESH TISSUE] — 150 prospective MAP/ROS with PMI <ul style="list-style-type: none"> ◦ Prefrontal cortex (BA10) - Region code 1101 replaced MF (BA9/46) - Region code 1100 in October 2015. Region changed back to Midfrontal gyrus in April 2016.: 1.5 x 1.5 x 1.0 cm ◦ AWS. Replaced anterior corpus callosum, region code 2078 8/2016 rej.:

Specimen Distribution Report

Start Date:

4/15/2018

End Date:

4/15/2019

Distribution Filter:

- ☒ All
- ☐ ROS Only
- ☐ Clin Core Only
- ☐ Latino Core Only
- ☐ All ADC
- ☐ MAP only
- ☐ MARS only

Submit

Sample Type	Total	Unique
SER	839	487
PLA	239	135
DNA	220	216
TISSUE	131	51
CSF	958	731
UNKNOWN	60	60
PBMC	45	44
BRAIN	8621	1357

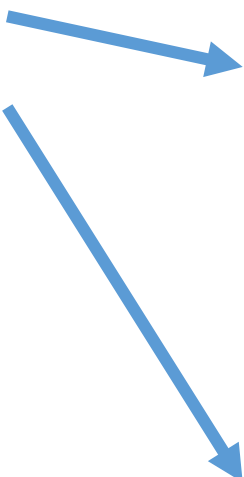
- Unique ROS projids distributed: 646
- Unique Clinical Core projids distributed: 82
- Unique LATC projids distributed: 0
- Unique ADC projids distributed: 728
- Unique MARS projids distributed: 141
- Unique MAP projids distributed: 797
- Total ROS distributions: 3243
- Total Clinical Core distributions: 124
- Total Latc distributions: 0
- Total ADC distributions: 3367
- Total MARS distributions: 286
- Total MAP distributions: 7460
- Unique PIs : 37
- Total projects : 41

Data Distribution Tracking > Ad Hoc Reports

Data Set ID	Distribution ID	Distribution Date
839	1059	5/2/2019

Distributions tracked by:

1. Date
2. Participant identifiers
3. List of included variables



The diagram shows two blue arrows originating from the 'Distribution ID' column of the first table. One arrow points to the 'Distribution ID' column of the second table, and the other points to the 'Distribution ID' column of the third table.

Distribution ID	ProjID
1059	00000136
1059	12399988
1059	34588343
1059	34588734

Distribution ID	Variable Name
1059	cogn_ep
1059	cogn_se
1059	cogn_global
1059	braak
1059	cerad

Team

David Bennett MD, Director

Annie Barz, ADC Administrator

John Gibbons, Data Manager

Alec Burgess, Data Programmer

Yan Li, Data Programmer

Tiffany Wu, Data Programmer

Greg Klein, Data Sharing Coordinator

Maylene Liang, Data Documentation Specialist

Ryan Johnson, Laboratory Manager, Pathologists' Assistant

Karen Skish, Laboratory Manager, Pathologists' Assistant

Srabani Mondal, Manager RADC Lab