

# Introduction to Studying Dementia in the Health and Retirement Study (HRS)

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## Support

This work was supported by the National Institute on Aging of the National Institutes of Health (award No. P30 AG066582). The Health and Retirement Study is funded by the National Institute on Aging (award No. U01 AG009740) and the Social Security Administration, and performed at the Institute of Social Research, University of Michigan.

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## Outline

- Introduction to the Health and Retirement Study (HRS)
- Cognition Measures in the HRS
- Dementia Sub-Studies (ADAMS and HCAP)
- Research Opportunities



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## HRS Essentials



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## Health and Retirement Study (HRS)

- Created in 1990 by an act of Congress to provide public data for the study of health and retirement
- First longitudinal study of older people to include detailed economic and health information in the same survey
- 16 Co-Investigators from different disciplines (PI: David Weir)
- The largest and most comprehensive nationally representative multi-disciplinary panel study of Americans over age 50
- Supported the NIA (U01 AG009740) and the Social Security Administration

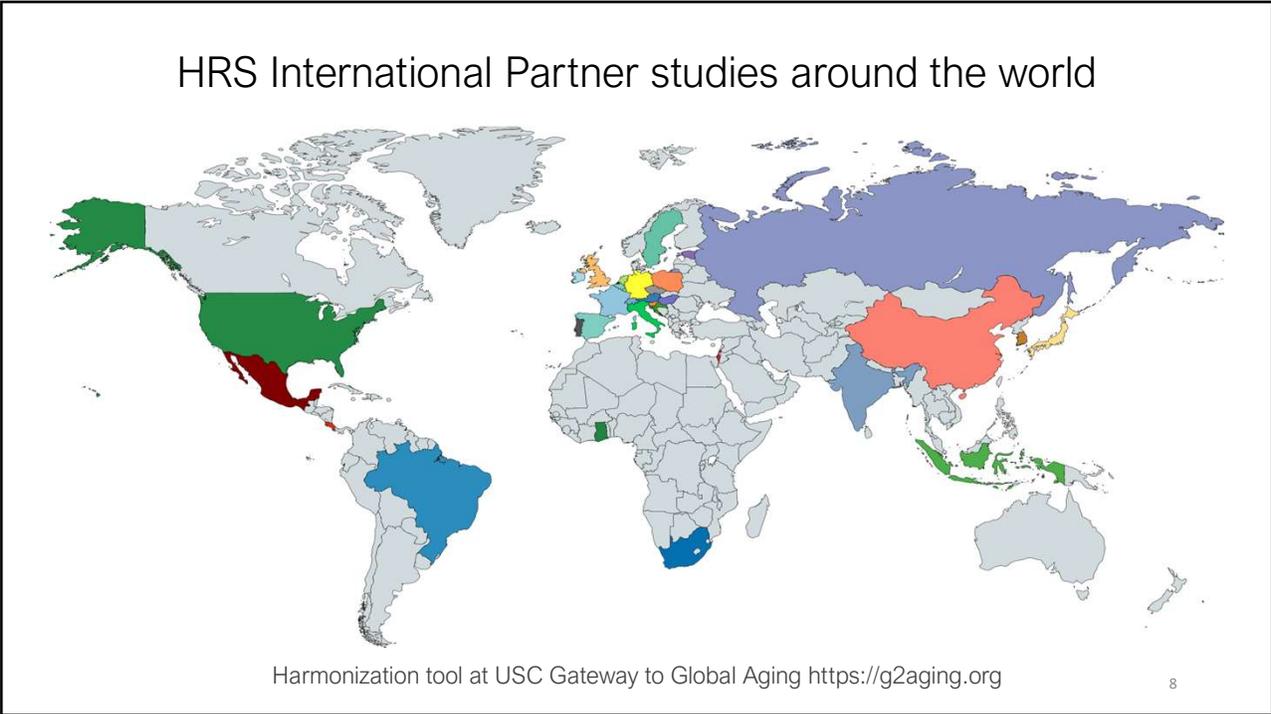
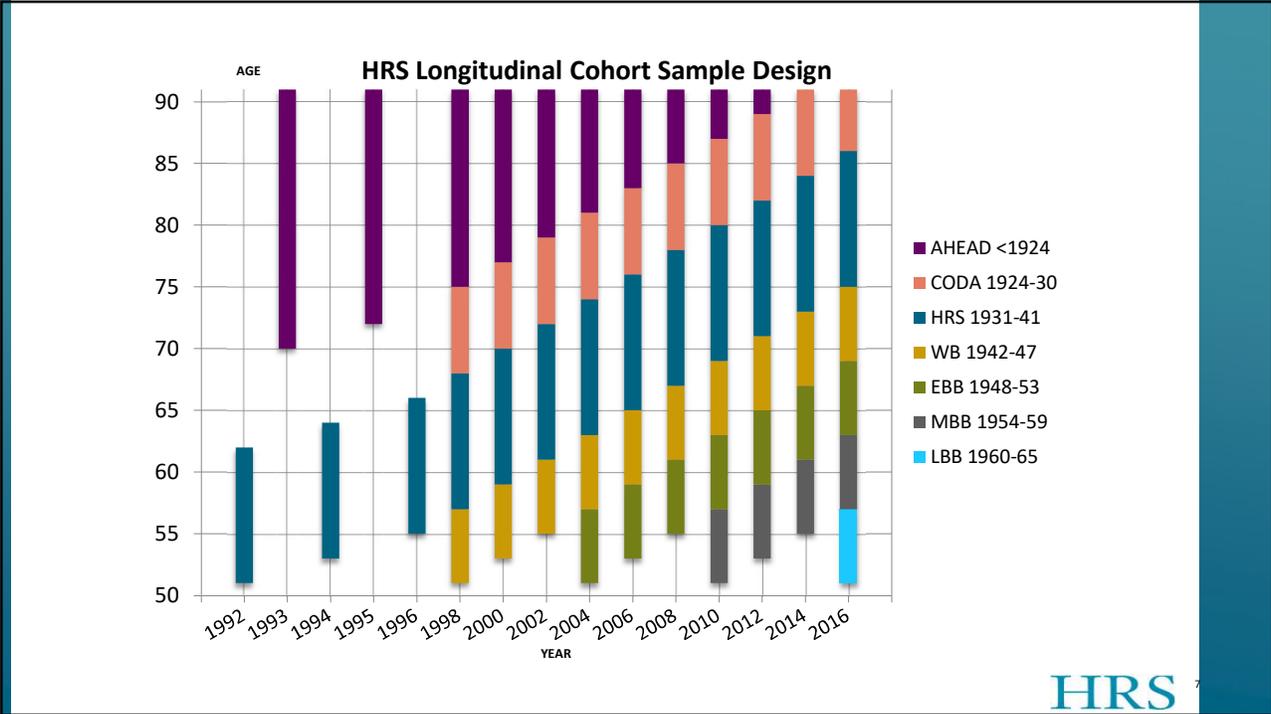
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## HRS Essentials

The HRS is a survey that:

- Is nationally representative of the population over age 50
- Follows individuals and their spouses or partners from the time of their entry into the survey until death
- Introduces a new 6-year birth cohort of participants every 6 years
- Any given wave has about 20,000 respondents, with over 43,000 respondents ever interviewed

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## HRS Survey Content

- Demographic characteristics
- Physical and functional health
- Cognitive testing
- Family structure and transfers
- Employment status, job history, and disability
- Retirement plans and perspectives
- Assets, income, and net worth
- Housing and services use
- Health insurance and pension plans
- Out-of-pocket health costs
- Links to data from employers, Medicare, NDI, VA, and SSA
- Biomarkers (2006)
  - Cholesterol, HgbA1c, CRP, Cystatin C, BP, Pulse, Peak flow, Balance, Gait
  - Venous Blood in 2016
- Genetics (2012)
  - 2.5 M SNPs on 20,000 people

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## Cognitive Measures in the HRS



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## Cognition measures in HRS core Survey

- Immediate and Delayed Free Recall of a list of 10 nouns (for a possible score of 0-10 on each measure).
- Serial 7s, a working memory and mental processing task in which respondents count backwards from 100 by 7 for a total of five trials (for a possible score of 0-5)
- Count Backwards from 20 and 86 (10 numbers)
- Vocabulary (crystallized knowledge). R's are asked to define 5 words from one of two sets: 1) repair, fabric, domestic, remorse, plagiarize, and 2) conceal, enormous, perimeter, compassion, audacious.
- Mental Status measures (with a possible combined score of 0-10):
  - (a) name the U.S. president and vice president by last name (>65yrs)
  - (b) name two described objects (scissors and cactus) (>65yrs)
  - (c) time orientation – report the day's date (>65yrs)

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## Additional cognition measures in HRS core

- Self-rated memory
  - How would you rate your memory at the present time? Would you say it is excellent, very good, good, fair or poor?
  - Compared with (previous wave interview), would you say your memory is better now, about the same, or worse now than it was then?"
- Self-reported Diagnosis
  - From 1998 to 2008: Has a doctor ever told you that you have a memory related disease?
  - Starting in 2010: Has a doctor ever told you that you have Alzheimer's Disease? Has a doctor ever told you that you have dementia, senility or any
  - Other serious memory impairment?

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## New measures in HRS core since 2010

### Quantitative Reasoning (Numeracy)

- Everyday Numbers.
  - If the chance of getting a disease is 10 percent, how many people out of 1,000 would be expected to get the disease?
- Number Series Problems
  - The Respondent hears a patterned series of numbers that includes one blank slot. The task is to determine the missing number. (6 series given)

### Verbal Fluency

- The Respondent is asked to name as many examples as possible from a given category within a 1-minute time period

### Verbal Analogies (10% HRS Sample in 2012; Alternates with Number Series beginning in 2014)

- E.g. Mother is to Father as Daughter is to \_\_\_\_\_.

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## Methodological issues

### Practice Effects:

- Four word lists and two vocab lists rotated across time and between spouses. Some evidence for slight increase in performance from baseline T1 to T2.

### Standardization of test administration:

- Potential effects associated with a) interviewer differences in instruction presentation, rate of reading words, accuracy in recording responses: and b) test environment – e.g. presence of spouse or others, background noise, interruptions, etc.

### Mode and Occasion effects:

- Telephone vs face-to-face interviews on alternate waves; different test environments; health and motivation on the day, etc.

### Incomplete data:

- Data not missing at random due to age skips, attrition, proxy respondents.
- Self/proxy status related to cognitive functioning
- Need to identify strategy for handling missing data and using imputations

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## Proxy questions

### Ratings

- How would you rate R's memory at the present time?
- How would you rate R's ability to make judgments and decisions?
- How would you rate R's ability to organize (his/her) daily activities?

### Jorm IQCODE: 16-item version – e.g.,

- Compared with two years ago, how is (R's first name) at remembering things about family and friends, such as occupations, birthdays, and addresses? Has this improved, not much changed, or gotten worse?

### Behavior Problems: e.g.,

- Now, thinking about some current behaviors, does (R's first name) ever get lost in a familiar environment?

Proxy Report of Dementia Diagnosis

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## ADAMS and HCAP



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## Aging, Demographics, and Memory Study (ADAMS)

- Supplemental study to the HRS funded by the NIA
- First US national, population-based study of dementia to include subjects from all regions of the country
- Initial field period: 2001 – 2005, follow-up through 2010
- 856 HRS subjects, evaluated in their homes
  - 3-4 hour neuropsychological assessment, neuro exam, informant interview, ApoE genotype
- Consensus panel diagnosis of CIND or dementia, with differential diagnosis of cause (AD, Vascular, Other)

Source: Langa et al, *Neuroepidemiology*, 2005.

## Defining Dementia using HRS-ADAMS

### Equipercntile Equating

- Define cut-points on HRS cognitive (and other) measures that result in similar dementia prevalence estimates as the “gold-standard” ADAMS estimates

### Regression-based Algorithms

- Multivariable models derived from relevant HRS cognitive, health, and sociodemographic measures that provide probability of dementia for each respondent
- Wu – Glymour, 2012; Hurd et al, 2013; Cleret de Langavant – Yaffe 2018; Gianattasio et al, 2019 and 2020
- Accuracy  $\geq$  90% with most models; important to consider differing accuracy across race / ethnicity (Gianattasio papers)

Sources: Langa et al, *Alz Assoc*, 2009; Crimmins et al, *J. of Geron*, 2011; Wu et al, *ADAD*, 2012; Hurd et al, *NEJM*, 2013; Cleret de Langavant et al, *Med Int Res*, 2018; Gianattasio et al, *Epid*, 2019, 2020.

OPEN

## Comparison of Methods for Algorithmic Classification of Dementia Status in the Health and Retirement Study

Kan Z. Gianattasio,<sup>a</sup> Qiong Wu,<sup>b</sup> M. Maria Glymour,<sup>c</sup> and Melinda C. Power<sup>a</sup>

**Background:** Dementia ascertainment is time-consuming and costly. Several algorithms use existing data from the US-representative Health and Retirement Study (HRS) to algorithmically identify dementia. However, relative performance of these algorithms remains unknown.

**Methods:** We compared performance across five algorithms (Herzog–Wallace, Langa–Kabeto–Weir, Crimmins, Hurd, Wu) overall and within sociodemographic subgroups in participants in HRS and Wave A of the Aging, Demographics, and Memory Study (ADAMS, 2000–2002), an HRS substudy including in-person dementia ascer-

younger, highly-educated, and non-Hispanic white participants versus their complements in both weighted and unweighted analyses.

**Conclusion:** Algorithmic diagnoses provide a cost-effective way to conduct dementia research. However, naïve use of existing algorithms in disparities or risk factor research may induce nonconservative bias. Algorithms with more comparable performance across relevant subgroups are needed.

**Keywords:** Algorithms; Alzheimer’s disease; Dementia; Health and Retirement Study

Source: Gianattasio et al,<sup>19</sup> *Epid.*, 2019.

## HRS Harmonized Cognitive Assessment Protocol (HCAP)

New HRS Dementia Sub-Study fielded in 2016, 2020

- 1-hour of cognitive testing for respondent
- 20 minutes of questions for informant
- ~3,500 HRS respondents aged 65+ (random sample)
- Battery of cognitive tests developed in collaboration with international partners, and HCAPs in progress in England, Mexico, India, China, S. Africa, EU, Chile, Ireland, N. Ireland, S. Korea
- Provides much better characterization of cognitive function in HRS sub-sample, embedded in ongoing HRS

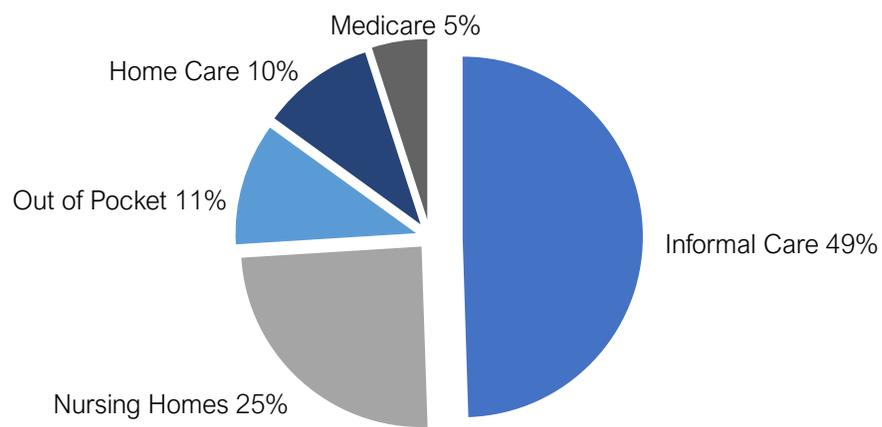
Source: Langa et al, *Neuroepidemiology*, 2020.

# Research Opportunities



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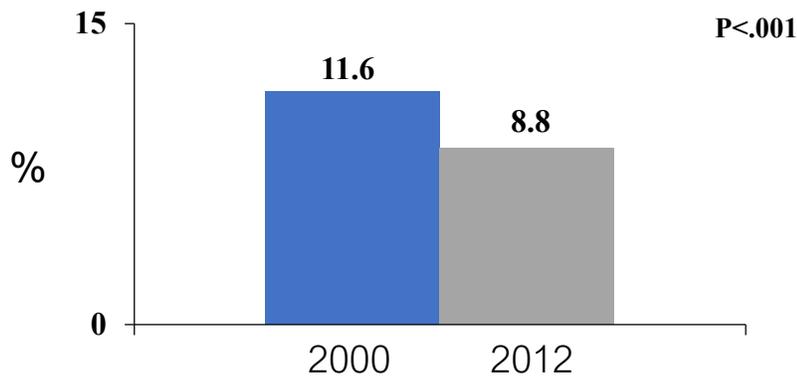
## Dementia Annual Cost Per Case in the United States, 2010



Total: \$50,000 per case;  
\$200 billion nationwide

Source: Hurd et al, *NEJM*, 2013.

## HRS: Dementia Prevalence, Age 65+



Source: Langa et al, *JAMA Internal Medicine*, 2017.<sup>23</sup>

**CARING FOR THE  
CRITICALLY ILL PATIENT**

## Long-term Cognitive Impairment and Functional Disability Among Survivors of Severe Sepsis

Theodore J. Iwashyna, MD, PhD

E. Wesley Ely, MD, MPH

Dylan M. Smith, PhD

Kenneth M. Langa, MD, PhD

Severe sepsis was independently associated with substantial and persistent new cognitive impairment and functional disability among survivors. The magnitude of these new deficits was large, likely resulting in a pivotal downturn in patients' ability to live independently.

Iwashyna et al, *JAMA*, 2010

## Conclusion

- Population-based studies of dementia are especially important now given aging of populations around the world
- HRS-ADAMS-HCAP designed to leverage existing HRS family of nationally-representative studies
- Goal is to collect multi-disciplinary data to compare and track dementia burden on patients, families, and health systems in countries around the world
- All data publicly-available at the HRS and Gateway to Global Aging websites

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## Work with us!



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**HRS** HEALTH AND  
RETIREMENT  
STUDY



GATEWAY TO  
GLOBAL  
AGING  
DATA

<https://hrs.isr.umich.edu>

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Thank You

