

# Add Health Parent Study

A Biosocial Resource for the Study of  
Multigenerational Racial/Ethnic Disparities in  
Alzheimer's Disease and Alzheimer's Disease-  
Related Dementias (AD/ADRD)

2024 Add Health Users Conference

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Add Health  
Parent Study



Duke

CENTER for POPULATION HEALTH & AGING  
*at the* Social Science Research Institute

# Outline

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- Origins of the Add Health Parent Study (AHPS)
- AHPS Phase 1
  - Design
- AHPS Phase 2
  - Design
  - Potential research
  - Timeline
- Data access
- Q&A

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# Add Health Parent Study (AHPS) Team

- **University of North Carolina at Chapel Hill**

- Kathleen Mullan Harris (MPI)
- Krista Perreira (MPI)
- Todd Jensen (Co-I)
- Maria Marrufo (Project Manager)
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- **Duke University**

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- **Columbia University**

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- **Research Triangle Institute - RTI**

- Sue Pedrazzani, (RTI PI)

- **University of Texas, Houston**

- Eric Boerwinkle (Co-I)
- Megan Grove (Co-I)

# What is the AHPS?

- A data source to study aging processes in 2+ generations & intergenerational linkages in health, cognition, behaviors & relationships.



# Origins of AHPS

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- National Longitudinal Study of Adolescent to Adult Health (Add Health)
  - Wave I (1995) when Add Health Sample Members (**AHSMs**) were first interviewed
  - A parent/caregiver (mostly biological mothers) of AHSMs were invited to participate in a brief in-home interview ( $N = 17,670$ ; 85%)
- Wave I Parents (**W1Ps**) were between 35 and 50 years of age at Wave I
- Participating W1Ps provided survey data about (a) themselves, (b) their current spouse/partners, and (c) their AHSM child(ren)

# AHPS – Phase 1 (2013-2018)

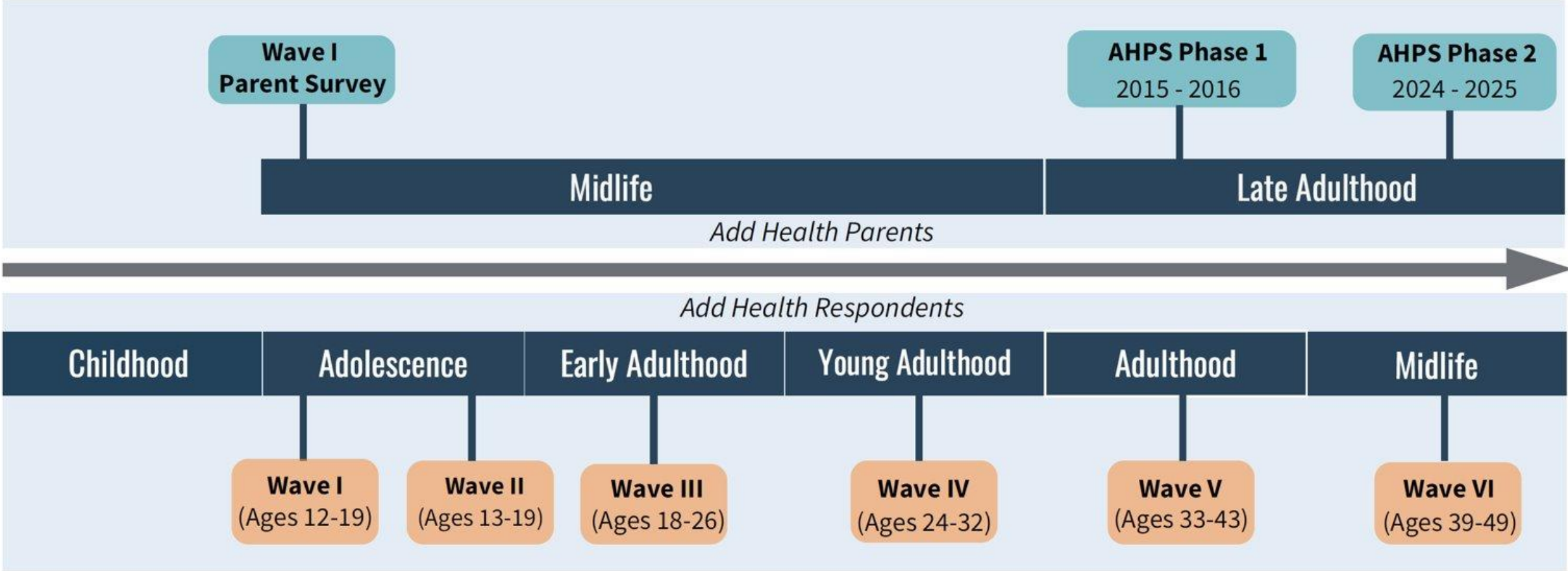
- **Add Health Parent Study [AHPS, 2015-2017]** 20-year follow-up study of subsample of **W1Ps**.
  - Sample of **W1Ps** re-interviewed around **Wave V** of **Add Health Study** in years 2015-2017.
    - Sampled *biological, adoptive* or *step parents* of living **AHSMs**.
    - Data collected paralleled that in previous waves of **Add Health & other aging studies**
  - Also interviewed current *spouses or partners (S/Ps)* of **W1Ps**.
    - Some are **biological parent** of **AHSMs**.
    - Data collected from **S/Ps** paralleled that collected from **W1P**.

# AHPS – Phase 2 (2023-2028)

- Add Health Parent Study: A Biosocial Resource for the Study of Multigenerational Racial/Ethnic Disparities in Alzheimer's Disease and Alzheimer's Disease-Related Dementias (AD/ADRD)
- Focus on increasing AHPS sample diversity
  - Recruit all remaining Black and Hispanic W1Ps
  - Proxy and/or assisted interviews
- Add Health Wave VI (AHSMs) will be finishing up fieldwork



# Intergenerational Life Course Overlap of AHPS and Add Health Interview Timelines





# Add Health Parent Study Phase 1

# AHPS Phase 1 Sample

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- Completed interviews for:
  - 2,013 Biological, step or adoptive W1Ps
  - 988 current spouse/partners (S/Ps)
  - 3,001 total of parents
- These are parents of 2,247 AHSMs

# Data Collected in AHPS Survey

## 1. Health and Health Conditions

- Physical and mental health, medications inventory (**Add Health, HRS, NSHAP**)
- Health insurance, access to care (**HRS**)
- Health behaviors (**Add Health, HRS, NSHAP**)
- Chronic disease, disability, acute health shocks (**Add Health; HRS**)
- Social integration, support, strain and stress (**NSHAP, HRS, MIDUS**)

## 2. Personality, Cognitive Processing & Preferences

- Big 5 (**Add Health, Wave IV**)
- Duckworth Grit Index (**New**)
- Word Recall Tests (**Add Health, Wave IV**)
- Counting Backwards (**HRS**)
- Risk & Patience/Time Preferences (**GSOEP**)

## 3. Relationships between generations

- Gathering Family Rosters (one up, one down) (**PSID**)
- Time & Money Transfers (**PSID**)
- Long Term Transfers & Financial Help (**PSID**)
- Notions of Safety Net provided & expected (**New**)
- Parents' Perceptions & Knowledge of (Adult) Child's situations & behaviors (**New**)

## 4. Economic & time capabilities

- Employment (**HRS**)
- Labor Market Earnings (**HRS**)
- Retirement: Pensions received & expected (**HRS**)
- Housing (**HRS, PSID**)
- Assets & Income from Assets (**HRS**)
- Debt (**HRS, PSID**)

# Other Data Collected in AHPS

## Additional Information Collected:

- ***Family Health Histories*** as a leave-behind questionnaire
  - We collected ***health data*** on ***3 generations***.
  - 75% completion rates
- ***Consents*** to link ***Administrative Records*** (present, past & future)
  - ***Medicare & Medicaid***
  - ***Housing valuations*** & foreclosures of place-of-residence
- ***Residential Locations*** for linking to data on:
  - Economic, demographic status of neighborhoods
  - Food environments
  - Environments for exercise, etc.

**Add Health Parent Study  
Family Health History**

ID:

Is your parent still alive?

**Biological Mother**

- yes → How old is she? Age in years:
- no → When did she die? Age at death:
- don't know

**Biological Father**

- yes → How old is he? Age in years:
- no → When did he die? Age at death:
- don't know

Consider only your biologically related relatives, and please fill the answers for each of the following conditions. . . .

Your biological . . .	mother			father			any brother /sister			aunts/uncles			any grandparent		
	yes	no	don't know	yes	no	don't know	yes	no	don't know	yes	no	don't know	yes	no	don't know
Coronary Heart Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If yes, diagnosed before age 55?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heart Attack	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If yes, 1st one before age 55?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stroke	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If yes, 1st one before age 55?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diabetes or high blood sugar	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hypertension or high blood pressure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
High Cholesterol or Hyperlipidemia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cancer ever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prostate Cancer ever				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# Family Health History (FHH)

Add Health Parent Study  
**Family Health History (continued)**

ID:

# Family Health History (FHH)

	<i>mother</i>			<i>father</i>			<i>any brother /sister</i>			<i>aunts/uncles</i>			<i>any grandparent</i>		
	<i>yes</i>	<i>no</i>	<i>don't know</i>	<i>yes</i>	<i>no</i>	<i>don't know</i>	<i>yes</i>	<i>no</i>	<i>don't know</i>	<i>yes</i>	<i>no</i>	<i>don't know</i>	<i>yes</i>	<i>no</i>	<i>don't know</i>
If yes, prostate cancer before age 60?				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breast cancer ever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If yes, breast cancer before age 50?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Colorectal (or colon) cancer ever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If yes, Colorectal (or colon) cancer before age 55?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ovarian Cancer ever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>				<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lung cancer ever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Cancer ever	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If so, which ones (specify): →	_____			_____			_____			_____			_____		
Depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dementia or Alzheimer's Disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heavy alcohol use or alcoholism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Obesity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Asthma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Arthritis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



# Add Health Parent Study Phase 2



# AHPS Phase 2 objectives

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- Interview additional sample of ~2,500 Black and Hispanic parents with the AHPS survey
  - Combined with Phase 1 parents, total AHPS sample ~5,500 parents.
- On the total AHPS sample of ~ 5,500:
  - Administer assessments of cognitive aging and risk of AD/ADRD
  - Collect DNA for SNP genotyping and DNA methylation data
    - Intergenerational genomic database of PGSs, epigenetic clocks, other genomic constructs
  - Collect family health histories (FHH)
- Document, disseminate, and promote use of AHPS data

# Significance of the AHPS Phase 2 design and data

- Harmonize cognitive and genomic data collected on parents with those collected on their adult children in Wave VI
- Collect data on AHPS members' caregiving experiences, including that provided by the Wave VI AHSM
- First multi-generational study with sufficient samples to study racial and ethnic disparities in intergenerational processes of socioeconomic status, health, cognition and behavior
- Unique genomic database on 2 generations to advance our understanding of gene-environment interplay in the etiology of AD/ADRD

# Cognitive Assessment

## Test Sequence, Domains, and \*Duration

Test	Domain Measured	Avg Duration*
<b>Test My Brain (TMB) - 15 minutes (Laptop)</b>		0:16:00
TMB Verbal Paired Associates	Associative and episodic memory	
TMB Digit Symbol Matching	Processing speed	
TMB Gradual Onset Continuous Performance Test	Executive function	
<b>Grip Strength - Jamar Plus Digital Hand Dynamometer (Laptop)</b>		0:05:00
1 Practice, 2 Main trails	Functional cognition	
<b>Cognitive Assessments</b>		0:05:00
Immediate Word Recall -15 Words / (90 Seconds)	Verbal episodic memory	
Digits backwards	Short-term memory processing	
Delayed Word Recall - 15 Words / (60 Seconds)	Verbal episodic memory	
<b>Animal Naming Test (Laptop)</b>		0:02:00
Name as many animals as you can in 60 seconds	Semantic fluency	
<b>NIH Toolbox Cognition V3 (iPad)</b>		0:13:00
Dimensional Change Card Sort Test	Executive function	
Pattern Comparison Processing Speed Test	Processing speed	
Picture Vocabulary	Receptive vocabulary	

\*Duration is based on Add Health Wave VI

# Other data collected on the total AHPS sample

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- ADLs & IADLs
- Hearing
- COVID-19
- Skin Color
- Stigma and Discrimination
- Caregiving and Caregiving Stress

# Proposed research

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- Examine novel longitudinal and intergenerational social, health, and behavioral risk and preventive factors for AD/ADRD across racial/ethnic groups and social strata
- Examine AHPS members' caregiving experiences and the socioeconomic consequences of caregiving experiences related to AD/ADRD conditions or risks

# AHPS research opportunities with Phase 2 data

- National sample of adults (N~5,500) aged 58-90 years, parents or parent S/Ps of participants in Add Health (overlap in timing with Wave VI)
- Address knowledge gaps with linked data
  - Intergenerational dimensions of cognitive aging and risk for AD/ADRD
  - How aging and risk for dementia differ across current 3 largest US race/ethnic groups
    - Structurally-rooted inequities and other socioenvironmental/socioeconomic disparities
    - Interpersonal stressors, caregiving contexts
  - Biosocial processes as core features of AD/ADRD risk transmission
- 1<sup>st</sup> national, multigenerational data source with multilevel contextual data and individual social, cognitive, genomic, behavioral data designed to address disparities in cognitive aging and AD/ADRD risk and protective factors

# Timeline

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- Pilot study: Fall 2024
- Main fieldwork: Summer 2025-Fall 2026
- Data cleaning and documentation: Fall 2026-late Fall 2027
- Data available: January 2027

# Information on Acquiring Data

Add Health Parent Study Phase 1 data are available at CPC Data Portal – Add Health <https://data.cpc.unc.edu/projects/2/view>

Add Health data are available on the Add Health website (<https://addhealth.cpc.unc.edu/>).





# Thank you!

- Q&A

