

Tracking Dementia in the HRS: From ADAMS to HCAP

Advanced Psychometrics Methods in Cognitive Aging Research Conference

August 19, 2019
Lake Tahoe, CA

Kenneth M. Langa, MD, PhD
University of Michigan

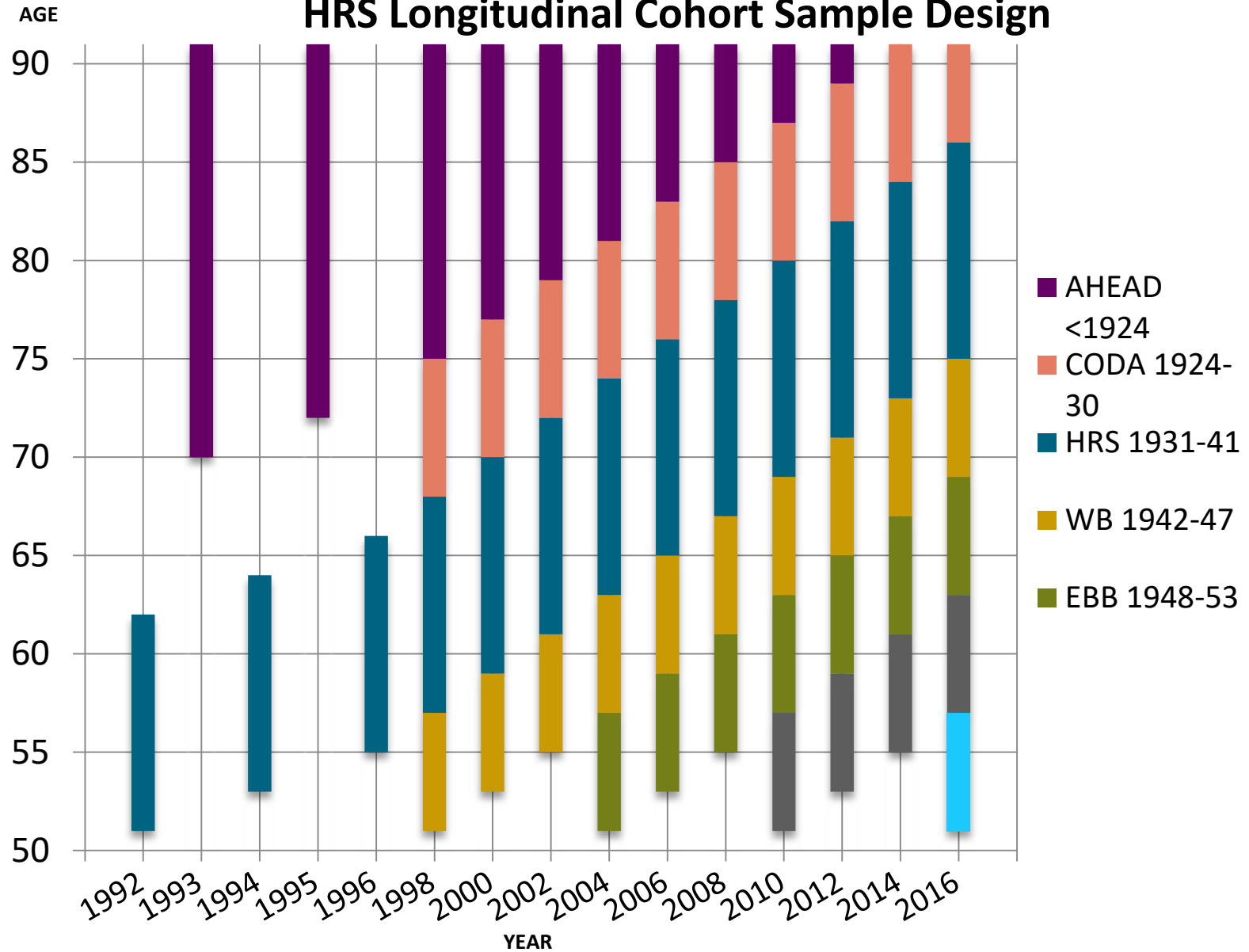
Health and Retirement Study (HRS)

- Ongoing, nationally representative, longitudinal, biennial survey of ~ 20,000 Americans aged > 50
- Performed at the UM Institute for Social Research, funded by the NIA and SSA
 - PI: David Weir; Co-Is: Jones and Manly
- Data collection started in 1992
- Extensive data on health, cognition, economics, work, and family from a national sample
- Face-to-face and telephone interviews (50 / 50)
- > 3,500 HRS publications by > 2,000 authors;
>20,000 registered data users

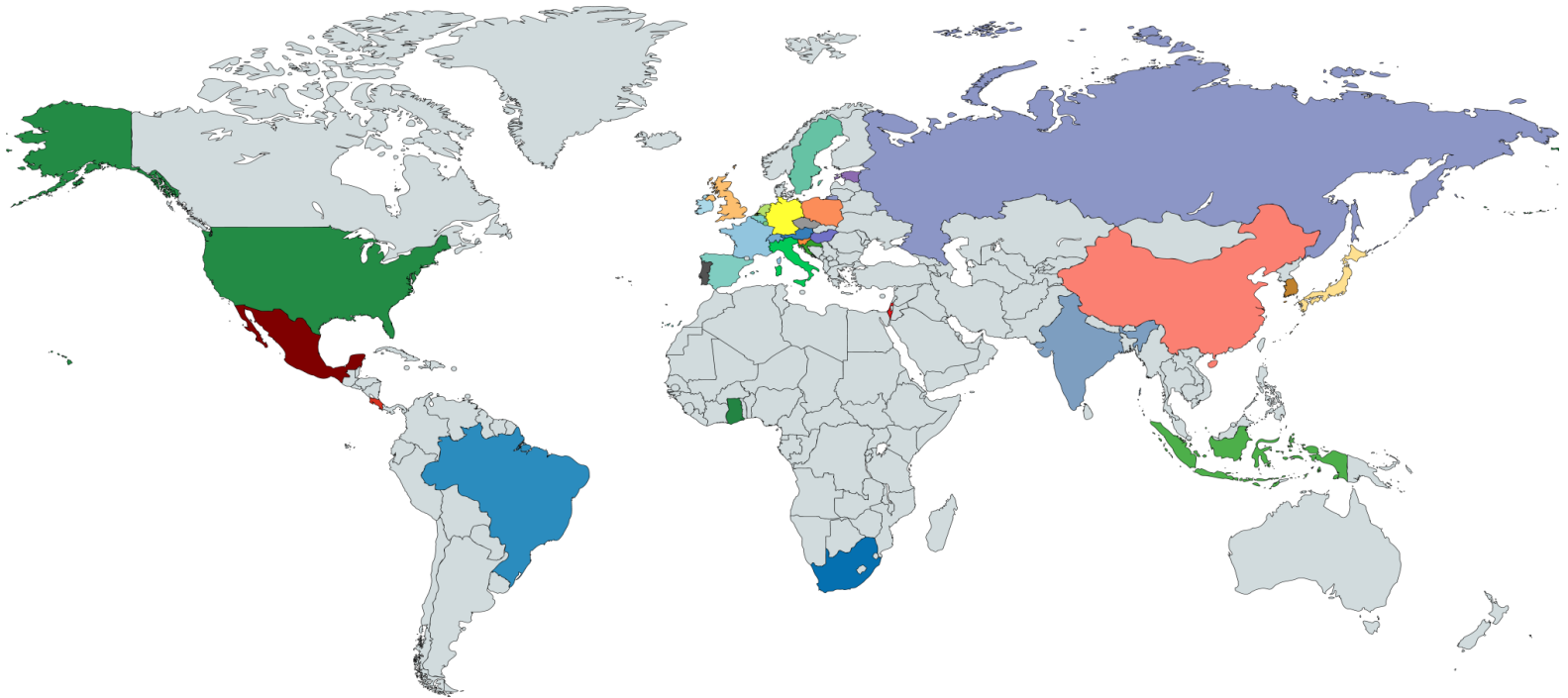
HRS Survey Content

- 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

HRS Longitudinal Cohort Sample Design



HRS INTERNATIONAL PARTNER STUDIES AROUND THE WORLD



Harmonization tool at USC Gateway to Global Aging
g2aging.org

Tracking Brain Health in the HRS

- Modified Telephone Interview for Cognitive Status
 - orientation to day, date, month, year
 - immediate and delayed recall of 10 nouns
 - serial 7 subtraction
 - counting backwards
 - object naming
 - naming of the president and vice-president
- Verbal fluency
- Number Series
- Numeracy questions
- Speed of processing
- Self report of:
 - Memory function; ADL / IADL limitations; prior diagnosis of AD or dementia; medications for AD or dementia

Tracking Brain Health in the HRS (2)

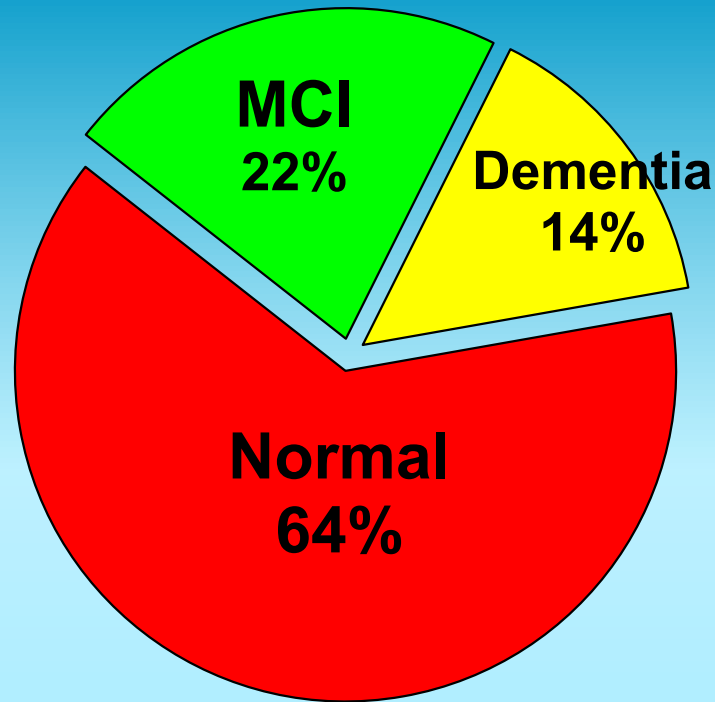
- Protective and risk factors for brain health
 - CV disease risks (measured BP, obesity, health behaviors)
 - Acute medical events (stroke, sepsis, CABG => Medicare)
 - Genetics (ApoE, 2.5 million SNPs)
 - Education and leisure time activities (reading, puzzles, etc.)
 - Employment history, wealth
 - Social ties and extent of social interactions
 - Early-life factors (childhood health, parents' education)
- Respondents represented by proxy:
 - IQCODE
 - Memory function, judgment, and change over the last 2 years
 - Doctor diagnosed AD or dementia
 - ADL / IADL limitations
- “Exit” Interview for those who’ve died

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.

ADAMS Estimates of 2002 US Population Prevalence, Age 71+



<u>US Population, Age 71+:</u>	
Dementia	3.4 million
CIND	5.4 million
Total Pop	24.3 million

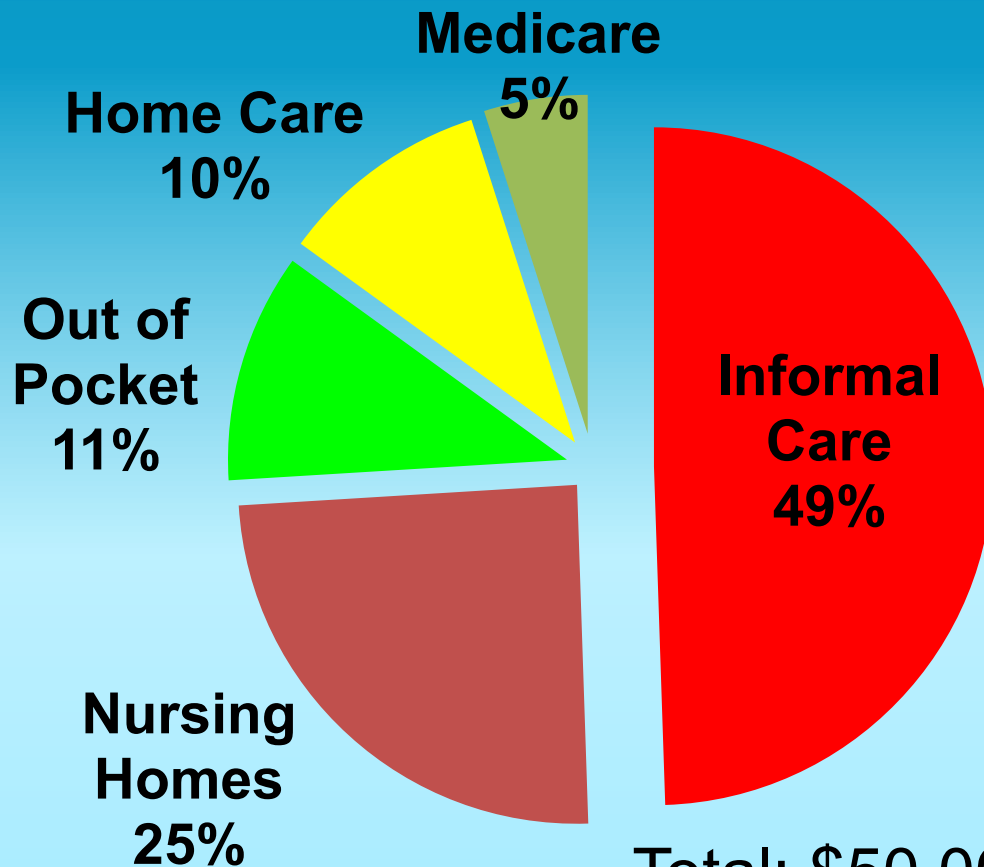
Sources : Plassman, et al, *Neuroepidemiology*, 2007; *Annals of Internal Medicine*, 2008.

Defining Dementia using HRS-ADAMS

- Equipercentile Equating
 - Define cut-points on HRS cognitive (and other) measures that result in similar dementia prevalence estimates as the “gold-standard” ADAMS estimates
 - Self-respondents: 27-point HRS cognitive scale
 - 0-6 => Dementia; 7-11 => CIND
 - Proxy-respondents: 1) proxy assessment of memory; 2) proxy assessment of IADL limitations; and 3) interviewer assessment of cognitive impairment
 - 11-point combined scale
- Probabilistic Imputation
 - Multivariate models derived from relevant HRS cognitive, health, and sociodemographic measures that provide probability of dementia for each respondent
 - See Gianattasio et al, *Epidemiology*, 2019.

Source: Crimmins et al, *J. of Gerontology*, 2011; Hurd et al, *NEJM*, 2013; Wu and Glymour, *ADAD*, 2012

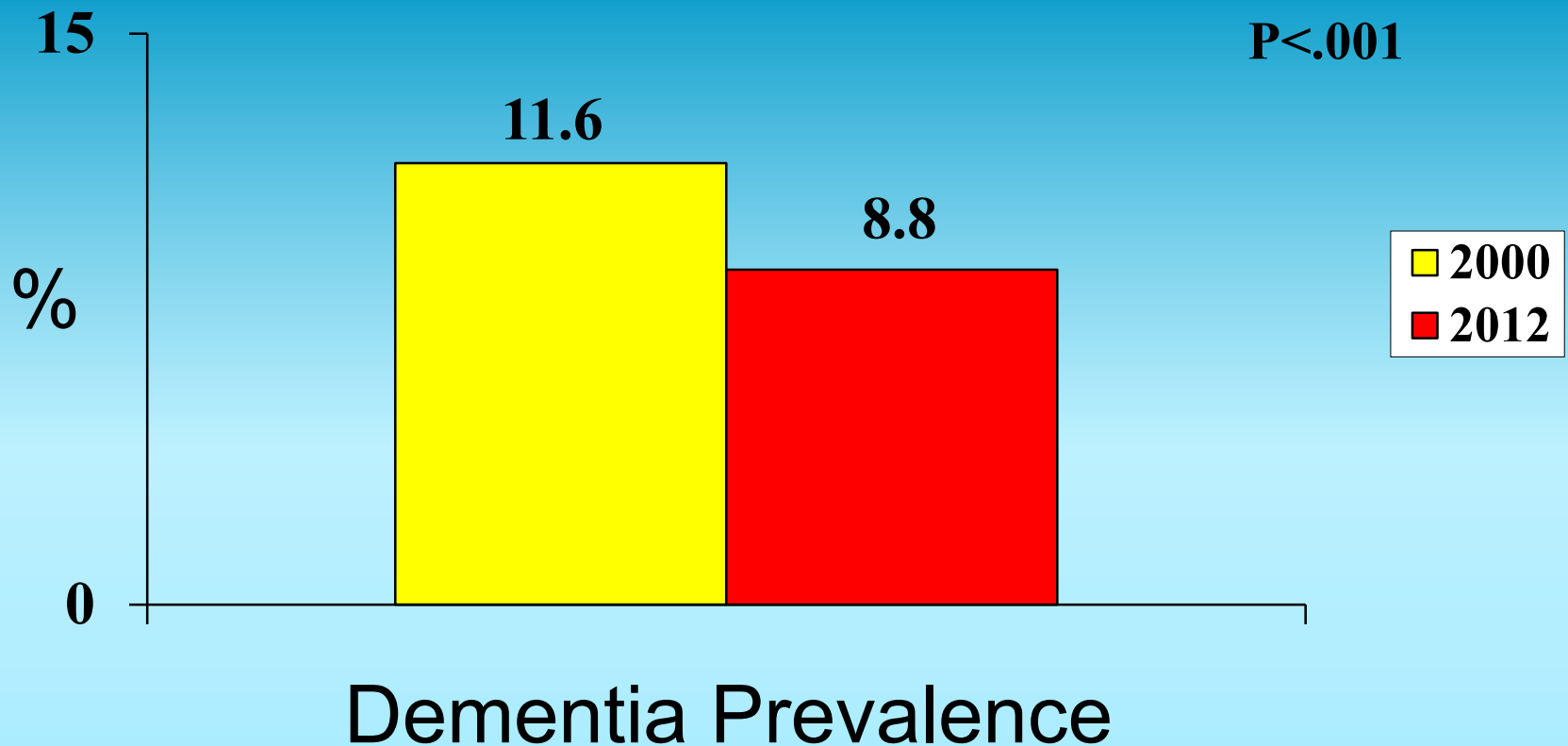
Dementia Annual Cost Per Case United States, 2010



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.

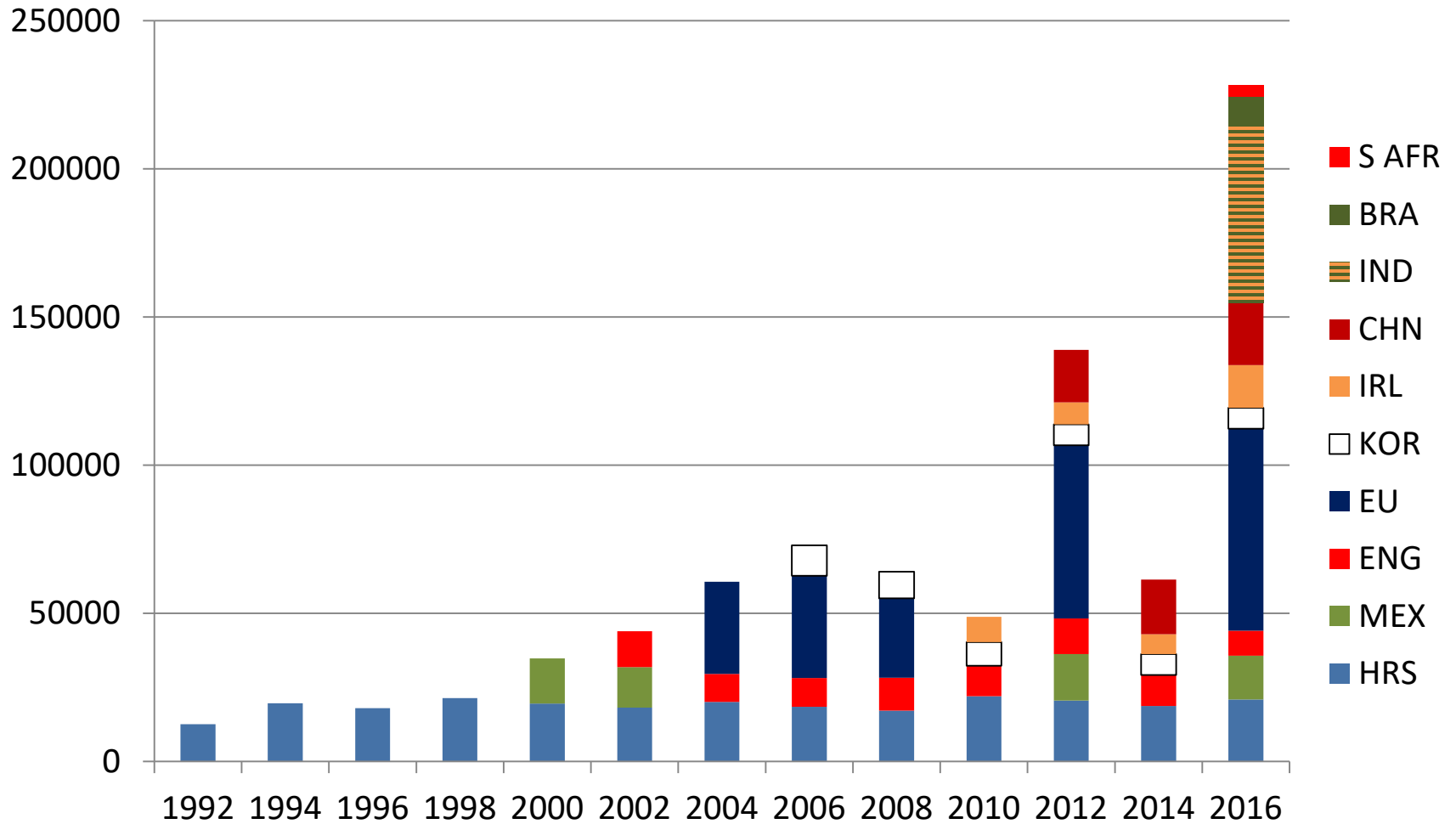
From ADAMS to HCAP

- ADAMS showed embedding a valid dementia diagnosis in a representative longitudinal study provides valuable information on the impact of cognitive decline on patients, families, and public programs
- ADAMS was expensive due to traveling teams of neuropsychology technicians
- NIA requested that the HRS team develop a less expensive method of identifying dementia in the HRS to:
 - Allow a larger sample size of in-depth cognitive assessments
 - Increase opportunities to study trends in dementia incidence / prevalence in the US
 - Increase opportunities for international comparisons of dementia prevalence and trends across the HRS family of studies

HCAP Has Multiple Purposes

- Create, from within larger ongoing longitudinal studies, stand-alone cohorts with deep cognitive measurement
 - For epidemiology (e.g., genetic consortia)
 - For population prevalence
 - For international comparisons (e.g., cross-walk to 10/66 Brief CSI-D screener)
 - For future incidence studies by follow-up
- Goal is a replicable algorithmic diagnosis
- Use HCAP subsample to formulate rules for assigning diagnostic status to everyone in all waves of main HRS family of studies using more limited set of cognition variables
- Create public data resource so different diagnostic approaches can be used for comparison

HRS INTERNATIONAL NETWORK: NUMBER OF INTERVIEWS BY WAVE



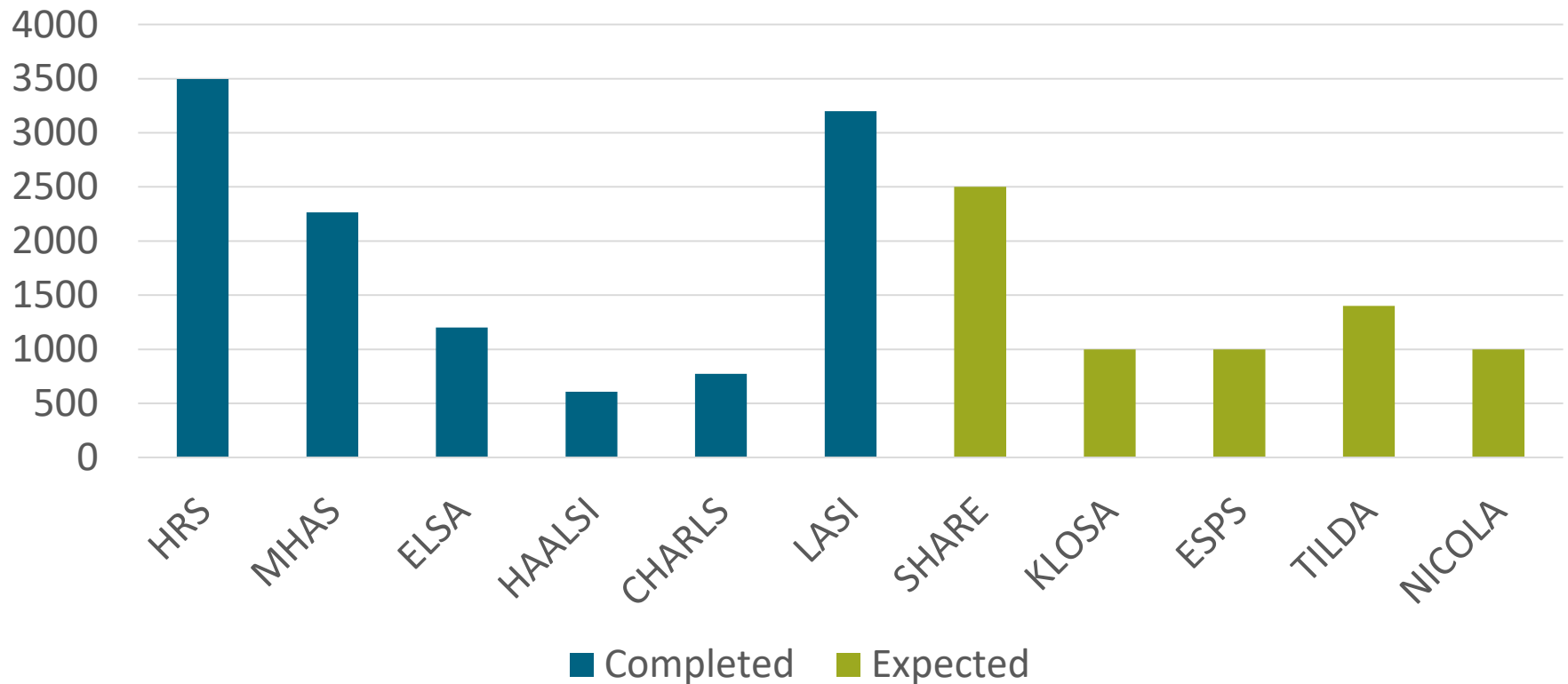
HCAP PROTOCOL DEVELOPMENT

- 2014
 - Jan-June chose tests based on analysis of ADAMS (n=856)
 - August/Sept conducted pilot of this protocol
 - Broadened analysis to include Rush ROS/MAP (n=16,000)
 - Broadened choice of tests
 - November: Weir, McCammon, Ryan and Langa working paper on tests
- 2015
 - New version of protocol administered in two pilots
 - CogUSA (McArdle) – high functioning
 - Seattle ACT – oversample of dementia
 - Hugh Hendrie added as consultant for CSI-D harmonization
 - Harmonization meetings
 - Oct: London, England (Steptoe, Batty, Llewellyn, Brayne, Deary, Gallacher, Prince)
 - Nov: Aguascalientes, Mexico (Wong, Mejia, Sosa)
 - Dec: New Delhi, India (Lee, Bloom, Dey, Varghese)
 - Acquired 10/66 data to validate harmonization to CSI-D 10/66
- 2016
 - Final US pilot January-March (Michigan AD Center subjects)
 - HRS Interviewer trainings attended by sister study representatives
 - Sister study trainings assisted by HRS representatives

HCAP WAVE 1 STATUS REPORT

Country	Study	Applied	Funded	Begun	Completed	Data Released
USA	HRS	✓	✓	✓	✓	✓
Mexico	MHAS	✓	✓	✓	✓	✓
England	ELSA	✓	✓	✓	✓	
S. Africa	HAALSI	✓	✓	✓	✓	
China	CHARLS	✓	✓	✓	✓	
India	LASI	✓	✓	✓	✓	
EU	SHARE	✓	✓			
S. Korea	KLOSA	✓	✓			
Chile	ESPS	✓	✓			
Ireland	TILDA	✓				
N. Ireland	NICOLA	✓				
Brazil	ELSI					

NUMBER OF HCAP PARTICIPANTS*, BY STUDY



*Full cognitive testing not available for all participants; check missing data patterns!

HARMONIZATION IN HCAP

- Ex-ante design and content
- Administration, scoring
- Ex-post statistical
- Diagnostic algorithms
- Weighting for national prevalence
- Imputation of diagnosis to full study
 - (leverage ~20,000 HCAP cases to >200,000 HRS sister study participants)

EX ANTE HARMONIZATION

Table 4: HCAP Test Harmonization Across Studies

Respondent Test	HRS-HCAP	ELSA	TILDA/NICOL A	HAALSI	LASI	MHAS	CHARLS
Mini-Mental State Examination (MMSE)	Y	Y	Y	H	H	H	Y
HRS-TICS (3 items: Object naming; Naming President)	Y	Y	Y	Y	Y	Y	Y
CERAD Word List Learning and Recall – Immediate	Y	Y	Y	Y	Y	Y	Y
Semantic Fluency (Animal Naming Test)	Y	Y	Y	Y	Y	Y	Y
Letter Cancellation Test	Y	Y	Y	H	H	H	
Timed Backward Counting Task (from MIDUS)	Y	Y	Y	Y		H	
Community Screening Instrument for Dementia (4 items)	Y	Y	Y	Y	Y	Y	Y
CERAD Word List Recall – Delayed	Y	Y	Y	Y	Y	Y	Y
Logical Memory (Story recall) – Immediate	Y	Y	Y	Y	Y	Y	
CERAD Word List - Recognition	Y	Y	Y	Y	Y	Y	Y
CERAD Constructional Praxis – Immediate	Y	Y	Y	Y	Y	Y	
Symbol Digit Modalities Test (SDMT)	Y	Y	Y	Y		H	
CERAD Constructional Praxis – Delayed	Y	Y	Y	Y	Y	Y	
Logical Memory (Story recall) – Delayed	Y	Y	Y	Y	Y	Y	
Logical Memory (Story recall) – Recognition	Y	Y	Y	Y	Y		
HRS Number Series	Y	Y	Y	H			H
Raven’s Standard Progressive Matrices	Y	Y	Y	Y	Y		
Trail Making Test (Part A and Part B)	Y	Y	Y	H			
Y = Same test items administered; H = Similar test items administered							
Coverage of HRS-HCAP Tests (% Y)	100	100	100	78	67	56	39
Coverage of HRS-HCAP Tests (% linear composite score variance explained by Y tests)	100	100	100	96	96	93	87

HCAP Informant Report

- Valuable complement to testing
- Report on cognitive changes, activity levels and limitations
- HRS HCAP includes
 - Blessed
 - Jorm IQCODE
 - CSI-D
- Somewhat redundant, but permits harmonization to studies with more limited data

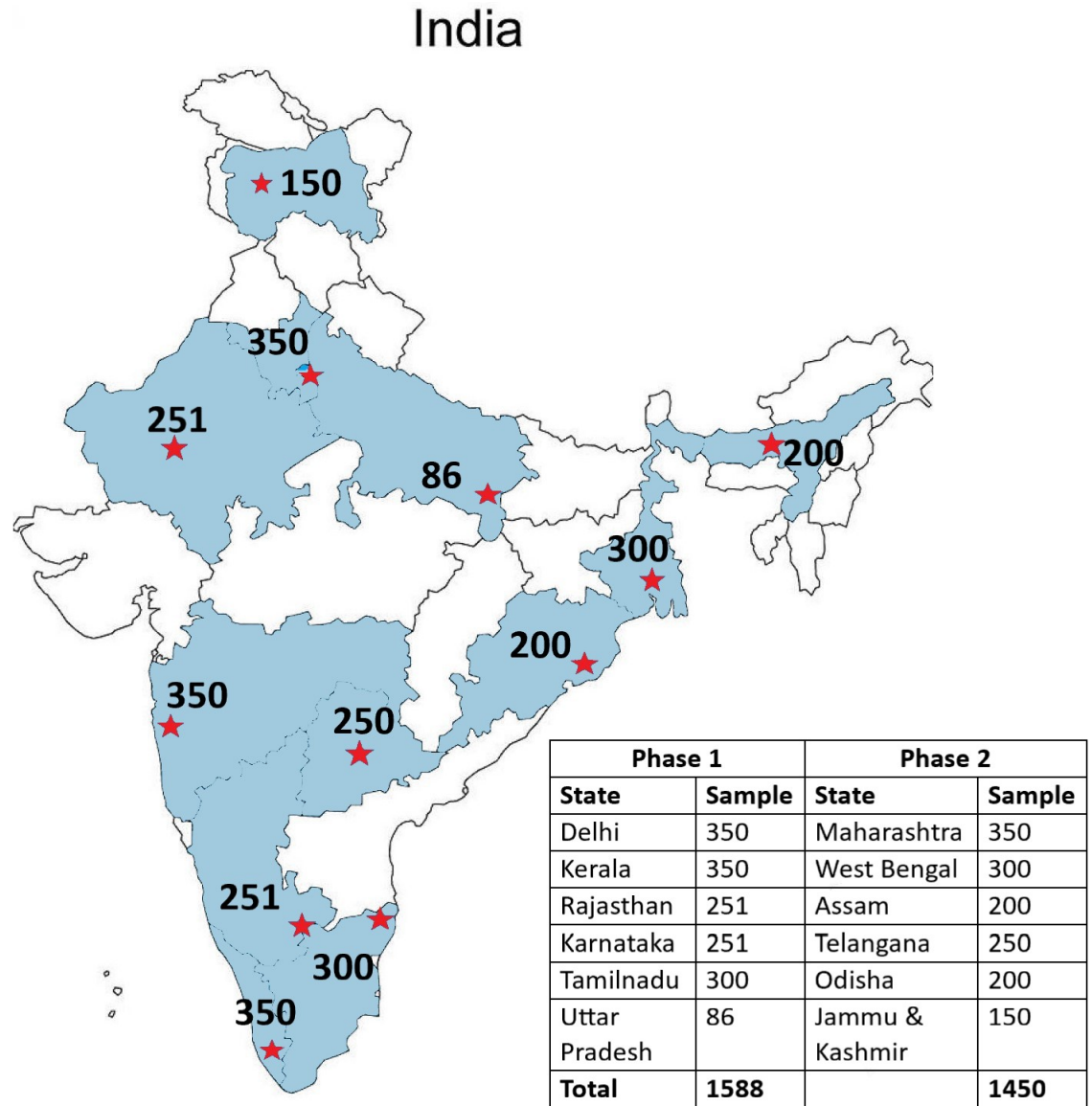
HRS HCAP RESPONSE RATE, BY COGNITIVE STATUS AT HRS 2016 INTERVIEW

HCAP Response Rate				
HRS status	Both	R only	Inf only	Total
High normal	73.8	5.8	0.1	79.7
Low normal	69.0	7.2	3.1	79.3
MCI	67.8	9.8	2.9	80.5
Dementia	50.8	5.7	16.6	73.1
All	68.6	7.1	3.4	79.0

LASI-DAD Sample

- Sampling strategy
 - Oversampling of high risk of cognitive impairment
 - The sample consists of about $\frac{1}{2}$ high risk of cognitive impairment and $\frac{1}{2}$ not high risk
 - Risk of cognitive impairment is based on the LASI main wave
 - Select the state where a partner hospital is located and set a target sample size based on the main LASI sample size within each state
 - Randomly select age 60+ with equal number of high and not high risk of cognitive impairment for the target sample size within each state
- Released to HCAP in batches, after 2-month interval from the main LASI
- Response rate $\sim 83\%$
- Target sample size 3,200

LASI-DAD Study Sites



MHAS Mex-Cog Sample

- Sample selected from 8 of 32 states
 - States selected for coverage of urban/rural, cost/efficiency of survey operations
 - 3,250 of MHAS 2015 respondents, aged 55 and older, with direct interview or proxy for health reasons
 - Full sample – single and coupled households
- Response rate ~70% of selected
- Effective sample size: 2,265 (25.1% of 55+ in MHAS 2015)
 - Both cognitive and informant 1849
 - Cognitive assessment only 193
 - Informant only 223

Conclusions

- Population-based studies of dementia are especially important now given aging of populations
- HRS-HCAP is designed to leverage existing HRS family of nationally-representative studies
- The goal is to provide publicly-available data on comparable dementia diagnostic classifications to help track dementia burden on patients, families, and health systems in countries around the world

HRS-HCAP Funding

National Institute on Aging
Social Security Administration

More HRS-HCAP Information

HRS website
Gateway to Global Aging website

The background of the slide features a collage of vertical strips showing the faces of diverse elderly individuals, mostly smiling. A blue dotted line arches across the middle of the image, passing behind the text.