



# ACT U19 Clinical Core Achievements

Linda K McEvoy

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[Linda.K.Mcevoy@kp.org](mailto:Linda.K.Mcevoy@kp.org)

# The Adult Changes in Thought Study



- a longitudinal cohort study of older adults recruited from an integrated healthcare delivery system.
- Focused on determining risk and protective factors across the life course to better understand risk and etiology of Alzheimer's disease and related dementias (ADRD), with the long-term goal of promoting cognitive health in aging.

# Mission of the Clinical Core



- To rigorously collect data and samples in support of ACT's research objectives, Program Projects, Ancillary Studies, and the broader aging and ADRD research community.

# ACT U19 Clinical Core Goals

- **Expand** the cohort from a steady state of 2000 dementia-free participants to 3000.
- **Increase** the representativeness of the cohort.
- **Establish** a blood-based biorepository using best recommended practices to enable measurement of current and future blood-based biomarkers.
- **Modernize** data collection
- **Consent** participants for brain donation and maintain contact to enable rapid procurement.
- **Ensure** state-of-the-art quality control and documentation of all data collected in conjunction with the Admin and Data and Analysis Cores.

# ACT Enrollment

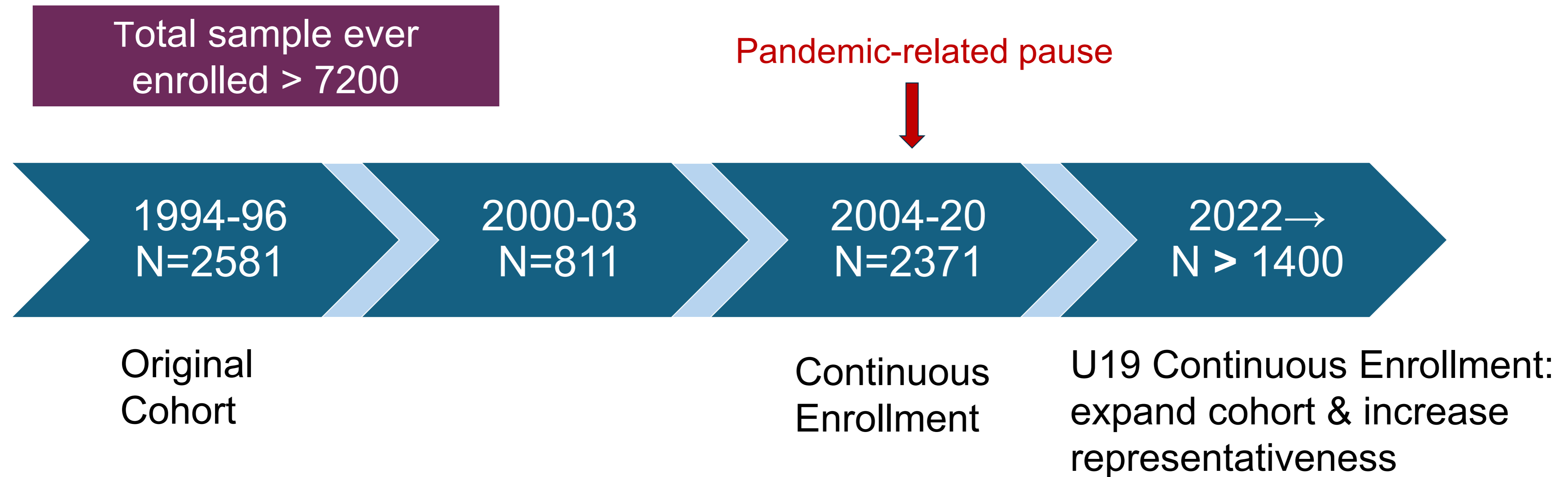


We randomly\* select Kaiser Permanente Washington Health members to invite to participate, using data from the Virtual Data Warehouse to invite members of different racial groups and Hispanic ethnicity.

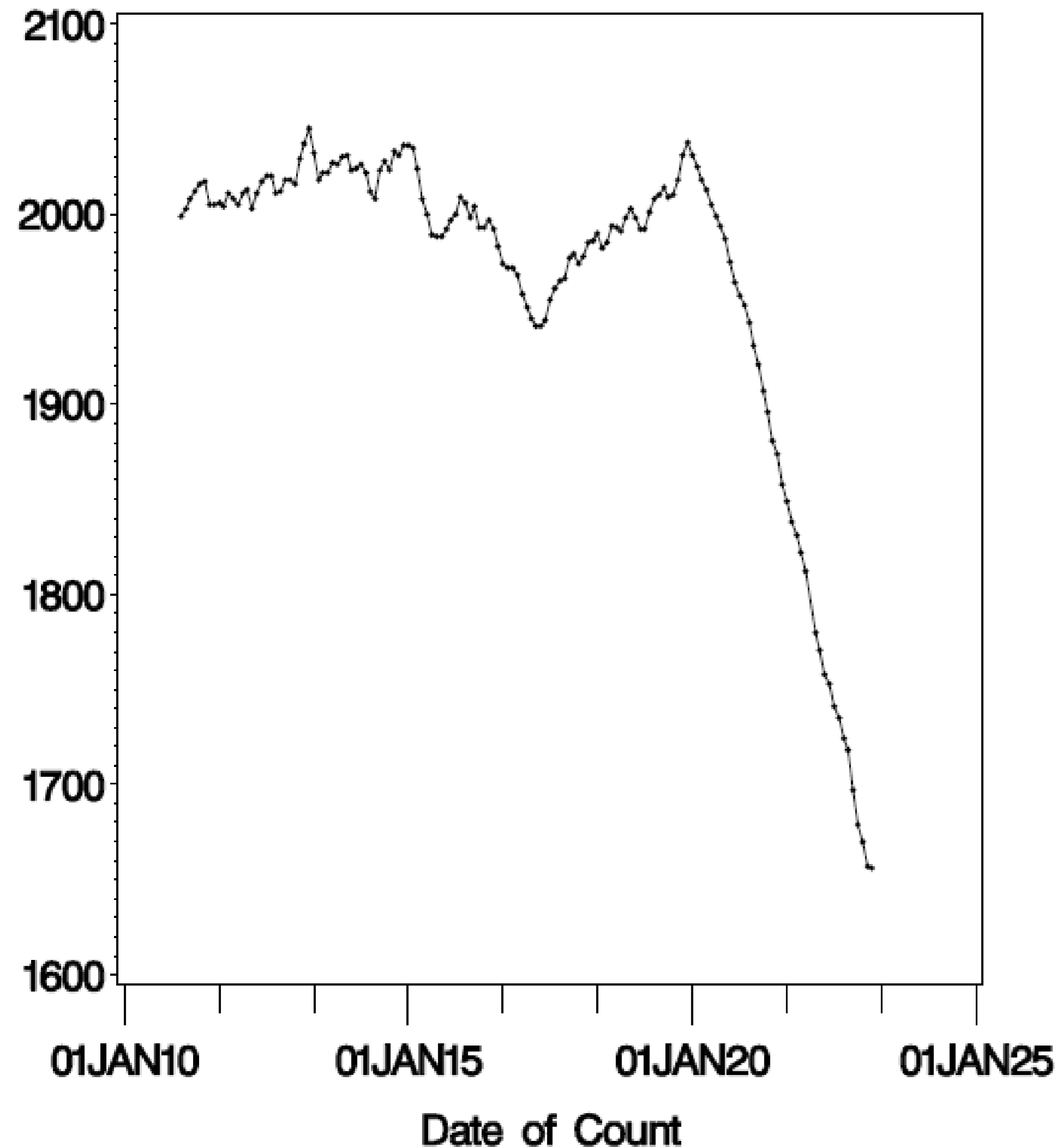
Inclusion criteria:

- At least 65 years of age
- Free from dementia at time of enrollment
- Able to speak and read English and have sufficient visual and hearing abilities to complete tasks.
- Enrolled in the health plan for at least 2 years (*median 20 years*)
- Receive primary health care from one of our catchment clinics in the greater Seattle area of King County

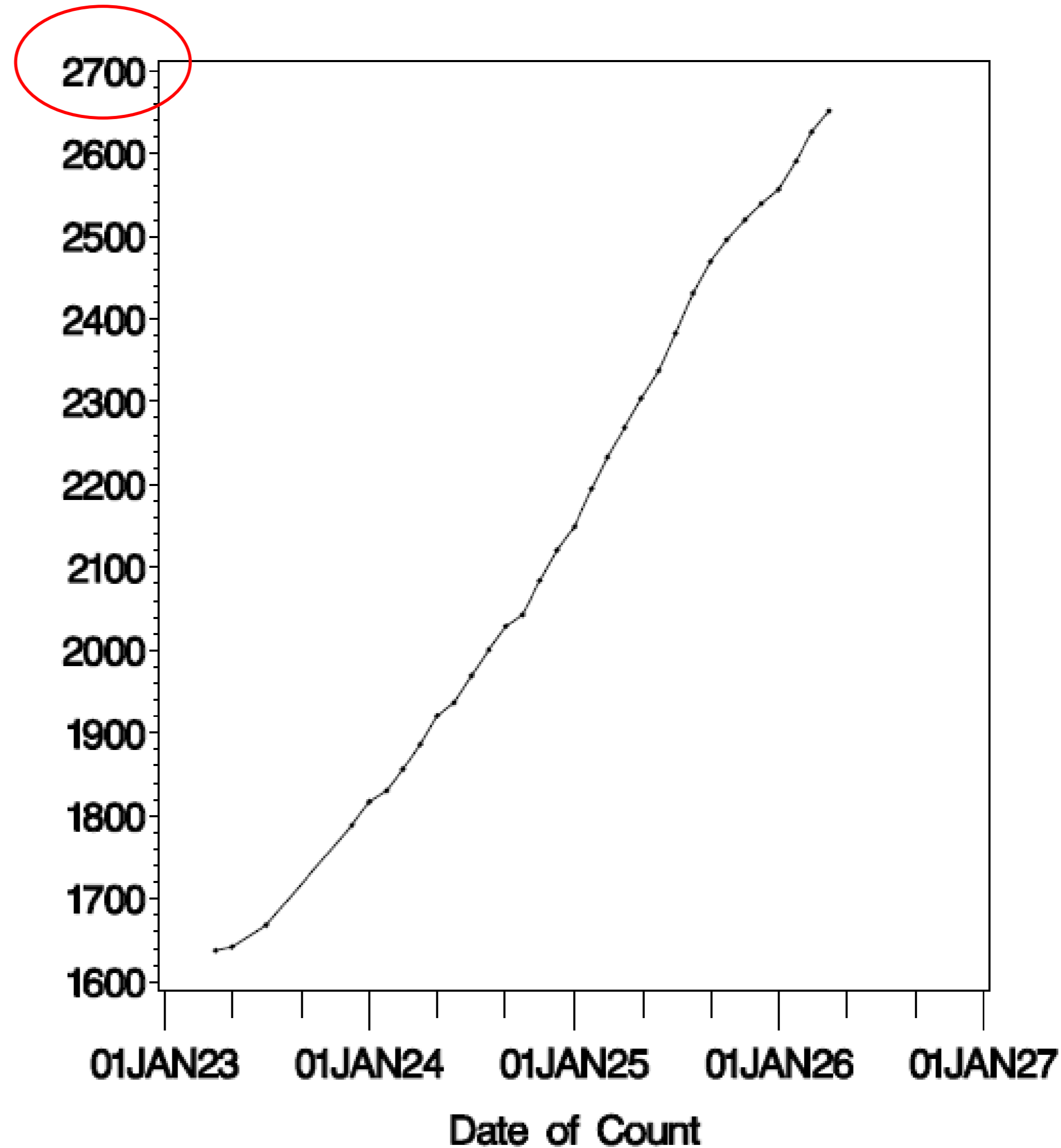
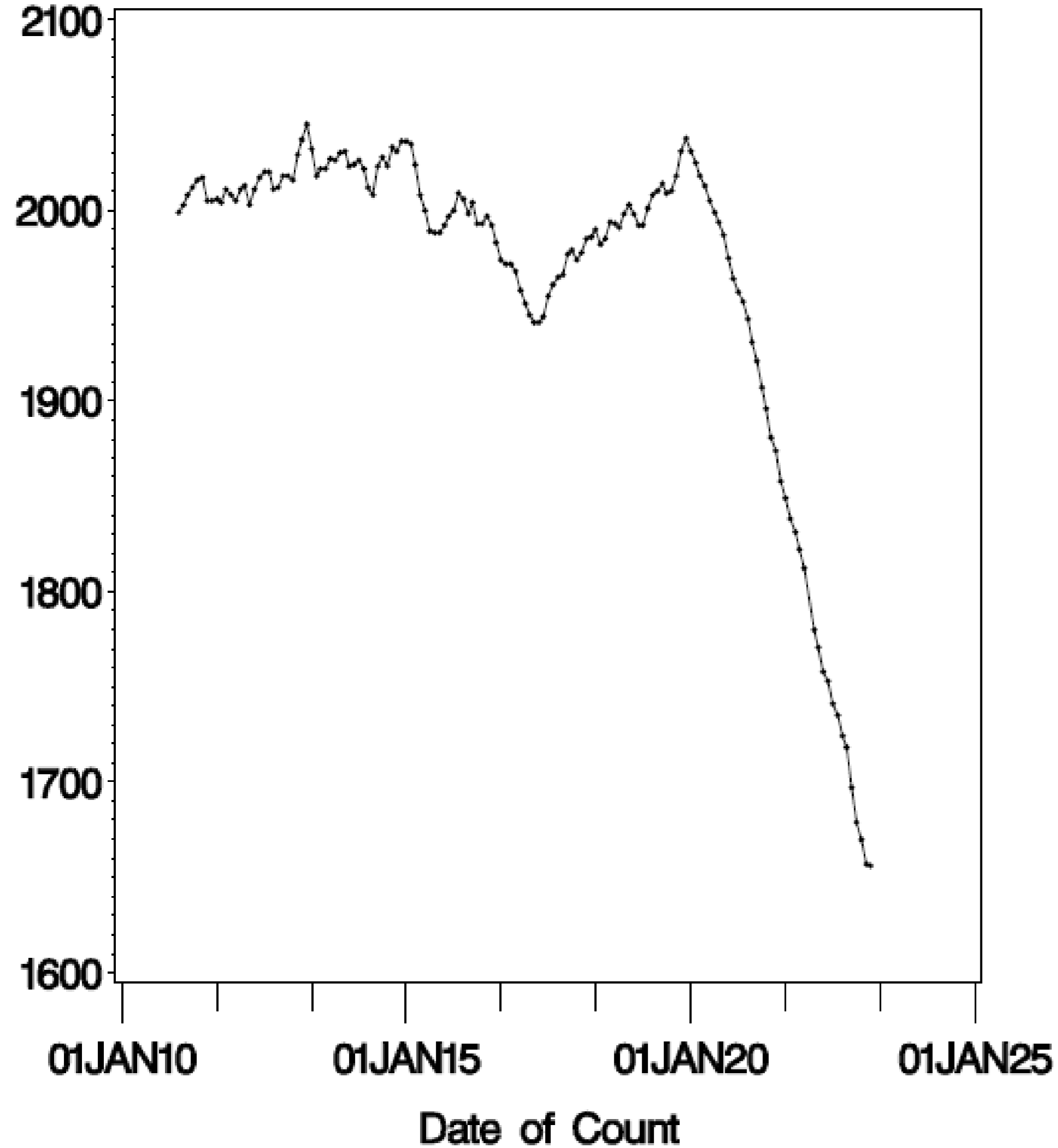
# History of ACT Enrollment



# Impact of the Covid-19 Pandemic on Active (Biennial) Cohort Size

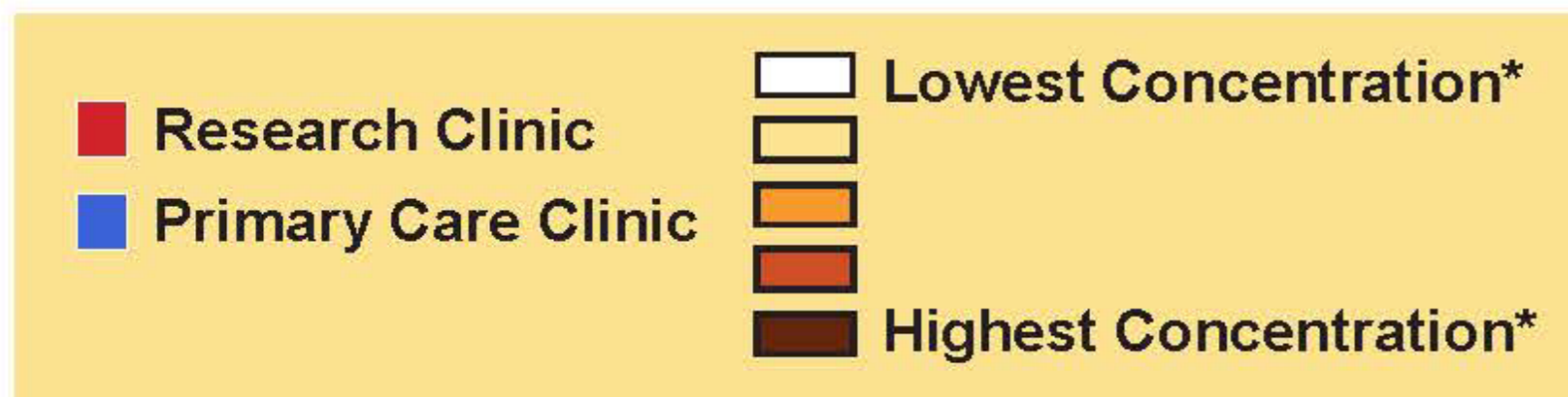
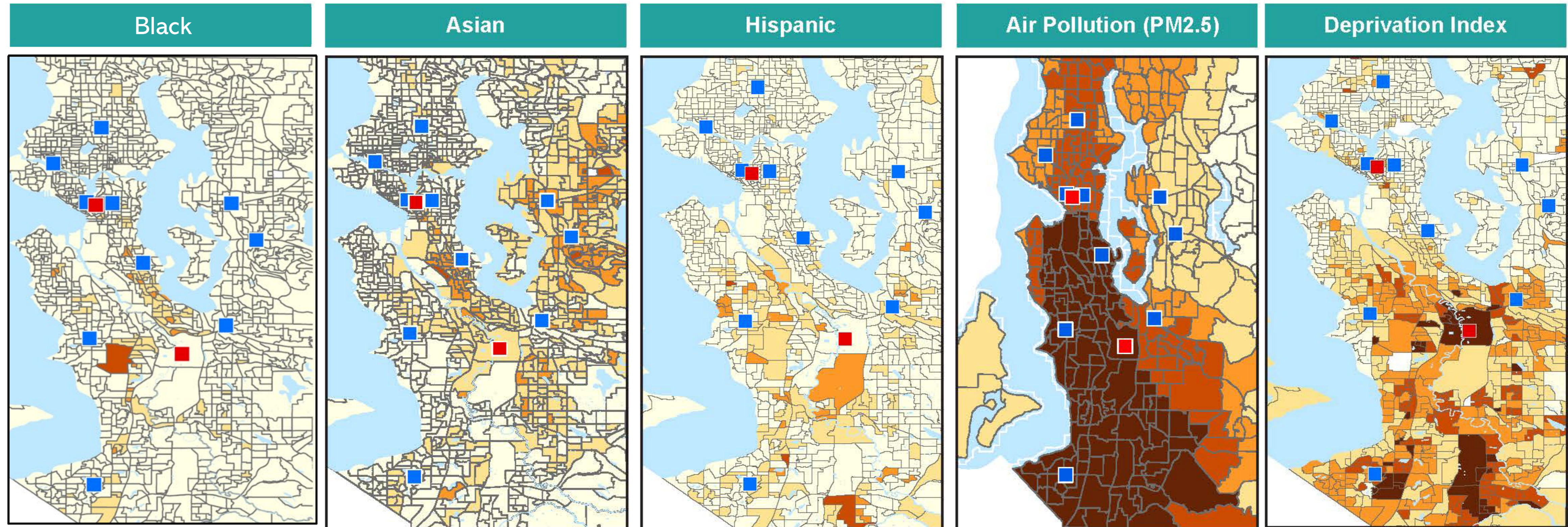


# Post-Pandemic Cohort Recovery



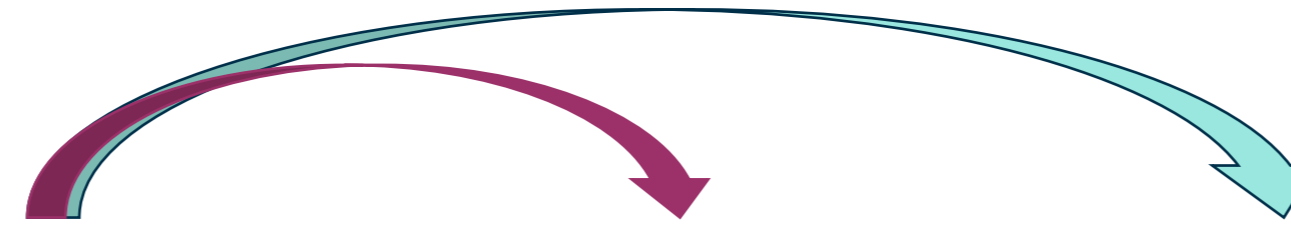
**N=2652**  
04/01/2026

# Recruitment from a population with representation across demographic and environmental exposures



\*Area Deprivation Index: Least disadvantage (ADI=1-2) to Most disadvantage (ADI=9-10)  
 Race and Ethnicity: 0-20% to 80-100%  
 Air Pollution: Lowest WA state quintile (~3.8 - 5.5  $\mu\text{g}/\text{m}^3$ ) to highest WA state quintile (~7.1 - 7.9  $\mu\text{g}/\text{m}^3$ )

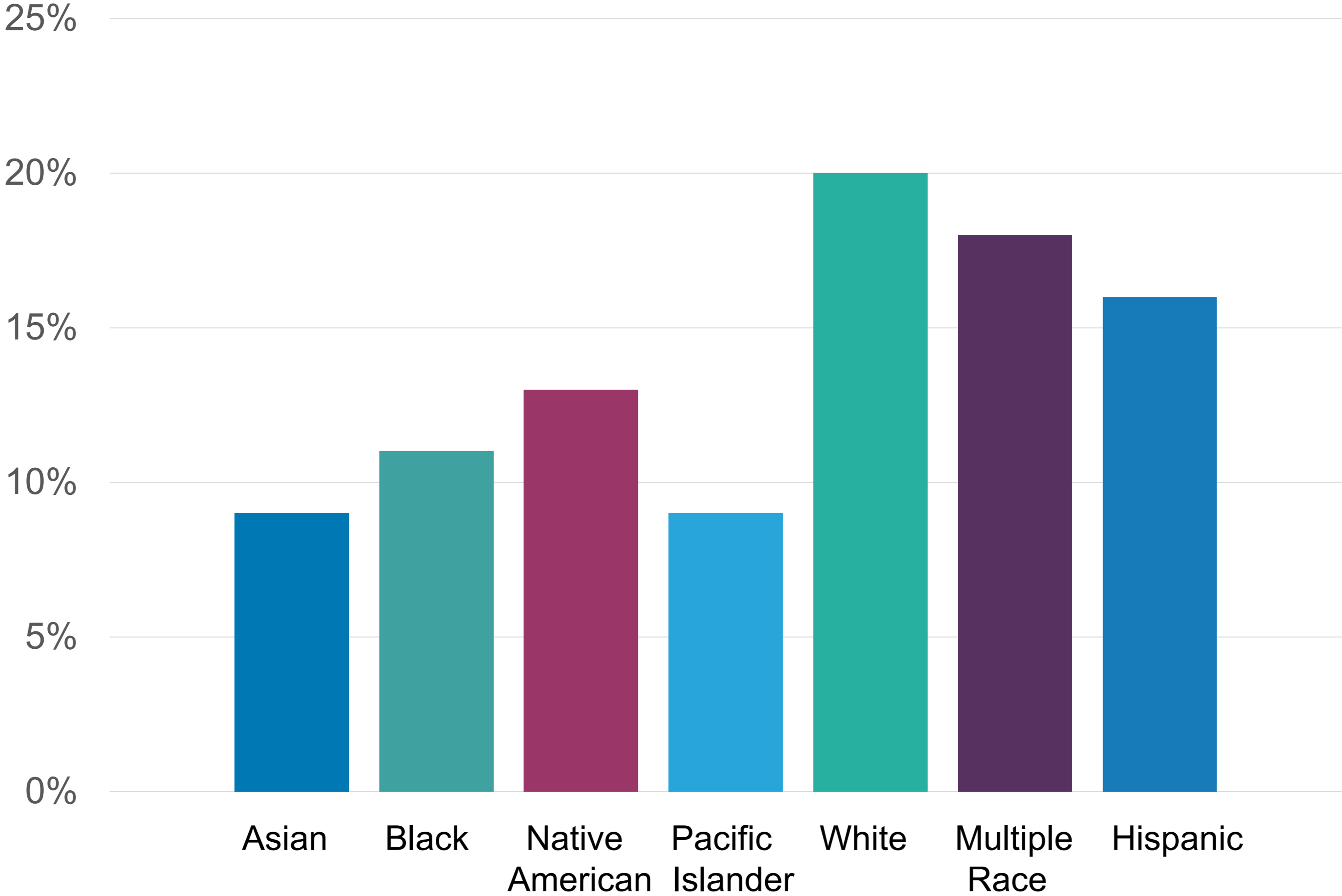
# Cohort Diversity



	U19 New Enrollees		Biennial Cohort		Ever Enrolled	
	N	%	N	%	N	%
Asian	259	18	296	11	453	6
Black/ African American	150	10	185	7	366	5
Native American	15	1	17	< 1	31	<1
Pacific Islander	8	< 1	9	< 1	20	<1
White	823	58	1926	73	5918	82
Multiple	69	5	73	3	123	2
Other	76	5	86	3	112	2
Unknown	29	2	41	2	170	2
<b>Total</b>	<b>1429</b>	<b>100</b>	<b>2633*</b>	<b>100</b>	<b>7193*</b>	<b>100</b>
<b>Hispanic</b>	162	11	194	7	309	3

\*as of 03/11/2026

# Enrollment Rate

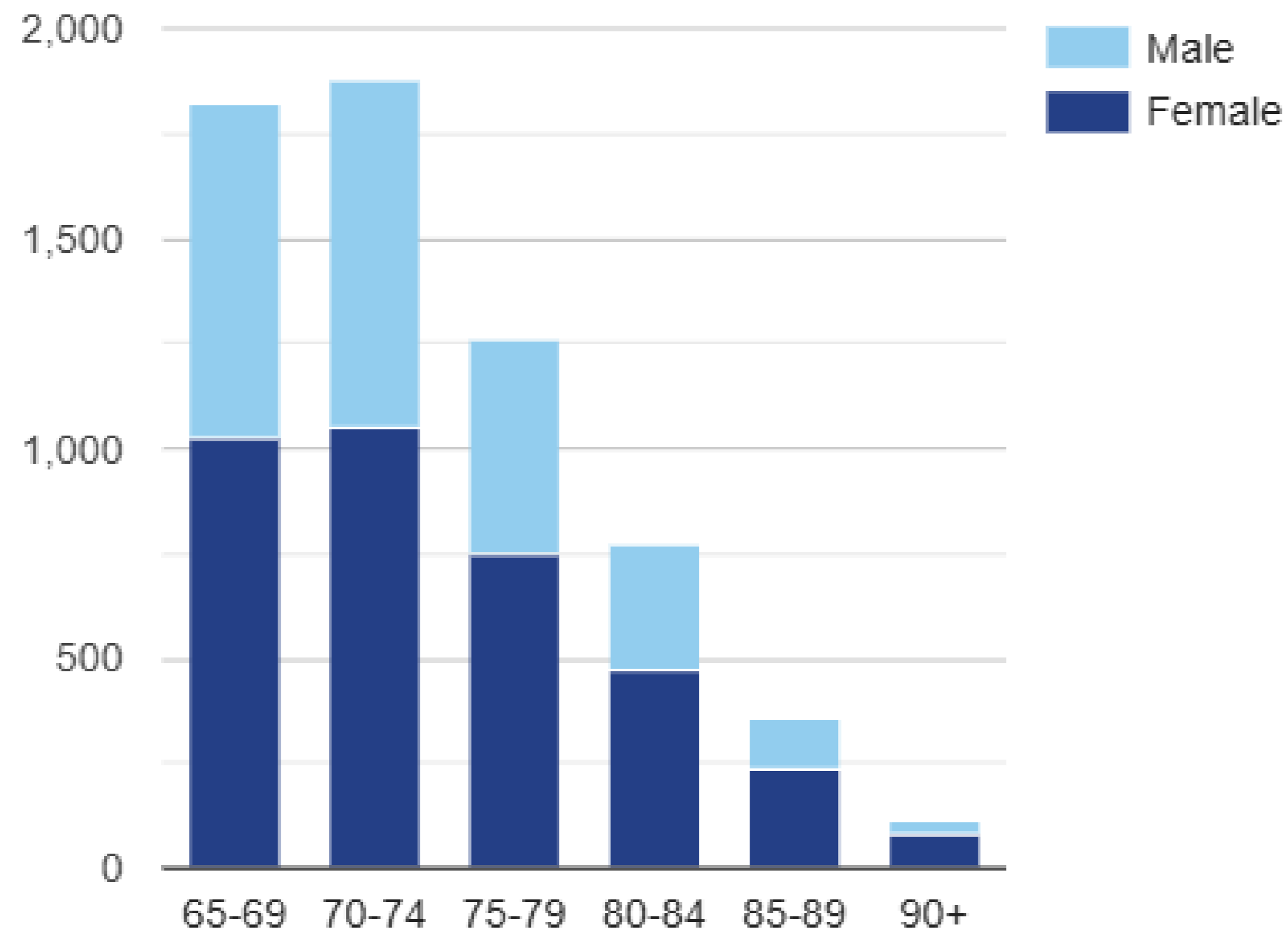


Little difference in rates of eligibility, refusal.

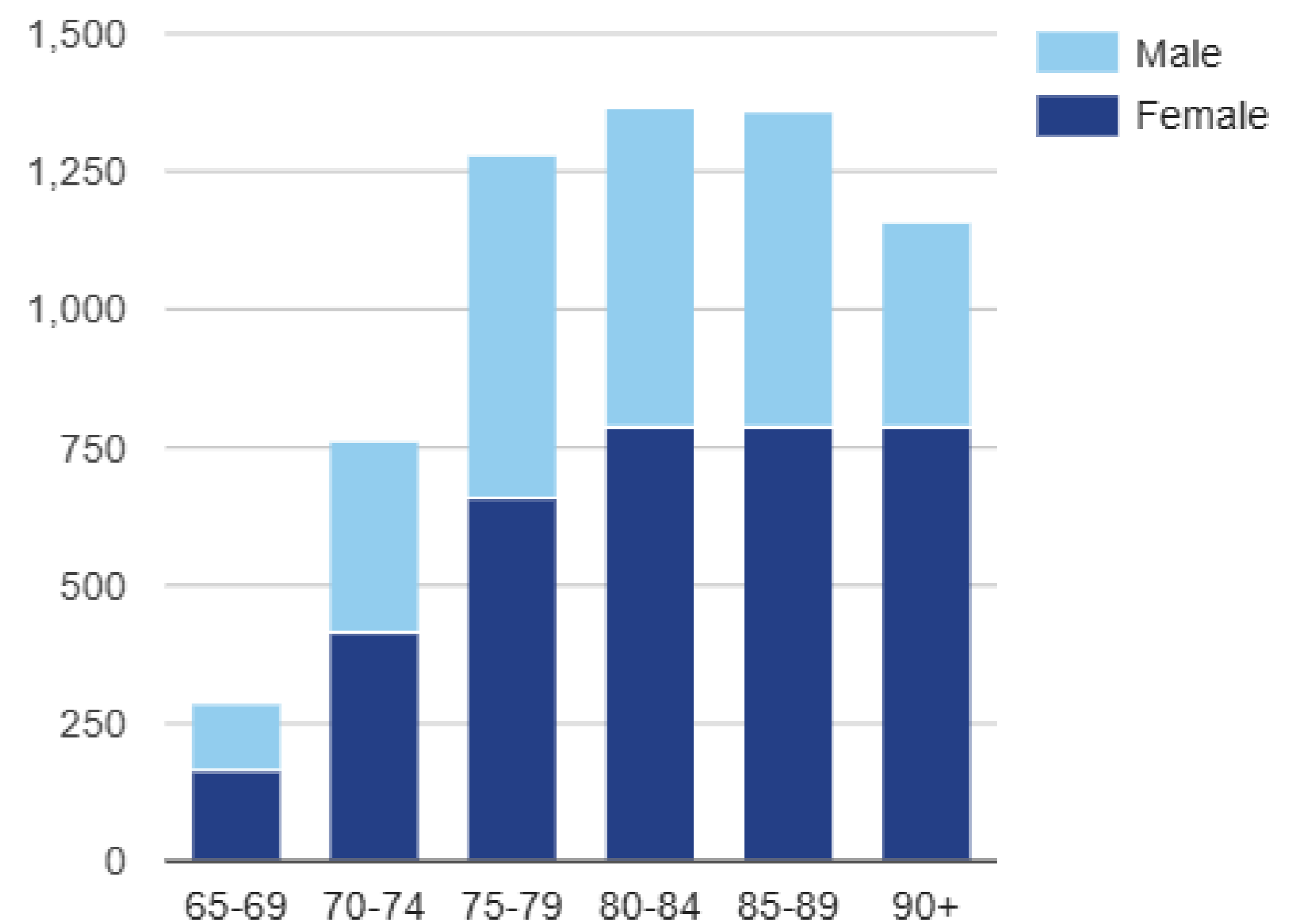
Larger differences in rate of inability to contact.

# Cohort Demographics

### Age at Enrollment

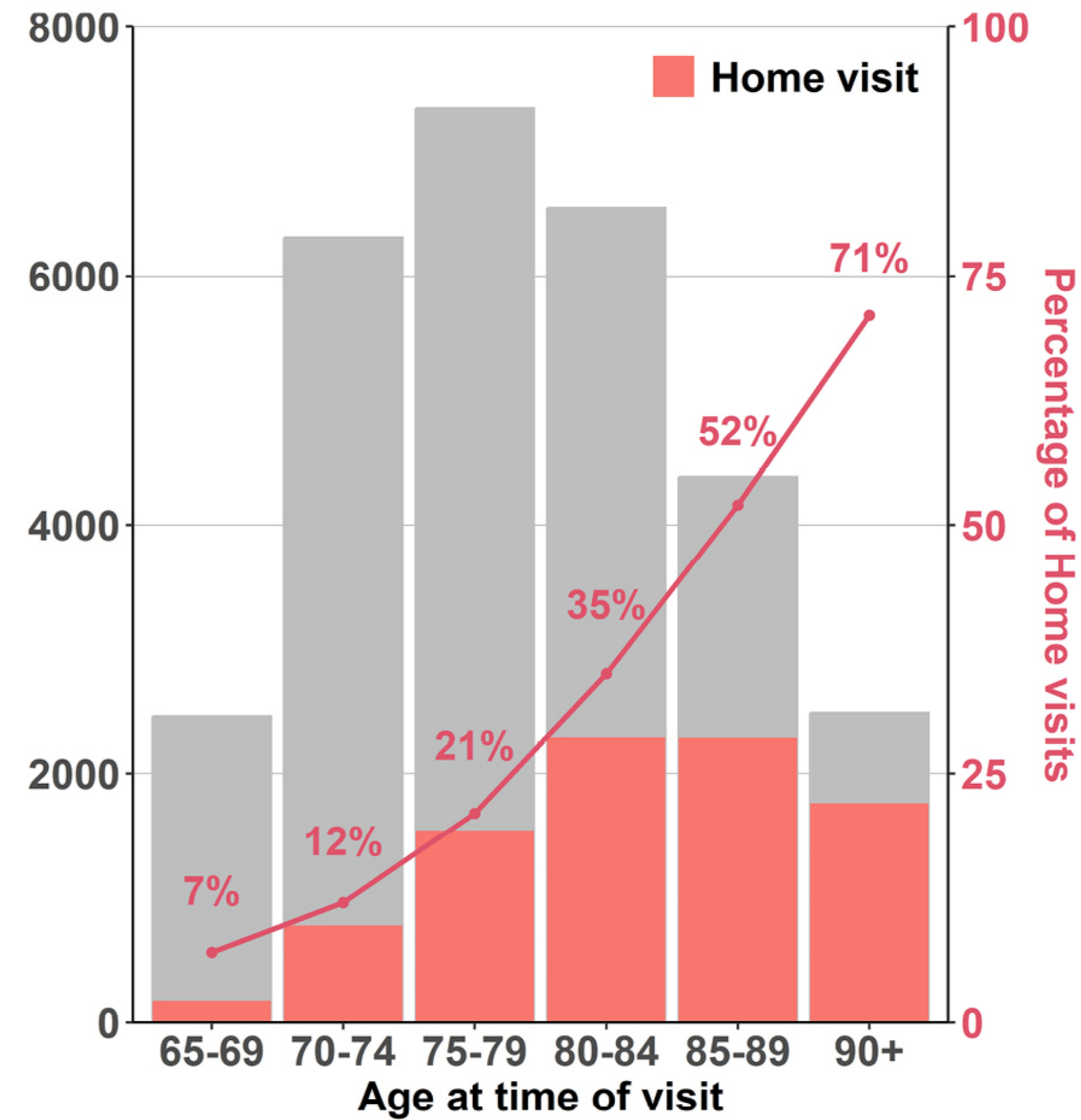
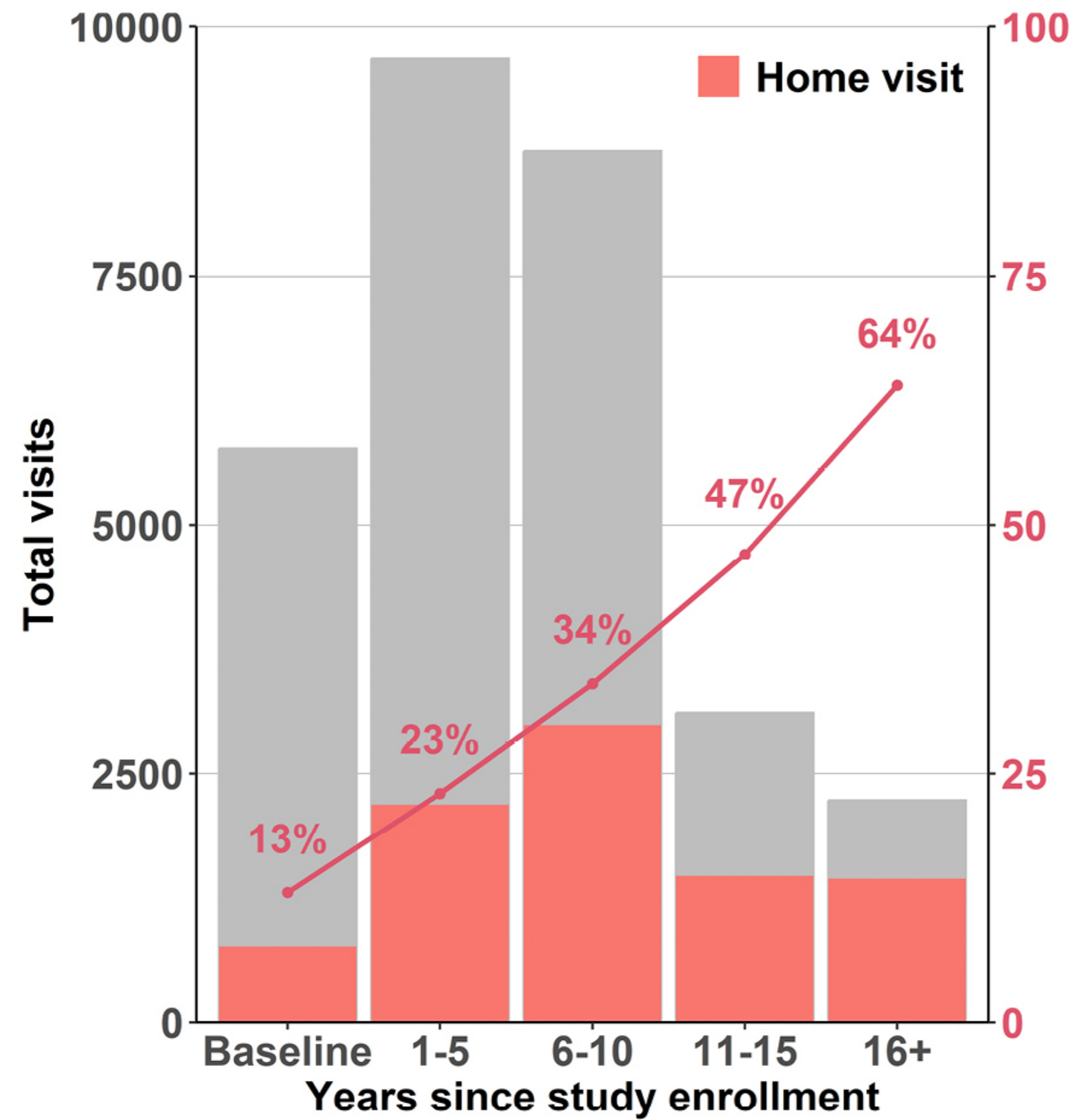


### Age at Most Recent/Last Visit



*Summaries from our public-facing data query tool on our website*

# Importance of Home Visits



# Rigorous Diagnosis of Dementia

- Evaluation triggered by a CASI score <86; or concern.
- Medical chart review; neuropsychological evaluation; neurological evaluation
- Consensus meeting to review findings:
  - DSM IV criteria for dementia and NINCDS-ADRDA criteria for probable and possible AD; DSM V diagnostic criteria added in U19
  - NINDS-AIREN, California, and DSM-IV criteria for vascular dementia.
- Those who are determined not to have dementia (including those with MCI) continue to be followed with biennial visits. Those with dementia are followed with annual phone check ins (“annual cohort”), or not enrolled, if evaluation is triggered at baseline visit).

**>1500 participants have been diagnosed with dementia; 80% with possible or probable AD**



# Establish a Blood-Based Biorepository

**Goal:** obtain samples from each participant once per funding cycle.

**Achievements:** in collaboration with NCRAD established protocol to enable measurement of plasma biomarkers.

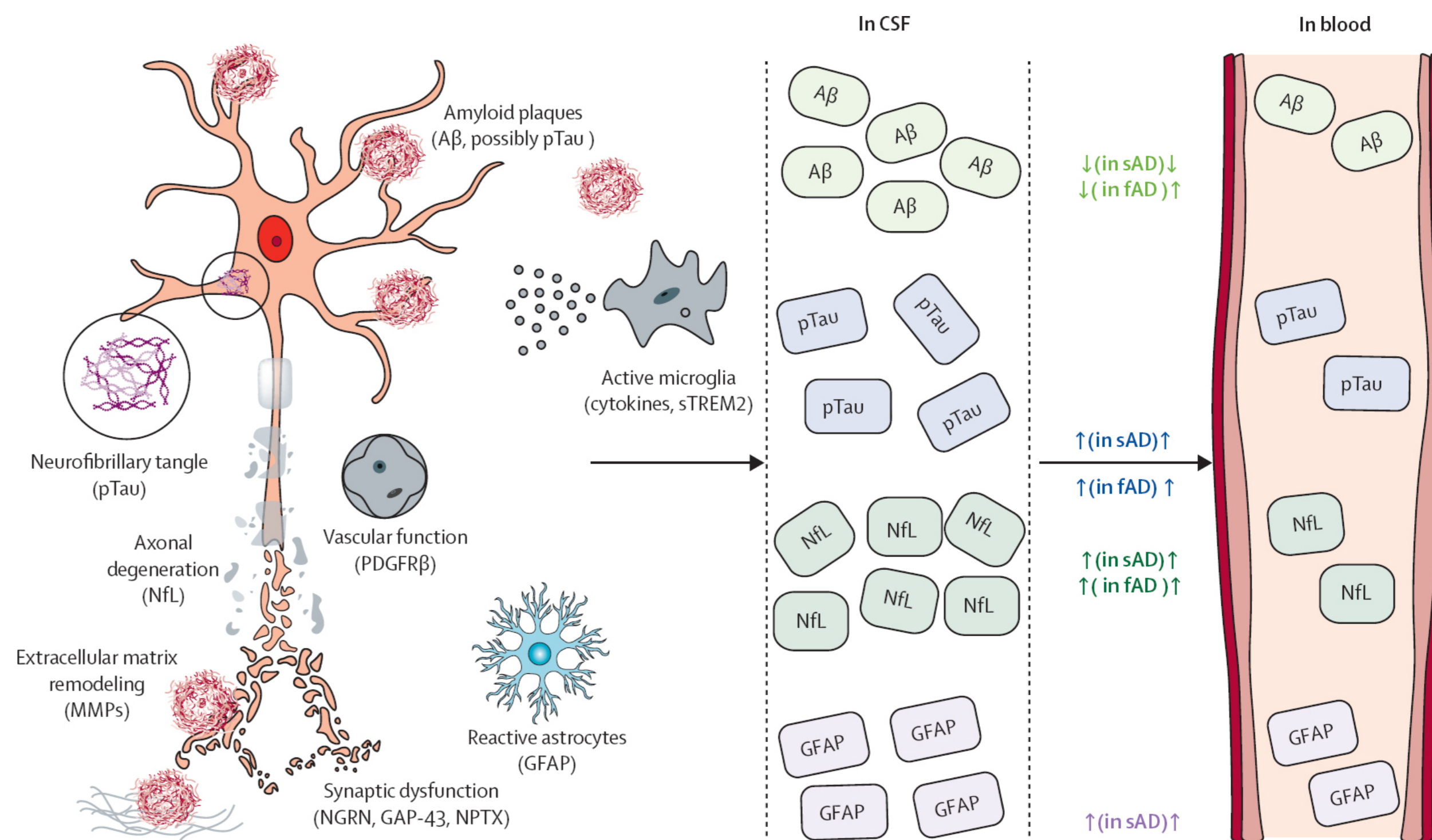
**Status:** > 1270 complete blood draws; (~90% consent to blood draw); collection ongoing at two clinics.

**Biorepository** of plasma, buffy coats, DNA, available for sharing from U19 participants only.

**APOE** genotype available on most participants; genetic data (from participants enrolled prior to 2021) are included in ADGC.

**Biomarker assays:** Expected end of May from NCRAD.

NfL, GFAP, and pTau<sub>217</sub> (Quanterix Simoa HD-X platform)  
Aβ<sub>40</sub> and Aβ<sub>42</sub> (Fujirebio Lumipulse G1200).



# Shift to Digital Data Collection

- Implementing REDCap-based direct data entry for forms and surveys.
- Developing and piloting a digital neuropsychology battery (“Interviewer App”) in conjunction with Aaron Seitz and his team at Northeastern Univ.
  - Recording digital and audio responses increases information obtained that may aid in early detection of impairment without impacting participant burden.
- Attention to quality assurance and backwards compatibility.

# Select Measures Collected at Baseline and Biennial Visits



Cognitive & Functional Measures	Objective Physical Function & Physical Activity	Health Behaviors	Diagnostic Evaluation
*WMS-R Logical Memory	SPPB, grip strength, gait	Smoking, diet, sleep	WMS-R Logical Memory
CASI	Accelerometer devices	Physical activity	Word list Memory Task
Trails A & B	<b>Body Measurements</b>	Sedentary behaviors	Constructional praxis & recall
Verbal Fluency	Height, weight	Cognitive leisure activities	WMS-R Paired Associates
Clock Drawing	Waist, hip, neck circumference	<b>Psychosocial Measures</b>	WAIS-R Comprehension
Functional Status	Blood pressure	Subjective memory	WAIS-R Information
<b>Demographics</b>	<b>Health History</b>	Psychosocial support	Object Naming
Race/Ethnicity	Medical history	Depression (CES-D)	Mattis DRS
Sex/Gender	History of head injury	Quality of life	Clinical Dementia Rating (CDR)
Marital Status	Falling history / risk	Social activities	Informant Questionnaire (IQCODE)
Education	Medications, vitamins,	Living situation	ADLs, iADLs
Parental Education	Supplements	Financial information	Medical Chart Review
Childhood SES	Reproductive Health	Occupational History	Neurological Exam

\* Baseline visit only

We use all available cognitive data from each person to generate composite domain scores of memory, executive function, language, and visuospatial ability, based on test items, which are co-calibrated on the same metric as other studies in the cognitive data harmonization for the Alzheimer's Disease Sequencing Project Phenotype Harmonization Consortium (ADSP-PHC).



**Thank you!**