

# 2023 Meeting of the HRS Around the World Studies

August 22-23, 2023

Dublin, Ireland

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## Acronym Definitions

AD	Alzheimer's Disease
ADRD	Alzheimer's Disease Related Dementias
ATW	Around the World
CADA	Caribbean American Dementia and Aging
CAPI	Computer-assisted personal interview
CAVI	Computer Assisted Video Interviews
CHARLS	China Health and Retirement Longitudinal Study
CSO	Central Statistics Office (Ireland)
DG RTD	Directorate-General for Research and Innovation
EFTF	Enhanced face-to-face
ELSA	English Longitudinal Study on Ageing
EMA	Ecological momentary assessment
ERIC	European Research Infrastructure Consortium
EU	European Union
ESRC	Economic and Social Research Council (United Kingdom)
GDPR	General Data Protection Regulation
HAALSI	Health and Aging in Africa: Longitudinal Study of an INDEPTH Community
HAGIS	Healthy Ageing in Scotland
HART	Health, Aging, and Retirement in Thailand
HCAP	Harmonized Cognitive Assessment Protocol
HRS	Health and Retirement Study
JSTAR	Japanese Study of Aging and Retirement
LASI	Longitudinal Aging Study in India
LHMS	Life History Mail Survey (HRS)
LHQ	Life history questionnaire (ELSA)
LMIC	Low- or middle-income countries
MARS	Malaysia Aging and Retirement Study
MCI	Mild cognitive impairment
MHAS	Mexican Health and Aging Study
NfL	Neurofilament Light Chain
NHS	National Health Service
NIA	National Institute on Aging

NIAGADS	NIA Genetics of Alzheimer's Disease Data Storage Site
NICOLA	Northern Ireland Cohort for the Longitudinal Study of Ageing
NIDS	National Income Dynamics Study (South Africa)
NIH	National Institutes of Health
NRCT	National Research Council of Thailand
NSFC	National Natural Science Foundation of China
PI	Principal Investigator
RIETI	Research Institute of Economy, Trade and Industry (Japan)
SAPRIN	South African Population Research Infrastructure Network
SCQ	Self-completion questionnaire
SHARE	Study of Health, Ageing and Retirement in Europe
SPACE	Supportive environments for Physical and social Activity, healthy ageing and CognitivE health
SPS	Chilean Social Protection Survey
TILDA	The Irish Longitudinal Study on Ageing
UAS	Understanding America Study

## Executive Summary

The Health and Retirement Studies (HRS) Around the World (ATW) network met in person at Trinity College, Dublin, Ireland on August 22 and 23, 2023. The meeting's purpose was to discuss study updates and challenges. There were also panels on specific topics including life histories, biomarkers, pollution, and COVID-19. The study updates were grouped by geographic location: Europe, Asia, the Americas, and Africa.

Several common themes emerged from the study updates. Many studies struggle with funding multiple waves of data collection. Training and retaining interviewers have become more challenging over time. Several study investigators commented on the need to do outreach to funders and policymakers on the importance of longitudinal data, especially for public health. The importance of harmonizing data, both before and after data collection, to enable cross-national comparisons was emphasized by both the National Institute on Aging (NIA) and study leads. Many of the studies collected data related to COVID, which will provide insight into the long-term effects of the pandemic.

### Action Items:

- RLA to share [registration link](#) for September 7-8 National Academies Workshop on Developing an Agenda for Population Aging and Social Research in Low- and Middle-Income Countries (LMIC), chaired by Rebeca Wong [Completed 8/29/23]
- HAGIS team to determine how outside researchers can access the Scottish administrative data.
- NIA to connect with EU Directorate-General of Research. SHARE to send potential contacts to John Phillips and Minki Chatterji.
- Jinkook Lee to share current list of harmonized measures from Gateway.
- Langa will update the HCAP Network website with breakdown of publications using HCAP data.

### Potential Topics for Further Discussion:

- Sharing restricted data with researchers across countries (e.g., virtual enclaves)
- Engaging policymakers and funders on the value of longitudinal aging studies
- Interventions in the context of longitudinal observational studies
- Developing harmonized measures of sensory loss
- Approaching sample refreshment after COVID
- Strategies for retaining interviewers, such as moving to a full-time labor model
- More positive aging language/recruitment/retention
- Evaluating the quality of the life history data (e.g., residential and employment history)
- Creating a harmonized biological aging protocol
- Cognitive test selection for the HCAP
- Providing feedback from survey to participants
- Harmonization of content from accelerometers, income modules

## Meeting Summary

### Introductions

The Health and Retirement Studies (HRS) Around the World (ATW) network met in person in Dublin, Ireland on August 22 and 23, 2023. The meeting's purpose was to discuss study updates and challenges. There were also panels on specific topics including life histories, biomarkers, pollution, and COVID-19. The study updates were grouped by geographic location: Europe, Asia, the Americas, and Africa. The meeting agenda and list of participants are included as Appendices A and B. The individual presentations, which include more detailed information on each of the studies, are available [here](#).

**Minki Chatterji** welcomed attendees on behalf of the National Institute on Aging (NIA). NIA funds research on how behavioral and social factors influence outcomes related to aging and the life course, and on Alzheimer's Disease/Alzheimer's Disease-related dementias (AD/ADRD) in varying contexts, such as through cross-national comparisons. One way that NIA facilitates cross-national research is through support for the HRS ATW Network and the Harmonized Cognitive Assessment Protocol (HCAP) Network. HRS studies have been conducted in over 40 countries and cover over 70% of people ages 60+ worldwide. HCAP studies have been conducted in seven countries (United States, China, Chile, England, India, Mexico, and South Africa), are in progress in three countries (Brazil, Ghana, and Egypt), and are being discussed in four countries (Malawi, Cote D'Ivoire, Vietnam, and the Philippines).

Chatterji emphasized the importance of harmonizing data among the HRS ATW studies to facilitate cross-national comparisons. She encouraged study directors to make use of the HRS ATW network when implementing a new measure or study feature to learn from others' experiences. NIA would like to expand the HRS ATW network to add new contextual information, such as Sub-Saharan Africa, Central Asia (including former Soviet countries), Mongolia, Turkey. Chatterji described two possible paths to establishing a new HRS study: (1) apply to NIA for a new R01 award to support an HCAP-comparative study, or (2) apply to NIA for an R21 award to pilot an HRS-comparative study and then apply for in-country support when the full study team is ready. Existing HRS-comparative studies can apply for funds to add an HCAP to the core study. Grant applications that include a focus on AD/ADRD (i.e., HCAP studies) are currently more likely to be funded. A [notice of funding opportunity](#) is currently open to fund HCAP data analysis. Contact Chatterji for more information.

**David Weir** paused to remember and honor **James P. Smith**, the former Principal Investigator (PI) for the HRS ATW grant who played an integral role in the development of HRS studies in many countries. Weir reported that the Harmonization Network is transitioning from Rose Li and Associates (RLA) to the University of Michigan with Weir as successor PI, and retaining RLA for contractor support. Weir underscored the continuing focus on harmonization, facilitated by the partnership with the Gateway Network (led by Jinkook Lee), and with Chatterji providing oversight as the NIA program official. The HRS ATW network of investigators has the unique opportunity to shape and harmonize data collection before it is archived. The goal of this network is to support data creators in enhancing the quality and promoting the use of their

data. This aim is achieved through in-person meetings, virtual meetings, and funding pilot studies. Weir reviewed the history of past meetings, and aims to hold three in-person meetings during the 5-year project period.

The goals for in-person meetings are to build a sense of community among study PIs, to experience other countries (rotate locations), and to maintain contact with regular intervals between meetings (ideally every 18 months). The next HRS ATW in-person meeting will be hosted by Rebeca Wong in Mexico in 2025, with a planned focus on new studies in low- or middle-income countries (LMICs), e.g., Africa, central/south America, Lebanon, Nepal. Wong is chairing a National Academies of Sciences, Engineering, and Medicine (NASEM) [meeting on September 7-8, 2023](#) on developing an agenda for population aging and social research in LMICs. Virtual meetings held between in-person meetings will allow for in-depth discussion of topics such as new studies and harmonization strategies. Limited funds are available through the Network to fund pilot studies, including data harmonization projects or human subjects research. The first pilot will occur in Egypt to demonstrate the feasibility of an HRS-like study there.

## **Study Updates: Europe**

### **Study of Health, Aging, and Retirement in Europe (SHARE)**

*Axel Boersch-Supan and David Richter*

The SHARE study is currently planning for Wave 10 of data collection to start at the end of 2023 in the 28 countries (27 countries in Europe plus Israel) where it is fielded, involving 140,000 respondents aged 50+. With generous funding by the European Union (EU), SHARE conducted two very productive COVID surveys by telephone to inform policy recommendations for future pandemics. As example, the data indicate that use of short-term employment aid has in the long run created higher unemployment. SHARE has also collected 120,000 retrospective life histories, and will be releasing in winter the final biomarker data from 23,000 dried blood spots collected in Seattle and Copenhagen from 23,000 participants. The SHARE HCAP substudy was completed in a subset of five countries immediately after Wave 9 with high cooperation rate (78-86 percent), and revealed strong age and education gradients in cognitive performance across countries. The design of HCAP wave 2, part of SHARE Wave 11, is expected to be finalized at a meeting at the end of October in Slovakia.

International coordination of SHARE has moved from Munich to Berlin. The SHARE European Research Infrastructure Consortium (SHARE-ERIC) in Munich continues to operate under a complex European-based legal framework, and oversees governance, strategic direction, and overall funding. SHARE Berlin Institute (nucleus for SHARE Central embedded in a collaboration of four leading German research institutions) is now responsible for the international coordination of the 28 country teams responsible for local data collection. Boersch-Supan serves as managing director of SHARE-ERIC, and Richter serves as the Director of the SHARE Berlin Institute.

Richter noted interest in pension linkages, and reported on plans for a new SHARE study on preventing or delaying onset of multimorbidity (a condition that affects over 30 percent of Europeans aged 50+), which will involve recruiting new samples in five EU countries of about 2,000 individuals per country, and inviting 80,000 SHARE participants to contribute saliva in 2026. A small subset of high-risk participants (about 800 per country) will be selected for an intervention, and this sample will be followed longitudinally with the other SHARE participants.

### **English Longitudinal Study on Ageing (ELSA)**

*Andrew Steptoe*

ELSA completed Wave 10 in 2023, after transitioning from Computer Assisted Video Interviews (CAVI) in late 2021 to face-to-face Computer Assisted Personal Interviews (CAPI) in 2022. The data (n=7,242) are expected to be deposited with the UK Data Service before end of 2023. Steptoe attributed the lower response rate in Wave 10 compared to previous waves to survey workforce issues. Half of the nurse-conducted health assessments were postponed until Wave 11. Wave 11 is due to be fielded September 2023-May 2024 and features a large refreshment sample (including ethnic minority boost), health visits (anthropometry, physical function tests, blood pressure, lung function), and venous blood samples.

ELSA and CHARLS have a joint accelerometry study involving cross-cohort comparisons of activity data, which is co-funded by the UK's Economic and Social Research Council (ESRC) and National Natural Science Foundation of China (NSFC). The CHARLS team employs an accelerometry device that has been validated with the device used by ELSA, at about half the per unit cost. ELSA HCAP Wave 1 was completed in 2018 and Wave 2 should be complete by the end of September 2023 with a target sample of 2,000 to include all living Wave 1 participants, an ethnic minority sample, and a random sample of ELSA participants aged 65+.

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

*Cathal McCrory*

The TILDA study has completed Wave 6 of data collection (with replenishment sample) in 2023 and is currently immersed in planning for Wave 7 (to be fielded in 2024), as well as planning for Waves 8 (2026-27) and 9 (2028).

The TILDA study design for Wave 6 included CAPI conducted in the home (which transitioned to CATI during the pandemic), a leave behind self-completion questionnaire (SCQ), and a health assessment completed at the TILDA health assessment center (or abridged version in participant's home). As part of its adaptation to the pandemic, TILDA administered a COVID-19 SCQ in June 2020 (71 percent response rate), collected SARS CoV2 saliva antibodies in January 2021 (68 percent response rate), and conducted a microbiome postal substudy in March 2021 (85 percent response rate).



Recruitment of the Wave 6 replenishment sample was slow initially due to the narrow age band (50-62), a dated sampling frame (registry of household addresses), the length of the survey (CAPI averaging two or more hours to complete), and negative perceptions associated with the concept of “ageing.” In response to these challenges, TILDA widened the age band to 45-64, reduced the length of the interview to 90 minutes, and updated the study branding to reflect a positive approach to aging (e.g., title refers to “Health and Life” instead of “Ageing”). The measures that were removed from the interview included some objective health measures that were time-consuming to collect (e.g., chair sit-to-stand test, walk test). These changes resulted in improved recruitment rates, similar to those in Wave 1.

### **Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA)**

*Bernadette McGuinness*

The NICOLA study completed Wave 2 in 2020, and Wave 3 is planned with a tentative start date of the end of 2023. Like TILDA, NICOLA includes a CAPI, SCQ, and health assessment (in Wave 1 and planned for Wave 3). A retinal imaging substudy can identify participants with early age-related macular degeneration. High resolution images are generated during the clinic-based health assessment with optical coherence tomography. NICOLA also collects blood and saliva for biomarkers and genotyping, and shares data with several genetics consortia. Wave 3 will include some additional content related to COVID and poverty.

NICOLA-HCAP just finished fieldwork involving 1,000 NICOLA participants aged 65+. NICOLA-HCAP participants were invited to wear accelerometers and GPS devices for one week as part of the Supportive environments for Physical and social Activity, healthy ageing and Cognitive health (SPACE) project, funded by the ESRC, which studies whether the environment in which people live influences brain health and vulnerability to cognitive impairment.

Data from NICOLA data has generated over 100 papers in scientific journals and contributed to multiple data repositories.

### **Healthy Ageing in Scotland (HAGIS)**

*Elaine Douglas*

The HAGIS study is undergoing preparations for Wave 1 of data collection. The HAGIS Covid Fear Study is a mixed-methods survey (online/telephone/postal) fielded from December 2020-November 2022, including harmonized measures from other HRS COVID protocols. The Wave 1 sample frame is being generated using administrative data from the Scotland 2022 Census and the National Health Service (NHS) general practitioner list to include households with at least one person aged 50+. The survey data will be linked with health records, including laboratory results and hospital information, prescriptions, and the 2022 Census. The HAGIS study intends to collect environmental pollution and climate data in Scotland as part of their dataset.

With funding by the ESRC, HAGIS hosted the British & Irish Longitudinal Studies (BILS) Conference in November 2022.

## General Discussion

At any given time, some countries can be restricted from receiving U.S. government funding through the NIA (e.g., Russia, Cuba, Iran, and North Korea). Chatterji can provide guidance as needed. She noted that some studies, such as the Caribbean American Dementia and Aging (CADA) Study, involve multiple countries and are funded by other agencies to support work in U.S.-restricted countries.

In response to a question about how U.S. investigators might be able to access administrative data linkages in HAGIS, Douglas replied that agreements are in place and that Research Data Scotland (created by the Scottish government) and the NHS are supporting this work. She will investigate how outside researchers will be able to use the linked data. Weir noted that sharing restricted data would be a good topic for future discussion.

**Jonathan W. King** asked how the General Data Protection Regulations (GDPR) in the EU affected TILDA data collection. **Rose Anne Kenny** replied that GDPR is interpreted differently in different countries. TILDA has an agreement until 2029 that they will have joint control of their data with the Irish Central Statistics Office (CSO). The CSO archives the TILDA data, and TILDA also has independent archiving control. TILDA will work with the Gateway to Global Aging site and the University of Michigan to archive data.

Boersch-Supan noted that it would be helpful for NIA to meet with the EU Directorate-General for Research and Innovation (DG RTD) in Brussels, to discuss these issues. GDPR makes it difficult to store participant addresses, which makes it very difficult to do longitudinal surveys. GDPR also makes cross-Atlantic cooperation very challenging, such as shipping biological materials between labs in Seattle and Germany. King said that Mike Lauer (director of the NIH Office of Extramural Research) is aware of these issues and agreed that more dialogue is needed. He requested that SHARE send any potential contacts for the DG RTD office. Kenny agreed that the value from these studies have not been publicized well enough at a political level in Europe. It would be helpful to think as a group about how to engage policymakers about the value of this research. Boersch-Supan acknowledged the mandate to harmonize, and clarified that the intervention study in SHARE is a side project with a new sample that will be followed up with the rest of the SHARE study. Weir commented that interventions are an important topic for future discussion.

**Carlos Mendes de Leon** commented that the question of framing these studies to recruit participants warrants broader discussion. He wondered how to make the surveys more enjoyable for participants to take. Kenny emphasized the importance of presenting health and living rather than aging, and removing more objective health measures that were time consuming to collect. Weir highlighted the importance of Gateway in creating harmonized measures. The HRS ATW studies are encouraged to compare their measures with the current list in Gateway. **Jinkook Lee** offered to share a spreadsheet with all the current harmonized measures.

## Study Updates: Asia

### China Health and Retirement Longitudinal Study (CHARLS)

*Yaohui Zhao*

CHARLS is currently collecting Wave 5 data, which has been in process since 2021. COVID restrictions in China ended at the start of 2023, and data collection has improved since then. CHARLS includes an individual survey, non-blood biomarkers (e.g., height, weight, blood pressure, balance), and blood sample collection. It typically features sample sizes of around 20,000 respondents. CHARLS-HCAP was fielded in 2018, but the data are currently being reviewed (with help from Alden Gross) to detect and correct biases due to illiteracy, dialects, and sensory function loss. The next CHARLS wave is planned for 2025 and will include a re-survey of CHARLS-HCAP, with adjustments to preempt issues found in the previous wave. Zhao recommended that the HRS ATW studies work on a harmonized measure of sensory loss. CHARLS data have been widely used, with over 5,200 users outside of China, and close to 2,000 publications in English.

Zhao indicated that CHARLS is not currently planning to collect saliva to test antibodies, but it might be possible to do so as the study is collecting tongue coating samples. Steptoe observed that Chinese participants exhibit different physical activity patterns compared to study participants in the United States or Europe. Zhao reported that CHARLS is adding more participants and have had to design ways to incentivize participants to wear the accelerometer. Many Chinese participants are not accustomed to wearing a watch, so the CHARLS team must ascertain that the device is being worn appropriately.

### Longitudinal Ageing Study in India (LASI)

*T.V. Sekher*

LASI is co-funded by the Ministry of Health of India and NIA. LASI covers four major topic areas: (1) health, including disease burden and risk factors; (2) health care and health financing; (3) family and social networks, and welfare programs; and (4) economic factors. LASI is fielded in 35 states and 18 regional languages, and the sample includes adults aged 45 and older. Wave 1 was fielded in 2017-2019 (n=73,396 individuals aged 45+, including 31,902 persons aged 60+, interviewed), and data were released in January 2021. Wave 1 included household, individual, and community surveys and biomarker collection (functional and physical measurements and dried blood spots).

LASI Wave 2 will begin in two phases starting December 2023. It will include new age eligible respondents from Wave 1 households and will not add new households. Wave 2 will include modified questionnaires from Wave 1 and a COVID-19 module; survey instruments will be translated into 18 regional languages. The LASI Diagnostic Assessment of Dementia (LASI-DAD) substudy, which is led by Lee, is part of the HCAP network of studies and is currently in Wave 2 of data collection.

In response to questions, Sekher clarified that any adult member over age 18 can answer the household questionnaire, and can ask other members of the household for help. In Wave 2, the household income module was simplified due to participants' reluctance to answer those questions. The team also shortened the time for experimental modules due to the length of time the interviews require. The community module will not be used in Wave 2 due to the lack of changes expected since Wave 1, but it may be used again in future waves.

### **Japanese Study of Aging and Retirement (JSTAR)**

*Haruko Noguchi*

Noguchi shared the passing in 2020 of Dr. Masaru Yoshitomi, former president of the Research Institute of Economy Trade and Industry (RIETI), and champion of JSTAR since 2005.

JSTAR completed Wave 5 in 2018 and includes 10 participating municipalities. Participants were randomly selected from local prefecture registration records of adults over age 65. The JSTAR team has observed higher attrition rates in the first and second waves of data collection for each municipality. The primary cause of attrition was attributed to household-related issues; a large number withdrew for unknown reasons. The advancing age of JSTAR participants makes it critical to understand the precise reasons for withdrawal from the study. Data through 2013 (four waves) are publicly available, and the 2016 data should be available by 2024. The 2018 wave, which includes a postal life-history survey, is currently undergoing data preparation. Funding for additional waves and data preparation has been difficult to secure, but a post-COVID survey has been funded for either 2024 or 2025 (PI: Yasuyuki Sawada). The data archive needs to be moved from its current location at the RIETI to another location due to both the limited capacity of the current archive center at RIETI and the mandated retirement of the current PI, Hidehiko Ichimura (moving to the University of Arizona). Hideki Hashimoto or Sawada (both at the University of Tokyo) will serve as co-PI.

Noguchi indicated that the Japanese government is now interested in population-based data and is pursuing its own sample. There are therefore no plans to continue the JSTAR longitudinal sample in Japan.

### **Malaysia Ageing and Retirement Survey (MARS)**

*Norma Mansor*

MARS recently completed Wave 2 in October 2020-April 2022. The study includes respondents 40 years and older who live in the Malaysia Peninsula and East Malaysia. Wave 1 used similar measures to the US HRS, and Wave 2 added a financial literacy questionnaire and a module on COVID-19. MARS had challenges with retaining interviewers, gaining trust with respondents and their family members (especially with questions related to income), language barriers, and movement restrictions due to the COVID-19 pandemic. There were also challenges reaching some respondents due to wrong addresses or remote locations. The team found that building trust with participants in Wave 1 carried over to Wave 2 and made the follow up interviews easier. The MARS team incorporated several processes to improve fieldwork, including sending interviewers in teams of three to five people, matching interviewers to respondents in

background, monitoring the fieldwork in real-time, promoting MARS project through various local media, and continuously recruiting interviewers. A harmonized data set from Wave 1 is available on the Gateway to Global Aging website.

Chatterji asked about the response rates for Wave 1 by ethnic groups and whether the MARS team were able to recruit leaders in the ethnic Chinese community to increase response rate by this group in particular. Mansor replied that the national census was used as the sampling frame, and recruitment of new respondents is underway to supplement the ethnic Chinese sample for Wave 2. Chatterji also asked about how the team acquired data on income when participants were reluctant to answer those questions. **Halimah Awang** replied that questions ask about income ranges instead of specific values for income. Most respondents were self-employed without regular income. About 40 percent of participants were dependent on the government social assistance. Mansor added that they are seeking funding from NIA to conduct the HCAP study on a subsample.

### **Health, Aging, and Retirement in Thailand (HART)**

*Dararatt Anantanasuwong*

The HART study completed Wave 5 in 2023. HART is primarily funded through a grant from the National Research Council of Thailand (NRCT). HART includes one participant per household over age 45, selected from 13 provinces. Wave 1 and 2 datasets are available on the Gateway to Global Aging Data. The HART team does not have access to public health or medical PIs which limits their ability to add an HCAP study. The funding agencies in Thailand are currently more interested in actionable aging research, such as how to implement a long-term care system, and less interested in observational data collection. Starting in Wave 2, HART transitioned to using CAPI in the face-to-face interview. Funding constraints restrict the ability of the HART team to add new measures or update survey content.

Kenny highlighted the importance of securing continuous funding for multiple waves of data collection, especially in countries where longitudinal survey research is new. Anantanasuwong noted the challenge in helping the funding agencies understand the need to collect these data and in connecting researchers with the government agencies who use the data. Many agencies do not want to share data.

Boersch-Supan observed that the EU created a research infrastructure but left the funding and implementation to the individual nation states, which are often opposed to long-term financial commitments to the EU. This model has not worked well. He highlighted the importance of this type of data infrastructure for social science research, especially related to public health. Steptoe agreed that continuous funding for longitudinal studies is challenging; in the UK, it is difficult to get funding for more than 2 years at a time. Matching the project timeline with the funding timeline can be difficult.

The true value of longitudinal studies is not always obvious. King noted that prevalence estimates of diseases can be done with a cross-sectional study at lower cost. However, understanding how the processes of aging change over time needs longitudinal data. For

example, HRS found that a particular biomarker, neurofilament light (NfL), measured in 2016 predicted mortality in 2020, and that kind of finding is only possible with longitudinal data. Weir emphasized that all studies should spend some time thinking about what potential study additions would be helpful if a funding opportunity becomes available, even if the money is not currently available.

## **Studying the Effects of COVID-19**

### **COVID Tracking in the Understanding America Study (UAS)**

*Arie Kapteyn*

UAS began tracking pandemic effects on March 10, 2020 as part of biweekly UAS surveys. The biweekly cadence continued through June 2021, and since then the frequency was reduced to once every 4 months. The data were available for public download every 2 weeks, and approximately 150 publications have used UAS COVID-19 data to date.

The UAS team has used these data for several research questions related to COVID. The UAS percentage vaccinated by date aligns well with data reported by CDC and the Axios Knowledge Panel. Among UAS respondents with jobs where working from home is technically possible, the preference to work from increased between Summer 2021 and Spring 2022. The accuracy of self-reported COVID infections was validated with data from the subsample of participants who have a Fitbit, a wearable device able to detect physical symptoms associated with COVID-19 infection (e.g., higher resting heart rate, worse sleep). The UAS team also studied perceived stress, depression, and anxiety and found that younger participants (under 40 years old) reported higher rates of psychological distress than older participants (aged 65+), perhaps because of differences in economic security between the age groups.

The UAS panel incorporates periodic ecological momentary assessments (EMAs), typically consisting of six prompts a day for 7 days. EMA bursts occurred over 4 weeks in 2020. Questions about social interactions captured significant differences at different points in the pandemic; the probability of being alone (as opposed to with a partner, family, and/or friends) increased between wave 1 and 4.

When looking at the impact of extended unemployment benefits, UAS respondents who lost their jobs and were eligible for unemployment benefits reported significantly higher wellbeing than those who were not eligible for unemployment benefits. There was also a striking correspondence between self-reported long COVID and associated symptoms, and differences in protective behavior depending on political affiliation.

Weir asked whether the work identifying the biomarker signatures of COVID could be applied to other diseases. Kapteyn replied that Ritika Chaturvedi, who is the PI for the UAS accelerometry project, is studying the use of Fitbit signals to detect illnesses. Validating the biometric data is important, and the next step is to detect a signal and then validate the finding by asking participants how they are feeling. Kenny wondered whether there were biomarkers

that might predict falls. Kapteyn agreed that this might be possible, and the UAS team has submitted a proposal to increase the number of participants in the accelerometry study to research more topics like this.

### **COVID-19: The NICOLA Perspective**

*Charlotte Neville*

The NICOLA team had just finished Wave 2 of data collection (2017-2020) when the pandemic began. ELSA and TILDA began collecting COVID data in 2021, and NICOLA had the opportunity to align data collection with these partner studies to examine the impact of the COVID pandemic on the health and wellbeing of older adults. The NICOLA team mailed a COVID questionnaire to NICOLA participants that included questions on health, health care, employment, social connectivity, and finances.

Participants reported increased social isolation during the pandemic. Self-perceived lack of relational and social connections was higher among females than males, among those aged 50-64 than older, and among single participants than those who were married or partnered. Religions is a key source of connectivity, and 44% of participants engaged with online religious activity. More participants reported feeling lonely some of the time or often during the pandemic than pre-COVID, and symptoms of depression more than doubled during COVID.

Participants also reported significant changes in lifestyle behaviors, including less physical activity; more sedentary time; and half of older adults started a health supplement (such as Vitamin D). The economic impact of the pandemic was worse for people who reported that they were “just about getting by” before the pandemic began than for people who were doing well financially before the pandemic.

Wave 3 of the main NICOLA survey expects to include post-COVID questions. NICOLA, along with 19 other studies, belong to the UK Longitudinal Linkage Collaboration, which was established to study the UK’s response to the COVID-19 pandemic. Several of these projects relate to long COVID, including one that aims to retrospectively identify patterns of symptoms of COVID-19 that also occur with long COVID. These projects highlight the importance of harmonizing measures across studies to capture impacts from events like the pandemic. The long-term effects of COVID are still uncertain, and longitudinal research is important to understand how these effects play out after the pandemic is over.

Boersch-Supan noted that early retirement increased in continental Europe during COVID. In response to questions, Neville confirmed that the NICOLA questionnaire in 2021 retrospectively captured participants’ general experiences during COVID, and Frank Kee indicated that the study is using machine learning to combine questionnaire data with clinical encounter data, which might pick up indications of mood changes in the long COVID study.

## **The Impact of COVID – China**

*Yaohui Zhao*

China had three phases of the pandemic: (1) early 2020, when the Wuhan outbreak was quickly contained; (2) mid-2020 to late 2022, the Zero COVID policy; and (3) late 2022, the end of the Zero COVID policy. Before the end of the Zero COVID policy, the impact of the COVID-19 pandemic in China was mostly related to the quarantine policies and not COVID infection. After the end of 2022, the impact of COVID in China was mostly related to COVID infection. The World Health Organization (WHO) reports 99,238.850 confirmed cases of COVID-19 with 120,896 deaths during the period January 3, 2020 to September 13, 2023. It also reports a total of 3,516,880,717 vaccine doses administered. <https://covid19.who.int/region/wpro/country/cn>

CHARLS fielded two COVID survey waves, one in 2020 and one in 2021-2023, with all interviews conducted in July-August. The first COVID survey asked about individual experiences with infection, death, and quarantine and community experiences with quarantine. The second survey asked about vaccine status in each year (2021, 2022, 2023); individual quarantine experiences (2022, 2023); and community quarantine experiences, confirmed infection or symptoms of infection, and death (2023). Data on infections confirmed through testing were accurate through the large spike in cases at the end of 2022 but may be inaccurate afterwards in 2023 due to reduced testing requirements.

The CHARLS team is creating a model to map reported symptoms to confirmed test results, which may be useful to determine how widespread COVID infections were when testing was no longer common. The questionnaire also asked about experiences with long COVID, and 39.5 percent of participants reported at least one COVID-related symptom in July-August 2023.

Women, older adults, unmarried or widowed adults, and those with chronic diseases were less likely to receive COVID-19 vaccinations. Those who live in urban areas or who were functionally dependent were also less likely to receive COVID-19 vaccinations. Low vaccination rates among older and people with health issues are partly due to vaccine clinics refusing to vaccinate older people with potentially life-threatening conditions. The next research question that the CHARLS team will address is the relationship between fear and anxiety of COVID (which were asked in all years, 2020-2023) and other health outcomes. The team will use the 2018 and 2020 wave data as baseline to study questions related to the effects of quarantine and infection on CHARLS participants.

## **Effects of COVID-19 using the Mexican Health and Aging Study (MHAS) Cohort**

*Rebeca Wong*

The MHAS team did not conduct a special COVID survey but compared their post-pandemic survey data (Wave 6, conducted in late 2021) with the pre-pandemic MHAS data from Waves 3-5. For those who were still alive in Wave 6, the MHAS team examined mental health outcomes. The MHAS team also asked whether participants had a confirmed infection between March 2020 and the survey or experienced a major event (e.g., lost a child or spouse, cared for a sick



person, had a financial setback). Few participants experienced both a COVID infection and major event; 78 percent were neither infected nor experienced a major event.

Among participants over age 50, the mental health outcome variables (loneliness, depressive symptoms, life dissatisfaction, and foregone health care) showed flat or slightly declining trends across Waves 3 to 6. Participants who experienced a major life event were more likely to have negative mental health outcomes across all four outcome variables than those who did not, but participants who reported a COVID infection only had slight increases in the likelihood of reporting depressive symptoms. Subgroup analysis showed differential effects among age groups and by sex. Future research will investigate potential survival selection bias and longer-term impacts of the pandemic to identify resilient and vulnerable groups of participants.

There were approximately 50 percent more deaths in MHAS participants between 2018 and 2021 than in previous inter-wave periods, and a higher percentage of these deaths were due to health reasons. Excess deaths were higher in absolute numbers among participants over age 70 but higher in relative numbers among participants aged 50-59. Wong raised the question of sample refreshment and wondered whether studies should refresh the younger cohort, as is normally done, or whether they should also add participants to the older cohorts due to the higher loss of participants from COVID.

MHAS can complete a wave in 8-10 weeks because it partners with the Statistical Bureau of Mexico, which has permanent infrastructure in place across Mexico to collect data on a continual basis.

## **Pollution**

### **Environmental Exposome in the Gateway to Global Aging Data**

*Jinkook Lee*

Sara Adar is leading the Gateway to Global Aging Data's initiative to add contextual information to understand environmental risk factors of dementia and cognitive health. The goal is to provide science-ready, harmonized data to link with study participants based on location; to develop a data masking strategy that optimizes data integrity while protecting participant privacy; and to create statistical guidance on using these data. The process for adding exposome data to the Gateway includes data generation, quality assurance and checks, data transfer, and documentation.

The Gateway includes harmonized PM<sub>2.5</sub> data from 2000-2019 at a resolution of 1km<sup>2</sup>, PM<sub>2.5</sub> source data from 2017, outdoor NO<sub>2</sub> data from 2005-2020, and outdoor ozone estimation from 1990-2017. Data are currently available for the United States, Ireland, Northern Ireland, England, Mexico, and Chile, and there are population-weighted descriptive statistics available for these datasets. HRS, LASI, TILDA, and NICOLA have successfully linked cohorts with exposome measures. The Gateway is in the process of geocoding the data for ELSA, MHAS, and Chile-Cog.

The website is currently under development and will include documentation on the data and sample methods. The Gateway team are working on adding physical environment and climate data. It appears that these data are more available in high-income countries than in low-income countries; the Gateway team is trying to create AI models to capture the physical environment to compensate. The LASI team has also started using mobile devices to measure indoor pollution levels during fieldwork.

The Gateway team is also working on developing methods to use these data, including geomasking and spatial confounding to assess the impacts of different methods on statistical inference and participant privacy.

McCrary asked whether the LASI team had considered using bracelets for indoor air pollution monitoring. Lee replied that they have looked at different options. Because some of the rural areas of India do not have connectivity, they must use monitors that do not require GPS or external connectivity to work. The UPAS monitors have filters that capture pollutants that can be analyzed later.

King highlighted the sensitivity of geographic data and praised the approach of the Gateway team to ensure participant privacy. Lee confirmed that the Gateway team has tried identifiability exercises to test the privacy settings.

### **Update on Air Pollution Work in ELSA**

*Andrew Steptoe*

The ELSA team is collaborating with Gateway to expand the collection of natural and physical environmental exposures as risk factors of cognitive impairment and dementia. The environmental data includes total PM<sub>2.5</sub>, PM<sub>2.5</sub> source data, NO<sub>2</sub>, O<sub>3</sub>, nighttime light pollution, access to green and blue space, and hourly temperature and precipitation data. The addresses of ELSA participants are being geocoded, and those coordinates will be used when linking the pollution data to the ELSA survey data.

One research paper using these data examined the relationship between exposure to PM<sub>2.5</sub> and NO<sub>2</sub> pollution and hospitalization or asthma diagnosis among ELSA participants. The researchers found that there was a supra-linear association between PM<sub>2.5</sub> exposure and hospital admission. A second paper evaluated the associations between long-term exposure to PM<sub>2.5</sub> and NO<sub>2</sub> and cognitive functioning in ELSA-HCAP participants. Higher levels of long-term exposure to NO<sub>2</sub> were associated with poorer executive functioning and an increased risk of cognitive impairment or dementia, even after adjusting for known confounding factors. PM<sub>2.5</sub> exposure was associated with poorer executive functioning only.

In response to questions, Steptoe clarified that these studies only used overall measures of air pollution, and did not distinguish indoor air pollution. Wong wondered whether controlling for indoor air pollution would still show an effect from outdoor air pollution. Lee shared that she has found a stronger effect of indoor air pollution compared to outdoor air pollution but only in an LMIC setting. This effect may not be evident in a higher income country like ELSA.

Steptoe considered it very likely that pollution exposure might be related to occupation, but the ELSA team has not yet been able to examine the differences between working and non-working participants or occupational history. Kapteyn reported that when the UAS team outfitted participants with a wearable air quality monitor, they found that air quality at home was worse than anywhere else and that air quality at home was related to air quality at work. Steptoe added that the ELSA team did control for area of deprivation. Weir noted that the 1km<sup>2</sup> resolution of the air pollution datasets could predict home air quality well enough, but it also might vary widely in some areas. The UAS dataset could give more information on the quality of the air pollution data; Kapteyn added that Jennifer Ailshire is comparing the indoor monitor data to EPA ground monitors.

King cautioned that the nonlinear relationship found in the paper looking at the associations of air pollution and hospitalization might draw criticism from reviewers and would need to be explained. Kenny suggested that if the ELSA team has life history data with addresses, they could track exposure over the life course. Steptoe replied that ELSA does not have accurate pollution data before 1990. Weir noted that pollution is highly correlated with other variables like socioeconomic status. One advantage that the HRS ATW studies have when studying the impact of pollution on health is that these studies understand the sample composition over time, unlike a cross-sectional approach.

### **SPACE: The Impact of Place on Cognitive Health**

*Ruth Hunter*

The goal of NICOLA's SPACE project is to investigate the impacts, and possible mechanistic pathways, of urban environments on cognitive health. The SPACE project integrates environmental exposures, lifestyle behaviors, and multi-omics. The SPACE team is an interdisciplinary group that includes experts on aging, urban design and planning, geography, and molecular epidemiology. They have adopted a systems science approach that features a detailed causal loop diagram to capture the cause and effects of environmental and physical factors on mild cognitive impairment (MCI) and dementia. This diagram informed a literature review to understand where the knowledge gaps are.

The SPACE team is also linking spatial environmental data to NICOLA and NICOLA-HCAP survey data to investigate the contributions of urban environments and lifestyle behaviors (and related environmental exposures) to cognitive health. The urban environment data include variables related to densification, land use, pollution, and soil geochemistry. The SPACE team has also included climate change data that includes information on climate hazards (e.g., flooding and wildfires). The team is also building machine learning models of satellite imagery data to identify high quality, publicly accessible green spaces. As part of NICOLA-HCAP, some participants wore GPS and accelerometry devices for a 7-day period, which provides the ability to measure environmental exposures through space and time. Most of these data sources will be available soon on the SPACE geoportal website in easily accessible formats.

The SPACE team is also working to disseminate the data and information on these topics to various policy and practice partners through white papers, workshops, and fact sheets.

In response to questions, Hunter confirmed that the environmental data would be linked longitudinally. **Mauricio Avendano** asked about the timescale of environmental changes and noted that changes in urban space often take a long time to occur. Hunter agreed and mentioned that the Gateway team is considering how meaningful change should be defined in the context of environmental exposure datasets. King highlighted the data pipelines that SPACE is developing and encouraged the team to share their best practices for working with these data. Lee noted that the Gateway team plans to add best practices to its website.

## **Study Updates: Americas**

### **U.S. Health and Retirement Study (HRS)**

*David Weir*

HRS completed HRS 2022 (Wave 16) and is planning for HRS 2024 (Wave 17). The COVID pandemic greatly impacted HRS 2020 (Wave 15), which had just started fieldwork before the pandemic began in 2020. During COVID, no in-person contact was allowed, HCAP and whole blood draws were completely deferred to 2022, enhanced face-to-face (EFTF) interviews were converted to phone. Although some content (e.g., blood pressure) was lost, the study realized cost savings. COVID content was added to the 2020 and 2022 core surveys, and a COVID-focused mail survey was sent to most of the sample in 2021. COVID-related data collection activities also included antibody testing using mailed self-administered Orasure kits.

HRS recently submitted a renewal proposal to NIA for years 35-40 of the study (covering 2024-2029) that unifies HRS and HCAP into a single project. The HRS team has experts in several areas (e.g., data collection, biomarkers, cognition) and can be a resource for both new and established studies in the HRS ATW network. The HRS team is greatly expanding the number of contextual data linkages available to the HRS survey data. For the renewal, the HRS team plans to maintain the longitudinal design and innovate aggressively to improve response rates. Each 6-year grant cycle has roughly doubled the number of previous cycle's publications. Areas of innovation include biomarkers, linkages to administrative and contextual data, and sampling and fieldwork.

Response rates for HRS started declining around 2014 across all racial and ethnic groups, and the current response rate takes increasing effort to maintain. The interview length and difficulty has not increased, and 80 percent of the content has remained stable over time. HRS is focusing attention on recruiting and retaining interviewers. Currently, fewer than one out of four survive the field period. Data quality is higher with experienced interviewers, but it is difficult to retain them with the current interview schedule characterized by long gaps between waves. Solving this requires either changing the interview process to provide full-time work for interviewers or partnering with other studies or organizations to hire interviewers. Both approaches will be more expensive than the conventional approach of employing part-time labor. Weir has considered moving the recruitment phase to a continuous refreshment model, but recognize challenges of hiring interviewers everywhere participants live, especially those in rural areas.

## **U.S. Understanding America Study (UAS)**

*Arie Kapteyn*

UAS is a nationally representative sample of the United States (n=13,000 panel members) and includes an oversample of California and Los Angeles County residents. UAS fields 17 core surveys every 2 years but also includes frequent experiments to improve response, recruiting, and retention rates. The core surveys include surveys on Social Security usage, financial services and wellbeing, the HRS core measures, and cognitive assessments. The UAS team collects additional data sources from participants, including Atmotube wearable air quality monitors, digital biomarkers using Fitbits, and EMAs.

UAS has just been renewed for 5 years and intends to grow its panel to a sample size of closer to 23,000. The aim of the renewal is to investigate the causes of differences in life courses and how these differences culminate in observed inequality. The team supports a broad data collection program, and plans to add a wealth of contextual data. It has been funded with the University of Michigan to provide Fitbits to caregivers. It hopes to genotype the panel, provide Fitbits to 10,000 panel members, and has started experiments with avatars and ChatGPT. The UAS team continues to innovate on ways to engage respondents. For example, acting on a suggestion provided by the NIA Data Monitoring Committee, the UAS team is working on a way to appropriately provide feedback to participants about study findings. Kenny also suggested collecting data on creativity.

## **Mexican Health and Aging Study (MHAS)**

*Emma Aguila*

MHAS celebrated 20 years of longitudinal data across all six waves, interviewing about 15,000 respondents each wave. MHAS completed Wave 6 in 2021 and released it for public use in July 2023. MHAS data have been used in many cross-national comparison studies, appearing in over 385 publications. The sample cohort is growing older over time, which reflects the aging population in Mexico.

MHAS data has been used to study the prevalence of health conditions such as obesity and diabetes in Mexico. The long, 20-year follow up also allows for studying the effects of structural reforms and policy changes Mexico. MHAS has collected venous blood, saliva, and hair samples. Two waves of HCAP data (Mex-Cog) have also been collected and are publicly available. The MHAS team has linked several contextual and administrative sources to the survey data. MHAS Wave 7 (for 2024) and 8 (for 2027) are currently being planned, with new survey content proposed on perceived discrimination, telehealth, languages used, and long COVID. Mex-Cog Wave 3 (for 2025) is also in the planning phase.

King asked about the new survey content on language use and noted that there is strong interest in the role of bilingualism in AD. Wong clarified that the interviews will be conducted in Spanish but will ask about use of other languages (including indigenous languages). This content has been added due to relevance to the HCAP measures. Aguila added that there are 76

indigenous languages in Mexico, and it would be too difficult to translate the survey into so many languages.

In response to a question about how administrative data are linked to survey respondents, Wong explained that Mexico does not have a national identification number, so participants cannot be linked to census records or the equivalent of a National Death Index record. Most linkages are at the community level, and the MHAS data are linked with community- and not individual-level data. There is complete coverage at the community level. Lee suggested that the LASI and MHAS teams could collaborate on the multilingualism project.

Boersch-Supan asked how many participants were lost due to not speaking Spanish. Wong said that according to census records, about 5 percent of the population does not speak Spanish. If the participant does not speak Spanish, then a proxy is interviewed, and the reason for the proxy is noted. In Wave 1, the team tried translating the survey in real time, but it was not feasible for a long survey. Aguila added that older adults have different levels of fluency in Spanish and their indigenous languages, but their children mostly speak Spanish.

## **Study Updates: Africa**

### **Health and Aging in Africa: A Longitudinal Study in South Africa (HAALSI)**

David Canning

HAALSI currently fields a study in Agincourt, which is a community of 100,000 people near Mozambique. This study collected three waves of core survey data and two waves of HCAP data. The HAALSI team is planning on moving to a nationally representative survey, starting with a pilot in 2025 (about 480 total respondents) and then the full national survey in 2026 (about 4,500 + spouses, 7,200 total). The team is partnering with the South African Population Research Infrastructure Network (SAPRIN) to collect survey data from a smaller comparison group through the SAPRIN surveillance infrastructure. Kick off meetings will be held in South Africa February 4-9, 2024.

Although the Agincourt sample is not nationally representative of South Africa, it provides important information and lessons for a national survey in South Africa. The goals of the HAALSI national survey are to (1) recruit participants and collect Wave 1 of data; (2) estimate the prevalence of cognitive impairment and investigate the variations in cognitive ability by SES in South Africa; and (3) study the generalizability of the findings from the Agincourt community to the national population.

The sample will include adults over age 40, oversampling adults over age 60, and their partners. A subsample (expected N=624) will be recruited for the HCAP study, including all those with suspected dementia or MCI and a random sample of those with normal cognitive function. The community level survey will link data from local leaders, administrative data, and satellite or map data. The household level survey has been developed in the Agincourt sample. The HAALSI team is partnering with the National Income Dynamics Study (NIDS) to field the national survey, and the teams need to harmonize some measures, such as definitions of household members.

The HAALSI team is working with the South African government on some of the individual survey topics, including health care utilization, mental health, and COVID. They will also collect some biomarkers and physical measures. The national survey will be fielded in 11 languages.

The HAALSI team expects an 80% response rate, based on the experience of NIDS. Refusal rates for blood testing can be high (>30%), and so the team is concerned about response rates and the impact on data quality. The comparison sample in the SAPRIN clusters, which will be able to have more intense follow up through the SAPRIN team for people who initially refuse to participate, will help the team assess bias in missingness. They will also test the impact of different gifts on response rates.

The Agincourt survey has some additional content added for the next wave, including a social network module, additional biomarkers, and randomized trials of participation incentives. The Agincourt survey sample was randomly selected from the Agincourt community, so the HAALSI team is also studying the impact of being a participant in an aging study on health. The HAALSI team will use the Agincourt data together with the national survey data to test the generalizability of the data.

There is a high degree of mistrust in South Africa. The SAPRIN sites have already built trust with their communities. The HAALSI team recognizes that it too will need to build trust with the population through outreach and branding. There is concern that any negative publicity about the study could lead to high refusal rates. White communities can be more challenging to reach.

Chatterji asked about the surveillance sites and how the study team plans to handle refusals for blood spot collection. Canning explained that the demographic surveillance sites (SAPRIN) are an in-depth network in Africa and Asia that perform complete enumeration of their area. People who move out of the area are lost to follow up. These areas often have several randomized controlled trials happening due to the infrastructure in place for testing, but it is a different model from a nationally representative survey such as HRS. Linking the two models could provide important data. The sample in the SAPRIN clusters will have more follow ups due to the ongoing census enumeration. Those who refuse to give blood will have the opportunity to rejoin the study later. The national pilot will give the team important information on how to encourage responses. King emphasized the importance of appropriate stratification for the HCAP sample.

## **Life Histories**

### **Collecting Life History Information in ELSA: Plans for a Revised Life History Module**

*Andrew Steptoe*

ELSA first fielded a life history questionnaire (LHQ) in 2007, which had a response rate of about 85% (7,049 achieved interviews with core members). The LHQ 2007 comprised a FTF interview of about 50 minutes plus paper SCQ, and asked about childhood and experiences before a

participant joined the survey. The ELSA team used a computerized event history calendar as a recall aid. The LHQ 2007 data have informed research in a range of areas, including premature mortality risk, personality and depression, cognitive function, memory impairment, risk of hysterectomy, and hair cortisol concentration.

ELSA will field a second LHQ in 2023-2024 to interview study members who joined ELSA after 2007; they comprise around 4,000 participants (44 percent of the cohort), 75 percent aged 50-70 years. The new survey will use a mixed-mode sequential design involving web and telephone, repeat measures collected in LHQ 2007 (e.g., about children, partnerships, residences, work, and health histories, and difficult events over the life course), and add new measures adapted from other prominent studies (e.g., HRS, SHARE, PSID, NCDS) such as those associated with cognitive function, Alzheimer's disease and other dementias, as well as new questions on parental history (country of origin) and family health in childhood, health behaviors, early educational experiences, cognitive stimulation, social support, provision of care over the life course, and stressful events from childhood and adulthood. The event history calendar from 2007 likely cannot be reused but seemed to help recall, so the team is working on a replacement. The goal is to administer the LHQ at the end of the current wave of data collection (Wave 11), and limit the interview length to about 60 minutes.

In response to questions, Steptoe replied that the LHQ is a separate, freestanding module that can be done online at the end of data collection for the core survey, and that ELSA will assess cognitively stimulating activities in early adulthood based on jobs held at different timepoints. King also noted that some genetics studies identify country of origin for all four grandparents, not just parents. He added that the event history calendar was compelling as a memory aid.

Wong asked what questions studies should prioritize if it were possible to add only 5 minutes of survey time. Steptoe advised that adverse childhood experiences would be important to ask, and also midlife experiences, including exercise and social connections. It might be worth making a hierarchy of questions to ask. Steptoe also indicated that ELSA intends to capture positive childhood experiences and relationships with siblings, parents, and others.

### **HRS Life History Mail Survey (LHMS)**

*David Weir*

The HRS team did not have the resources to devote to a standalone interview to collect life history content, so they opted for a self-administered Life History Mail Survey (LHMS). It included retrospective questions about experiences and grids for residential, education, and job histories, and was designed to harmonize with ELSA and SHARE. The LHMS was initially fielded in 2015 and 2017, with nonresponders followed up in 2019 and 2023. The overall response rate was 63.1 percent. The youngest cohort had the lowest response rate (41.4 percent) but has not had much follow up yet for nonresponders. The questionnaire data are publicly available, but the residential, education, and job data are not. There is ongoing work to clean the address and name data and link them to historical contextual data.



In response to questions, Weir confirmed that the LHMS is still pencil and paper, but the HRS team is in the process of developing a web alternative. He estimated that the survey takes approximately an hour to complete. Steptoe commented that ELSA is concerned about data quality for participants' financial histories. Weir said that HRS has a linkage with Social Security data, so earnings can be matched over time. He would be concerned about the accuracy of self-reported earnings data.

Weir also indicated that it would be worth discussing metrics for evaluating the quality of residential data. The team can examine missing data, whether part of a particular address or there are gaps in history. They have not yet evaluated percent of lifetime covered by a correct address. Social Security data does not have residential information. Steptoe noted that ELSA does not know the accuracy of its life histories. Although the HRS team can compare job history data with Social Security data, the Social Security data are sometimes incomplete. HRS cannot link data to credit bureaus (which would likely have the correct data) due to privacy concerns.

### **SHARE Life Histories in Waves 3 and 7**

*Axel Boersch-Supan*

The SHARE team collected life histories (SHARELIFE) in Waves 3 and 7, about a decade apart. The Wave 7 SHARELIFE was conducted in 2017 for all new participants and new country cohorts that were added. If a third SHARELIFE were to be administered, Boersch-Supan would propose keeping to approximately a 10-year interval, as part of Wave 12 (in 2027). The SHARE team is interested in the influence of policy on life course trajectories, to take advantage of the policy variations that exist between the countries that participate in SHARE. SHARELIFE allows the linking of individual decisions to institutional background variables. The SPLASH project collects data on institutional context to ease cross-country evaluation of welfare state policies.

The SHARE team designed the survey questions to help with recall. The questions were ordered deliberately, and "landmark" events were used to help with anchoring (such as the job a participant held at the time they were married). Some of the data, such as year of first job or retirement can be validated through administrative records (e.g., German pension system).

Boersch-Supan recommends that new studies start with the life history survey because it can help with recruitment and retention. Participants like the questions in the life history survey better than the core survey questions, and interviewers find them easier to administer. The SHARE team found it easier to do as a standalone survey than alongside a core survey due to the length. The question about the number of books that a participant's parents had in the house was surprisingly powerful due to its association with other variables of interest. In the future, Boersch-Supan would add more questions on migration – not just country of origin but also the experience.

Boersch-Supan acknowledged ELSA for guidance and insights. He concluded that life histories have been very powerful for SHARE, as measured by number of users, and the number and quality of scientific papers, and data quality is much better than expected.

## **Biomarkers**

### **SHARE Dried Blood Spot Validations**

*Axel Boersch-Supan*

The SHARE team has completed a project to calibrate the biomarker values measured from the SHARE dried blood spots. Results of assays are highly sensitive to fieldwork conditions (e.g., amount of blood collected on collection paper, packaging for transport, mailing time to the laboratory before processing). SHARE performed many experiments to understand how the different conditions affected the values, compared to results from venous blood. These experiments yielded the appropriate calculations to convert the values from dried blood spots to standardized values. The SHARE team found that training interviewers was very important and that all collection variables should be documented when collecting the samples to be able to make the appropriate corrections later.

Kenny praised this work as a significant contribution to the field. Lee noted that the calibrations will be disseminated through the Gateway, and there will be a webinar in the fall to discuss recommended markers.

### **ELSA Biomarkers**

*Andrew Steptoe*

Harmonization of biomarker data across the HRS ATW studies has been challenging due to differences in how the biomarkers are collected. Biomarkers and physical measures have been collected during nurse home visits associated with four time points in ELSA: 2004/5 (Wave 2), 2008/90 (Wave 4), 2012/13 (Wave 6), and 2016/19 (Wave 8/9), and will be included in 2023/24 (Wave 11). Because mailing of the venous blood samples to the laboratory can take several days, biomarkers that are too evanescent cannot be included. Participants appreciate receiving feedback; some biomarkers are exploratory, so giving appropriate feedback can be challenging. In response to questions, Steptoe clarified that only cross-sectional data on each occasion is presented with normal ranges, without any history; they do not provide feedback on cognitive measures. It takes several months to get the results back to participants, and a study physician reviews all results first. The study physician may recommend that a participant talk about the results with their doctor.

The ELSA team is using the Olink proteomic platform to identify protein signatures relevant to AD/DRD risk. The team is using samples from Wave 4 so that they can link protein signatures with later dementia diagnoses. The samples are processed at the Olink lab in Sweden, and most samples (96 percent) passed quality control. The team has found some candidate proteins may be linked with developing dementia. The cost can be expensive (estimated at approximately £150 per sample). King noted that there can be variance in values between labs due to differences in handling.

## TILDA Ageing Biomarkers

*Cathal McCrory*

TILDA includes health assessment at a clinic for most participants, with those in frail health receiving a shorter health assessment at home. Wave 6 (2020-2023) includes collection of stool, saliva, and blood. The plan for Wave 8 (2026-2027) includes only blood. Clinic blood draws are processed within 24 hours, and home blood draws are processed within 48 hours. The clinic visits involve in-depth assessments, which allow the TILDA team to study the physical changes of aging very closely.

Epigenetic clocks are calibrated by the level of DNA methylation at specific CpG sites. To create epigenetic clocks, the DNA methylation age is regressed on chronological age. A positive residual indicates faster than normal aging, and a negative residual indicates slower aging. The TILDA team examined the association of GrimAge (a second-generation epigenetic clock) with economic, lifestyle, and psychosocial factors among TILDA participants. Smoking (either currently or in the past) was associated with accelerated aging, as were lower levels of education. Higher social connectedness was associated with decreased aging.

An upcoming paper compares the association between four epigenetic clocks and mortality across TILDA, HRS, and NICOLA, with remarkably similar results. GrimAge (a second generation epigenetic clock built to predict clinical outcomes and mortality) was associated with increased mortality across all the studies. Lifetime smoking history explained 50-60 percent of the effect of childhood poverty on biological aging.

The next step is developing DNA methylation surrogate biomarkers that can be used when DNA methylation data are available in place of a biomarker that is expensive or challenging to measure, such as cortisol, telomere length, NfL. Some of the surrogate biomarkers may predict outcomes more strongly than the biomarkers themselves. TILDA has longitudinal data for many of these biomarkers, which allows the team to look at changes in metabolomic age over time. McCrory suggested that the group should consider creating a harmonized biological aging protocol.

King cautioned that researchers need to be careful with these data due to the ability of epigenetic clocks to predict mortality well. Participants could experience negative effects related to life or health insurance coverage if this information were to be released. McCrory added that the first-generation epigenetic clocks are being used to obtain an accurate age for asylum seekers. This knowledge could have unexpected consequences.

In response to questions, McCrory stated that the TILDA team has not analyzed those individuals who seem to be getting younger according to the epigenetic clock over time. People have managed to reverse their epigenetic age, but it is not yet known if that also reduces the risk of disease. Kenny suggested exploring how to use these clocks in intervention trials.

## **HRS – Biomarkers and Genetics**

*Ken Langa*

The current plan for HRS is to collect one venous blood draw per respondent in each 6-year cycle. The consent for the blood draw happens at the end of the core survey, and a national phlebotomy contractor schedules an in-home visit for blood collection. Participants receive results from 28 assays within 2 weeks of collection. Among all panel HRS respondents in 2016, 79 percent consented and 83 percent who consented completed the venous blood draw (N=9,934). An additional 3,089 draws were completed in 2018 from 2016 respondents who had not consented earlier. Current consent is around 75 percent.

HRS has released 13 epigenetic clocks and longitudinal DNA methylation at Time 2 is being collected (2022). There are several HRS pilot studies examining associations between biomarkers and health outcomes. NfL was associated with both dementia onset and mortality within 4 years. The HRS team recently received a supplement to study exposure to heavy metals in dried blood spots using X-ray fluorescence. The team will be examining associations between heavy metal exposure and later development of AD/ADRD.

HRS has released genotype data through the NIA Genetics of Alzheimer's Disease Data site (NIAGADS). The team has also released polygenic score data publicly on the HRS website. They are working with NIA to establish a public biorepository of aging by setting aside small amounts of serum and plasma for use by outside researchers.

McGuinness commented that the biorepository is a good idea but that maintenance and upkeep costs seem high. King responded that HRS is responding to NIA's request to make samples available to outside researchers. He agreed that the logistics might be challenging but it will be worth the cost. Wong commented that NIAGADS is difficult to access from a user perspective. Weir clarified that NIAGADS is a resource for digital data. The biosample repository already exists as part of the HRS storage, and the challenge is to establish a process to allow non-HRS researchers access to the physical samples.

## **Collecting Person-Generated Health Data in the UAS**

*Arie Kapteyn*

The UAS does not collect physical biomarkers, but it does collect data related to participants' health, including:

- Linguistic data through an end-of-day survey in which participants record a narrative. The team has examined associations between the words that participants use in these narratives and their reported mental or emotional state.
- Paradata, such as response times or mistakes people make when answering questions; these data can predict later cognitive decline.
- Accelerometers show significant and substantial differences across countries and across age groups, not captured by self-reports. A subsample of UAS participants is part of an accelerometry study, which tracks sleep and activity data. The UAS team found that sleep efficiency predicted processing speed the next day. The UAS team also tested

whether activity trackers like Fitbits that provide feedback influence physical activity compared to accelerometry devices that do not provide feedback. Although they detected a difference when comparing activity over 2 weeks, there is evidence that the difference fades over time. The UAS team is planning a new project, American Life in Realtime (ALiR) led by Ritika Chaturvedi) to use Fitbits to develop digital biomarkers with a much larger sample size.

- Air quality monitoring – the UAS team also developed a pilot project that provided participants with Atmotubes, a wearable air quality monitor that collects data at 1-minute intervals. Air quality at home is generally worse than in other locations. Indoor pollution is worse for participants who live near a busy road or highway. There seems to be little correlation between individually worn monitors and EPA ground station monitors of air quality, which provide county-level data. The UAS team is planning to recruit more participants and model the air quality by Census tract.

## Partner Networks

### Gateway to Global Aging Data

*Jinkook Lee*

The mission of the Gateway to Global Aging Data ([g2aging.org](http://g2aging.org)) is (1) to be a data and information hub for global aging research, (2) to make data ‘science ready’ and easy to use for cross-national comparisons, and (3) to stimulate global aging research. The Gateway provides a library of harmonized measures, harmonized datasets, documentation, a policy explorer, and other helpful resources for global aging research.

The Gateway site hosts harmonized datasets on the core HRS survey measures, life histories, end-of-life surveys, HCAP, and COVID. The HCAP data harmonization process includes pre-statistical, statistical, and algorithmic classification stages. The Gateway team has hosted several workshops on the HCAP data, prepared a number of user guides on the available measures, and recently launched a policy explorer that enables researchers to investigate the effects of past and current policies on participant outcomes. The policy data have been linked to some of the harmonized survey data. An infrastructure upgrade has just been completed and will be tested through the beginning of September 2023. The new site is available at [beta.g2aging.org](http://beta.g2aging.org) and will be formally launched at the end of October 2023. The updated site includes a data enclave that builds on the system and security measures endorsed by the NIH’s Health and Aging Data Enclave.

Gateway team members have developed statistical methods for imputation, synthetic datasets for teaching, and harmonization of measures. The Gateway team has several partnerships with other research networks and disseminates their work through conferences, workshops, and webinars. There has also been greater emphasis on scientific publications (e.g., Health Economics, 2024 special issue based on November 2023 long term care conference; American Journal of Epidemiology, 2024 special issue based on HCAP Investigator workshop and HCAP 2023 Hackathon).

Chatterji congratulated the Gateway team on the work, especially on the data enclave. Lee explained that after completing a user agreement form, users will be able to combine data files in the enclave workspace. There will be example code. Users will only be able to link data from countries that have data use agreements in place with the Gateway (currently includes HRS, ELSA, LASI, SPS, NICOLA, CADAS; in progress with TILDA, planning for HAGIS-COVID).

## **HCAP U24 International Network**

*Ken Langa*

The HCAP Network is similar to the HRS ATW network but is focused on the HCAP studies only. The HCAP includes 1-hour cognitive assessment for participants and a 20-minute informant/friend/family interview. The goal is to provide detailed information on cognitive function across different cognitive domains. The HCAP Network facilitates international comparisons of current and future trends in the incidence, prevalence, and burden of MCI and dementia in low-, middle-, and high-income countries.

Members of the HCAP Network team have compared the validity of HCAP test items and the correlations between items and cognitive domains across countries. Fifteen HCAP studies have been funded, and nine have completed one wave of data collection to date. Wave 2 HCAP has only been completed in Mexico, has begun for HRS, LASI, ELSA, and HAALSI, are planned for SHARE, TILDA, and NICOLA. There have been several papers using the HCAP data to study the prevalence of dementia and MCI in the United States and India. The HCAP Network is currently supporting pilot studies in Brazil, Ghana, and Egypt. There are also pilot studies examining questions related to data analysis. Langa will update the HCAP Network website (<https://hcap.isr.umich.edu>) with more information on the breakdown of publications using HCAP data.

In response to a question about shortening the HCAP assessment, Langa noted that the tradeoff between precision and comparability across countries is an area of continuing research for the HCAP team. King suggested that the HCAP Network should discuss updating the tests used in the HCAP assessment, and emphasized the importance of including both cognitively impaired and cognitively normal individuals in the sample. Weir added that a shorter HCAP instrument would dictate that the current, five-domain model of cognitive functioning (which is the standard used by neuropsychologists) will need to be changed to a one-domain, global model of cognitive functioning. A one-domain model would require many fewer tests to measure each domain.

Lee commented that the object naming test has not been powerful for country-level analysis and might be a candidate for dropping. Paradata or timing data and audio recordings may be good sources of data outside of the assessment itself. Langa noted that there are disciplinary differences in how these measures are evaluated and in how diagnoses are made.

## **Closing**

Phillips closed the meeting by emphasizing the importance of harmonizing the data and learning from the experiences of the other studies in the network.

## Appendix A. Meeting Agenda

### 2023 Meeting of the HRS Around the World Studies

August 22-23, 2023

Dublin, Ireland

#### MEETING AGENDA

##### Tuesday, August 22

- 8:45           **ARRIVAL**  
*Trinity Business School, Top Floor Boardroom*  
*Luce Hall, Pearse St, Dublin 2, D02 H308, Ireland*  
*(6-minute walk from The Mont Hotel)*
- 9:00           **NIA Welcome and Introductions**  
Minki Chatterji, John Phillips
- 9:15           **HRS Around the World Updates**  
David Weir
- 9:30           **Study Updates: Europe (David Weir)**
- SHARE (EU) – Axel Boersch-Supan and David Richter
  - ELSA (England) – Andrew Steptoe
  - TILDA (Ireland) – Rose Anne Kenny
  - NICOLA (N. Ireland) – Bernadette McGuinness
  - HAGIS (Scotland) – Elaine Douglas
- 10:30          **BREAK**
- 10:45          **Study Updates: Asia (Rebeca Wong)**
- CHARLS (China) – Yaohui Zhao
  - LASI (India) – T.V. Sekher
  - JSTAR (Japan) – Haruko Noguchi
  - MARS (Malaysia) – Norma Binti Mansor
  - HART (Thailand) – Dararatt Anantanasuwong
- 12:00          **LUNCH | Trinity Business School**

- 13:00      **Studying the Effects of COVID-19 (Ken Langa)**
- Arie Kapteyn, UAS
  - Charlotte Neville, NICOLA
  - Yaohui Zhao, CHARLS
  - Rebeca Wong, MHAS
- 14:00      **Pollution (David Weir)**
- Jinkook Lee, Gateway
  - Andrew Steptoe, ELSA
  - Ruth Hunter, NICOLA
- 15:00      **BREAK**
- 15:30      **Study Updates: Americas (Jinkook Lee)**
- HRS (US) – David Weir
  - UAS (US) – Arie Kapteyn
  - MHAS (Mexico) – Emma Aguila
- 16:30      **Study Updates: Africa**
- HAALSI (South Africa) – David Canning
- 17:00      **ADJOURN**
- 17:40      **Meet in Hotel Lobby | Depart for Group Dinner**  
*10-minute walk from The Mont Hotel*  
*15-minute walk from the boardroom*
- 18:00      **GROUP DINNER**  
***FIRE Steakhouse & Bar***  
*The Mansion House, Dawson Street, Dublin 2, Ireland*



**Wednesday, August 23**

- 8:45           **ARRIVAL**  
*Trinity Business School, Top Floor Boardroom*  
*Luce Hall, Pearse St, Dublin 2, D02 H308, Ireland*  
*(6-minute walk from The Mont Hotel)*
- 9:00           **Life Histories (Yaohui Zhao)**
- Axel Boersch-Supan and Martina Boersch-Supan, SHARE
  - Andrew Steptoe, ELSA
  - David Weir, HRS
- 9:45           **Biomarkers (Bernadette McGuinness)**
- Andrew Steptoe, ELSA
  - Cathal McCrory, TILDA
  - Ken Langa, HRS
  - Arie Kapteyn, UAS
- 10:45          **BREAK**
- 11:00          **Partner Networks**
- Gateway to Global Aging Data – Jinkook Lee
  - Harmonized Cognitive Assessment Protocol – Ken Langa
- 11:30          **Group Discussion and Next Steps**
- Solicitation of ideas for small-group follow-up sessions
  - Future priorities and directions from NIA’s perspective (Minki Chatterji, Jonathan W. King, John Phillips)
- 12:00          **ADJOURN | Depart for Group Lunch**  
*10-minute walk from the lecture hall*  
*12-minute walk from The Mont Hotel*
- 12:30          **GROUP LUNCH**  
*The 1592 Restaurant*  
*Trinity College Dublin - Buttery / Dining Hall, Dublin, Ireland*
- 14:00          Brief Walking Tour of Trinity College  
*Starts at the 1592 Restaurant and ends at the memorial venue.*

**Memorial events honoring Dr. James P. Smith will take place at Stanley Quek Hall from 15:00 – 19:00.**  
*Trinity Biomedical Sciences Institute, 152 - 160 Pearse St, Dublin, D02 R590, Ireland*

## Appendix B. Participant List

### 2023 Meeting of the HRS Around the World Studies

August 22-23, 2023

Dublin, Ireland

#### LIST OF PARTICIPANTS

*\*day one only | \*\*day two only*

<b>UNITED STATES</b>	<b>Health and Retirement Study (HRS), Harmonized Cognitive Assessment Protocol (HCAP)</b> David Weir Kenneth Langa  <b>Understanding America Study (UAS)</b> Arie Kapteyn
<b>CHINA</b>	<b>The China Health and Retirement Study (CHARLS)</b> Yaohui Zhao
<b>ENGLAND</b>	<b>English Longitudinal Study on Ageing (ELSA)</b> Andrew Steptoe
<b>EUROPE</b>	<b>Survey of Health, Ageing and Retirement in Europe (SHARE)</b> Axel Boersch-Supan Martina Boersch-Supan David Richter
<b>INDIA</b>	<b>Longitudinal Aging Study in India (LASI)</b> Jinkook Lee T. V. Sekher
<b>IRELAND</b>	<b>Irish Longitudinal Study on Ageing (TILDA)</b> Rose Anne Kenny Nollaig Bourke Niamh Clarke** Delaney Coppola Celine De Looze** Lucy Doogan** Joanne Feeney** Ann Hever Cathal McCrory Christine McGarrigle** Aisling O'Halloran Mark Ward

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<b>N. IRELAND</b>	<b>Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA)</b> Frank Kee* Amanda Coulter* Ruth Hunter Calum Marr Michael McAlinden Bernadette McGuinness Charlotte Neville Leeanne O'Hara
<b>JAPAN</b>	<b>Japanese Study of Aging and Retirement (JSTAR)</b> Haruko Noguchi
<b>MALAYSIA</b>	<b>Malaysia Aging and Retirement Study (MARS)</b> Norma Binti Mansor Halimah Awang
<b>MEXICO</b>	<b>Mexican Health and Aging Study (MHAS)</b> Rebeca Wong Emma Aguila
<b>SOUTH AFRICA</b>	<b>Health and Aging in Africa: Longitudinal Study of an INDEPTH Community (HAALSI)</b> David Canning
<b>SCOTLAND</b>	<b>Healthy Aging in Scotland (HAGIS)</b> David Bell Elaine Douglas
<b>THAILAND</b>	<b>Panel Survey on Health, Aging, and Retirement in Thailand (HART)</b> Dararatt Anantanasuwong Preecha Vichitthammaros
<b><u>STUDIES IN DEVELOPMENT</u></b>	
<b>COLOMBIA</b>	<b>Colombian Longitudinal Study of Ageing (COSA)</b> Mauricio Avendano (day one only)
<b>LEBANON</b>	<b>Lebanon Study on Aging and HeAlth (LSAHA)</b> Carlos Mendes de Leon

**NON-ATTENDING STUDIES**

BRAZIL	The Brazilian Longitudinal Study of Aging (ELSI-Brazil)
CHILE	Chile Cognitive Aging Study (Chile-Cog)
EGYPT	A Longitudinal Study of Egyptian Healthy Aging (AL-SEHA)
INDONESIA	Indonesian Family Life Survey (IFLS)
S. KOREA	Korean Longitudinal Study of Ageing (KLoSA)
URUGUAY	Study of Health and Aging in Uruguay (ELSE Uy)

**NATIONAL INSTITUTE ON AGING**

John Phillips, Chief, Population and Social Processes Branch (PSP), Division of Behavioral and Social Research (BSR)

Minki Chatterji, Program Official, PSP, BSR

Jonathan W. King, Project Scientist; Program Director, BSR

**ROSE LI AND ASSOCIATES**

Rose Maria Li, Project Manager

Sofia Jones, Meeting Planner

Lawrie Green, Project Coordinator