

**National Institute on Aging**

# **Interlinkages Between HRS Parent and HCAP Studies**

**September 30–October 1, 2024**

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## Acronym List

A $\beta$	beta amyloid
AD/ADRD	Alzheimer's Disease and Alzheimer's Disease Related Dementias
ADL	activity of daily living
AL-SEHA	A Longitudinal Study of Egyptian Healthy Aging
APOE4	apolipoprotein E allele 4
ATW	Around the World
BSR	Division of Behavioral and Social Research
CERAD	Consortium to Establish a Registry for Alzheimer's Disease
CHARLS	China Health and Retirement Longitudinal Study
CRELES	Costa Rican Longevity and Healthy Aging Study
CSID	Community Screening Interview for Dementia
CSPS	Chilean Social Protection Survey
CVFS	Chitwan Valley Family Study
ELSA	English Longitudinal Study of Ageing
ELSI	Brazilian Longitudinal Study of Health, Ageing & Well Being
GECC	Gateway Exposome Coordinating Center
GFAP	glial fibrillar acidic protein
GPS	global positioning system
HAALSA	Health and Aging in Africa: Longitudinal Studies in South Africa
HAALSI	Health and Aging in Africa: A Longitudinal Study of an INDEPTH Community in South Africa
HCAP	Harmonized Cognitive Assessment Protocol
HRS	Health and Retirement Study
IADL	instrumental activity of daily living
IQCODE	Informant Questionnaire on Cognitive Decline in the Elderly
IRT	Item Response Theory
ISCED	International Standard Classification of Education
JSTAR	Japanese Study of Aging and Retirement
KLoSA	Korean Longitudinal Study of Aging
KNBS	Kenya National Bureau of Statistics
LASI-DAD	Longitudinal Aging Study in India Diagnostic Assessment of Dementia
LMIC	low- and middle-income country
LOSHAK	Longitudinal Study of Health and Ageing in Kenya
LSAHA	Lebanon Study on Aging and HeAlth
LTC	long-term care
MARS	Malaysia Aging and Retirement Study
MHAS	Mexican Health and Aging Study
MLSFH	Malawi Longitudinal Study of Families and Health
MPI	multiple principal investigator
NfL	neurofilament light chain
NIA	National Institute on Aging

NICOLA	Northern Ireland Cohort for the Longitudinal Study of Ageing
NIH	National Institutes of Health
pTau	phosphorylated Tau
SCAN	Study on Cognition and Aging in Nepal
SES	socioeconomic status
SHARE	Survey of Health, Aging and Retirement in Europe
TILDA	The Irish Longitudinal Study on Ageing

## Executive Summary

The Health and Retirement Studies (HRS) Around the World (ATW) and Harmonized Cognitive Assessment Protocol (HCAP) networks held a hybrid meeting on September 30 and October 1, 2024, in Bethesda, Maryland, focused on interlinkages between HRS parent and HCAP studies. The meeting addressed harmonization of measures across HRS-ATW and HCAP Network studies and the appropriate risk factors and cognitive measures for assessing cognitive health and dementia.

### ***Common Core Variables Across HRS Studies***

The Gateway to Global Aging Data team reviewed all questions asked across 14 HRS-ATW studies and found that 48% of the more than 600 common core variables are represented across all studies. The team identified content modules with poor coverage of core variables, specifically (a) health behaviors, (b) end-of-life planning, (c) caregiving, (d) health and long-term care insurance and use, (e) stress and subjective wellbeing, (f) housing characteristics, and (g) cognition. The team emphasized that harmonization across studies requires not only common variables, but also for questions to be asked and administered consistently. Gateway has produced a [standardized common core questionnaire and two accompanying white papers](#) to set a framework for further harmonization.

### ***Core and Covariate Data for Stand-Alone HCAPs***

Presenters addressed cognitive tests and informant questions that should be incorporated into stand-alone HCAP studies. Depression, anxiety, cognitive stimulation, and fatigue are key psychological factors that can impact study participation, performance on cognitive tests, and overall cognitive function. Measures of social networks, loneliness, and caregiving should capture the strength and modality of social ties as well as the type and quantity of caregiving provided to family members across the age spectrum. Although many life experiences can contribute to the risk of developing dementia, a respondent's reading level, educational attainment, and factors that interfered with schooling are the most critical for interpreting cognitive test scores.

Presenters also reviewed the potential benefits and drawbacks of additional covariates and outcome measures. Blood-based biomarkers of Alzheimer's disease and related pathologies have been developed but may not be prioritized for HCAP studies because of the required cost and specialized equipment; instead, studies should focus on capturing measures of cardiovascular, metabolic, and other modifiable risk factors and health behaviors that have greater effect sizes than existing Alzheimer's disease biomarkers. Studies that include bilingual and multilingual populations should capture a respondent's usage of and proficiency in their second language, as well as the age of acquisition. Finally, neighborhood and contextual measures should prioritize a respondent's reports of safety, neighborhood cohesion, and available infrastructure, in addition to interviewer observations of the condition and characteristics of the physical and built environment.

### ***Parent Study Cognitive Tests***

Current cognitive testing across HRS parent studies does not consistently measure the five main domains of cognition: memory, executive functioning, language and fluency, orientation to time and place, and visuospatial functioning. The cognitive tests also face significant challenges in capturing the full range of cognitive functioning, detecting longitudinal change in cognition, and ensuring cultural validity in diverse cultural contexts. The brief nature of core batteries may hinder the use of statistical approaches to estimate latent traits consistently as the test battery changes.

Researchers must identify important cognitive domains to measure in a minimum test battery. The set of test items recommended by the Gateway to Global Aging Data team consists of (a) self-rated memory, (b) the ability to write or say a sentence, (c) immediate and delayed word recall, (d) orientation to time, (e) overlapping pentagons, (f) three-stage task, (g) symbol cancellation, (h) animal naming, and (i) Serial 7s or backwards day naming. Based on recommendations, studies aiming to increase precision of cognitive functioning estimates could add logical memory story recall, constructional praxis, and go/no-go tasks. This battery of tests may perform better than existing study protocols in precisely measuring cognitive ability while identifying dementia cases. The battery should be adapted to local context by adding tests or adapting existing test items to maintain cultural relevance.

### ***New Studies Balancing HRS and HCAP Content***

Presenters discussed three new HCAP studies in Ghana, Egypt, and Kenya, each of which have adapted HRS and HCAP methodologies to local contexts. In Ghana, researchers completed a pilot study that adapted existing test batteries to address challenges related to literacy, local context, language differences, and gender-based disparities while collecting comprehensive data on cognitive functioning across the range of ability. A Longitudinal Study of Egyptian Health (AL-SEHA) team conducted two pilot studies ahead of the anticipated start of the core study, focusing on adapting the Arabic HCAP (initially developed by the Lebanon Study on Aging and Health [LSAHA]) to the Egyptian context and validation of the core survey after the SHARE study one. The Longitudinal Study on Health and Aging in Kenya (LOSHAK) team will scale its recently completed pilot study to a full national core study while implementing a regional HCAP study in six coastal counties in Kenya, aiming to gather comprehensive data on cognitive aging, demographics, and social and environmental factors related to health.

### ***Lebanon Study on Aging and Health***

The LSAHA team successfully recruited a cohort of respondents across Beirut and Zahle in Lebanon and collected data between October 2023 and September 2024, including (a) a comprehensive health and social survey, (b) anthropometric measures, (c) physical performance tests, (d) blood samples, and (d) the full HCAP battery, which was embedded in the core interview. The study team adapted the test battery to challenges with local context, including low education levels, significant gender recruitment imbalances, and high political and economic instability, with over half of respondents reporting being affected by conflicts in Lebanon since the onset of the civil war in 1975, and 82% of respondents reporting being seriously affected by the economic downturn since 2019.

### ***Minimum HCAP Requirements***

HCAP studies should aim to prioritize cross-national harmonization efforts while adapting to achieve cultural validity in local contexts. The minimum required HCAP test battery should include optimized cognitive and informant measures to facilitate both of these goals. The Gateway to Global Aging Data team developed a document that outlines criteria for cognitive measures to be considered for a minimum HCAP, concluding that cognitive tests should assess each of the five main cognitive domains across a broad range of ability while identifying dementia cases in population-representative samples. These tests should be reliable, valid, and culturally appropriate. To achieve cross-national harmonization of HCAP studies, researchers must identify comparable tests, adapt existing tests, and link test items across studies through statistical co-calibration or alternative methods like calibration samples of linear linking.

Though informant reports provide valuable information, cultural differences across studies, as well as gender, age, and sociocultural reporting differences can limit cross-national comparisons. Researchers may consider statistical correction for differences by informant characteristics; however, objectivity is not the gold standard for informant reports, and capturing differences between performance on objective tests and informant reports may provide important information. Informant reports can be modified in other ways to decrease repetition, standardize administration processes, and collect information on informant characteristics to better understand these relationships.

To better achieve cross-cultural adaptation of the HCAP battery, Briceño emphasized the importance of working with local team members to develop cognitive assessment tools in an iterative process centered around cognitive constructs, rather than specific tests. The Nepal HCAP team demonstrated this process in the creation of the Chitwan Valley Family Study-Study on Cognition and Aging in Nepal (CVFS-SCAN) cognitive screening test, a freely available and license-free test that relieves administrative burden from the study team and enables sharing with local experts.

### ***Group Discussion and Next Steps***

Group discussion centered around three key themes: (a) essential HRS core variables required for standalone HCAP studies, (b) recommended cognitive measures for parent HRS studies without HCAP studies, and (c) defining the minimum requirements for an HCAP battery. Key challenges discussed included balancing local measurement validity with cross-national harmonization, promoting a better understanding of HCAP's cultural adaptability, and adapting HCAP batteries to clinical contexts.

## Meeting Summary

### Welcome and Introductions

The joint meeting of the Health and Retirement Study (HRS) Around the World (ATW) and the Harmonized Cognitive Assessment Protocol (HCAP) international networks was held in person in Bethesda, Maryland, on September 30 and October 1, 2024, with remote participation by 78 attendees in 25 countries. This was the largest hybrid gathering with the greatest number of countries represented to date from the networks.

After a warm welcome by the principal investigator of the HRS-ATW (**David Weir**) and co-principal investigators of the HCAP Network (**Kenneth Langa** and **Lindsay Kobayashi**), **Amy Kelley**, Deputy Director of the National Institute on Aging (NIA), added her welcome remarks, underscoring NIA's focus on supporting global research to help increase healthy and active years of life for all people. These international networks allow for cross-national measurements of health and longevity to elucidate how different environmental, social, and biological factors affect health outcomes in diverse populations. By understanding the factors that drive healthy and unhealthy aging, NIA research can inform the development of programs, interventions, and policies to prevent and treat disease.

HRS has been funded for more than three decades and is the leading source of data on aging and dementia within the United States and around the world. The study has served as a model for the longitudinal aging studies in more than 40 countries that compose the HRS-ATW network; the data collected by HRS-ATW studies are representative of greater than 70% of the global population of adults aged 60 and above. HRS-ATW data facilitate within- and cross-country analyses of the impact of different environmental, social, cultural, and economic contexts on health and aging. These data and the tools developed from them are harmonized and widely available to researchers whose work will inform programs and policies worldwide.

The initial set of all HCAP studies was embedded in established HRS-harmonized longitudinal studies of aging. The core HRS studies provide rich demographic and epidemiological data intended to be used with HCAP studies. NIA Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD) funding made it possible to initiate an HCAP study without an established HRS study, but that efficiently employ dementia assessments comparable to those in large population studies of aging around the world. HCAP data have been collected in seven countries thus far. Several additional HCAP studies are ongoing, and further expansion is planned.

**Minki Chatterji**, NIA Division of Behavioral and Social Research (BSR) Program Officer, presented the three major discussion topics for the joint HRS-ATW/HCAP meeting: (a) identifying key explanatory variables necessary for rigorous dementia studies, especially for stand-alone HCAP studies that might not have all HRS core variables, (b) determining which cognitive tests should be collected in parent HRS studies that do not have an HCAP study, and (c) determining what constitutes a minimum HCAP. She also shared NIA Notices of Funding Opportunity of likely interest, including ones related to promoting cross-national analyses using



HRS-ATW and HCAP Network data (RFA-AG-25-025) and AD/ADRD research in low- and middle-income countries (LMICs) ([RFA-AG-25-031](#)), and [a newly approved NIA concept to support institutional research training for AD/ADRD and aging research in LMICs](#). NIA also has released a Notice of Special Interest for R01 and R03 research examining [U.S. Health in the International Perspective \(NOT-AG-24-004\)](#). Finally, Chatterji noted the publication of [a report](#) on the NIA-commissioned National Academies of Sciences, Engineering, and Medicine workshop on Developing an Agenda for Population Aging and Social Research in LMICs held in September 2023.

**Jonathan W. King**, Senior Scientific Advisor to the Division Director, noted that the recent National Institutes of Health (NIH) [Alzheimer's Research Summit](#) identified research gaps and opportunities that may be of relevance to HRS-ATW and HCAP networks. He also recommended that attendees watch the recording of [Cognitive Aging Summit IV](#), which was held in March 2024.

## Overview of Meeting Agenda and HRS-ATW/HCAP U24 Network Updates

### Meeting Agenda and HRS-ATW Updates

*David Weir*

Weir outlined the agenda for the HRS-ATW/HCAP Joint Meeting, which focused on six topics: (a) common core variables across HRS studies, (b) core and other covariate data that should be collected for stand-alone HCAPs, (c) cognitive tests that parent studies should collect, (d) new studies balancing core and HCAP content (e.g., Ghana, Egypt, Kenya, Lebanon), (e) what set of cognitive and informant measures constitutes a minimum HCAP, and (f) identification of topics for virtual follow-up sessions.

Next, Weir provided HRS-ATW Network updates. HRS-ATW has supported two data collection pilot projects to date: (a) feasibility of the HRS design on a probability sample for the A Longitudinal Study of Egyptian Healthy Aging (AL-SEHA), which subsequently obtained R01 funding and (b) bridge funding to Northern Ireland Cohort for the Longitudinal Study of Aging (NICOLA) wave 3. HRS-ATW can also support analytic projects seeking to improve statistical harmonization. Weir welcomed suggested discussion topics for future Zoom meetings, citing as an example a recent meeting on sample refreshment. The Biomarker Network will hold its international meeting on Wednesday, April 9, 2025, during the Population Association of America meeting. Finally, the next full HRS-ATW meeting will take place in Aguascalientes, Mexico, on October 29–30, 2025.

### HCAP U24 International Network Updates

*Ken Langa; Lindsay Kobayashi*

Langa highlighted the productivity and accomplishments across the HCAP network, which supported 12 pilot studies, including HCAP pilots in Kenya, Egypt, and Ghana. Cumulative HCAP

publications have increased from 4 in 2019 to 89 in 2024, with several more in preparation. The most recent Africa HCAP meeting was held on February 2024 in Johannesburg with the next meeting scheduled for June 2025 in Nairobi. Finally, HCAP supported the August 2024 Advanced Psychometric Methods for Cognitive Aging Research meeting, which focused on international comparisons of cognitive functioning.

Kobayashi reviewed the details of the HCAP network renewal, which funds the network from September 2024 through June 2029. Kobayashi has replaced Weir as a multiple principal investigator (MPI). Emily Briceño and Miguel Arce Rentería have joined as collaborators on the Protocol and Administration Core to help develop a common protocol for HCAP studies, including providing guidance on item selection, translation, and adaptation. Langa, Weir, Jessica Faul, Richard Jones, Jennifer Manly, Lindsay Ryan, and Amanda Sonnega will continue as Core Leaders. The renewal includes funding for pilot studies, virtual “hot topic” meetings, a junior investigator exchange program to facilitate HCAP investigators learning from each other, and quarterly research-in-progress seminars.

Langa reviewed the progress across ongoing HCAP studies (**Table 1**). Data from eight HCAP Wave 1 studies have been cleaned and released to the public, and data from five more studies and four more Wave 2 applications (from Survey of Health, Aging and Retirement in Europe [SHARE], The Irish Longitudinal Study on Ageing [TILDA], NICOLA, and Lebanon Study on Aging and Health [LSAHA]) are being cleaned and prepared for release. Data collection has begun on HCAP studies in Kenya and Nepal and will soon begin in Egypt, while the Malaysian HCAP has applied for funding. Pilot or full studies have been funded in Guatemala, Ghana, and Pakistan, and pilot or full applications have been submitted or planned from an additional nine countries (Afghanistan, Côte d’Ivoire, Japan, Kenya [Longitudinal Study of Health and Ageing in Kenya, LOSHAK], Malawi, Philippines, Scotland, Sri Lanka, Viet Nam). Wave 2 data collection has been completed for all five funded studies (HRS, Mexican Health and Aging Study [MHAS], English Longitudinal Study of Ageing [ELSA], Health and Aging in Africa: A Longitudinal Study of an INDEPTH Community in South Africa [HAALSI], Longitudinal Aging Study in India [LASI]).

## What Are the Common Core Variables Across the HRS Family of Studies?

*Jinkook Lee*

The mission of the Gateway to Global Aging Data is to provide data for global aging research, to make these data ready for analysis by continually updating longitudinal data files and reducing the upfront costs of analyzing these complex data, and to stimulate global aging research.

**Table 1. HCAP International Network Study Status**

Country	Study	Wave	Applied	Funded	Begun	Completed	Data Released
USA	HRS	1	✓	✓	✓	✓	✓
		2	✓	✓	✓	✓	
Mexico	MHAS	1	✓	✓	✓	✓	✓
		2	✓	✓	✓	✓	✓
England	ELSA	1	✓	✓	✓	✓	✓
		2	✓	✓	✓	✓	
S. Africa	HAALSI	1	✓	✓	✓	✓	✓
		2	✓	✓		✓	
China	CHARLS	1	✓	✓	✓	✓	✓
India	LASI	1	✓	✓	✓	✓	✓
		2	✓	✓	✓	✓	
Chile	ESPS	1	✓	✓	✓	✓	✓
S. Korea	KLOSA	1	✓	✓	✓	✓	✓
EU	SHARE	1	✓	✓	✓	✓	
		2					
Ireland	TILDA	1	✓	✓	✓	✓	
		2					
N. Ireland	NICOLA	1	✓	✓	✓	✓	
		2					
Caribbean	CADAS	1	✓	✓	✓	✓	
Lebanon	LSAHA	1	✓	✓	✓	✓	
		2					
Kenya	KLPS	1	✓	✓	✓		
Kenya	LOSHAK	1	✓				
Nepal	CVFS-SCAN	1	✓	✓	✓		
Egypt	AL-SEHA	1	✓	✓			
Malaysia	MARS	1	✓				

Jinkook Lee discussed the [recommended questionnaire and two white papers](#) that Gateway released in September 2024 to highlight core content modules, variables, and question framing to maximize harmonization across studies. These resources are intended to promote harmonization in new studies and to support existing studies that want to add new constructs or strengthen harmonization of their existing survey protocols. Gateway has also produced a list of cross-study core question coverage and comparability, and the team welcomes feedback on any of these new resources.

HRS is characterized by its population representativeness, multidisciplinary content, longitudinal follow-up, data sharing, and comparable or harmonizable survey measures. Studies that are part of the HRS-ATW network are committed to ensuring all key measurements are comparable by design (ex-ante harmonization) to enable cross-country analysis, collaborating with other network researchers to share knowledge and experience, and releasing data to the larger research community in a timely manner.

Gateway has identified 13 content modules across studies, each of which contains a different number of variables and with differing coverage across studies. Gateway analyzed 14 studies<sup>1</sup> and identified the number of variables and median variable coverage of each module across the studies:

- Demographics (16 variables | 69% median variable coverage across studies)
- Health and health behavior (130 | 67%)
- Physical assessment and biomarkers (23 | 54%)
- Cognition and proxy cognition (17 | 68%)
- Family and social network (36 | 72%)
- Health and long-term care insurance and utilization (33 | 44%)
- Employment, retirement, and pension (129 | 40%)
- Wealth, income, and consumption (93 | 44%)
- Caregiving (62 | 44%)
- Stress and subjective wellbeing (86 | 26%)
- Childhood health and environment (20 | 30%)
- End-of-life planning (9 | 0%)
- Housing characteristics (20 | 28%)

Even among the modules with many common questions, such as family networks and health and health behaviors, how the questions are asked is not always consistent. Question-level comparability facilitates harmonization.

Lee outlined several easy-to-implement changes to improve harmonization: (a) utilize common reference periods for certain items (e.g., health care use and health behaviors), (b) standardize response options (e.g., frequency of and participation in social interactions), (c) add a common set of recommended questions on known dementia risk factors (e.g., history of brain injury, excessive alcohol intake), (d) collect global positioning system (GPS) information to link to exposome data, and (e) include common interviewer observations.

More difficult but important areas for harmonization include (a) strengthen health assessment, e.g., instituting objective measurements of vision, hearing, and physical activities, implementing Biomarker Network's recommendations; (b) harmonize question and response options for

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<sup>1</sup> HRS, MHAS, ELSA, SHARE, Korean Longitudinal Study of Aging (KLoSA), Japanese Study of Aging and Retirement (JSTAR), CHARLS, TILDA, NICOLA, Costa Rican Longevity and Healthy Aging Study (CRELES), Brazilian Longitudinal Study of Health, Ageing & Well-Being (ELSI-Brazil), Chilean Social Protection Survey (SPS), LASI, Malaysian Aging and Retirement Study (MARS)

functional limitations and caregiving module to capture care needs, quantify care received, and address cultural differences in caregiving patterns; (c) characterize employment and retirement status by capturing informal and changing labor markets; (d) specify whether income measures are before or after taxes; (e) capture the nature of health and long-term care (LTC) insurance within each country, including covered services, public vs. private providers, usage of different services, and out-of-pocket expenses; and (f) evaluate the translation of stress and psychological variable questions within a cultural context.

Lee noted that Gateway will host a Data Enclave Workshop on November 13, 2024, during the Gerontological Society of America meeting. Workshop participants will be able to analyze specialized datasets on cross-country cognition and longitudinal disability. The 2025 Gateway Data Enclave Workshop will focus on the exposome.

### **Core Variables by Content Module**

*David Knapp*

David Knapp presented examples of common and uncommon or inconsistent core variables across study content modules, along with harmonization recommendations and ideal variable additions. Within the health and health behavior module, common variables include diagnosis, onset, and treatment of health conditions; inconsistent variables include response scales for self-reported health measures and questions about activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Knapp recommended providing anchoring and culturally relevant vignettes to calibrate self-reported health measures and differentiating between needing help and receiving help with ADLs/IADLs. Other easy additions include traumatic brain injury, hearing and vision loss, self-reported height and weight, sleep, excessive alcohol use, and preventative care (e.g., mammogram). Although more difficult to collect, he suggested also including objective measurements of vision, hearing, physical activities, and physical assessments and biomarkers (including reasons for not completing).

Although studies commonly ask about the number of hospital stays and doctor visits, out-of-pocket spending, and private health insurance coverage, reference periods for health and LTC insurance questions are inconsistent. Standardizing the reference period to 1 year is recommended for harmonization, and Knapp considered it ideal to collect all insurances in a loop format and add questions about covered services, medication coverage and use, and use of LTC, dental, and vision care. In contrast, most studies do not ask questions about end-of-life planning; Knapp recommended adding brief questions about wills and trusts and end-of-life wishes. Knapp highlighted harmonization recommendations for the caregiving module, which focus on quantifying the care received and provided and tying caregiving with the family and friend network. Finally, Knapp directed attendees to his slides for harmonization recommendations for modules concerning stress and subjective well-being; demographics; family and social network; childhood health and environment; housing characteristics; employment, retirement, and pensions; and income, wealth, and consumption.

Knapp concluded that without survey harmonization, the feasibility and utility of cross-national research are limited. He emphasized that 48% of the common core variable questions are asked

across all studies (considered a great success) and that it would be impossible for studies to include the same set of questions because of the different contexts in each country. Finally, having common variables is not sufficient for harmonization; survey questions also must be asked and administered consistently.

### **Gateway Exposome Coordinating Center**

*David Knapp*

Knapp introduced the Gateway Exposome Coordinating Center (GECC), an interdisciplinary project funded by NIA that advances AD/ADRD research by serving as a centralized hub for accessing, harmonizing, linking, and sharing exposome data for AD/ADRD risk, resilience, and disparities. GECC aims to facilitate research on how exposures to environmental factors throughout life, starting from conception and pregnancy, interrelate and link to biological outcomes that lead to AD/ADRD. GECC will serve as the hub for (a) identifying research priorities through inclusive consensus building; (b) developing guidance for measuring, harmonizing, and using exposome data; (c) creating novel exposome measures and data; (d) disseminating open-access resources to the broader research community; and (e) capacity building through guidance documents, publications, and workshops. GECC is holding [virtual town halls](#) in October, November, and December during which attendees are encouraged to share their experiences and insight on aging and dementia.

### **Discussion**

#### ***Reference Periods***

Participants discussed the challenges in harmonizing reference periods across studies, noting that COVID disrupted the cadence of many studies and led to within-study inconsistencies. Although 1 year was recommended, many studies operate on 2- to 3-year intervals. One participant noted that the reference period often differs depending on the question; for example, although 1 year would be an appropriate interval when asking about insurance service utilization, a question about whether the participant has had a heart attack would extend over the lifetime rather than a single year. A second participant suggested utilizing the varied reference intervals already present in studies to map trajectories or growth curves.

#### ***Standardization***

Some participants expressed concern about longitudinal inconsistencies that would arise from adopting the Gateway questionnaire, noting that HRS has 15 waves of existing data that would conflict with those standard questions. Participants suggested using calibration samples, or auxiliary data collection to gather data on two versions of a question at the same time, to facilitate harmonizing existing data with the Gateway recommendations. For example, a pilot study could administer a new version of a question to 10% of a sample and an old version to 90% of the sample.

#### ***Cultural Context***

A participant reminded attendees that many of the study questions are framed by research traditions in high-income countries and that these questions are difficult to adapt for LMICs,

noting that questions about managing money or prescription medications may have a different salience in LMICs than they do in the United States. Study researchers must be conscious of how their own research and cultural experiences influence their harmonization efforts.

## **What HRS Common Core or Other Covariate Data Are Needed for Dementia Studies and Should be Collected in Stand-Alone HCAP Studies?**

### **Psychological Factors Relevant to Stand-Alone HCAP Studies**

*Andrew Steptoe*

Andrew Steptoe discussed psychological factors that might be relevant to participation in HCAP studies, performance on cognitive tests, determinants of cognitive function, and consequences of poor cognitive function. For example, depression or low mood are key factors that can affect all four aspects of stand-alone HCAP studies. Steptoe noted that depression was a top predictor of non-participation in the ELSA HCAP study; only dementia and IADL difficulties had stronger effects on participation. In addition, anxiety and COVID-19-associated fatigue and brain fog can affect cognitive test performance. Cognitive function can also be affected by health behaviors such as physical activity or smoking as well as the participant's history of engaging in cognitively stimulating work or leisure activities. Finally, poor cognitive function can contribute to depression and low mood, as well as affect a participant's decision making (particularly consequential to financial and health planning), risk preferences, personality, and future orientation (i.e., the extent to which an individual focuses on the long term vs. short term).

### **Social Networks, Loneliness, and Caregiving Domains**

*Lisa F. Berkman*

Lisa Berkman shared key questions related to social ties, loneliness, and caregiving that she is utilizing in HAALSA. She emphasized that the literature has shown a clear longitudinal relationship between social engagement and cognitive function. Berkman adapted social network questions from ELSA to identify the number and strength of a participant's social ties. These questions ask participants about closeness with their partner, children, relatives, and friends, as well as the mode of contact, to help researchers quantify the strength of social ties maintained by in-person visits, phone conversations, or writing. Berkman also shared questions about the participant's neighborhood to establish comfort felt in one's local area and the existence of weaker community ties. The study's loneliness questions are adapted from the UCLA Loneliness Scale and measure the participant's perception of lacking social contact and feeling left out or isolated. Finally, the caregiving questions capture who participants are caring for and how much time is spent on providing that care; crucially, the questions recognize that caregiving can occur across the age spectrum, from caring for parents and parents-in-law to grandchildren and near-peers.



## **Life Experiences Needed for Stand-Alone HCAP Studies**

*Jennifer Manly*

Manly discussed the need for more cross-national evidence on life experiences, many of which should be considered modifiable. HCAP studies should focus on understanding inequalities in dementia as mediated by mechanisms and experiences across the life course, including neuropathology, cognitive reserve, individual life experience, and family and community experiences. Manly emphasized that the most consequential life experiences for interpreting cognitive test scores to diagnose dementia are: (a) the respondent's literacy and educational attainment and (b) factors that interfered with the respondent's expected course of schooling. Other experiences are risk factors for dementia but are not needed for diagnosis of dementia, including early-life socioeconomic status (SES), schooling/educational experience, immigration/migration history, medical and psychiatric history, traumatic/stressful life events, occupational history, and marital history/family formation.

Several systems have been developed to manage non-comparability of educational systems across different countries, including the International Standard Classification of Education (ISCED). However, researchers must remember that these systems were developed in high-income countries and do not account for differences in schooling experiences between migrant and native-born communities, account for policy changes such as increases in compulsory levels or age at leaving, or include the historical educational data needed to understand the schooling experiences of older adults. ISCED maps educational pathways, compulsory schooling, and governmental support for early education across countries, providing the context needed to harmonize cross-country educational data.

Manly outlined the information needed to measure a respondent's educational experience: (a) literacy, (b) age entering school, (c) years of completed school, (d) credential attained and age at attainment, (e) location and/or names of schools attended, (f) reason for leaving before compulsory age or credential, (g) academic or behavioral problems, and (h) learning difficulties. In addition, Manly recommended that all HCAP studies ask about family SES across the life course, as well as stressful, adverse, or traumatic life events. These events should include natural disasters, minoritized status, and discrimination or unfair treatment. Finally, HCAP studies should incorporate sleep measures. In a study of adults in New York City, Manly found that individuals with too little or too much sleep performed worse on executive function.

## **Biomarkers Related to AD, Neuropathology, and Dementia for HCAP Studies**

*Jessica Faul*

Faul presented on biomarkers that should be included in stand-alone HCAP studies on behalf of the NIA Biomarker Network, which is developing a blood-based repository to harmonize laboratories across the country to facilitate harmonized measurement of biological measures for use by HCAP researchers around the world. She also emphasized that although biomarkers do contribute to cognitive dysfunction and dementia, their influence is weaker than demographic or SES factors. In addition, the difficulty in clinically diagnosing AD vs. other related dementias has complicated the discovery and application of biomarkers. Faul explained



that an estimated 40% of dementia cases worldwide could be prevented through modifying cardiovascular and metabolic risk factors and that HCAP studies should characterize the general health of their population by collecting glucose levels, height and weight, blood pressure, cholesterol levels, liver function, albumin, vitamin D, cystatin C, and other health biomarkers.

The most significant genetic risk factor for AD is apolipoprotein E allele 4 (*APOE4*) status; the allele is determined by only two nucleotide polymorphisms and can be assayed from blood or saliva for less than \$10. Blood-based biomarkers for both AD (i.e., beta amyloid [ $A\beta$ ], phosphorylated Tau [pTau]) and non-specific AD-related pathologies (i.e., neurofilament light chain [NfL], glial fibrillary acidic protein [GFAP]) can be measured but require blood to be processed within 1–2 hours for best results. Delayed processing requires expensive, specialized equipment and sensitive assays; currently, only GFAP and NfL can be ascertained using dried blood spots. HRS and the Longitudinal Aging Study in India Diagnostic Assessment of Dementia (LASI-DAD) have found that NfL and GFAP levels are associated with cognitive test performance, and HRS data have shown that NfL is a predictor of dementia onset and death within 4 years regardless of *APOE4* status. These blood-based biomarkers, in addition to measures of respiration and epigenetic clocks, are among the most important biomarkers in predicting cognitive dysfunction in the HRS. Faul recommended that HCAP studies (a) collect and store plasma and serum; (b) capture metabolic, cardiovascular, respiratory, renal, inflammatory, hepatic, and health behavior risk factors; and (c) collect genomic data through saliva or blood. More specific biomarkers and risk factors such as GFAP and NfL can be collected if protocols and equipment allow.

### **Measuring Bilingualism/Multilingualism Around the World**

*Miguel Arce Rentería*

**Miguel Arce Rentería** discussed measures of bilingualism and multilingualism, which are considered cognitively enriching activities associated with reduced risk of dementia. This “bilingual advantage” may occur through a strengthening of attentional and executive control neural networks as a result of switching between languages. However, studies have not consistently shown a bilingual advantage on cognitive tasks, potentially because of inconsistent definitions of bilingualism, lack of clarity on which aspects of bilingualism are more likely to benefit cognition, and inconsistent control for potential confounders (e.g., educational experiences, SES, immigration history). In addition, while most bilingualism and multilingualism research has been performed in high-income countries, linguistic diversity is far greater in many LMICs. LASI-DAD, MHAS, and HAALSA measure multilingualism, including measures of the number of languages spoken, self-reported proficiency in each of these languages, age of acquisition, and frequency of use. LASI-DAD wave 2 has also incorporated an objective proficiency test; participants are asked to tell a story in three of their spoken languages. Preliminary results from LASI-DAD suggest that greater proficiency in a second language is associated with improved performance on memory, language, and executive function tasks. Arce Rentería plans to compare the LASI-DAD results with those from his study of bilingual participants in New York City. Finally, he emphasized that incorporating measures of multilingualism enables researchers to evaluate hypotheses related to cognitive reserve and

resilience, gain more understanding about cognitive aging and late-life health outcomes in bilingual and multilingual populations, and better understand the social and environmental factors associated with bilingualism and late-life health.

### **Neighborhood/Contextual Data for HCAP Studies**

*Jennifer Ailshire*

**Jennifer Ailshire** presented the aspects of a participant's context and environment that affect their cognitive health and dementia risk. Within the physical and built environment, walkability and drivability can influence physical activity and the ease of accessing services, the presence of traffic generates pollution and noise, green spaces can improve psychological and cardiovascular health, and nascent weather research has suggested that heat can impact cognitive performance. While social disorder and crime serve as proxies for neighborhood stressors and isolation within the social environment, community cohesion and proximity to social networks have a strong positive influence on cognition. Ease of access to amenities such as health care, parks and recreation, third spaces for social gathering, and resources (e.g., grocery stores) are critical for reducing risk of cognitive deterioration and dementia. Finally, chemical exposures both outdoors (e.g., water toxicants, air pollution, soil contamination) and indoors (e.g., cooking fuel, building materials, pesticides) can be critical to understanding cognitive health, especially in LMICs.

Environmental context data can be measured through respondent reports, rater reports and observations, administrative data, and image data. Respondent reports can be harmonized through instrument alignment across studies, although this approach may require additional questions that could increase respondent burden or translate poorly across countries or modalities. Rater reports can be harmonized through instrument and protocol alignment and increased training for interviewers and other field team members. Administrative data are difficult to harmonize because of differences in spatial administrative units and measures across countries. Image data, such as satellite images, are very harmonizable, although harmonization may require additional data processing and decisions. Ailshire recommended that HCAP studies add (a) respondent questions about neighborhood safety, cohesion, disorder, and conditions; (b) respondent reports about the presence of infrastructure; (c) rater reports on the condition of the built environment; and (d) rater reports of physical environment characteristics. Administrative and image-based data (e.g., satellite-based measures of air pollution, green space, weather) should only be prioritized if they can be linked to respondents, and all measures should be context dependent, both in terms of the country and whether the location is urban or rural.

### **Discussion**

#### ***Data Collection Timing***

Participants discussed when to administer additional respondent questions for stand-alone HCAP studies, noting that respondents are generally unenthusiastic about answering questions following the 1-hour cognitive test. Study teams should instead incorporate additional

questions into a pre-test session, such as an informant interview, that is separate from the HCAP session.

### ***Literacy***

Participants emphasized the importance of capturing literacy measures in both LMICs and high-income countries because some aspects of the educational experience can modify the benefit of schooling years. For example, U.S. schools vary widely in quality, funding, academic curriculum, teacher training, and available resources; these factors influence student achievements and reading levels. Reading level is a relatively stable measure of verbal literacy that reflects an individual's pre-morbid cognitive level and is critical for detecting cognitive decline.

### ***LASI-DAD Linguistic Representation***

Participants expanded upon the reasoning behind the 12 languages chosen for administering the LASI-DAD survey instruments. Although India has 22 official languages, the LASI-DAD team determined that the 12 languages chosen would capture greater than 90% of the targeted sample population. The team employs language experts to develop the study protocols and translate the materials, as well as to evaluate the new language proficiency test. In addition, the study provides recordings of different dialects that the interviewers may encounter.

### ***Age and Mode of Language Acquisition***

LASI-DAD found no strong relationship between age of language acquisition and cognitive function; however, studies of bilingual, Spanish-speaking individuals in New York City found an association between age of acquisition and cognitive function for U.S.-born participants, but not immigrant participants. More research is needed to understand the effect of mode of acquisition, but most U.S.-born participants learned their second language (English) by age 2, while most immigrant participants learned English as adults.

### ***Inflammation Biomarkers***

Although inflammation is relevant to dementia risk, this association cannot yet be captured by one or two biomarkers. However, some of the recommended cardiovascular measures capture inflammation, and measures of DNA methylation might also serve as surrogate measures of inflammation.

### ***Neighbor Networks***

Participants emphasized the importance of neighbors in the social network, particularly for older adults. Capturing these relationships would require questions that differentiate neighbors from family and friends, such as asking about the respondent's familiarity with the people living next door.

### ***Identifiability***

Participants discussed potential privacy concerns related to using satellite or street-level image data. Currently, satellite images are used to measure air quality and pollution and do not elicit new privacy concerns. However, as image quality improves and satellite imagery becomes able to capture details of individual homes and yards, studies should analyze the spaces around

respondents' homes to avoid identifiability. GPS coordinates, which are highly valuable for locating the respondent's home and are relatively easy and inexpensive to gather, must also be carefully guarded. Although measures derived from image data alone do not provide enough information to identify a given participant, as more variables are added and combined, identifiability becomes more of a concern. To mitigate the "march of identifiability," researchers will likely only be able to access these combined data within an enclave.

### ***Participants with Cognitive Impairment***

HCAP stand-alone studies struggle to enroll participants with significant cognitive impairment. Each country has different nursing or LTC home systems, and it may be more difficult to sample the population in less-developed systems. Participants noted that longitudinal study designs that follow participants as they age may enhance researchers' ability to capture a range of impairment severity.

## **What Cognitive Tests Should Parent Studies Collect?**

### **Measurement of Cognition in Core HRS Studies**

*Emma Nichols; Alden Gross*

#### ***Existing Measures***

Cognitive testing is currently not uniformly measured across active core HRS-ATW studies. These studies assess aspects of (a) orientation to space and to time, (b) memory, (c) language and fluency, (d) executive functioning, and (e) visuospatial functioning to varying degrees. Some areas of cognitive functioning are measured across all HRS-ATW studies, such as orientation to time, and immediate and delayed word recall as a measure of memory. Most active core HRS studies assess object naming as a measure of language and fluency, but the need to adapt this measure to different cultural contexts limits harmonization efforts. No measures for language and fluency, executive functioning, or visuospatial functioning are used across all studies, demonstrating room for growth and harmonization in this area.

Existing cognitive measures in HRS-ATW studies face significant limitations and challenges, particularly in their ability to capture the full spectrum of cognitive functioning. A major challenge is that many questions are too easy for participants, yielding high correct rates. This problem is especially pronounced for assessments of orientation and language. A resulting lack of variability in responses can complicate the estimation of latent traits, leading to skewed distributions, particularly among individuals with moderate to high cognitive functioning. Current measures in HRS studies also struggle to accurately detect change in cognitive ability over time among these individuals.

Another challenge is that test items must be culturally appropriate and valid within each population to which they are applied. To address these challenges, a harmonized testing battery must balance consistency within and across studies with relevancy to the specific study population. The LASI-DAD utilized this balanced approach by adapting items in an object-naming task to be more culturally relevant to the local population at hand. Finally, studies must prioritize the ability to consistently estimate latent traits as test batteries change over time,

which requires sufficient precision across the distribution of the latent trait such that additions or subtractions to the battery do not lead to large shifts in precision. Provided the precision of the battery remains relatively constant, researchers can use confirmatory factor analysis to estimate latent traits despite changes to test items.

### ***Considerations Around HCAP***

Ultimately, researchers should aim to apply findings and lessons learned from HCAP studies to enhance the cognitive measures available in the core HRS studies. However, because of the time and resources required to add new test items to existing batteries, this effort is limited by the data that have already been collected. Evidence from ELSA shows that coefficient estimates from regression models using commonly used traditional cognitive measures, such as word recall, had higher standard errors compared to models using estimates leveraging information from gold standard factor scores in the full HCAP data. Confirmatory factor analysis is one methodological approach that can be implemented to use HCAP data to inform estimates of cognitive functioning in core HRS studies.

### ***Survey Mode***

Changes in survey mode for data collection are inevitable as researchers aim to retain samples and reduce costs. Researchers must consider whether cognitive tests can be adequately administered in different modes; phone administration can limit visual stimuli for cognitive tests, and web administration can provide advantages by enabling visual presentations in certain tests. Researchers must also consider how changes to mode can impact the data. Researchers can use calibration samples and randomization, as seen in HRS, to help estimate the effects of administration mode and incorporate these effects into analyses.

### ***Recommendations***

In order to identify a minimum set of cognitive tests for HRS studies that do not have an HCAP study, researchers must first identify the most important cognitive domains to measure. In addition, researchers must balance multiple considerations for each domain, such as (a) backwards compatibility with existing studies, (b) precision in measuring latent traits, (c) ability to classify dementia, (d) linkage to the HCAP studies, (e) adequate precision to estimate models with items that change over time, (f) enabling of comparisons across countries, and (g) time and resource constraints. For example, orientation tests, although useful for detecting dementia, do not provide information about the full range of cognitive ability, while the animal naming test can offer much more comprehensive information in a shorter time. When considering items to add to a test battery, researchers must balance these factors based on these competing priorities.

The items recommended for a common battery of test items for HRS studies include (a) self-rated memory, (b) the ability to write or say a sentence, (c) immediate and delayed word recall, (d) orientation to time, (e) overlapping pentagons, (f) three-stage task, (g) symbol cancellation, (h) animal naming, and (i) Serial 7s or backwards day naming. An extended list of recommendations items includes (a) logical memory story recall; (b) constructional praxis; and (c) go/no-go tasks that can be easily added to bolster cognitive measurement, especially in settings without active HCAP studies. Researchers might also consider incorporating

interviewer observations of factors that may have impaired performance as well as proxy reports for cognitive performance, particularly in cases in which participants cannot complete objective cognitive testing.

### **Discussion**

#### ***Precision***

Participants noted that parent study test batteries may be less ambitious than those of HCAP studies. To enhance parent study test batteries, researchers should consider what items from HCAP studies could enhance precision across all levels of cognition, rather than considering specific domains. Tests that do not provide precise and high-quality information across the spectrum of cognitive ability might be removed or substituted. Although measurement precision at the high end of the cognitive functioning spectrum may not be as important in identifying dementia cases for some current studies, it will be critical for longitudinal studies that assess decline over time.

#### ***Test Administration***

Participants expressed interest in how the animal naming tests are administered, raising questions about how variation across studies may limit harmonization. To maintain cultural relevancy, the task must feature animals known to the sample population. Notably, in existing harmonization work across HCAP studies, animal naming tests have been treated consistently, serving as an anchor item between studies. This consistency sets animal naming apart from other tests, such as word recall, where differences in administration between interviewers and studies are significant. This example underscores the importance of including details on test administration alongside recommendations for tests to include in HCAP. Interviewers should be trained extensively on administration of these tests, and consent language should allow interviews to be recorded when possible to permit checking for consistency in scoring and quality control.

#### ***Harmonization***

Participants emphasized that test selection must begin in the region or country where the study will be fielded, with input from local experts in cognitive aging. These experts can best determine which tests will effectively characterize both general cognition and specific domains within cultural contexts. Though harmonization is a priority, it should not override the importance of cultural relevance across all study regions.

## **New Studies Balancing HRS and HCAP Content**

### **Cognitive Aging in Ghana: Implementing HCAP in a Sub-Saharan African Low-Middle Income Country**

*Irma Elo*

The University of Pennsylvania, in partnership with the Regional Institute of Population Studies at the University of Ghana and the Navrongo Health Research Center, conducted a pilot study of cognitive aging in rural northern Ghana. The study included both a respondent survey and

caregiver/informant interviews. Researchers recruited a sample of 521 individuals from 800 individuals who participated in previous studies conducted in 2007 and 2015. In addition to cognitive tests included in the HCAP battery, the study team collected data on (a) sociodemographic characteristics; (b) ADLs, (c) IADLs, (d) mental health, (e) loneliness, (f) health behaviors, and (g) blood pressure, height, and weight. Findings from the study provide valuable insights into the importance of considering local context, language, and educational disparities when conducting cognitive assessments in diverse settings.

### ***Adapting the Respondent Survey to Local Context***

The study faced several challenges related to the local context and sample population. The sample population included 32 blind individuals and many participants who struggled with literacy or numerical tasks such as counting or recognizing numerals, requiring the team to adapt multiple test items. The sample had a significantly larger proportion of female participants (60.3%) than male, which was representative of the upper east region of Navrongo but not of the entire country. Men in the study were generally younger, had more schooling, and were more likely to be married compared to women. Men were also more likely to speak English than female participants in the study. The other languages used for data collection, Kassem and Nankam, are primarily spoken, not written, which creates additional challenges with the written survey method. To address the educational disparity between men and women, researchers compared men and women with no education; however, sex differences in cognitive performance persisted.

The pilot study team modeled its HCAP instruments after ones in India (LASI), Kenya (Kenya Life Panel Surveys [KLPS], LOSHAK), South Africa (HAALSI), Chile (Chile-Cog), and Malawi (MLSFH). It also adapted HCAP instruments to address challenges related to the local context. For example, the team could not use “address,” “street name,” or “district” as orientation items because of the lack of formal addresses in the region and instead used “name of town/community/village.” The team adapted test items such as delayed constructional praxis and symbol cancellation to accommodate individuals with physical impairments or lower literacy by allowing participants to draw with a stick in the dirt, or to apply ink on paper directly from their fingers. Finally, the team adapted trail-making and Serial 7 tests for participants who could not count.

### ***Caregiver/ Informant Samples***

The study team interviewed 102 caregivers or informants knowledgeable about respondents’ health, memory, and daily activities, for respondents in the bottom quartile of overall HCAP scores. All caregiver and informant interviews were conducted in person by trained interviewers and covered demographic characteristics as well as the health history of the HCAP respondent, incorporating tests such as the Jorm Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE), Blessed tests parts 1 and 2, and Community Screening Interview for Dementia (CSID).



## **A Longitudinal Study of Egyptian Health Aging (AL-SEHA) Update**

*Mohamed Salama*

The AL-SEHA study team recently conducted two pilot studies, “Harmonization of Cross-National Studies of Aging to HRS” and “Research Network for HCAP,” in Egypt to validate and harmonize cognitive assessment protocols ahead of the main AL-SEHA study.

The HRS-ATW pilot study closely followed the sample design approach of large national surveys in Egypt, such as the 2021 Demographic and Health Surveys in Egypt. The study divided the population into four strata across urban and rural areas in the Ismailia and Beni Suef regions, randomly selecting 645 households of older adults (aged 50 years and older) from each governorate, totaling 1,290 households. The study employed five questions to collect data from target groups: (a) a household questionnaire, (b) an individual questionnaire for qualified respondents aged 50 years and older, (c) individual questionnaires for the qualified respondents’ spouses, (d) a physical test questionnaire for a subsample of eligible individuals, and (e) a quality control questionnaire for the qualified respondent. Surveys achieved high response rates across all domains, with the sample population aligning well with census data.

The study also employed two teams, each comprising a fieldwork supervisor, five interviewers or researchers, a quality control officer, and a researcher for the application of the physical examination questionnaire. Although the interviewers had previous training, the study team provided extensive technical training for interviewers prior to data collection. This training included thorough discussion of the study tools, sensitivity to issues faced by aging populations, and the use of automated surveys on electronic tablets. The researchers devoted to the physical examination questionnaire were also trained extensively on measurement of weight, height, balance, grip strength, and finger strength.

The HCAP pilot study, conducted between January and June 2023, recruited participants and their informants from three health care facilities across Egypt. Participants were at least age 55, fluent in Arabic, and capable of providing informed consent. Researchers adapted the Arabic survey from the Lebanese LSAHA study team to fit cultural context in the Egyptian population. For example, the study team changed references to Lebanese-specific events to include relevant references to Egypt, while changing the language to align with the Egyptian dialect. The study team also replaced tests that required literacy with other tests such as the Go/No-go test to accommodate lower literacy rates in Egypt. The study team then conducted a small pilot study among 10 participants to determine the cultural acceptability and comprehensibility of the adapted HCAP.

Both the participants and their informants completed standardized questionnaires. Participants also completed clinical assessments, consisting of a thorough clinical interview, mental status examination, and a physical assessment. Cognitive testing assessed the key domains relevant to dementia diagnosis while ensuring alignment within the HCAP framework. These domains included: orientation, executive functioning, language fluency, memory, and visuospatial abilities. Factor analysis of the tested domains showed internal consistency, and resulting factors showed high sensitivity, specificity, and accuracy.



### **Next Steps**

The team will soon begin the core AL-SEHA study, employing a 2-hour survey. Researchers will potentially incorporate digital biomarkers and data related to air pollution into the study, in addition to remote sensing data that can be used to build 10-year environmental exposure profiles for participants based on their addresses.

### **Longitudinal Study of Health and Aging in Kenya (LOSHAK)**

*Joshua Ehrlich; Anthony Ngugi*

LOHSAK is a 5-year project with team members from the University of Michigan, Aga Khan University in Kenya, the Kenyan Ministry of Health, and several other institutions. The study recently completed its exploratory (R21) phase with promising results. The research team successfully adapted existing tools to local language and context. The project's statistical models demonstrated robust performance with moderate to very good fit statistics, as well as strong correlation of test items to underlying constructs across the four main domains of cognition: orientation, memory, executive function, and language fluency. These data have been publicly shared through the University of Michigan.

The next steps for the LOSHAK team include scaling the pilot to a full national core study and implementing a regional HCAP study in six coastal counties of Kenya. The team will prepare and publicly share data from both components of the project and will implement sustained capacity-building programs for all future waves of the project. The team submitted the project proposal to NIA in July 2024 and expects feedback between November 2024 and January 2025, aiming to begin the studies in April 2025.

For the core study, the LOSHAK team aims to establish a nationally representative sample of 6,580 participants, aged 45 and older from across all 47 counties of Kenya. This sampling approach, based on the National Sampling Framework that was developed by the Kenya National Bureau of Statistics (KNBS), systematically selects respondents from 20 households in each of 329 enumeration areas in rural and urban counties of Kenya. The team aims to cover key HRS domains by aligning Wave 1 data with HAALSI and LASI to then establish a national cohort for tracking in future waves. The LOSHAK team will also collect and assay biomarkers from venous blood samples and work with KNBS to translate the tools into 16 local languages. The team aims to recruit 2,375 participants for the regional HCAP study to estimate prevalence of mild cognitive impairment and AD/ADRD in the Kenyan population.

The LOSHAK core and regional HCAP studies will collect different data, as the core survey will include information on income, assets and debts, employment and retirement, pensions and cash transfers, and household consumption/expenditures, while HCAP will not. Similarly, the LOSHAK core survey will more extensively collect data on household and environment, family and social networks, psychosocial health, and health insurance and health care utilization.

## Lebanon Study on Aging and HeAlth (LSAHA)

*Carlos Mendes de Leon; Monique Chaaya*

LSAHA recruited a cohort of 3,029 older adults (aged 60 and older) from two areas in Lebanon, Beirut and Zahre, to provide a diverse and representative sample of the larger Lebanese population. The team collected data between October 2023 and September 2024, including a comprehensive health and social survey, anthropometric measures, physical performance tests, blood samples, and the full HCAP battery.

The LSAHA team modeled the study's core interview after the HRS core interview, collecting data on demographics, SES, physical health, health behaviors, and caregiving, as well as the HCAP cognitive battery. The informant interview consisted of five components: the demographics and SES module, a short IQCODE, the Blessed Dementia Rating Scale Parts 1 and 2, and the Informant CSID.

The study team faced several challenges associated with local context. Despite efforts to recruit even numbers of men and women, the study cohort was disproportionately female. Men were more difficult to reach because of higher employment rates and lower availability during daytime data collection hours. In addition, the team had to adapt questions regarding education to accommodate for low levels of formal education; almost 50% of the sample population had no formal education or primary education only.

The general population of older adults in Lebanon have also experienced significant conflict and instability for much of their lives, with over half of this sample reporting that they had been affected by “war and violence” in their lifetime. Researchers assessed these exposures based on the context that the sample population have lived with property loss, loss of work, and personal losses for many decades, given the onset of the country's civil war in 1975. Similarly, 82% of respondents reported being seriously affected by severe economic downturn that has widely affected the Lebanese population since 2019, with many participants reporting difficulty providing for regular household expenses such as food, electricity and heat, fuel or transportation needs.

The LSAHA study team aims to measure cognitive functioning in a universally applicable manner that is not only determined by specific cultural context. This goal can only be accomplished by learning and collaborating with other studies through “capacity exchange,” an expansion beyond the traditional idea of capacity “building” that places additional emphasis on collaboration with teams across cultural settings.

### Discussion

Multiple studies reported challenges recruiting male participants of all ages. Some speakers noted that men are more likely to work outside of the home during the day, while women are more often at home and available to participate in studies. Study teams often cannot collect data at night because of safety issues. Other speakers noted higher migration and mortality

levels among older men compared to women, potentially contributing to difficulties recruiting male participants.

## **What Set of Cognitive and Informant Measures Constitutes a “Minimum HCAP”?**

*Lindsay Kobayashi*

As the HCAP enterprise continues to grow and adapt to more country- and culture-specific contexts, it is critical to ensure that the battery is appropriate and suitable for the populations it serves around the world. This session aims to guide new HCAP studies in collecting high-quality data that align with community contexts while ensuring harmonization across all studies by considering different potential aspects of a common protocol.

### **Cognitive Measures**

*Alden Gross*

The goal of a harmonized HCAP battery of tests is to better measure cognitive performance (continuously) and dementia in population-representative samples to characterize risk factors for low cognitive performance and decline. To accomplish this goal, tests must distinguish cases from cognitively unimpaired individuals while accurately measuring cognitive ability across a broad range of performance. HCAP is not a brief battery; it takes an hour at minimum and represents a considerable investment on the part of participants who undertake it and study directors who agree to administer it.

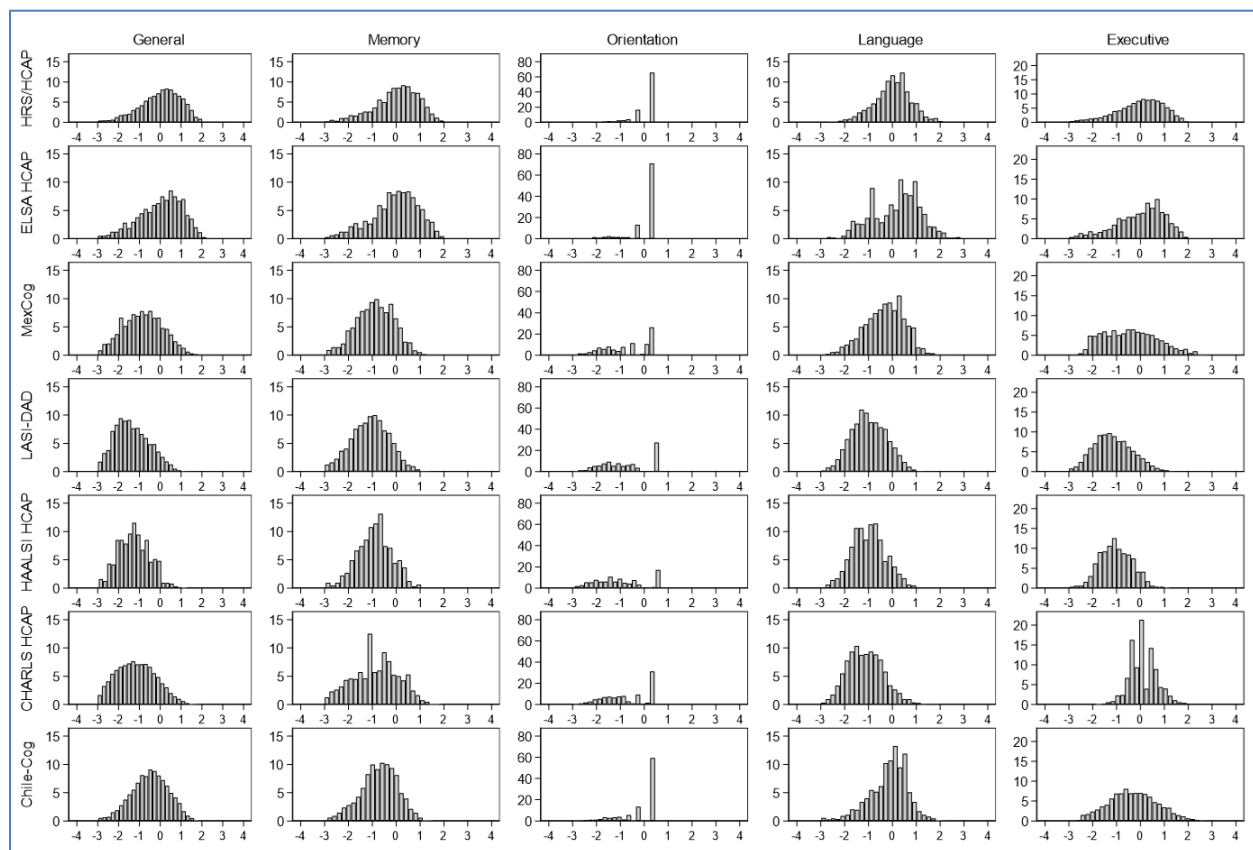
### **Cross-National Harmonization**

Gross illustrated what cross-nationally co-calibrated scores look like from seven HCAP studies (**Figure 1**). HCAP cognitive domains are measured with consistently high precision. To accomplish cross-national harmonization, researchers must consider what tests can be compared cross-nationally, to what degree other tests can be adapted, and how to identify linking items between tests. For example, some tests, such as those measuring orientation or language ability, are often only precise in populations with cognitive impairment, creating a ceiling effect in the results. These gaps in precision point researchers to possible areas of improvement for the testing battery. To better measure factors such as language ability, researchers should adapt test items to be more challenging for participants across all levels of the cognitive functioning spectrum. As measures become more consistently precise across different studies, study power and measures of association become stronger, allowing for more effective and harmonizable research.

Successful cross-national harmonization can be best achieved through statistical co-calibration with item banking that leverages common and unique cognitive testing items across HCAP studies. This item banking approach requires thorough pre-statistical harmonization and is readily scalable, but also requires linking items between studies. While co-calibration can be successful with as little as one common linking item, the quality and type of linking items are significant. For example, a polytomous linking item like 10-word immediate recall, which

provides information across the range of ability, performs better at reproducing performance across combined samples than simpler items such as orientation to time and place. Alternative approaches to cross-national harmonization in studies that have no linking items include utilizing calibration samples, in which researchers randomize test administration mode or swap tests. Another alternative approach to achieve cross-national harmonization involves linear linking for related traits, which can leverage information from related latent constructs (e.g., general cognitive performance) to assess specific subdomains of cognitive function, such as executive functioning. However, this approach assumes that scaling differences between HCAPs on general cognitive functioning are comparable to the differences that would be observed on the cognitive subdomain.

**Figure 1. Co-calibrated cognitive domain scores from seven HCAP country studies**



### ***Recommendations for a Core Battery***

The original HCAP battery includes 17 tests with 45 test items that assessed all major cognitive domains: memory, executive functioning, language, visuospatial functioning, and orientation. However, not all HCAP studies are able to perform some of these tests because of local considerations. If researchers were to only administer tests that had been successfully completed across all other HCAP studies, studies would lose nearly all measures of executive functioning, visuospatial functioning, and other potentially valuable tests that measure cognitive domains within their cultural contexts. For this reason, flexibility across studies should still be encouraged to accommodate cultural differences, because the goal of harmonization is

not to utilize a completely homogenous battery of tests across all studies, but to share many comparable and consistent test items across the studies that can then serve as linking items for co-calibration.

The Gateway to Global Aging Data team has determined that an ideal test battery that may constitute a minimum HCAP should include tests for each main domain of cognition, giving preference to polytomous tests (underlined below) over binary test items. Generally, any studies that administer this core set of cognitive tests in addition to tests that fit their local contexts may be considered HCAP studies, provided the total cognitive battery is approximately one hour long. The Gateway to Global Aging Data team compiled a [document](#) weighing tests' importance, feasibility, and time to complete to create this core battery, noting that studies should include tests for numeracy and literacy, as well as linking items between HCAP and the core interview.

- Memory: (a) Consortium to Establish a Registry for Alzheimer's Disease (CERAD) word list learning, (b) three-word immediate registration and delayed word recall, (c) Logical memory, (d) East Boston Memory Test, (e) Constructional praxis
- Executive functioning: (a) trail-making using circles and squares, (b) Ravens progressive matrices, (c) Go-No-Go tasks, (d) Symbol Cancellation Test, (e) similarities, (f) TokenTest, (g) digit span forward, (h) digit span backward, (i) backward day naming, (j) judgment and problem-solving
- Language: (a) Animal fluency, (b) confrontational object naming, (c) definitions, (d) follow three-stage instruction, (e) point to two objects in the vicinity
- Visuospatial functioning: (a) CERAD constructional praxis
- Orientation: (a) day of the month, (b) month, (c) year, (d) day of the week, (e) location, (f) season of the year

Although visuospatial functioning and orientation tests are included in this battery, more work is needed to determine precise measurements for these domains.

By utilizing a common HCAP battery of tests, HCAP studies can achieve better harmonization. By balancing standardization through this core battery with cultural adaptability, HCAP studies can provide valuable, comparable data on cognitive performance and dementia across diverse populations. Tests should include at least one polytomous linking item as well as some simple binary items to facilitate harmonization. An abridged version of the HCAP test battery should not be used in HCAP studies, because this approach would limit harmonization; however, some "required" tests may be omitted if they would not work effectively in a particular cultural context. Researchers must also develop detailed test manuals and continual training and guidance for interviewers to harmonize details of how researchers administer and scored tests across studies.

### **Informant Measures in HCAP**

*Emma Nichols*

Informant report measures provide a unique and important perspective on subjects in HCAP studies and serve a critical role in collecting information for participants who can no longer complete cognitive tests. However, these measures in HCAP studies face several challenges related to cultural validity and comparisons. For example, in India, the frequency “doesn’t do/never did” responses to IQCODE questions varied significantly between urban and rural settings and by informant type. Same-generation informants, typically spouses, are less likely to report “never did” responses to certain tasks compared to younger-generation informants, such as children or grandchildren, possibly because of their longer history with the respondent. These differences, along with varying proportions of informant types across countries and differential reporting patterns by age and gender, complicate cross-national comparisons. Researchers can address these challenges through statistical corrections across informant types, and can define reference informant groups for each country to estimate the impact of informant characteristics. They can then adjust summary scores based on informant characteristics to improve both cross-country comparisons and longitudinal trajectories.

To improve the content of informant measures, studies should retain the Jorm IQCODE and Blessed tests given their utility in cross-country comparisons, including the CSID for comparisons with the Mexican Cognitive Aging Ancillary Study (Mex-Cog). Because current informant report measures can also be highly repetitive, researchers should consider shortening some repetitive tests to reduce informant frustration and inconsistency in responses. To guide and inform decisions, additional research is needed to understand how shortening batteries affects performance. To improve the standardization of informant report measures, researchers should also focus on streamlining and standardizing test administration, and presenting all response options, including a “doesn’t do/never did” option, in all informant reports to enable informants to respond with higher fidelity. Researchers should also collect information on informant characteristics to better estimate necessary adjustments for substantive analyses.

### ***Discussion***

Although evidence shows that removing some redundancy in informant measures does not necessarily lead to a loss of information, participants noted that because the goal of HCAP is to serve as a hub of harmonization for studies around the world, all items were included to increase compatibility with other studies. Although some items may not be effective in some countries, decisions regarding removing items should also consider comparability. Researchers may consider using Item Response Theory (IRT), a statistical approach that models the relationship between test item performance and underlying cognitive ability, to develop more effective informant reports. Using IRT, researchers can identify which items across existing scales best differentiate between cognitive ability levels while maintaining measurement precision and the ability to harmonize across studies.

## **Key Issues in Cross-Cultural Adaptation of HCAP**

*Emily Briceño*

HCAP studies must balance local measurement validity with cross-national harmonization. The process of adapting HCAP items for local appropriateness should be iterative, guided by local experts and feedback from cognitively healthy older adults. Because local construct validity is essential, researchers may need to negotiate certain elements, such as construct equivalence or precision at higher cognitive functioning levels, to achieve harmonization. Although existing HCAP studies have developed their own pre-testing and adaptation procedures for local context, new HCAP studies may benefit from guidance on best practices developed by existing study teams.

Rather than focusing on specific tests, researchers should focus on construct measurement. A construct-centered approach can inform a harmonizable test battery that remains culturally valid. Researchers might start with a target construct (e.g., verbal learning, immediate verbal recall, delayed verbal recall, recognition of verbally presented information, recall of visually presented material) for a domain (e.g., memory), then work with a local team to select an HCAP core item (e.g., CERAD Word List Learning), determining whether the item is ready for pre-test, needs adaptation, or should be replaced. Then, the team can conduct pre-testing to ensure the item is ready for field use. The Nepal HCAP study team successfully employed this approach to develop the Chitwan Valley Family Study-Study on Cognition and Aging in Nepal (CVFS-SCAN) cognitive screening test in collaboration with local experts.

Notably, the licensing of tests often presents significant challenges for HCAP studies, because of high costs for procuring licenses, heavy administrative burden for license procurement, publisher control over translation work, restricted access to training materials, and inability to share products with local researchers or clinicians. The Nepal HCAP team addressed these challenges by developing CVFS-SCAN in collaboration with local experts, enabling independent pretesting, preliminary clinical validation, development of local normative data, and the ability to freely share the tool with local researchers. Ultimately, HCAP study teams should aim to evolve away from using licensed tests to make content freely available, fostering local capacity building and improving accessibility for future research.

## **Discussion**

### ***Characteristics of Local Teams***

Manly restated the importance of local teams in analysis, raising questions about the key characteristics of these team members. Briceño suggested that effective teams need local medical professionals (e.g., geriatricians, neurologists, psychiatrists) who understand how cognitive aging and dementia present in local context, as well as anthropologists and sociologists who can provide expertise on local ethnic groups and languages, and neuropsychologists who can provide expertise in cognition.



### ***Variation by Informant Characteristics***

Manly cautioned against adjusting for informant characteristics based on their correlation with objective cognitive testing, emphasizing that objective testing should not be considered the gold standard for validating informant reports. Informant reports should assess a subject's ability to live independently and track changes in the subject's daily activities over time. Some individuals may perform well on objective tests despite declining abilities, or vice versa, making this discrepancy valuable for dementia diagnosis. Instead of restricting or adjusting for informant characteristics, efforts should focus on improving the questions asked across different cultural contexts, particularly in non-Western settings.

### ***Adaptive Testing Measures***

Manly suggested considering adaptive testing approaches, similar to those in the [NIH Toolbox](#), in which test difficulty adjusts based on performance, although these tools may need to be adapted to accommodate respondents of all literacy levels. Participants emphasized that respondents with lower literacy still possess valuable skills for test completion, citing the HAALSI and LASI studies as examples. Briceño noted that pre-testing can help researchers understand how these adaptive tests can perform in local contexts, adding that illiteracy manifests differently across cultural contexts and settings. Participants also noted that adaptive tests require extensive interviewer training and test item banks, requiring more long-term work before test implementation.

### ***Licensure of Test Items***

Manly supported the idea of embedding license-free novel instruments within HCAP that can be shared across studies. While King acknowledged that licensed tests offer structured training and administration requirements, he suggested adapting public domain alternatives, such as reasoning tasks from the International Cognitive Ability Resource (ICAR), to avoid licensing burdens.

### ***Balancing Case Identification and Continuous Measurement***

Participants discussed the competing priorities of identifying dementia cases and measuring cognitive function across a continuous spectrum. Because public health and public policy often prioritize case identification, HCAP studies should maintain this focus, but should also include tests that can measure across cognitive ranges, as these tests will enable better assessment of potential risk factors over time. Manly noted that neuropsychological assessments can achieve both goals, though such comprehensive measurement requires significant time and resources.

## **Group Discussion and Next Steps**

*Minki Chatterji, Jonathan King*

The meeting centered around three key themes: (a) essential HRS core variables required for standalone HCAP studies, (b) recommended cognitive measures for parent HRS studies without HCAP studies, and (c) defining the minimum requirements for an HCAP battery. A summary of the main discussion points follows.



### ***Considerations for Standalone HCAP Studies***

Participants discussed whether incorporating all of Gateway's recommendations for test items to include in standalone HCAP studies would limit longitudinal data consistency. Nichols suggested that calibration exercises might address this issue and should be tested in future pilot studies.

Selection bias is an important consideration when conducting dementia studies. For example, recent ELSA data showed that individuals with depression are significantly less likely to consent to and complete HCAP interviews. This systematic underrepresentation of individuals with depression impacts study teams' ability to form nationally representative samples in their research. Researchers should continue to consider these selection effects as they aim to conduct thorough and representative research in their local contexts.

### ***Adaptation to Clinical Contexts***

HRS researchers should consider approaches to developing abbreviated HRS test batteries that can be applied to clinical contexts and as part of genomics or proteomics studies by the NIA Division of Neuroscience (DN). For example, data from clinical DN studies could be utilized by nationwide HRS studies if an abbreviated HRS test battery were included in clinical data collection. This approach could help bridge the gap between clinical and population-based research around the world.

### ***Minimum Requirements for an HCAP Battery***

Researchers must balance competing priorities while defining the minimum requirements for an HCAP battery. For example, researchers must balance capturing case identification with maintaining continuous measures for multivariate analysis. In addition, HCAP studies must balance the needs of local measurement and cross-national harmonization, particularly as studies expand to regions like Sub-Saharan Africa. The goal of harmonization across HCAP studies does not need to be strict homogenization, but rather to capture the same constructs across studies. As HCAP continues to expand, the U24 network may revisit suggestions to shorten or streamline test batteries to accomplish these goals.

### ***Better Addressing HCAP Cultural Validity and Adaptability***

The name "Harmonized Cognitive Assessment Protocol" itself may create misconceptions, suggesting a rigid protocol rather than an assessment approach adaptable to local context. To maintain scientific and cultural credibility and to address misconceptions about HCAP being a strictly Western approach, the team might publish a paper demonstrating how tools have been successfully adapted and contextualized in various LMIC settings. Researchers need to better communicate that while the main HCAP battery includes 17 tests, researchers can modify and contextualize these tools to work effectively in local settings with support from the network.

### ***Challenges with Cross-National and Longitudinal Comparisons***

Participants discussed a wealth of research questions that could create a better understanding of risk and protective factors for dementia in various country contexts, noting that relationships between risk factors and certain outcomes may differ or even be inverted between high- and low-income countries. Comparisons between low/middle income and high-income countries

can illuminate these differences and the role of factors such as SES and health care access on cognition. Participants also noted the potential for differential selective survival among HCAP studies, particularly between participants in high- and low-income countries. These complexities underscore the importance of longitudinal data in understanding how various factors influence cognitive outcomes over time.

### ***Next Steps***

Kobayashi presented two major updates from the HCAP network. First, the network will soon launch several pilot projects this year. Identified priority areas include cross-national comparisons of sex and gender differences in cognition and examining long-term cognitive impacts of the COVID-19 pandemic. Additional priority areas may include topics raised in the meeting, such as exploring calibration samples for cognitive test administration methods. Second, a new quarterly virtual research-in-progress seminar series will begin in November, featuring the work of junior investigators working with HCAP data. The seminar will encourage the presentation of ongoing work to facilitate meaningful discussion and feedback. The November session will focus on statistical harmonization of HCAP cognitive data.

### ***Open Discussion***

A participant raised challenges with HCAP study weights, particularly when dealing with different weights for multiple waves of data collection and diverse sample populations. Although weighting is crucial for national estimates, NIA encourages researchers to release data without weights initially to prevent delays in data accessibility, enabling immediate data utilization as researchers develop more complex weighting schemes.

## Appendix A: Meeting Agenda

A Joint Meeting of the HRS-ATW Network and the HCAP International Network

### *Interlinkages Between HRS Parent and HCAP Studies*

Canopy by Hilton Hotel  
940 Rose Avenue • North Bethesda, MD 20852  
September 30 – October 1, 2024  
*\*Virtual Presenter*

*Rev. September 30, 2024*

#### Monday, September 30

- 8:30 a.m.      **COFFEE AND TEA**
- 9:00            **Welcome and Introductions**  
                  *David Weir, Lindsay Kobayashi, Ken Langa*
- NIA Welcome**  
                  *Amy Kelley*  
                  *Minki Chatterji*  
                  *Jonathan W. King*
- 9:15            **Overview of Meeting Agenda & HRS-ATW / HCAP U24 Network Updates**  
                  *David Weir, Lindsay Kobayashi, Ken Langa*
- 9:30            **What Are the Common Core Variables Across the HRS Family of Studies?**  
                  *Jinkook Lee and Gateway team*
- 10:30          **BREAK (Light Refreshments)**
- 11:00          **What HRS Common Core or Other Covariate Data Are Needed for Dementia Studies and Should Be Collected in Stand-Alone HCAP Studies? (10 minutes each)**
- Psychology | *Andrew Steptoe*
  - Social Networks | *Lisa Berkman*
  - Life experiences | *Jennifer Manly*
  - Biomarkers | *Jessica Faul*
  - Bilingualism / Multilingualism | *Miguel Arce Rentería*
  - Neighborhood / Contextual Data | *Jennifer Ailshire*
- Discussants: *Lindsay Kobayashi, Ken Langa, Jinkook Lee*

- 1:00 p.m.      **GROUP LUNCH | Commonwealth Indian Restaurant**  
11610 Old Georgetown Road, North Bethesda, MD 20852
- 2:15            **What Cognitive Tests Should Parent Studies Collect?**  
*Emma Nichols*  
Discussant: *Alden Gross*
- 3:15            **BREAK (Light Refreshments)**
- 3:45            **New Studies Balancing HRS and HCAP Content (15 minutes each)**
  - Ghana | *Irma Elo*
  - AL-SEHA (Egypt) | *Mohamed Salama*
  - LOSHAK (Kenya) | *\*Joshua Ehrlich and Anthony Ngugi*
- 4:30            **Lebanon Study on Aging and Health (LSAHA)**  
*Carlos Mendes de Leon*  
*\*Monique Chaaya*
- 5:00            **ADJOURN**
- 6:00            **GROUP DINNER | Fogo de Chao**  
11600 Old Georgetown Rd, North Bethesda, MD 20852

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**Tuesday, October 1**

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- 8:30 a.m.      **COFFEE AND TEA**
- 9:00            **What Set of Cognitive and Informant Measures Constitutes a “Minimum HCAP”?**  
Intro/Discussants: *Lindsay Kobayashi, Jennifer Manly*
  - Cognitive measures | *Alden Gross*
  - Informant Measures | *Emma Nichols*
  - Cross-cultural adaptation | *Emily Briceño*
- 11:00            **BREAK (Light Refreshments)**
- 11:30            **Group Discussion and Next Steps**
  - Current concerns and roadblocks
  - Plans for joint analyses and publications
  - Solicitation of ideas for small-group follow-up sessions
  - Future priorities and directions from NIA’s perspective*Minki Chatterji, Jonathan W. King*
- 12:30 p.m.      **ADJOURN**

## Appendix B: Meeting Attendees

### Interlinkages between HRS Parent and HCAP Studies

A Joint Meeting of the HRS ATW and HCAP Networks

September 30–October 1, 2024

#### PARTICIPANTS BY STUDY

\*Virtual Participant

Rev. October 2, 2024

#### **USA** **Health and Retirement Study (HRS) and HCAP Network Team**

**David Weir**, PI, HRS ATW; Co-PI and Sampling Core Leader, HCAP Network; Co-I, HRS-HCAP; PI, Irish HCAP R01; MPI, Co-Director, HRS; University of Michigan (UM)

**Ken Langa**, Co-PI and Diagnosis and Validation Core Leader, HCAP Network; PI, HRS-HCAP; MPI, Co-Director, HRS; Co-I, BASIC-Cog; Co-I, LASI-DAD; UM

**Lindsay Kobayashi**, Co-PI, HCAP Network, Collaborator, LASI-DAD; Co-I, Gateway to Global Aging Data; UM

**Jessica Faul**, HCAP Network Biomarker Core Leader; Co-I, HRS-HCAP; Associate Director, HRS; UM

**Jennifer Ailshire**, Co-I, HRS; PI, Columbian Survey of Aging (COSA) Biomarker Pilot (2022-2023); Collaborator, LASI-DAD; Co-I, Gateway to Global Aging Data; University of Southern California (USC)

**Richard Jones**, HCAP Network Statistical Harmonization Core Leader; Co-I, HRS-HCAP; Co-I, HRS; Collaborator, Gateway to Global Aging Data; Brown University

**Sarah Kwiatek**, Project Manager; UM

**Jennifer Manly**, Co-I, HRS-HCAP; Co-I, HRS; Columbia University

**Lindsay Ryan**, HCAP Network Protocol Content and Administration Core Leader; Co-I, HRS-HCAP; Collaborator, HRS; UM

\***Ryan Jay McCammon**, Collaborator, HRS-HCAP; UM

#### **BRAZIL** **Brazilian Longitudinal Study of Health, Ageing & Well Being (ELSI-Brazil)**

\***Cesar Messias de Oliveira**, Co-PI; University College London

\***Laiss Bertola**, Team Member; Universidade Federal de São Paulo

\***Mateo Farina**, Team Member; Collaborator on HCAP in development in Colombia; University of Texas at Austin

#### **CARIBBEAN** **Caribbean American Dementia and Aging Study (CADAS)**

\***William Dow**, PI; Co-PI, Costa Rican Longevity and Healthy Aging Study (CRELES – Costa Rica: Estudio de Longevidad y Envejecimiento Saludable); Collaborator, Gateway to Global Aging Data; University of California, Berkeley

\***Jorge Llibre-Guerra**, Team Member and PI of 2022 HCAP Pilot Award; Washington University in St. Louis (*Day 2 only*)

\***Juan J. Llibre-Rodriguez**, Co-I; Study PI, 10/66, MHAS harmonization advisors (Cuba/USA); Medical University of Havana (*Day 1 only*)

- CHILE**      **Chilean Social Protection Survey (CSPS) and Cognitive Aging Study (Chile-Cog)**  
\*Jere R. Behrman, Co-PI; Collaborator, Gateway to Global Aging Data; University of Pennsylvania  
Irma Elo, Co-PI; PI of 2023 HCAP Pilot Awards on Ghana, and Chile and Mexico; Collaborator, Gateway to Global Aging Data; University of Pennsylvania
- CHINA**      **China Health and Retirement Longitudinal Study (CHARLS)**  
\*Yaohui Zhao, PI; Peking University (*Day 2 only*)
- EGYPT**      **A Longitudinal Study of Egyptian Healthy Aging (AL-SEHA)**  
Mohamed Salama, PI; The American University in Cairo  
\*Sara A. Moustafa, Co-I; The American University in Cairo  
\*Muhammad Iqbal, Professor; King Saud University (*Day 1 only*)
- ENGLAND**      **English Longitudinal Study of Ageing (ELSA)**  
Andrew Steptoe, PI; Collaborator, Gateway to Global Aging Data; University College London  
\*Sarah Assaad, Co-I on 2023 HCAP pilot award; University College London  
\*Shabina Hayat, PI of 2023 HCAP Pilot Award; University College London
- EUROPE**      **Survey of Health, Aging and Retirement in Europe (SHARE)**  
\*Axel Boersch-Supan, Munich Center for the Economics of Aging and SHARE Analysis; and National Bureau of Economic Research (*Day 1 only*)  
\*Radim Bohacek, Country Team Leader; Senior Researcher, Economics Institute of the Czech Academy of Sciences (*Day 1 only*)  
\*Salima Douhou, Coordinator; Munich Center for the Economics of Aging and SHARE Analysis; and Max Planck Institute  
\*Giacomo Pasini, Head of Department at the Department of Economics at Ca' Foscari University of Venice and SHARE Analysis  
\*David Richter, Director SHARE Infrastructure; SHARE Berlin Institute (*Day 1 only*)  
\*Beatrice Baaba Tawiah, Research Scientist; Munich Research Institute for the Economics of Aging and SHARE Analyses
- GUATEMALA**      **The Longitudinal Study of Aging in GUatemala (AGUA)**  
\*Jere R. Behrman, Co-PI; University of Pennsylvania  
\*Manuel Ramirez-Zea, Co-PI; Instituto de Nutrición de Centro América y Panamá (INCAP) (*Day 1 only*)
- INDIA**      **Longitudinal Aging Study in India (LASI); Diagnostic Assessment of Dementia (LASI-DAD)**  
Jinkook Lee, Co-PI LASI; PI, LASI-DAD; PI, Gateway to Global Aging Data; USC  
Alden Gross, Co-I, LASI-DAD; MPI, Gateway to Global Aging Data; John Hopkins Bloomberg School of Public Health  
Emma Nichols, Co-I, LASI-DAD; Co-I, Gateway to Global Aging Data; USC  
\*Pranali Kohbragade, Survey Director, LASI-DAD; USC  
\*Sarah Petrosyan, Project Manager, LASI-DAD; USC
- INDONESIA**      **Indonesia Family Life Survey (IFLS)**  
\*John Strauss, PI; Co-PI, CHARLS; USC

**IRELAND     *The Irish Longitudinal Study on Ageing (TILDA)***

\***Joanne Feeney**, Team Member and PI of 2023 HCAP Pilot Award; Collaborator, Gateway to Global Aging Data; (TCD)

\***Ann Hever**, R&D Manager; Collaborator, Gateway to Global Aging Data; TCD

\***Christine McGarrigle**, Team Member and Co-I of 2023 HCAP Pilot Award; TCD

**KENYA     *Kenya Life Panel Surveys (KLPS-5A)***

\***Michael Walker**, Economist; Team member, LOSHAK; University of California, Berkeley  
(Day 1 only)

**KENYA     *Longitudinal Study of Health and Ageing in Kenya (LOSHAK)***

\***Joshua Ehrlich**, Co-PI; Co-I, LASI-DAD; UM

**Anthony Ngugi**, Co-PI; Aga Khan University, Kenya

\***Jean Ikanga**, Team Member; developing HCAP in Congo; Emory University (Day 1 only)

\***Niranjani Nagarajan**, Team Member; Team member, LASI-DAD; UM

**LEBANON     *Lebanon Study on Aging and Health (LSAHA)***

**Carlos Mendes de Leon**, PI; PI, Nepal Study on Dementia and Aging (NSDA), Georgetown University

\***Monique Chaaya**, Co-PI; American University of Beirut (AUB)

**MALAWI     *Malawi Longitudinal Study of Families and Health (MLSFH)***

\***Hans-Peter Kohler**, PI; University of Pennsylvania

**Iliana Kohler**, Team Member, MLSFH; University of Pennsylvania

**MALAYSIA     *Malaysia Aging and Retirement Study (MARS)***

\***Halimah Awang**, Co-PI; Universiti Malaya

\***Yamunah Devi Apalasamy**, Team Member; Universiti Malaya

\***Nur Fatimah Mohd Ali**; Intel Corporation

**MEXICO     *Mexican Health and Aging Study (MHAS) – Cognitive Aging Ancillary Study (Mex-Cog)***

\***Rebeca Wong**, PI, Mex-Cog; PI, MHAS; Co-I, 2023 HCAP Network Pilot Award; Collaborator, Gateway to Global Aging Data; Center for Hispanic Health Aging, Barshop Institute for Longevity & Aging Studies, University of Texas Health Science Center San Antonio (UTHSA) (Day 2 only)

**Miguel Arce Rentería**, Co-I, Mex-Cog; Co-PI, 2021 HCAP Network Pilot Award; Collaborator, LASI-DAD; Collaborator, HCAP Network; Collaborator, Gateway to Global Aging Data; Columbia University

\***Silvia Mejia-Arango**, Co-I, Mex-Cog and MHAS; Univ of Texas Rio Grande Valley

**NEPAL     *Chitwan Valley Family Study-Study on Cognition and Aging in Nepal (CVFS-SCAN)***

**Emily Briceño-Abreu**, Collaborator, HCAP Network; Team member, Nepal HCAP study; Co-PI, 2021 HCAP Network Pilot Award; Co-I, Gateway to Global Aging Data; Co-I, Brain Attack Surveillance in Corpus Christi (BASIC-Cog); UM

**N. IRELAND**    **Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA)**

- \*Bernadette McGuinness, PI; Collaborator, Gateway to Global Aging Data; Queen's University Belfast (QUB)
- \*Gareth McKay, Co-I, Gateway to Global Aging Data; QUB
- \*Calum Marr, Research Fellow; QUB
- \*Leeanne O'Hara, Research Fellow; QUB

**PAKISTAN**    **Leveraging Consanguinity in Pakistan to Uncover the Genomic Architecture of Alzheimer's Disease: Feasibility Study with ENIGMA-PAK**

- \*Maheen Mausoo Adamson, PI; Clinical Professor, Neurosurgery, Stanford School of Medicine; Research Director, Women's Operational Military Exposure Network, Center of Excellence (WOMEN CoE), VA Palo Alto Health Care System (*Day 1 only*)

**SCOTLAND**    **Healthy Aging in Scotland (HAGIS)**

- \*David Bell, Co-PI; University of Stirling
- \*Elaine Douglas, Co-PI; University of Stirling
- \*Ian Deary, Collaborator; The University of Edinburgh

**S AFRICA**    **Health and Aging in Africa: A Longitudinal Study of an INDEPTH Community in South Africa (HAALSI)**

- Lisa Berkman, PI; Harvard University
- \*Darina Bassil, HAALSI-HCAP Project Director; Co-I on HAALSI/HAALSI-HCAP; Harvard University
- \*Tamara Taporoski, Senior Research Analyst, HAALSI-HCAP; Harvard University

**SRI LANKA**    **Sri Lanka Health and Ageing Study (SLHAS)**

- \*Ravindra Rannan-Eliyah, Project Director; Executive Director, Institute for Health Policy (*Day 1 only*)
- \*Azrah Ghaffoor, Health Researcher, Institute for Health Policy (IHP), Sri Lanka
- \*Nilmini Wijemunige (Wijemanne), Research Associate, IHP, Sri Lanka

**THAILAND**    **Health, Aging, and Retirement in Thailand**

- \*Pailin Chuayok, Project Manager; NIDA-CASR

**GATEWAY**    **Gateway to Global Aging Data**

- Jinkook Lee, MPI; Co-PI, LASI; PI, LASI-DAD; USC
- David Knapp, MPI; USC
- \*Ying Liu, Team Member; USC
- \*Jenny Wilkens, Team Member; USC

**NIMLAS**    **Network for Innovative Methods in Longitudinal Aging Studies**

- \*Sunghye Lee, MPI, NIMLAS; Team member, HRS; UM

**OTHER Interested Study Contributors**

- \*Rana Jamaan Alghamdi, Assistant Professor, Psychology Department; King Saud University, Saudi Arabi
- \*Shaea Alkahtani, Professor of Exercise Physiology, College of Sport Sciences and Physical Activity; King Saud University, Saudi Arabia



- \***Elizabeth Frankenberg**, Co-PI, Study of the Tsunami Aftermath and Recovery (STAR); University of North Carolina, Chapel Hill (*Day 1 only*)
- \***Ericka Mendez-Chacon**, Co-I, CRELES; University of Costa Rica, Centro Centroamericano de Población (CCP)
- \***Carolina Santamaría Ulloa**, Co-PI, CRELES; Professor at the Human Nutrition Department and the Public Health and Human Nutrition Graduate Programs, University of Costa Rica
- \***Duncan Thomas**, Co-PI, STAR; Duke University
- \***Yuan Zhang**, Assistant Professor and PI of 2023 HCAP Network Pilot Award; Columbia University

### **NON-ATTENDING STUDIES**

JAPAN	Japanese Study of Aging and Retirement (JSTAR)
S KOREA	Korean Longitudinal Study of Aging (KLoSA)
URUGUAY	Study of Health and Aging in Uruguay (ELSE Uy)
USA	Understanding America Study (UAS)

### **National Institute on Aging (NIA)**

- \***Dallas Anderson**, Director, Epidemiology of Dementia Program, Division of Neuroscience (DN) (*Day 1 only*)
- \***Jill Beaver**, Health Science Policy Analyst, Office of the Director (OD)
- Michael Bennani**, Program Official, ADSP, DN
- \***David Braudt**, Program Official, Division of Behavioral and Social Research (BSR)
- Minki Chatterji**, Program Officer, Population and Social Processes (PSP) Branch, BSR
- \***Luigi Ferrucci**, Scientific Director (*Day 1 only*)
- Maryam Ghaleh**, Program Official, DN
- \***Dianne Hannemann**, Health Science Policy Analyst, OD (*Day 1 only*)
- Amy Kelley**, Deputy Director
- \***Theresa Kim**, Program Official, BSR
- Jonathan King**, HRS Project Scientist; Program Director, BSR
- \***Richard Kwok**, Program Director, Population Studies and Genetics, DN (*Day 1 only*)
- \***Damali Martin**, Chief, Population Studies and Genetics, DN (*Day 2 only*)
- \***Carmen Moten**, Health Scientist Administrator, DEA (*Day 2 only*)
- \***Lis Nielsen**, Director, BSR (*Day 1 only*)
- \***Priscilla Novak**, Program Official, BSR
- \***Antoinette Percy-Laurry**, Program Director, DN
- \***John W.R. Phillips**, Acting Deputy Director, and Chief, PSP, BSR; HRS Program Officer (*Day 2 only*)
- \***Lisa-Marie Rowell**, Scientific Review Officer, Division of Extramural Activities (DEA)

### **Other NIH**

- \***Rosalind (Roz) King**, Chief, Scientific Development and Coordination Section, Office of Behavioral and Social Sciences Research (OBSSR) (*Day 1 only*)
- Michael Spittel**, Health Scientist Administrator, OBSSR (*Day 1 only*)

### **Rose Li and Associates, Inc.**

- Amanda Curran**, Senior Project Coordinator
- Rose Li**, Senior Project Director
- Chanley Mash**, Conference Coordinator
- Gregory Richards**, Technology Manager
- Erica Schipper**, Science Writer