National Institute on Aging

6th Annual Meeting of the Harmonized Cognitive Assessment Protocol (HCAP) International Network

September 29 – 30, 2025

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Acronym List

AA	Alzheimer's Association
AD	Alzheimer's Disease
ADAMS	Aging, Demographics, and Memory Study
ADDI	AD Data Initiative
ADRD	Alzheimer's Disease and related diseases
AL-SEHA	A Longitudinal Study of the Egypt Healthy Aging Initiative
BUILD-FSA	Building Unique Infrastructure for Large-scale Dementia Research in French-Speaking Africa
CADAS	Caribbean American Dementia and Aging Study
CHARLS	China Health and Retirement Longitudinal Study
Chile-Cog	Chile Cognitive Aging Study
COSA	Colombian Study of Aging
COSMIC	Cohort Studies of Memory in an International Consortium
CRELES	Costa Rican Longevity and Healthy Aging Study
CVFS	Chitwan Valley Family Study
CVFS-SCAN	Chitwan Valley Family Study-Study of Cognition and Aging in Nepal
DBS	Dried blood spots
EEA	European Economic Area
ELEGUA	Estudio Longitudinal de Envejecimiento en Guatemala/Longitudinal Study of Aging in Guatemala
ELSA	English Longitudinal Study of Ageing
ENSEA	École Nationale de Statistiques et d'Économie Appliquée
EU	European Union
GDPR	General Data Protection Regulation
HAALSA	Health and Aging in Africa: Longitudinal Studies in South Africa
HAALSI	Health and Aging in Africa: Longitudinal Study of an INDEPTH Community in South Africa
HCAP	Harmonized Cognitive Assessment Protocol
HRS	Health and Retirement Study
INS	International Network of Studies
IQCODE	Informant Questionnaire on Cognitive Decline in the Elderly
IRB	Institutional Review Board
KLPS-5	Kenyan Life Panel Survey Wave 5
LASI-DAD	Longitudinal Aging Study in India Diagnostic Assessment of Dementia
LOSHAK	Longitudinal Study of Health and Aging in Kenya
LSAHA	Lebanon Study on Aging and Health
MCI	Mild cognitive impairment
Mex-Cog	Mexican Cognitive Aging Ancillary Study
MHAS	Mexican Health and Aging Study
MMSE	Mini-Mental State Examination

MPI	Multiple Principal Investigator
MRI	Magnetic resonance imaging
NICOLA	Northern Ireland Cohort for the Longitudinal Study of Ageing
NIA	National Institute on Aging
NIH	National Institutes of Health
NOFO	Notice of Funding Opportunity
PI	Principal investigator
PMA	Performance Monitoring for Action Platform
RAISE	Recovery After an Initial Schizophrenia Episode
RFA	Request for Applications
SeRP UK	United Kingdom Secure e-Research Platform
SHARE	Survey of Health, Ageing and Retirement in Europe
SPS	Chilean Social Protection Survey
TICS	Telephone Interview for Cognitive Status
TILDA	The Irish Longitudinal Study on Ageing
VISTA	Virtual Infrastructure for Secure TILDA data Access

Meeting Summary

Welcome

Kenneth Langa, Lindsay Kobayashi, Richard Hodes, Minki Chatterji, Jonathan King

On September 29 and 30, 2025, the Harmonized Cognitive Assessment Protocol (HCAP) International Network convened in Bethesda, MD for its sixth annual meeting to (a) review updates on ongoing and recently funded HCAP studies, and upcoming pilot studies, (b) discuss challenges and potential strategies for analyzing longitudinal HCAP data, including imputation strategies for missing HCAP data, (c) consider how HCAP data could inform dementia classification in HRS core data and harmonized classification algorithms, and (d) discuss funding challenges, strategies, and opportunities. University of Michigan multiple principal investigators (MPIs) Kenneth Langa and Lindsay Kobayashi welcomed attendees to the meeting and especially thanked the National Institute on Aging (NIA) for supporting globally harmonized research on aging populations. It was the largest HCAP Network gathering with the greatest number of countries represented to date.

HCAP Network Updates

Study Status Overview

Within the past year, the HCAP U24 network has funded three network pilot grants, and welcomed new members to the network that have received NIA study funding, including two R01s for A Longitudinal Study of the Egypt Healthy Aging Initiative (AL-SEHA) and the Longitudinal Study of Health and Aging in Kenya (LOSHAK), two UG3 exploratory or developmental cooperative research grants for Côte d'Ivoire and Cameroon, an R21 exploratory/developmental grant for the Longitudinal Study of Aging in Guatemala (ELEGUA) study, and an R03 small grant for the Recovery After an Initial Schizophrenia Episode (RAISE) study in Botswana.

Kobayashi outlined the status of Wave 1 data collection across the 20 studies in the HCAP network, including both embedded and standalone HCAP studies (**Table 1**). Data have been released by 11 country studies as of September 2025. In addition to the full studies captured in Table 1, the HCAP network also includes pilot studies funded and completed in Cameroon, Guatemala, Colombia, Ghana, Malawi, Pakistan, and Botswana. The HCAP network is also advising and supporting research teams preparing pilot or full study applications, including Afghanistan, Vietnam, Scotland, and Malaysia, the Philippines, Japan, and Sri Lanka.

Table 1. HCAP International Network Wave 1 Study Status

Country	Study	Applied	Funded	Begun	Completed	Data Released
United States	HRS	✓	✓	✓	✓	✓
Mexico	MHAS	✓	✓	✓	✓	✓
England	ELSA	✓	✓	✓	✓	✓
South Africa	HAALSI	✓	✓	✓	✓	✓
China	CHARLS	✓	✓	✓	✓	✓
India	LASI-DAD	✓	✓	✓	✓	✓
Chile	ESPS	✓	✓	✓	✓	✓
South Korea	KLOSA	✓	✓	✓	✓	✓
European Union	SHARE	✓	✓	✓	✓	✓
Ireland	TILDA	✓	✓	✓	✓	✓
Northern Ireland	NICOLA	✓	✓	✓	✓	✓
Caribbean	CADAS	✓	✓	✓	✓	
Lebanon	LSAHA	✓	✓	✓	✓	
Kenya	KLPS	✓	✓	✓		
Kenya	LOSHAK	✓	✓	✓		
Nepal	NSDA	✓	✓	✓		
Egypt	AL-SEHA	✓	✓	✓		
Brazil	ELSI	✓	✓			
Côte d'Ivoire		✓	✓			
Costa Rica	CRELES	✓	✓			

Multiple studies also have begun collecting Wave 2 data (**Table 2**). Wave 2 data have been released by the Mexican Health and Aging Study (MHAS), English Longitudinal Study of Aging (ELSA), Health and Aging in Africa: Longitudinal Study of an INDEPTH Community in South Africa (HAALSI), and Longitudinal Aging Study in India (LASI); the U.S. HRS HCAP is planned for release in Fall 2025. Wave 2 study applications are expected from the Survey of Health, Ageing and Retirement in Europe (SHARE), The Irish Longitudinal Study on Ageing (TILDA), the Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA), and the Lebanon Study on Aging and Health (LSAHA).

Table 2. HCAP International Network Wave 2 Study Status

Country	Study	Applied	Funded	Begun	Completed	Data Released
Mexico	MHAS	✓	✓	✓	✓	✓
United States	HRS	✓	✓	✓	✓	✓
India	LASI	✓	✓	✓	✓	✓
England	ELSA	✓	✓	✓	✓	✓
South Africa	HAALSI	✓	✓	✓	✓	✓

Cross-Cohort HCAP Meetings

In June 2025, several African HCAP studies convened in Nairobi, Kenya to share protocol strategies and connect researchers across studies. After meeting with the AL-SEHA team in Cairo in September, the University of Michigan team has connected with additional research teams in Africa (e.g., Gambia) who are interested in exploring potential future HCAP studies. Given the success of the June meeting, the HCAP network plans to host a virtual meeting for HCAP studies in Latin America and the Caribbean in November 2025 and hopes to have a future in-person follow-up meeting of Latin America and Caribbean countries in 2026 or 2027.

HCAP Publications

HCAP network output continues to increase annually, with 110 publications using HCAP data to date. Three in-press manuscripts focus on the importance of tailoring HCAP content to suit the cultural contexts of the study population. For example, a recent paper[1] by Emily Briceño and colleagues provides detailed guidance for adapting HCAP measures and fieldwork based on insights from ten HCAP case studies. Emma Nichols and colleagues have also published a detailed narrative review[2] of important considerations for fielding cognitive measures in large-scale cross-national studies, while Alden Gross and colleagues have developed guidance[3] on the importance and benefits of the fixed-flexible framework for the HCAP battery, discussing HCAP items, protocols, and scoring.

[1] Briceño EM, Bassil DT, Khobragade P, Ngugi A, El Bejjani M, Ochieng E, Mejia-Arango S, Douhou S, Kulisewa K, Arce Rentería M, Gross AL, Jones RN, Lee J, Langa KM, Kobayashi LC. Recommended best practices for construct-centered adaptation of the Harmonized Cognitive Assessment Protocol. J Gerontol B Psychol Sci Soc Sci. 2025:gbaf201. doi: 10.1093/geronb/gbaf201. Epub ahead of print.

[2] Nichols E, Gross AL, Kobayashi LC, Langa KM, Lee J. The measurement of cognition in large-scale cross-national surveys: Lessons from the Health and Retirement International Network of Studies and the Harmonized Cognitive Assessment Protocol. J Gerontol B Psychol Sci Soc Sci. 2025:gbaf200. doi: 10.1093/geronb/gbaf200. Epub ahead of print.

[3] Gross AL, Mani SS, Weir D, Briceño EM, Rentería MA, Nichols E, Jones RN, Manly JM, Langa KM, Ikanga J, Lee J, Kobayashi LC. Harmonized Cognitive Assessment Protocol (HCAP): What Makes an HCAP an HCAP? An Adaptive Architecture for Measuring Cognitive Aging Around the World. J Gerontol B Psychol Sci Soc Sci. 2025:gbaf202. doi: 10.1093/geronb/gbaf202. Epub ahead of print.

The LOSHAK team has published a paper[4] describing the primary strategies that their team used to adapt aspects of the HCAP to the Kenyan study population. The team outlines their experience with tailoring pre-testing, item translations, interviewer training, and the HCAP battery itself to ensure the adapted protocol was as analogous as possible to the original HCAP. As with other African HCAP studies, the LOSHAK team's focus on meaningful community engagement may have contributed to the high response rates the study has maintained.

R25 Short Courses

In 2024, the NIA issued a Request for Applications (RFA) for R25 short courses to encourage cross-national data analysis. Three short courses have been funded since then, including courses by (a) Kobayashi and Rich Jones, (b) Rebeca Wong, Silvia Mejia-Arango, and Joseph Saenz, and (c) Aaron Kaat (not affiliated with the HCAP Network).

Kobayashi and Jones have planned a dual series of courses on using cross-national HCAP data. The first series, aimed at investigators and laboratory leadership, focuses on data availability, logistics, and ethical considerations. The second series, aimed at data analysts, will address data harmonization and measurement analyses. The courses will be held in-person at various locations, starting with a first meeting in May 2026 in Ann Arbor, MI. The short courses aim to build online communities of practice and offer future online resources, sessions, and training modules.

To build capacity for working with cross-national HCAP data between Latin American countries, Rebeca Wong and colleagues are developing a series of five annual courses (offered in English and Spanish on alternating years) to encourage interactions between American and Latin American HCAP researchers. The first course will be a five day, in-person workshop held in March 2026 in San Antonio, TX. The team will then engage with workshop participants at virtual follow-ups from April to September, followed by participant presentations at the annual Mexican Health and Aging Study (MHAS) meeting in Mexico each October. In subsequent years, the team hopes to involve HCAP researchers from Central America and Colombia in course development. A call for applications will be released in December 2025.

The HCAP network is anticipating further details on Kaat's short course, which will review methodologies for modeling cross-national data.

National Institutes of Health (NIH) Funding Updates

As of May 2025, the NIH will no longer support subawards for recipients outside the United States. The non-competing applications (i.e., Type 5) for FY2025 containing foreign subawards have been addressed, but will need to be re-addressed in FY2026 if they are still active. All new

[4] Riang'a RM, Mwangi EM, Nagarajan N, Agoi F, Mwangala PN, Gross AL, Ikanga J, Langa KM, Miguel E, Gichu M, Ehrlich JR, Ngugi AK. Contextualization of Harmonized Cognitive Assessment Protocol (HCAP) in an aging population in rural low-resource settings in Africa: Experiences and strategies adopted to optimize effective adaption of cognitive tests in Kenya. *Alzheimers Dement.* 2025 Aug;21(8):e70552. doi: 10.1002/alz.70552. PMID: 40835849; PMCID: PMC12367447.

competing applications (e.g., Types 1, 2, or 4), including those that previously included a foreign subaward, must follow the new NIH funding application structure.[5]

Per notice NOT-OD-25-104, NIH no longer accepts grant applications that request funds for foreign components—that is, the performance of any significant scientific element or segment of a project outside of the United States—using the traditional grant subaward or consortium structure. [6] Foreign components that would previously have been funded as subawards will now need to submit a new International Project Component application separate from the primary awardee. Foreign components not supported by subawards or consortia agreements may continue under their respective activity codes unless otherwise instructed in the Notice of Funding Opportunity (NOFO).

Under the new International Project Component structure, foreign institutions that were formerly sub-awardees will now become standalone components, receiving their own allocated funding. Applications with these multiple components will use the NIH multi-component or complex application package.[7] Currently, only the PF5 (grant) and UF5 (cooperative agreement) activity codes support international project components. These codes may additionally support funding opportunities for special cases that combine other component types (e.g., Cores) with international project components. PF5 and UF5 applicants will need to provide (a) one Overall Component that addresses the project's overarching objectives, (b) at least one Research Project component addressing the scientific and technical directions of the project, and (c) at least one International Project component that addresses the foreign collaborator's role. Notably, the primary applicant organization must be based in the United States, and leadership must include at least one principal investigator (PI) from the primary organization as well as one or more individuals from the international projects to serve as PIs of a standalone Linked International Research Project award. NIH will release a parent NOFO for the PF5 and UF5 activity codes with further guidance on the application structure.

During application review, applications with international project components will be reviewed in the same manner as other multi-component applications. Reviewers will provide specific review criteria for each international component according to the NIHGPS 16.3[8] criteria, alongside an Overall Impact Score for the application. PF5 and UF5 applications will be reviewed by the appropriate National Advisory Council or Board consistent with current procedures for reviewing applications from foreign organizations. Following review, applications considered for funding will be disaggregated, and international funding components will receive distinct grant numbers. The foreign organizations will also receive a new activity code for either the Linked International Research Project Grant (RF2) or Linked International Cooperative Agreement (UL2). Each organization receiving a Notice of Award within the multi-component application will be responsible for meeting the terms and

[5] The New Application Structure for NIH-Funded International Collaborations (NOT-OD-25-155) was released on September 12, 2025: https://grants.nih.gov/grants/guide/notice-files/NOT-OD-25-155.html
[6] https://grants.nih.gov/grants/guide/notice-files/NOT-OD-25-104.html
[7] https://grants.nih.gov/grants/how-to-apply-application-guide/forms-i/multi-project-forms-i.pdf
[8] https://grants.nih.gov/grants/policy/nihgps/HTML5/section_16/16.3_application_review.htm

conditions of their activity code funding, and will be responsible for submitting their own financial reports; however, research performance progress reports will continue to be bundled under the composite project to reduce administrative burden.

NIH will develop and share resources to support the transition to International Project components, including training workshops on the new activity codes and applications. NIH may also need to host additional discussions to confirm how funding for indirect costs would be distributed between components.

Discussion

King confirmed that primary applicant organizations would no longer be responsible for making sure that International Project components complete their outlined objectives and submit evidence of their completion. He added that NIH is working to provide additional resources to support foreign organizations and small institutions with the transition, as both entities will likely experience a steeper acclimation curve than larger domestic institutions due to their limited workforce. Chatterji recommended that primary applicant organizations start training their sub-awardees early to prepare for the new application structure, especially because the new structure may eventually also apply to domestic subawards. Additional questions about the new structure can be emailed to King or Chatterji.

HCAP Study Updates

Kenya | Longitudinal Study of Health and Aging in Kenya (LOSHAK)
Roselyter Riang'a

Following the successful completion of the LOSHAK pilot study in 2022 – 2024, the LOSHAK team recently received grant funding through 2030 to continue collecting longitudinal data on health, dementia prevalence, and economics among aging populations in Kenya. The pilot study, which collected data from 208 participants in Kilifi County, observed high acceptance of its measures and data collection protocols (e.g., surveys, dried blood spots (DBS), air pollution monitors). The LOSHAK team is currently sharing data from the pilot study and has submitted four manuscripts on their approaches for adapting HCAP measures to a Kenyan context.

The specific aims of the LOSHAK Core and LOSHAK HCAP are to (1) develop items and collect Wave 1 data, (2) estimate the prevalence of mild cognitive impairment (MCI), Alzheimer's Disease and related dementias (ADRD) by region, (3) analyze and publicly share LOSHAK HCAP data, and (4) build capacity across LOSHAK teams by training graduate students and post-doctoral researchers. To further improve alignment with the cultural context, the LOSHAK team will be translating HCAP measures into 16 languages. The LOSHAK Core study will establish a nationally representative health and wellness survey cohort of 6,580 participants across all 47 counties. Overlapping 30% with the Core, the LOSHAK HCAP will focus on a sample of 2,375 participants across six coastal counties to establish a regionally representative HCAP survey. Key changes to the protocol since the LOSHAK pilot study include (a) venous blood sample collection, (b) population-level cognition and AD/ADRD analyses, (c) herbalism and alternative

medicine modules, (d) migration pattern analyses, (e) caregiver experience collection, (f) wearable sensors, (g) oral and sensory health modules, and (h) collaborations with the Kenya National Bureau of Statistics, Ministry of Health, and Kenya Medical Research Institute. The LOSHAK team expects to onboard all project collaborators and key personnel by December 2025. Through the end of 2025, the LOSHAK team will continue recruiting staff and updating the study budget to accommodate recent budget cuts. Starting in 2026, the team will begin survey development, item translations, staff training, and ethics committee submissions. The LOSHAK project will nationally launch in June 2026 and continue data collection through 2027.

Kenya | Kenya Life Panel Survey (KLPS)
Edward (Ted) Miguel

KLPS and the associated Primary School Deworming Project have collected longitudinal data from approximately 6,500 Kenyan individuals who were enrolled in school health programs in 1998 and are now 35 to 43 years old, linking the outcomes of childhood health experiments to national economic outcomes over a span of nearly 30 years. In coordination with the LOSHAK team, the KLPS team has developed a harmonized HCAP instrument for both studies. The ongoing fifth round of data collection will establish a midlife baseline of aging-related measures.

KLPS Round 5 (KLPS-5) data are collected over three visits. During the first visit in 2023 – 2024, respondents completed the Kenyan HCAP cognitive battery and exposome measures (e.g., air pollution, job complexity, social network). The team administered a second module in 2024 – 2025 to collect health measures, demographic data, anthropometrics, and DBS. From 2025 – 2027, the KLPS team will administer a final module to gather economic data and information on caregiving and planning for retirement. Across all three modules, respondents will provide contemporaneous data on the Lancet Commission's 12 modifiable risk factors for ADRD.

Preliminary demographics data for KLPS-5 respondents shows that they tend to be slightly younger, better educated, and reside in more urban areas than the average Kenyan resident. The sample, split roughly evenly between men and women, saw only 26% of the population working in agriculture, suggesting that aging African populations may have even higher levels of education and urbanization in the future. Using available HCAP data, the team has found that respondents who successfully tested into secondary school as children performed significantly better on HCAP cognitive tests. Other insights include increasing rates of sensory impairment and depression with successive rounds, whereas other risk factors such as drinking and smoking decline over time. Twenty percent of respondents have blood pressure recordings consistent with hypertension, a finding which the team is investigating. The KLPS team is also working on several publications; a paper on their HCAP validation work has recently been published in *BMJ Open*.[9] All KLPS data and publications are publicly available through the KLPS website.

The KLPS team plans to complete data collection for Round 5 and to publish four additional research articles using HCAP cognitive data and exposome measures. KLPS is working to secure

[9] https://bmjopen.bmj.com/content/bmjopen/15/8/e096619.full.pdf

funding for DBS analyses to investigate potential links between APOE4 gene expression and midlife cognition. Finally, the KLPS team is in the early stages of grant applications for KLPS Round 6, with data collection planned between 2027 and 2030.

The Caribbean Islands | Caribbean American Dementia and Aging Study (CADAS)
William Dow

More than 30% of older adults in the United States who identify as Hispanic immigrants are from the Caribbean (i.e., Cuba, Dominican Republic, and Puerto Rico). However, available research on Hispanic American immigrants often focuses on Mexican immigrants, who differ from immigrants from the Caribbean on several sociodemographic factors (e.g., education, living alone, household-reported cognitive difficulties).[10] CADAS builds on the existing framework of the 10/66 Dementia Research Group to develop a nationally representative characterization of aging and dementia in Hispanic Caribbean adults.[11] CADAS uses the majority of the 10/66 cognitive battery, with some substitutions (e.g., replacing the Geriatric Mental State exam with more common HCAP depression inventories) for alignment with the HCAP. When applied to the HRS Aging, Demographics, and Memory Study (ADAMS), the existing 10/66 dementia prevalence algorithm performs similarly to the clinical gold standard tests in sensitivity, specificity, and accuracy, but performs more poorly on aspects such as estimating dementia-related education gradients. [12]

CADAS extends the 10/66 team's work to investigate the life course determinants and social consequences of AD/ADRD in Caribbean-origin adults above 65 years of age. The study is harmonized with the 10/66 study, the U.S. HCAP, and some sister studies, such as the MHAS Mexican Cognitive Aging Ancillary Study (Mex-Cog). In addition to cognitive items, CADAS collects venous blood, plasma, and serum from participants for additional biological analyses. Data collection has concluded for all sites except those in Puerto Rico; the study team anticipates data to be nationally representative in the Dominican Republic and Puerto Rico (with purposive rural and urban samples in Cuba), and will be publicly available by February 2026. Building on initiatives by other HCAP studies, CADAS has implemented an online consensus dementia diagnosis protocol, which uses three independent data reviewers to ensure that data coding has high interrater reliability and aligns with the NIA-Alzheimer's Association (AA) Research Framework.[13] CADAS has applied the protocol to 900 CADAS

[10] The Cuban Aging and Cognition Study is a parallel study with Juan Llibre Rodriguez as PI, Medical University of Havana, and Jorge Llibre, Washington University, which receives no U.S. government funding.
[11] Prina AM, Acosta D, Acosta I, Guerra M, Huang Y, Jotheeswaran AT, Jimenez-Velazquez IZ, Liu Z, Llibre Rodriguez JJ, Salas A, Sosa AL, Williams JD, Prince M. Cohort Profile: The 10/66 study. *Int J Epidemiol.* 2017 Apr 1;46(2):406-406i. doi: 10.1093/ije/dyw056. PMID: 27154633; PMCID: PMC5837706.
[12] Llibre Guerra JJ, Weiss J, Li J, Soria C, Rodriguez-Salgado A, Jesús Llibre Rodriguez J, Jiménez Velázquez IZ, Acosta D, Liu MM, Dow WH. Assessing the 10/66 dementia classification algorithm for international comparative analyses with the United States. Am J Epidemiol. 2025 Nov 4;194(11):3117-3125. doi: 10.1093/aje/kwae470. PMID: 39745806; PMCID: PMC12634119.
[13] Jack CR Jr, Bennett DA, Blennow K, Carrillo MC, Dunn B, Haeberlein SB, Holtzman DM, Jagust W, Jessen F, Karlawish J, Liu E, Molinuevo JL, Montine T, Phelps C, Rankin KP, Rowe CC, Scheltens P, Siemers E, Snyder HM,

participants and, to harmonize cross-national coding strategies, is now comparing ratings for a subset of 300 participants across rating teams in Puerto Rico, India, Mexico, the Dominican Republic, and the United States. The CADAS team has also conducted clinical diagnoses for overlapping subset of 300 CADAS participants, which will be compared against the 10/66 algorithm and the HCAP Manley-Jones algorithm to evaluate their performance.

Costa Rica | Costa Rican Longevity and Healthy Aging Study (CRELES)
William Dow

In 2005, Dow and colleagues launched CRELES, collecting economic, household, and community data from older adults alongside other physical health measures (e.g., venous blood, anthropometry, health care spending, DNA, mortality). Using these data, the study team found that mortality gradients are generally less steep for adults in Costa Rica, and that mortality rates for individuals in the lowest socioeconomic brackets are significantly lower in Costa Rica than in the United States. Life expectancy rates in Costa Rica are especially high in the region of Nicoya, and these rates correlated with lower prevalences of other risk factors (e.g., cognitive decline) in Nicoyan residents. This regional advantage has waned with successive generations, marking a point of interest for future study.

Cognitive testing has historically been assessed in CRELES by a mini-mental state exam (MMSE); however, Wave 6 of the study will utilize an embedded HCAP based on the protocol developed for CADAS. The new Wave will interview all surviving CRELES main respondents, who now range 70 years of age and older, as well as their spouses and a new oversampling of older adults in Nicoya. Alongside the new cognitive tests, CRELES will repeat longitudinal questionnaires with participants and collect venous blood samples.

South Africa | Health and Aging in Africa: Longitudinal Study of an INDEPTH Community in South Africa (HAALSI)
Lisa F. Berkman, Darina T. Bassil

Embedded within the HAALSI, the HAALSI HCAP launched its first wave of data collection in 2020 following the completion of HAALSI Core wave 2. The HAALSI HCAP collects data on older adults (aged 50 years or older) in 30 rural villages within the Health and Demographic Surveillance System.[14] Components of the HAALSI HCAP cognitive battery include an adapted and validated battery, as well as a literacy test and a traumatic brain injury module. Over sequential waves, the HAALSI team has made additional edits to the cognitive battery to improve fit with a South African population, such as dropping the phoneme fluency test and adding both the Stroop test and African facial perception test. Other data collected include informant interviews, neurological and clinical examinations, and biomarker data using blood

Sperling R; Contributors. NIA-AA Research Framework: Toward a biological definition of Alzheimer's disease. *Alzheimers Dement.* 2018 Apr;14(4):535-562. doi: 10.1016/j.jalz.2018.02.018. PMID: 29653606; PMCID: PMC5958625.

[14] https://www.agincourt.co.za/agincourt-maps-2

samples and magnetic resonance imaging (MRI). Response rates for the main study have remained at 89% or higher; the lower response rates for clinical and MRI data collection can be mostly explained by limited site resources to secure MRI access.

Early data suggest that participants perform slightly better on tests from Wave 1 to Wave 2, but these effects level off by Wave 3. The HAALSI team has also conducted two study consensus samples, which found that roughly 50% of reviewed data scores require further adjudication. More participants were classified as cognitively normal in the 2025 consensus than in the 2021 consensus, and the team is working to see whether this decrease in dementia classifications results from changes in HCAP algorithm power across subsequent Waves. Using HAALSI HCAP diagnoses, the HAALSI team developed an algorithm to predict probabilities of dementia in the HAALSI core study. The HAALSI HCAP algorithm performed similarly to normal weighted prediction models, with a reduced sensitivity for classifications based on education level.

Wave 4 of HAALSI and Wave 3 of the HAALSI HCAP have now been completed, with the study moving forward in 2026 as a national study called the Health and Aging in Africa: Longitudinal Studies in South Africa (HAALSA). The study team is currently cleaning Wave 3 HCAP data and preparing materials for the national HAALSA study and subsequent HAALSA HCAP, which will launch once funding concerns have been resolved. HAALSI-HCAP waves 1 and 2 data (respondent, informant, Neuro) are available and publicly released on Harvard Dataverse; HAALSI-HCAP wave 3 data public release is planned for 2026.

Nepal | Chitwan Valley Family Study (CVFS) Study of Cognition and Aging in Nepal (SCAN)
Emily Briceño

The CVFS-SCAN is a longitudinal cohort study focused on surviving members (aged 50 years or older) in the CVFS cohort (target sample size: ~3,300). CVFS-SCAN data are collected from respondents, informants, and community contexts (e.g., schools, health services). After an initial HCAP interview, participants answer a sociodemographic questionnaire, provide a blood sample, and complete a physical health assessment. Study staff began data collection in February 2025; 97% of eligible CVFS cohort members have completed the main HCAP interview and are in the process of completing health assessment follow-ups. Staff are also conducting a centralized review of photo and audio recordings from participant interviews to standardize test administration.

CVFS-SCAN protocols had to adapt to the population's broad range of caste backgrounds and educational backgrounds, as nearly half of the sample had no formal schooling. Using multidisciplinary adaptation teams, focus groups, and pilot testing, the study team identified several major changes for HCAP adaptation, such as removing most tests with literacy or numeracy requirements. For example, the MMSE is ubiquitously considered an acceptable clinical assessment, but it has not been validated in Nepal and could present significant challenges for individuals with no formal schooling. Instead, the team developed a separate, education-neutral cognitive screening test for older adults in Nepal that is now being validated for wider use in the country. Other adaptations to the HCAP included adjusting unfamiliar tasks, such as using paper and pencil, to using household items to complete cognitive analogs. The

CVFS-SCAN team has ensured that novel and adapted HCAP items are balanced with linking items to enable harmonization with other HCAP studies.

Cote D'Ivoire | Measurement of Cognition Among Older Individuals in Cote d'Ivoire
Philip Anglewicz

Cote d'Ivoire has one of the lowest life expectancies at age 60 (10.8, higher only than Nigeria and Sierra Leone), reflecting the impact of past colonization and recent civil wars. Together with the École Nationale de Statistiques et d'Économie Appliquée (ENSEA), the Johns Hopkins Bloomberg School of Public Health aims to develop a nationally representative study on aging in Cote d'Ivoire, building from the frameworks of the Performance Monitoring for Action Platform (PMA).

The Cote d'Ivoire HCAP team received their Notice of Award in April 2025 and has since finalized Institutional Review Board (IRB) approval and all subcontract agreements. The study itself comprises two phases: a Phase One UG3 for 2025 and a Phase 2 UH3 for 2026. During Phase One, the study team will establish data collection and research protocols for adults aged 40 years or older in Cote d'Ivoire and develop a network of stakeholders with experience in aging-related policies and programs in Cote d'Ivoire. Phase Two will specifically collect dementia data for a representative sample of approximately 4,500 adults aged 40 and older in Cote d'Ivoire and investigate potential risk factors for dementia. The study's milestones include establishing an external advisory board and building capacity for training future AD/ADRD researchers in Cote d'Ivoire. To achieve this, the team will focus on developing (a) substantive, culturally relevant neuroscience training, (b) guidance on HCAP measures and key items for AD/ADRD surveys, (c) AD/ADRD data collection infrastructure, and (d) skills training for content and methodology of neuroscientific surveys.

Cameroon | Building Unique Infrastructure for Large-Scale Dementia Research in French-Speaking Africa (BUILD-FSA)
W. Yembe Njamnshi

With over 250 ethnic groups, languages, and cultures, Cameroon has a rich geographical, cultural, and biodiversity that contributes to an especially rich dataset to introduce in cross-national HCAP work. Most Cameroonians are trilingual with fluency in both French and English. Although Francophone Africans comprise 40% of Sub-Saharan African residents, these populations have been historically understudied. The BUILD-FSA (UG3) study aims to address this gap by investigating the epidemiology, clinical presentation, determinants of risk, and biological correlates of AD/ADRD in Cameroon while also capturing community perspectives on aging, dementia, and biomedical research participation.

The study team is currently adapting neuropsychological tests used in prior work in HIV and cognition in a Cameroonian context for BUILD-FSA, which will be followed by qualitative research studies within the community, outreach efforts, and project staff training. Once preparations are complete, the study team will screen 3,600 adults above 50 years of age who have resided in one of the six project regions (three rural and three urban) for more than one

year. During this time, project staff will collect blood and stool samples from participants, as well as create a registry of participants by cognitive status. The clinical assessment includes (a) social determinants of health, linguistic, and environmental data, (b) neuropsychological test battery under development, to be administered by trained mental health nurses, (c) neurological examination, (d) behavioral assessments, and (e) functional assessments. The Cameroon HCAP study embedded in BUILD-FSA will focus data collection within the Ntui Health District and is especially focused on adapting the protocol to consider sensitive contexts. For example, cultural stigmas around terms such as dementia require softer language during clinical recruitment efforts to avoid intimidating participants. Alongside contributions from local linguistic experts and community pilot studies, the study team is currently working to harmonize neuropsychological tests for the Cameroon HCAP with other HCAPs across Africa.

Previews of Upcoming Pilot Studies

Colombia | Colombian Study of Aging (COSA)
Jennifer Ailshire, Mateo Farina

With a rapidly aging population and some of the largest global displacement rates of older adults, Colombia offers unique insights on aging and dementia. The COSA team plans to launch a full COSA study that (1) conducts two waves of data collection, including biomarker data, in ~5,000 Colombian adults aged 50 years or older, (2) implements the HCAP battery in a subsample of respondents to develop a dementia classification algorithm, and (3) estimates the prevalence of disease, disability, and dementia in Colombia and compares cross-nationally with HRS and its international sister studies. Ailshire and colleagues recently completed a pilot study focused on investigating the feasibility and acceptability of an HRS study across aging populations in Colombia, both in remote/rural and urban areas as well as across populations. Pilot sampling included 740 respondents (36 proxies) across three rural and three urban sites, with a subsample of 100 participants also contributing whole blood samples and functional performance data. Although some items on the pilot survey (e.g., caregiving, displacement, and violence) were uniquely tailored to suit the Colombian context, the majority of survey sections were mostly or fully harmonized with the HRS. From the pilot data, the COSA team found that MMSE and Telephone Interview for Cognitive Status (TICS) score distribution across the sampled population resembled the score distribution for older adults in Colombia. Missing data presented somewhat of a challenge for specific items, namely attention tasks on the MMSE and delayed recall tasks on the TICS. Cognitive classifications based on the MMSE and TICS classified 4.5% of participants as having dementia and roughly 32% as having MCI.

COSA pilot data will be available within the year. In early 2026, the team will launch a COSA HCAP pilot on a subsample of 300 participants aged 50 years or older from the initial COSA pilot study. The HCAP pilot will evaluate neuropsychological tests within the HCAP battery for their suitability to the Colombian context, including the pilot's cross-national compatibility with Latino populations in HRS HCAP and Mex-Cog. Ailshire noted that although HCAP items are new to Colombian clinicians, several have expressed interest in harmonizing existing infrastructure with the HCAP battery to improve their population-based data measures.

Guatemala | Longitudinal Study of Aging in Guatemala/Estudio Longitudinal de Envejecimiento en GUAtemala (ELEGUA)
David Flood

Older adults in Guatemala represent not only a unique population for study but also an especially vulnerable population experiencing policy-based health impacts. The Guatemalan population is also rapidly aging and anticipates the number of adults aged 60 years or older to triple by 2050. This population faces potential health impacts from numerous factors, such as limited social protections for older adults, low pension coverage, high baseline poverty rates, and a remittance-based economy. In addition, Guatemala's significant indigenous Mayan population speaks 22 distinct languages with unique linguistic cases. The ELEGUA team is developing and validating an HCAP battery in Mayan for a 2026 pilot study, followed by a national study in 2028 and follow-up waves of core HRS and nested HCAP data collection every 4 – 5 years. The ELEGUA team hopes to engage key stakeholders within the government and other national initiatives in ELEGUA administration to improve sustainability of the study. The ELEGUA battery uses the Mex-Cog cognitive battery as a baseline model that researchers are currently harmonizing with cultural contexts unique to Guatemala. For example, items such as the 3-step command do not directly translate into Mayan languages, which have limited conceptualization of handedness or space.

Discussion

HCAP network members highlighted these translation issues as a reminder that preserving the cognitive purpose of an item is more important than preserving semantic values. Other members also noted that because Mayan languages use unique cases such as the ergative case, HCAP adaptations may need to consider cross-linguistic considerations in addition to cultural adaptations.

Considerations Across HCAP Studies

Using HCAP to Inform Dementia Classifications in HRS Core Data
Richard N. Jones, Maria Glymour

Using data from 2016 HRS HCAP participants, Jones and colleagues investigated the extent to which HRS Core interview data can be used to approximate the HCAP-based cognitive classifications. Replicating the HRS HCAP algorithm using Core data can help researchers assess alignment between Core and HCAP cognitive instruments and potentially shift harmonization efforts towards more clinically interpretable options than imputation. The HCAP classifications are based on the HCAP Manly-Jones algorithm, which uses a combination of cognitive assessment and functional assessment data to classify participants as having dementia, MCI, or no cognitive impairment.

After standardizing cognitive data in the HRS Core sample to the HRS HCAP normative reference sample, Jones and colleagues used comparable thresholds for cognitive impairment between the HRS Core and HCAP and self-reported Activities of Daily Living and Instrumental Activities of

Daily Living to develop an algorithm that sorts Core participants into the three cognitive impairment categories. Jones and colleagues then compared the Core- and HCAP-based categories for the non-imputed 2016 HRS/HCAP sample. For HRS/HCAP participants with no cognitive data imputed (N = 2,993), 70% of the categorizations were the same, and the weighted kappa was 0.51, implying a fair level of agreement.

Jones noted that because the comparison study did not include imputed cognition data, it excluded participant data from participants with only informant responses. The exclusion of these participants, who might have been "easier" to classify, may have reduced agreement between HRS Core and HRS/HCAP categorizations. The agreement statistics also do not reflect complex sampling weights. Future steps will examine using prediction-based classification to train HRS Core data using HRS HCAP classifications, potentially using a profile mixture model or supervised learning models. These probabilistic models use more information and retain sociodemographic adjustments, though potentially at the cost of more straightforward cutoff thresholds.

Discussion

Glymour acknowledged that because dementia develops over several years with multiple phenotypic presentations, even clinicians struggle to definitively classify individuals. The HRS Core is also not a perfect model: HRS core measures only correlate with each other at a score of approximately r = 0.65, meaning that even if Core data correlate with an underlying disease trajectory, the feasible weighted kappa for this model is not likely much higher than that score.

Notably, the lived experiences of people seeking dementia or MCI diagnoses may have symptoms that fall within ambiguous cutoff areas in dichotomous classification models. Moreover, Glymour argued that because dichotomous classifications require significant financial and time resources but continue to perform at only fair levels of prediction, studies may wish to consider shifting their focus to developing high-quality, dynamic, and continuous functional assessments. Manly asked how researchers might test this approach, such as by collaborating with cognitive psychologists or oversampling of participants with ambiguous classifications. Glymour noted that while clinical assessments themselves might not be feasible due to the already heavy burden on clinicians, the HCAP network should discuss potential options for improving data collection between waves.

Meeting attendees agreed that future efforts to improve HRS performance might consider adding HCAP items to the HRS protocol. Although the HRS algorithm initially focused on predicting cognitive classifications, some attendees suggested that the HCAP-enriched HRS protocol could potentially predict other outcomes, such as the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) or mortality. Nichols noted that the value of any items added to Core studies should be evaluated within the context of existing items in the Core.

Validation of the Manly-Jones Algorithm in Aging, Demographics, and Memory Study (ADAMS)

Emma Nichols, Zachary Kunicki

The 2002 ADAMS offers a large sample for further validation of HCAP cognitive classifications (i.e., dementia, MCI, no impairment) based on an actuarial algorithm and robust neuropsychological norms. Nichols and Kunicki conducted a pilot study to (1) develop the Manly-Jones algorithm within the ADAMS sample, (2) validate the algorithm against clinical diagnoses and the 10/66 project algorithm, and (3) evaluate predictors of misclassification.

To replicate the Manly-Jones algorithm in ADAMS, the study team considered either fully replicating an HCAP normative sample, harmonizing cognition measures across HCAP and ADAMS to use HCAP sample norms, or defining the normative sample for ADAMS using existing clinical classifications. Due to time constraints and concerns around longitudinal norm variance, the team chose to use known clinical classifiers to develop a normative sample. The study team was able to approximate all five HCAP cognitive domain inputs within the ADAMS algorithm, with an overall acceptable model fit. Other inputs included functional measures (e.g., Blessed, IQCODE) and demographic data for neuropsychological norms. The study team also condensed detailed classifications for cognitive impairment from ADAMS to match the three classifications of the HCAP algorithm.

When compared, the HCAP and ADAMS algorithms aligned more closely with each other in performance than with the clinical gold standard tests, with a weighted kappa value of 0.63. Two marked differences between the algorithms were that the ADAMS study had a higher percentage of participants with multiple domain impairments, and the HRS HCAP had a larger proportion of participants with informant-rated “moderate impairment” scores. These findings align with the slightly increased prevalence of dementia found by the ADAMS algorithm and the slightly increased prevalence of MCI found by the HCAP algorithm. By comparing discordant results with the original detailed classifications from ADAMS, the study team found that ADAMS algorithm may be more likely to misclassify other severe neurological disorders as ADRD. Compared to other dementia prevalence algorithms, the HCAP Manly-Jones algorithm had overall higher sensitivity, specificity, and accuracy in classifying dementia in the ADAMS cohort.

Discussion

Meeting attendees agreed that normative reference samples should exclude individuals with any neurocognitive concerns (e.g., stroke), because a reference group should be as reflective of normal function as possible. Nichols noted that the team might expect dementia prevalence estimates to increase by doing so; other attendees suggested that restricting the normative sample could support further analyses of cohort differences affecting dementia prevalence.

Manly highlighted that clinical classifiers include unavoidable biases; thus, a mismatch between the classifiers does not necessarily indicate poor algorithmic performance. She further suggested that no algorithmic classifications are sufficiently validated or free from bias that they can serve as a performance test for other algorithmic classifications.

Challenges in Analyzing Longitudinal HCAP Data

Measuring Longitudinal Change in a Co-Calibration Framework

Alden L. Gross

As new waves of HCAP data come in, the Gateway to Global Aging Data team must consider how to integrate these data into ongoing cross-national study harmonization efforts. Although cognitive scores across all HCAP studies should ideally be aligned with HRS HCAP Wave 1, in practice subsequent study waves may need special calibration to reflect within-study changes for participants. The Gateway team has adopted an item banking approach to conduct this calibration, which enables the team to add multiple harmonized study items to a growing set of items with standardized parameters. Initially, the team attempted to add Wave 2 data from the ELSA HCAP, the LASI Diagnostic Assessment of Dementia (LASI-DAD), and MHAS Mex-Cog. However, item banking Wave 2 of LASI-DAD revealed minimal to no decline in participant cognitive scores in the five years following Wave 1. Given that the team had previously found annual rates of cognitive decline between -0.02 to -0.04 standard deviations per year,[15] this result was unexpected.

Gross noted that unlike the HCAP procedure for estimating cross-national factor scores, LASI-DAD acknowledges item residual dependencies in its repeated measures, which more precisely recovers the rates of change. The Gateway team subsequently revised their HCAP pipeline for longitudinal data to include residual dependencies. The revised pipeline also replicates probable method factors for all waves and restricts residual variance on continual indicators to a consistent longitudinal value. Using the new pipeline, annual rates of cognitive decline for both the ELSA HCAP and Mex-Cog were consistently negative, with the annual change magnitude falling around -0.03 to -0.05 standard deviations per year. These results align with rates of change found in multiple other studies. The Gateway team aims to expand their investigations on temporal residual correlations to ensure that the co-calibration procedure is working, potentially by using Bayesian statistics.

Discussion

Kobayashi noted that the grant renewal for these further analyses will likely be funded, and that any study teams with cleaned data from Waves 1, 2, or 3 should reach out to her or Gross for inclusion in their work.

Descriptive Analysis of Longitudinal Changes in Harmonized Cognitive Factor Scores

Tsai-Chin (TC) Cho

On average, the duration between follow-up waves for the Mex-Cog, LASI-DAD, and ELSA HCAP is between 4.5 – 5.5 years. The majority of participants interviewed in Wave 2 for these studies are refreshment samples, as many Wave 1 participants either refuse to re-interview or have died prior to Wave 2. Forty-four percent of baseline ELSA HCAP participants agreed to re-

[15] Rates of cognitive decline were also found to steepen with age.

interview for Wave 2, whereas 63.3% of the LASI-DAD cohort and 67.8% of the Mex-Cog cohort agreed to re-interview for their Wave 2 studies. When comparing Wave 2 status against baseline cognitive function, all three studies show a similar pattern: individuals in the lowest tertile rank of cognitive function had higher mortality and the lowest rates of retention into Wave 2.

Comparisons of score distributions revealed that although ELSA HCAP participants scored slightly higher on cognitive tests at baseline than participants in LASI-DAD or Mex-Cog, ELSA HCAP participants who re-interviewed in Wave 2 had a slightly lower distribution of cognitive scores than Wave 1, suggesting cognitive decline since the initial study. Conversely, LASI-DAD participants who re-interviewed showed a slight improvement in language scores. A scatterplot of annualized changes in cognitive function across the studies additionally revealed that ELSA HCAP participants with lower baseline cognitive function showed a much steeper decline in cognitive function annually than participants in LASI-DAD and Mex-Cog with low baseline cognition. This decline became even steeper for ELSA HCAP participants with higher education levels; by contrast, in LASI-DAD and Mex-Cog, participants with low education actually slightly improved in specific domains, such as executive function.

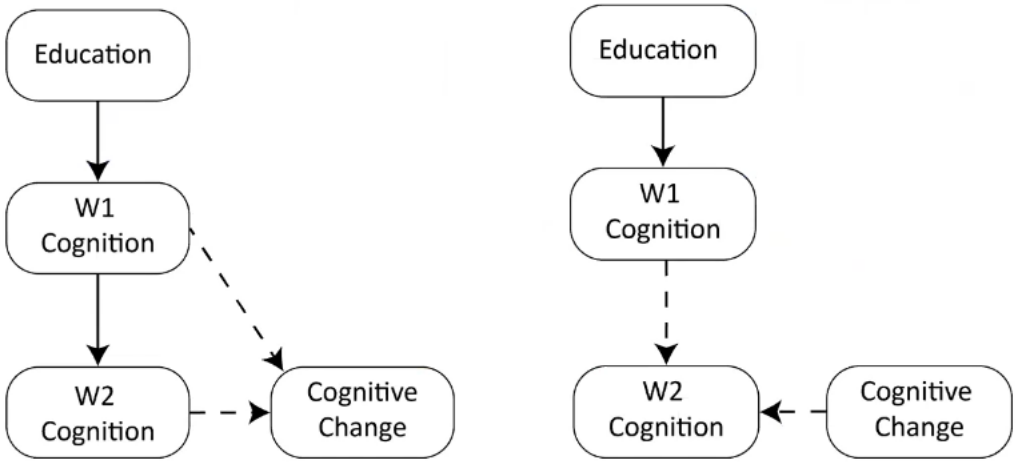
An Example Longitudinal Analysis: the Associations Between Education and Cognitive Decline in LASI-DAD
Emma Nichols

LASI-DAD participants with higher education levels experience a sharper decline in cognitive function over time than participants with minimal schooling. These results were generally consistent across cognitive outcomes and data subsets by age, gender, and urbanicity, suggesting that another underlying factor (e.g., practice effects or selective mortality) might be influencing results.

To test whether practice effects might have played a role in the correlation, Nichols and colleagues compared Wave 2 cognitive scores for participants who had previously completed Wave 1 against participants from the Wave 2 refreshment sample.[16] The team found some evidence of practice effects for global cognitive performance, with significant effects observed in memory and visuospatial function (i.e., constructional praxis). However, they did not observe larger practice effects for participants without schooling than participants with schooling, indicating that practice effects should not explain the observed association between education and cognitive decline. Because LASI-DAD participants with minimal education also had a higher mortality rate than higher education groups, selective survival may have influenced the correlations between education and cognitive decline. However, the baseline mixed effects model of annualized cognitive decline was similar to both a general estimating equations model weighted by mortality and a joint model of the two models, suggesting that selective mortality also did not significantly impact results.

[16] The study team restricted refreshment sample participants by eligibility for Wave 1 and inverse probability weights.

Nichols then modeled how education could be impacting cognitive change by running simple simulation models.



If Wave 1 cognition influences Wave 2 cognition, then education would have a significant effect on cognitive change. If cognition between waves is independent, however, then education would not affect cognitive change. The interpretation of findings, therefore, depends on ones assumptions about the underlying causal structure. Nichols also emphasized that these analyses highlight the importance of considering both the level of cognitive function as well as the rate of decline when interpreting results. HCAP network investigators should consider underlying assumptions on how cognition changes over time and acknowledge how these may impact data interpretation.

Discussion

King highlighted the observed practice effects for memory in the LASI-DAD Wave 2 cohort and suggested that the study team compare practice effects for participants stratified by cognitive score quantiles. Manly suggested that the team could analyze specific HCAP items to evaluate practice effects in the future.

Because practice effects were estimated using participants within the same wave, any potential practice effects were likely not due to differences in the test itself. However, drawing shapes may not have been a familiar task in rural areas, which may have contributed to the size of the practice effect seen for constructional praxis. Manly noted that study staff might have had more experience by Wave 2, leading to apparent practice effects when compared against naïve administration in Wave 1 data. Jinkook Lee clarified that Wave 2 LASI-DAD was administered by a combination of staff from Wave 1 and new staff recruited for Wave 2.

Harmonized Dementia Algorithms: Considerations for the Normative Sample
Alden L. Gross, Jennifer Manly

Initially developed for the HRS HCAP study, the Manly-Jones algorithm estimates the prevalence of dementia and MCI in older adults using three key components: domain-based cognitive impairment, informant-reported impairments, and self-rated memory. To operationalize a definition for impairment and abnormal memory, study teams must first define expected cognitive function based on population norms using a normative reference group consisting of people thought to be free of cognitive impairment and excluding people who will develop dementia in the near future.

The criteria used to define a normative reference group influences calculations of dementia prevalence within a population. Exclusions from the normative reference group should therefore aim to maximize sensitivity and specificity of the algorithm without over-restricting the sample. Gross's team examined how normative sample exclusion criteria across seven HCAP studies affect dementia prevalence estimates. Specifically, the study team investigated (a) how applying normative sample criteria from other HCAP studies to normative samples for the HRS HCAP and ELSA HCAP would affect dementia prevalence estimates for both studies, and (b) how adding extraneous exclusion criteria to normative samples in existing HCAP studies would affect dementia prevalence estimates.

Gross and colleagues compared exclusion criteria across seven HCAP cohorts—HRS HCAP, ELSA HCAP, the Chile Cognitive Aging Study (Chile-Cog), LASI-DAD, Mex-Cog, HAALSI HCAP, and the China Health and Retirement Longitudinal Study (CHARLS) HCAP. Using baseline inclusion criteria, the Manly-Jones algorithm estimated a normative sample for most studies that consisted of between 30 – 50% of the population (except for the Chile-Cog normative sample, at 73%). Dementia prevalence estimates ranged between 3.3% in the CHARLS-HCAP to 10.3% in the HAALSI-HCAP and 12.2% in the ELSA-HCAP. Paring down ELSA and HRS normative sample criteria to match other studies' criteria resulted in slightly lower dementia prevalence estimates for both studies, with a greater reduction in prevalence for the ELSA-HCAP. Conversely, adding extraneous normative sample criteria (e.g., exclusions for social isolation, hypertension, or diabetes) to any of the HCAP studies increased dementia prevalence estimates. Based on these findings, Gross argued against using a blanket set of normative sample criteria for all HCAP studies. Instead, he recommended that study teams should emulate the Manly-Jones normative sample criteria matrix within their protocols and consider how each criterion fits the context of their specific cohort. To validate their normative sampling, study teams may consider comparing (a) cognitive domain scores between the normative and overall samples, (b) proportions of participants with impairments for each cognitive domain, and (c) age and education distributions between the normative and overall samples.

Discussion
Manly noted that the four goals of neuropsychological testing are to (a) describe individual function compared to reference populations, (b) detect and classify cognitive impairment, (c) measure cognitive changes over time, and (d) assess individual function in daily life. Descriptive

testing labels such as “average” or “below average” can capture individual performance against a larger reference population. In *diagnostic* testing, labels such as “mildly impaired” or “moderately impaired” instead distinguish cognitive performance cutoffs for individuals based on their expected prior performance, also known as their pre-morbid status. Manly emphasized that these cutoff scores, which are generally defined by performance across individuals in a larger reference population, depend on appropriate demographic adjustments to ensure as high sensitivity and specificity to an individual’s actual performance change as possible.

The Bronx Aging Study first introduced a case for robust normative sampling criteria when the study team found evidence that including preclinical adults in the normative sample reduced the sample sensitivity to MCI-associated cognitive changes.[17] Study teams need longitudinal data to construct robust normative samples, which introduces several questions for study protocols on how to define potential cutoffs or exclusions. However, over-restricting the normative sample would derail the specificity of the sample and decenter functional cognitive status as a primary indicator of MCI. Manly encouraged HCAP network researchers to increase infrastructure for appropriate normative sampling by prioritizing longitudinal data collection on both cognitively impaired and functionally normal populations to better understand what exclusion criteria are actually necessary for an HCAP normative reference group. She commended the inclusion of multiple international HCAP studies in the presentation data and emphasized that utilizing the global network could lead to additional insights on normative sampling.

Meeting attendees agreed that HCAP studies should focus on identification of both normative and preclinical indicators. Berkman expressed concern that additional risk factors for dementia in the normative sample criteria could potentially introduce bias; Manly agreed that additional risk factors should not be included in normative sample criteria because these criteria should focus on just defining a functional cognitive range for a population.

Meeting attendees acknowledged that each normative sample cutoff has a margin of error for classification, and that HCAP participants with scores within those margins may have less precise classifications than those on clearer sides of the cutoff. However, given that certain risk factors for dementia develop over several decades, Glymour suggested that current HCAP longitudinal data are still not robust enough to accurately predict which individuals should be excluded from a normative sample. Gross suggested that the HCAP network should explore how demographic factors affect normative cognitive function prior to making adjustments to the HCAP data. Jones proposed using multiverse analyses to identify appropriate normative sample criteria, and noted that reference standard criteria should reflect clinical standards for dementia diagnosis.

[17] Nadelmann J, Frishman WH, Ooi WL, Tepper D, Greenberg S, Guzik H, Lazar EJ, Heiman M, Aronson M. Prevalence, incidence and prognosis of recognized and unrecognized myocardial infarction in persons aged 75 years or older: The Bronx Aging Study. *Am J Cardiol*. 1990 Sep 1;66(5):533-7. doi: 10.1016/0002-9149(90)90477-i. PMID: 2392974.

In response to a concern about variance in dementia prevalence estimates across HCAP studies, Gross emphasized that this variance could be due to discrepancies (e.g., differing reports, test administration issues) within each study, and that future analyses should consider effective strategies to measure how study features affect prevalence estimates. Weir suggested that instead of using normative samples to compare dementia prevalence, researchers could instead compare cognitive impairment prevalence between studies. Miguel Arce-Rentería added that additional timepoints will likely yield more robust results, and that cross-country comparisons might not be necessary until the methodology for each HCAP study has been fully validated.

With Wave 2 data collection now underway for several HCAP studies, Nichols asked how researchers should account for longitudinal changes within individuals. Comparing Wave 1 and Wave 2 data for the LASI-DAD study found that the increase in data available for Wave 2 participants led to more exclusions from the normative sample than there were for Wave 1. As a result, longitudinal data will likely further restrict normative sample populations. Glymour highlighted that exclusion criteria functionally shift the distribution cutoffs for a population, and suggested that setting standard deviation cutoffs might be simpler for defining a normative sample than trying to harmonize exclusion criteria.

Data Sharing

TILDA-VISTA Enclave
Christine McGarrigle

TILDA has historically housed data and provided in-person hotdesks within TILDA offices. In response to research requests, these hotdesks generate aggregated, bespoke datasets that cannot be exported from the platform. Recently, the study team launched the TILDA Virtual Infrastructure for Secure TILDA Data Access (VISTA), which enables remote hotdesk use through a cloud-connected data platform. The team partnered with the United Kingdom Secure e-Research Platform (SeRP UK), which hosts sensitive data for multiple other studies, to replicate the TILDA hotdesks within a trusted research environment. Researchers can access the database as independent users or within collaborative project environments. The remote hotdesk functions are virtually identical to the in-person hotdesks and provide several types of analysis software and a mixture of both standard and high-performance computing power for working with large, multinational datasets. TILDA VISTA currently supports up to 20 users at a time but can scale up capacity based on demand.

Due to the complex data protection landscape for the European Union (EU), the TILDA team navigated a series of legal requirements to launch TILDA VISTA in June 2025. To access the TILDA VISTA platform, researchers must submit an application to the TILDA Data Access Committee and, once approved, provide proof of data protection training. The researchers then complete specific TILDA Hotdesk Data training before signing a data use agreement and receiving access to the encrypted platform. TILDA data are considered personal data under the EU General Data Protection Regulation (GDPR), which means that even viewing secure data is considered data processing. As a result, TILDA VISTA access is currently restricted to countries within the European Economic Area (EEA), and EU Adequacy Decision countries that already

have acceptable data protection safeguards. The TILDA team is working to develop special data transfer agreements for countries that do not already align with GDPR safeguards, such as the United States. The TILDA team has begun data transfers from TILDA VISTA to the Gateway to Global Aging Data Enclave to facilitate data sharing for these additional countries. The EU Court of Justice also recently ruled that under certain anonymized conditions, pseudonymous data can be considered untraceable, which will greatly assist with future data sharing efforts.

Secure Data Access through the Gateway to Global Aging Data Enclave
Drystan Phillips

The Gateway to Global Aging Data supports AD/ADRD research by providing access to multiple datasets, such as core cognitive measures of the HRS International Network of Studies (INS), HCAP data, linked environmental data, and modifiable risk factors, and builds harmonized individual-level, cross-wave data files. The Gateway leads harmonization efforts on this data through a combination of pre-statistical and statistical harmonization methods, imputation, data standardization, and algorithm-based classifications (e.g., mild cognitive impairment and dementia).

Despite the success of data sharing so far across the HCAP network, access to some HCAP studies and linked datasets remains a challenge. Further analyses, such as linking geographic data to environmental factors, also raise data privacy concerns. To help address these challenges, NIH launched the Gateway Data Enclave, a secure, remotely accessible data platform that seeks to improve data sharing across the HCAP network. To deposit data in the Gateway Data Enclave, study teams must first sign a data sharing agreement to confirm the data being deposited (e.g., public, sensitive, Core) and the procedures for researcher access. Researchers can also upload additional data into an Enclave workspace for combination with Enclave data. The Enclave currently houses data from HRS, LASI, ELSA, the Chilean Social Protection Survey (SPS), and NICOLA. This includes household-linked sensitive-use data from LASI-DAD and ELSA-HCAP, as well as cross-country cognition analyses and longitudinal disability analyses. The Enclave anticipates additional data available soon, including (a) pollution and extreme weather estimates for LASI-DAD, ELSA, and NICOLA, (b) CADAS data, and (c) TILDA data.

Due to current restrictions with the NIA Data LINKAGE program that hosts the Gateway Enclave, user access is currently restricted to researchers in the United States who are affiliated with a U.S.-based institution. The Gateway has partnered with the AD Data Initiative (ADDI) to address this restriction by expanding the Gateway Enclave to ADDI's AD Workbench platform, which can create specific servers for other countries. ADDI houses a range of datasets ranging from granular genomics and molecular data to large-scale observational and survey data.

Missing Data and Imputation in HCAP Studies
Erik Meijer

Data missingness within HCAP studies can result from a number of sources, including item non-response, missing sub-interviews (e.g., informant interviews), and missing responses from Core

participants who do not complete the HCAP protocol. Some types of missingness can be addressed by weighting for nonparticipation and attrition, or by using statistical harmonization for different items administered. In HCAP studies, proportion missingness on the administered items varies between 1% and 15%.[18] Missingness reduces statistical power due to the loss of information and contributes to biased statistical analyses when it correlates with the outcome variables. Although proactive strategies to reduce data missingness are preferable to post-collection adjustments, nonresponses are unavoidable and preventing them should not be prioritized over participant comfort.

Imputing data is a leading strategy for dealing with missing data, but imputation also requires several methodological decisions. For example, survey items typically code responses such as "don't know" as missing data eligible for imputation, but in knowledge/ability tests, it is often coded as incorrect. The latter approach may not be appropriate in certain cultural contexts where participants might try to avoid explicitly refusing an answer. Refusing to answer could be a refusal to share information or participate in a test, in which case it would be missing data, or a way to avoid admitting not knowing the answer to a test item, in which case it would be coded as incorrect**.** Therefore, coding these responses requires context-specific considerations.

Meijer and team coded "don't know" responses at 0 and imputed refusals for most of the HCAP studies they were involved in besides the CHARLS HCAP, in which both answers were imputed to account for cultural considerations. In contrast, the HRS-HCAP team set both answers to 0. Missing sub-interviews also present concerns about biases in analyses, but imputing them is challenging, because relatively little information is available for imputation. Meijer and team originally dealt with missing sub-interviews by only imputing them in HCAP studies with small fractions of observations in which sub-interviews were missing, but for Wave 2 of LASI-DAD, the team decided to impute only a few key summary scores for any missing sub-interviews.

Meijer shared additional cases where imputation is not the best strategy for missing data, such as when (a) items are skipped for irrelevance, (b) items are skipped due to consistent performance on the previous items, or (c) the contextual purpose of the analysis does not warrant imputation. Because imputations can always be disregarded, imputing is generally preferable if it depends on the context of the analysis whether an item should be treated as missing or not.

Next Steps

The University of Michigan is developing an online HCAP item repository of core measures for inclusion in an HCAP study. The repository provides an overview of all active studies in the HCAP network, as well as the measures available for each study. Each study will have a standalone page with more granular information about each test used, cognitive domains and subdomains, citation links, cultural adaptations, translations, changes between study Waves, licensing information, and points of contact for the study. The team will continue adding

[18] The Gateway to Global Aging Data team at USC has done imputations for LASI-DAD, ELSA-HCAP, Mex-Cog (wave 1), Chile-Cog, and CHARLS-HCAP, and has assisted/advised on imputations for Mex-Cog (wave 2), SHARE-HCAP, TILDA-HCAP, LSAHA, and CADAS.

content to the repository through 2025 and will meet with newer study teams to solicit feedback on important content for studies to include. In early 2026, HCAP study teams will be asked to confirm that their study is accurately reflected in the repository before the final repository and accompanying protocol are posted to the NIA website.

The University of Michigan is in the early stages of collaboration with the Cohort Studies of Memory in an International Consortium (COSMIC). COSMIC includes roughly 60 cohort studies on age-related cognitive decline, which the University of Michigan is currently harmonizing with available HCAP study data. Researchers interested in joining these harmonization efforts should contact Langa or Kobayashi.

Throughout the year, the HCAP network hosts several small, virtual sessions for subgroups of the network. Any suggestions for session topics or subgroups can be sent to the University of Michigan team. The next HCAP virtual seminar is scheduled for November 18; Iris Strangman will present on literacy and multilingualism in cognition. The seminars will re-commence in January 2026; researchers interested in sharing their results at a seminar can contact the University of Michigan team. The network will also be hosting an HCAP Gateway Policy Explorer workshop in Summer 2026 to analyze correlations between policy explorer data and cognitive outcomes.

Appendix A: Agenda

*Virtual Participant

Monday, September 29

8:30 AM **Morning Refreshments**

9:00 **Welcome and Introductions**
Kenneth Langa, Lindsay Kobayashi

NIA Welcome
Richard Hodes, Director
Minki Chatterji, Program Officer
Jonathan W. King, Project Scientist

9:15 **Overview of Meeting Agenda & HCAP U24 Network Updates**
Kenneth Langa, Lindsay Kobayashi

9:30 **Updates from HCAP Studies Recently Funded and/or in the Field (10 mins per study)**
*Kenya (LOSHAK) | *Roselyter Riang'a*
*Kenya (KLPS) | *Edward (Ted) Miguel*
Costa Rica (CRELES) and Caribbean (CADAS) | William Dow
HAALSI | Lisa Berkman & Darina Bassil
Nepal (CVFS-SCAN) | Emily Briceño
Côte d'Ivoire | Philip Anglewicz
Cameroon (BUILD-FSA) | Yembe Njamnshi

11:00 **Break**

11:30 **Previews of Upcoming Pilot Studies (15 mins + 5 mins discussion each)**
*Colombian Study of Aging (COSA) | *Jennifer Ailshire & Mateo Farina*
Longitudinal Study of Aging in Guatemala (AGUA/ELEGUA) |David Flood
Development and validation of the Manly-Jones algorithm in the HRS-ADAMS sample | Zachary Kunicki & Emma Nichols

12:30 **LUNCH | Commonwealth Indian**

2:00 **Challenges in Analyzing Longitudinal HCAP Data (60 mins)**
Alden Gross, Tsai-Chin Cho, Emma Nichols

3:00 **Imputation Strategies for Missing HCAP Data (30 mins)**
Erik Meijer

3:30 **Break**

4:00 **Using HCAP to Inform Dementia Classifications in HRS Core Data (45 mins)**
Richard Jones
Discussant: Maria Glymour

4:45 **Adjourn**

6:00 **GROUP DINNER | Pinstripes Bethesda**

Tuesday, September 30

8:30 AM **Morning Refreshments**

9:00 **Harmonized Dementia Algorithms (45 mins)**
Alden Gross
Discussant: Jennifer Manly

9:45 **Funding Challenges & Solutions**

10:15 **Break**

10:30 **Data Sharing**
*The Irish LongituDinal Study on Ageing (TILDA) Enclave| *Christine McGarrigle*
*Gateway to Global Aging Data Enclave| *Drystan Phillips*

11:00 **Group Discussion and Next Steps**

12:30 **Adjourn**

Appendix B: Meeting Participants

Rev. September 28, 2025

* Indicates virtual attendee

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

Kenneth Langa, MPI and Diagnosis and Validation Core Leader, HCAP Network; MPI, Co-Director, HRS; UM

Lindsay Kobayashi, MPI, HCAP Network; Co-I, HRS; Collaborator, LASI-DAD; Co-I, Gateway to Global Aging Data; Collaborator, HAALSI; University of Michigan (UM)

David Weir, PI, HRS ATW; MPI, Co-Director, HRS; UM Co-Investigator and Sampling Core Leader, HCAP Network; UM

Emily Briceño, Collaborator, HCAP Network; Co-I, 2025 HCAP Network Pilot; Co-I, BASIC-Cog; Co-I, CVFS-SCAN; Co-I, AGUA/ELEGUA; Co-I, Gateway to Global Aging Data; UM

Tsai-Chin Cho, Collaborator, HCAP Network, UM

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

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

Sarah Kwiatek, Project Manager; UM

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

*Eileen Crimmins, Collaborator, HRS-HCAP; Co-I, HRS; Co-I, LASI-DAD; USC

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

*Steven Heeringa, Co-I, HRS-HCAP; Co-I, BASIC-Cog; UM

*Deborah Levine, Co-I, HRS-HCAP; Co-I, BASIC-Cog; UM

*Ryan McCammon, Collaborator, HRS-HCAP; UM

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

*Amanda Sonnega, HCAP Network Outreach and Dissemination Core Leader; Collaborator,
HRS; UM

*Bharat Thyagarajan, Co-I, HRS; Co-I, LASI-DAD; University of Minnesota

USA ***Brain Attack Surveillance in Corpus Christi (BASIC-Cog)***

Emily Briceño, Co-I; Co-I, CVFS-SCAN; Co-I, AGUA/ELEGUA; Co-I, 2025 HCAP Network Pilot; Co-I, Gateway to Global Aging Data; Collaborator, HCAP Network; UM

*Steven Heeringa, Co-I; Co-I, HRS-HCAP; UM

*Deborah Levine, Co-I; Co-I, HRS-HCAP; UM
*Lewis Morgenstern, PI, UM

BOTSWANA ***Research on Aging, AD/ADRD, and Its Social Determinants in Botswana (RAISE-Botswana)***
*Lillian Okui, PI; Botswana University of Maryland School of Medicine Health Initiative

BRAZIL ***Brazilian Longitudinal Study of Health, Ageing & Well Being (ELSI-Brazil)***
*Maria Fernanda Lima-Costa, PI; Universidade Federal de Minas Gerais, Belo Horizonte, Minas Gerais, Brazil
*Cesar Messias de Oliveira, Co-PI; University College London
*Laiss Bertola, Team Member; Universidade Federal de São Paulo
*Cleusa Pinheiro Ferri, Team Member; Universidad Federal de São Paulo

CAMEROON ***Building Unique Infrastructure for Large-scale Dementia research in French-Speaking Africa (BUILD-FSA)***
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*Bernard Fongang, PI; UT Health San Antonio
*Alfred K. Njamnshi, PI; BRAIN & The University of Yaoundé I

CARIBBEAN ***Caribbean American Dementia and Aging Study (CADAS)***
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Washington University in St. Louis

CHILE ***Chilean Social Protection Survey (CSPS) and Cognitive Aging Study (Chile-Cog)***
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*Jere Behrman, Co-PI; Co-PI, AGUA/ELEGUA; Co-I, 2025 HCAP Network Pilot; University of Pennsylvania
*Irma Elo, Co-PI; Collaborator, Gateway to Global Aging Data; University of Pennsylvania
*Catalina Bravo, Team Member; Pontifical Catholic University of Chile

CHINA ***China Health and Retirement Longitudinal Study (CHARLS)***
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*Yafeng Wang, Co-PI; Peking University

COSTA RICA ***Costa Rican Longevity and Healthy Aging Study (CRELES)***

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*Carolina Santamaría-Ulloa, Co-PI; Professor at the Human Nutrition Department and the Public Health and Human Nutrition Graduate Programs, UCR

CÔTE D'IVOIRE ***Building Research Infrastructure for ADRD in Côte d'Ivoire***

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*Jean Ikanga, Team Member; Investigator, LOSHAK; Investigator, KLPS-5A; Emory University

EGYPT ***A Longitudinal Study of Egyptian Healthy Aging (AL-SEHA)***

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ENGLAND ***English Longitudinal Study of Ageing (ELSA)***

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EUROPE ***Survey of Health, Aging and Retirement in Europe (SHARE)***

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*Agnieszka Burzynska, Research Coordinator, SHARE Berlin Institute

*Salima Douhou, Coordinator; Max Planck Institute

*Denis Gerstorf, Professor, Developmental Psychology, Humboldt University Berlin and SHARE Analysis

*Marcela Otero, Senior Research Scientist; Munich Research Institute for the Economics of Aging (MEA); Max-Planck-Institute for Social Law and Social Policy
*Giacomo Pasini, Area Coordinator; Head of Department at the Department of Economics at Ca' Foscari University of Venice and SHARE Analysis
*Beatrice Baaba Tawiah, Research Scientist; Munich Research Institute for the Economics of Aging and SHARE Analyses

GUATEMALA ***The Longitudinal Study of Aging in GUAtemala/Estudio Longitudinal de Envejecimiento en GUAtemala (AGUA/ELEGUA)***

David Flood, Co-PI; PI, 2025 HCAP Network Pilot; Collaborator, LASI-DAD; UM
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*Manuel Ramirez, Co-PI; Institute of Nutrition of Central America and Panama (INCAP)
*Karen Corzantes, Project Manager; INCAP

INDIA ***Longitudinal Aging Study in India (LASI); Diagnostic Assessment of Dementia (LASI-DAD)***

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*Jennifer Ailshire, Collaborator, LASI-DAD; Co-I, HRS; PI, Colombian Survey of Aging (COSA) Biomarker Pilot (2022-2023); Co-I, Gateway to Global Aging Data; University of Southern California (USC)
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*Pranali Khobragade, Survey Director, LASI-DAD; USC
*Peiyao Zhu, Collaborator, LASI-DAD; UM

INDONESIA ***Indonesia Family Life Survey (IFLS)***

*John Strauss, PI; Co-PI, CHARLS; USC

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

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JAPAN Japanese Study of Aging and Retirement (JSTAR)
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KENYA Kenya Life Panel Surveys (KLPS-5A)
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*Madeline Duhon, Team Member; University of California, Berkeley
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KENYA Longitudinal Study of Health and Ageing in Kenya (LOSHAK)
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PAKISTAN ***Leveraging Consanguinity in Pakistan to Uncover the Genomic Architecture of Alzheimer's Disease: Feasibility Study with ENIGMA-PAK***

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

*David Bell, Co-PI; University of Stirling
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S AFRICA ***Health and Aging in Africa: A Longitudinal Study of an INDEPTH Community in South Africa (HAALSI)***

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S KOREA ***Korean Longitudinal Study of Aging***

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

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ZAMBIA ***Zambian Cohort of Healthy Aging and Dementia (Z-CHAD)***

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

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*Shaea Alkahtani, Professor of Exercise Physiology, College of Sport Sciences and Physical Activity; King Saud University, Saudi Arabia
*Ganesh Babulal, Washington University, Preparing an Afghanistan HCAP application
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