HRS AROUND-THE-WORLD HARMONIZATION VIDEOCONFERENCE

November 13 & 20, 2020

Revised February 9, 2021



This meeting summary was prepared by Rose Li & Associates, Inc. (RLA), with support by the National Institute on Aging (NIA) of the National Institutes of Health (NIH) under Award Number R24AG037866. The views expressed in this document reflect both individual and collective opinions of the meeting participants and not necessarily of the official views of the NIA or the NIH. Writing, editing, and review by the following individuals is gratefully acknowledged: Elizabeth A. Finch, Rose Li, James P. Smith, John Phillips, Ann Hever, Axel Boersch-Supan, Andrew Steptoe, Jinkook Lee, Mohamed Salama, Norma Binti Mansor, and Rebeca Wong.

Acronym Definitions

| Acronym | Definition |
|----------|--|
| AP | Air pollution |
| ATW | Around the World |
| AL-SEHA | A Longitudinal Study of Egyptian Healthy Aging |
| BSR | Division of Behavioral and Social Research |
| CADAS | Caribbean American Dementia and Aging Study |
| CAPI | Computer-assisted personal interview |
| CATI | Computer-assisted telephone interview |
| CHARLS | China Health and Retirement Longitudinal Study |
| COVID-19 | Coronavirus disease 2019 |
| DIMAQ | Data Integration Model for Air Quality |
| ELISA | Enzyme-linked immunosorbent assay |
| ELSA | English Longitudinal Study of Ageing |
| ELSE Uy | Study of Health and Aging in Uruguay |
| ELSI | Brazilian Longitudinal Study of Health, Ageing and Well Being |
| FTF | Face to face |
| GBD | Global Burden of Disease |
| HAALSI | Health and Aging in Africa: A Longitudinal Study of an INDEPTH Community in South Africa |
| HAGIS | Healthy Aging in Scotland |
| HART | Panel Survey on Health, Aging, and Retirement in Thailand |
| НСАР | Harmonized Cognitive Assessment Protocol |
| HRS | Health and Retirement Study |
| IFLS | Indonesian Family Life Survey |
| JSTAR | Japanese Study of Aging and Retirement |
| KLoSA | Korean Longitudinal Study of Ageing |
| LASI | Longitudinal Aging Study in India |
| LASI-DAD | Diagnostic Assessment of Dementia for LASI |
| MARS | Malaysia Aging and Retirement Study |
| MHAS | Mexican Health and Aging Study |
| NIA | National Institute on Aging |
| NICOLA | Northern Ireland Cohort for the Longitudinal Study of Ageing |
| NO2 | Nitrogen dioxide |
| NSF | National Science Foundation |

| PERFAR | Population Europe Resource Finder and Archive |
|------------|--|
| PM | Particulate matter |
| RLA | Rose Li & Associates |
| SARS-CoV-2 | Severe acute respiratory syndrome coronavirus 2 |
| SAWA-L | Dementia and Related Health and Social Challenges in Lebanon: A Population Study |
| SHARE | Survey of Health, Ageing and Retirement in Europe |
| TILDA | The Irish Longitudinal Study on Ageing |
| UAS | Understanding America Study |
| VA | Verbal Autopsy |
| WHO | World Health Organization |

Table of Contents

| Acronym Definitionsii |
|--|
| Table of Contents iv |
| Meeting Summary1 |
| Overview1 |
| 2020 Normal Data Collection: Summary of Approaches, Current Status, and What Should Be Done $$ 2 |
| Actions or Survey Additions Due to COVID-194 |
| Accelerometry6 |
| Harmonized Cognitive Assessment Protocol (HCAP)7 |
| Project Updates from Selected Studies8 |
| Additional Areas for Harmonization9 |
| Closing Remarks |
| Next Steps for HRS Around the World Network12 |
| Appendix A: Meeting Agenda13 |
| Appendix B: Meeting Attendees15 |

Meeting Summary

Overview

On November 13 and 20, 2020, Rose Li & Associates (RLA) convened a meeting of the network of health and retirement studies from around the world (ATW) by videoconference, as part of a project funded by the National Institute on Aging (NIA) to promote harmonization of a network of cross-national studies of aging with the U.S. Health and Retirement Study (HRS). This network fosters a cross-country research agenda by encouraging the development of new health and retirement longitudinal studies on aging around the world and facilitating further innovations among this network of surveys. The meeting welcomed participation by 19 individual projects representing 46 countries. The overall purpose was to discuss study progress, to identify opportunities and priorities for enhanced harmonization to facilitate crosscountry comparisons, and to promote further innovations among this network of surveys. A central focus of the meeting was on the impact of COVID-19 on studies and study outcomes.

In welcome remarks by Lis Nielsen, Director of the NIA Behavioral and Social Research Division (BSR) and John Phillips, Chief of the Population and Social Processes Branch within BSR, NIA staff underscored the core principles of the participating studies, chief among them multi-domain, multi-disciplinary data, nationally representative samples, and data sharing. Many of the surveys have submitted their instruments to NIH Public Health Emergency and Disaster Research Response (DR2) Data Collection Tools & Resources Repository.

In preparation for the meeting, RLA conducted its own survey of participating study directors in late October, inviting them to respond to a brief questionnaire about study progress, adjustments made due to COVID-19, and plans for the future. The information was assembled and shared by James P. Smith, the project Principal Investigator, at the meeting. He began with an overview of the effects and consequences of the COVID-19 pandemic on current and future data collection and the tremendous value of these studies for understanding the impact of the pandemic world-wide. Subsequent sessions addressed accelerometry, the Harmonized Cognitive Assessment Protocol (HCAP) international research network, additional areas for harmonization, and two lightning rounds of invited study updates.

Over the course of the meeting, several suggestions for next steps emerged for the Network:

- Make plans to publish a special issue in a peer-reviewed journal and/or a set of publications about the impact of COVID-19 on aging adults and their families, with a focus on what has been learned from HRS ATW studies.
- Produce a list of desirable features that can be used for developing a videoconferencing software-based interviewing platform.
- Further develop strategies to increase the sharing of ideas, plans, protocols, and data with the goal of improving comparability and harmonization of COVID-19 focused substudies. Specifically:
 - Develop a list of common survey questions for ongoing and future COVID-19 substudies.
 - Compare the HRS saliva and French ELISA antibody testing protocols.
 - Share protocols for antibody testing to facilitate cross-country comparability.

- Compare accelerometry data obtained by the Axivity AX3 worn on the thigh and the wrist, by different wrist-worn accelerometers, and by using different software with the same accelerometers.
- Convene more frequent, shorter, topic-focused virtual meetings aimed at promoting increased interactions among project team members and more rapid study progress. Topics might focus on accelerometry, cause-of-death including coding deaths as COVID-19 and multiple causes, pollution, life histories, and the BRICS countries (specifically Brazil, India, China, and South Africa).

This document summarizes the presentations and discussions and identifies common themes, recommendations, and future goals that emerged from the meeting. Appendix 1 contains the meeting agenda with a full list of presenters, and Appendix 2 contains the list of participants. The level of country participation was unprecedented and can be attributed in part to the relative ease of joining a videoconference rather than having to travel to attend in person. Unfortunately, it was impossible to find a meeting time ideal for all participants around the globe. There was widespread consensus that HRS ATW should continue to utilize videoconference meetings to enable more frequent interactions among study teams and to focus on specific topics of interest.

2020 Normal Data Collection: Summary of Approaches, Current Status, and What Should Be Done

Discussion Leader: James Smith, Principal Investigator

The COVID-19 global pandemic has presented numerous challenges for in-person survey administration yet provides enormous opportunities for this network of studies. The biggest challenges are the disruptions to data collection in 2020, and the need to quickly implement effective alternate modes of data collection. The potential benefit of the HRS ATW studies for understanding the widespread and multi-domain effects on seniors during this unprecedented time is immense, largely because of several unique features of the HRS ATW endeavor. First, because these are long-term longitudinal and multi-domain studies, and will therefore have data from both before and after the pandemic, the consequences of the pandemic can be analyzed across multiple domains (health, economic, social and behavioral, etc.). Second, the samples being collected represent the age groups that are the most vulnerable and suffer the greatest consequences of COVID-19. Third, most of the 48 countries in HRS ATW are affected by the pandemic, yet the impact appears to vary substantially by country. Effective cross-country comparisons of the effects of COVID-19 among countries is likely to provide insights into a wide range of factors (disparities is health and health systems, cultural, socioeconomic, and political factors, etc.) that influence how participants in different countries experience the pandemic and its consequences for their current and future health and well-being.

Of the 19 studies represented at the meeting, six studies fielded a 2020 wave (HRS, ELSI, SHARE, TILDA (End of Life only), MARS, KLoSA), seven ongoing studies had not planned to field a 2020 wave (CHARLS, MHAS) or delayed their 2020 wave (ELSA, NICOLA, LASI, HAALSI, HART, TILDA (main data collection)), two studies are not currently active (IFLS, JSTAR), and four studies had not yet started (AL-SEHA, SAWA-L, HAGIS, ELSE Uy). The studies that are fielding a 2020

wave and collecting data amidst the pandemic have largely been quite successful, with most of the studies thus far completing between 69.3 and 102.8 percent of their usual cases. However, for most studies this has required a number of changes to data collection methodology (protocols and modes) because of limitations on physical interactions between interviewers and participants. The biggest modifications are that in-person interviews have been largely stopped or delayed, requiring the use of alternate interview modes, and that physical, cognitive, and health assessments (e.g., blood draws) are on hold.

Meeting participants representing studies fielding a 2020 wave were invited to share their experiences, insights, and plans regarding the modes of data collection they found (most) effective and ineffective and the new content that is and should be included in COVID-19 focused sub-studies. SHARE, which involves 28 countries, ran normal face-to-face (FTF) interviews in early 2020, then paused FTF interviews in mid-March and added two computer-assisted telephone interviews (CATI) surveys in between its waves 8 (2019/20) and 9 (planned for 2021/22). TILDA halted computer-assisted personal interviews (CAPI) in mid-March and switched to CATI, commencing End of Life interviews in August 2020, with the main wave of data collection via CATI to take place in 2021 without health assessments nor extensive cognitive tests. HRS suspended in-person interviews, including blood draws and physical measures, relying instead on web and phone interviews in March 2020 and MARS stopped physical assessments and in-person interviews in areas where COVID is active and switched to phone contact.

The ensuing discussion raised a number of key issues. It was generally agreed that going forward, in-person interviews are likely to decline. The possibility of carrying out virtual FTF interviews using videoconferencing software (e.g., Zoom) was suggested as a very effective mode. Discussion of virtual interviewing centered on cost, whether it should be supplemented with other interviewing modes, whether it should be a shared platform, and the impact of language, health care, and other differences among countries. It was noted that it is difficult for studies to rapidly change to a new mode (e.g., building a web version of the interview) and that this type of effort would take at least a year to develop and program and require dedicated funding. While there would be savings in travel costs, there would be costs associated with software development. Several cautionary comments were made about relying solely on virtual interviews. For example, hearing, visual, cognitive, and technology challenges for older adults could pose an impediment to this mode of data collection and some countries are not as amenable to virtual interviews for cultural, accessibility, and other reasons. Both TILDA and SHARE indicated that phone interviews yield higher response rates than virtual interviews; ELSA estimated that at least 25% of their participants will not adapt to only digital, video, or phone interviews and that an alternate mode will always be needed. The possibility was also raised that virtual interviews might allow interviewing to be centralized, for example by SHARE. However, given the diversity of countries and differences in language, pension systems, health care systems, and other factors, there was some skepticism that virtual interviews could be effectively implemented broadly or that a common platform for all countries would be feasible. Additional concerns were raised about several related issues, including how to carry out health measures that require in-person contact (e.g., blood draws).

Actions or Survey Additions Due to COVID-19

Discussion Leader: James Smith, Principal Investigator

The HRS ATW project has the potential to be an invaluable resource for understanding the wide-ranging impact and long-term consequences of COVID-19 on aging adults and families around the world. To further this goal, a substantial number of long-standing and new HRS ATW studies have fielded (HRS, ELSI, SHARE, TILDA, MARS, CHARLS, ELSA, HAALSI) or plan to field (LASI, MHAS, HART, JSTAR, AL-SEHA, SAWA-L, HAGIS) COVID-19 sub-studies and there is substantial enthusiasm for building this effort further. Thus far, these sub-studies are encouraging, with large sample sizes (3,600 – 60,000/wave) and respectable response rates (70 – 84%). Most studies are fielding multiple waves, which is important for understanding how the impacts of various factors progress throughout the course of the pandemic as well as the persistent consequences once the pandemic is over.

There was a focused discussion about COVID-19 survey methodology, including modes and content. Most studies that have fielded or plan to field COVID-19 surveys are using telephone interviews, almost all of which are also using at least one other mode (e.g., CAPI, internet or mail surveys). Discussion of survey content included key categories and ideas about specific sample questions. Questions included can be grouped into four broad categories: 1) COVID-19 indicators, 2) economic indicators, 3) social/behavioral indicators, and 4) health indicators. However, there was substantial variability in the extent to which these categories and different sub-categories were addressed by each study. Questions about COVID-19 indicators focused on COVID-19 exposure, testing, infection, and symptoms of the respondent and, in some surveys, other individuals within and outside of the family. Economic indicators focused on loneliness, social relationships/networks, and caregiving/care receipt. Finally, health indicators included health behaviors and other physical health issues, mental health (including stress and anxiety), health services use/engagement, medications use, and antibody testing.

The follow-up discussion also included a detailed and productive dialog about SARS-CoV-2 antibody testing protocols, with particular interest in recent advancements in the saliva antibody protocol developed by HRS, which uses the ELISA method and has the same sensitivity (100%) and specificity (99.6%) as blood, and a saliva multiplex assay developed by INSERM in France that recognizes IgGs to multiple SARS-CoV-2 epitopes, which thus overcomes detection issues caused by the rapid decay of some IgGs, and provides more than 90% sensitivity and specificity. General enthusiasm was expressed for comparing these and other antibody detection protocols being developed and used in different projects and for the sharing of protocols with other projects in order to facilitate cross-country comparability.

There was widespread consensus that the COVID-19 surveys and health assessments within the context of the larger HRS ATW project could provide an invaluable resource to the research community and to society more broadly. The importance of focusing on efforts to harmonize methodology and survey content in order to achieve this goal was emphasized. Further, meeting participants and NIA staff were enthusiastic about the idea of publishing a journal special issue and/or a set of publications about the impact of COVID-19 on aging adults and

families, with a focus on what has been learned from HRS ATW studies.

The Understanding America Study (UAS) COVID-19 Pulse Survey Arie Kapteyn, Director, Understanding America Study (UAS)

The Understanding America Study, funded by the NIA, Gates Foundation, and National Science Foundation (NSF), is a longitudinal study that began in 2014 and currently maintains a panel of approximately 9,000 U.S. residents who are surveyed at multiple time points per year on economic, labor, attitudinal, and health measures. The UAS began tracking the effects of the COVID-19 pandemic beginning on March 10, 2020, with the goal of identifying as many factors as possible that might affect households. There are about 7,000 participants in the UAS COVID-19 survey, with approximately 500 participants interviewed each day and waves repeated every 2 weeks. The survey generates almost 3,000 new data charts per day; data are updated every night and released to the public every 2 weeks. Since the beginning of the pandemic, 16 national waves have been completed thus far.

The UAS COVID-19 survey approach reveals how frequent tracking illuminates developments in real time. In particular, the repetition of the collection protocol every 2 weeks has enabled the flexibility to follow the course of the pandemic despite uncertainties about its duration, and to analyze the impacts of spikes in infection rates, government measures, job loss and unemployment benefits, and a range of other factors. Moreover, the COVID-19 survey guestions build on six years of data collected from the same households and UAS has thousands of background variables that can inform understanding of how families experience the pandemic. Several examples of the results from this study illustrate the power of this approach. In one example, the study found that psychological stress, including anxiety and depression, peaked in early April and declined substantially by mid-June. Thus, a survey that began in June would have missed the peak entirely and knowing the time path yields substantially greater insight into the effects of the pandemic on mental health. A second example addressed the percent of individuals who participated in various types of social and non-social activities. This revealed that while close contact with household members and non-social outdoor activities have remained relatively constant since March, close contact with non-coresidents increased substantially during May and June, which may be one factor contributing to the increase in infection rates over that time period. Thus, the approach and methodology used by UAS and UAS-COVID-19 provides useful insights into the power of real-time, repetitive, frequent, and harmonized data collection that can help inform and guide data collection and study design considerations for COVID-19 surveys by HRS ATW studies going forward.

In sum, the COVID-19 pandemic has presented substantial but not insurmountable challenges for the HRS ATW network. Indeed, study leaders and teams are developing innovative ways to address these challenges. There was widespread consensus that the COVID-19 issues are incredibly important and deserve additional discussion, perhaps for a focused videoconference meeting. The dedication of HRS ATW teams to continuing to pursue the mission of their studies to the extent possible ensures that the data collected during this time will be an invaluable resource for the research community, and for our society as a whole, for years to come.

Accelerometry

The collection and analysis of physical activity measures using accelerometry is a relatively recent addition to HRS ATW studies and was the focus of the May 1, 2019 HRS ATW meeting. A lack of physical activity and exercise and high levels of sedentary behavior are associated with multiple health conditions and contribute to impairments in physical, cognitive, and mental health. Conversely, accumulating evidence shows that physical activity and exercise can promote healthy physical and cognitive aging and curtail age-related dysfunction and diseases of the body and the brain. Accelerometry provides objective measurements of physical activity. While previous studies have shown that not only is accelerometry more accurate than self-reported physical activity, the difference between measured and self-reported activity varies widely by country and different countries have different thresholds for what is considered "vigorous activity."

Accelerometry is currently being carried out by two studies (SHARE and TILDA) and is also planned by three future studies (CHARLS, ELSA, and NICOLA). These studies have the common goals of 1) distinguishing different types of activities, including sitting, standing, walking, biking, mixed activity, and sleeping, and 2) improving data comparability to facilitate cross-country comparisons.

The ELSA Experience

Andrew Steptoe, ELSA

ELSA initially collected accelerometer data in wave 6 (2012/2013). Of the 499 individuals invited to participate in 8 days of monitoring, 400 (80%) agreed to participate and 333 (66%) completed the study. Thus far, study investigators have not utilized this accelerometer data further. While the original study used the GENAActive accelerometer, the next phase of data collection will use the Axivity AX3 triaxial accelerometer. Advantages of the Axivity AX3 include open-source software and its use by the UK BioBank and China Kadoorie Biobank studies. The UK Biobank experience illustrates several advantages of this device. These include a shorter monitoring period (3 – 7 days) and the development of a tailored machine learning model to quantify sleep, walking, and other activities. ELSA plans to use the Axivity AX3 to collect data from 3,500-4,500 participants in wave 10 (2021). The device will be worn on the wrist for 7 days per participant then reused for other participants, enabling each device to be used three to four times every 2 months. CHARLS will use some of ELSA's devices to help with calibration and comparison, including with respect to how data are processed (e.g., sleep time).

The SHARE Experience

Axel Boersch-Supan, SHARE

The main goals of the SHARE accelerometry project are to compare activity levels in different European countries and to distinguish different types of activities. Similar to future studies planned by ELSA, SHARE is using the Axivity AX3 device; however, the device is worn on the thigh instead of the wrist. Data collection began in wave 8 (11/2019 - 3/2020) but was stopped due to COVID-19. The original plan was to collect data from 750 individuals per country, with oversampling of inactive and older respondents; thus far, data have been collected from a total of ~840 respondents. The output is measured using the Euclidean norm and analyzed using an R

package. Results thus far show that the data analysis approach (calculated activity/standardized scores) yields general activity levels that are consistent with those from self-reported activity, providing a simple measure of face validity. Moreover, activity levels not only vary by country (some of which can be distinguished statistically), but the difference between standardized scores of self-reported and measured activity also varies widely by country. The next step is to relate accelerometry data to other covariates. Ultimately, the real value of these studies will come not from comparing countries per se, but by understanding how comparison of physical activity with covariates differs country to country.

Accelerometry Harmonization

Arie Kapteyn, UAS

Harmonization of accelerometry data remains a key issue. While in theory accelerometry should yield more comparable results among studies than self-reported activity, harmonization of several factors is required to ensure this is the case. There are three dimensions of harmonization to consider for these studies: 1) comparability across devices, 2) comparability across different modes of wearing the devices, and 3) equivalence of data analysis algorithms. One way to determine comparability among devices is for individual study participants to concurrently wear multiple devices on the same part of the body. Analysis of this type of data obtained by wearing the GENEActive, Actigraph, and iPhone on the wrist and measurements at 60 Hz yielded correlation coefficients of between 0.86 and 0.99. Moreover, the correlation coefficients were higher than those for data collected at 50 Hz, showing that higher collection frequency leads to more accurate measurements. The location where the device is worn on the body is also an important consideration. The wrist is the simplest and most common mode, whereas the waist or thigh have advantages for measuring some types of movements. Body location is particularly relevant for measuring activity in the elderly, who often have more limited physical abilities that may skew data measured from different locations on the body. Thus, while there are good reasons for different wearing modes, it is critical to compare data across modes to understand this influence. Finally, the format of data output and analysis method are key factors determining the final results. Devices that provide raw data are preferable because this enables data to be analyzed using the same or comparable algorithms, thereby increasing data comparability. Moreover, machine learning algorithms are generally more powerful than the algorithms used by commercial devices and may enable features of different types of activity to be more accurately captured.

Harmonized Cognitive Assessment Protocol (HCAP)

Ken Langa, HCAP

Langa was invited to update HRS ATW study leaders about the progress and plans of the HCAP network and to welcome new studies to join the HCAP collaboration. The HCAP network was formed several years ago as a parallel project to HRS ATW to develop harmonized supplemental data collection on cognition, cognitive decline, and dementia that can be implemented in partner studies around the world. The HCAP network was funded by the NIA in 2019 to support the harmonization, dissemination, and use of HCAP data. Funding further supports Cores that help international partner activities field, interpret, and disseminate HCAP data as well as pilot projects and junior faculty exchanges. It held its first international meeting in Bethesda in

October 2019, and its planned meeting for October 2020 was postponed to February 2021 due to COVID-19. The high level of interest expressed by studies outside of HRS ATW in joining the HCAP network, even though HCAP was originally envisioned as an add-on to the HRS, is a testament to the value and importance of the HCAP network to the Alzheimer's Disease and dementia research community.

The HCAP protocol entails 1 hour of cognitive testing of respondents and a 20-minute interview with informants. This protocol has been adjusted by study partners to meet country-specific needs, thus creating challenges for harmonization and comparability. The COVID-19 pandemic has presented additional challenges for HCAP as well, including the inability to carry out FTF cognitive testing and physical measurements. Currently, thirteen studies have funding for wave 1 data collection, eight of which (HRS, MHAS, ELSA, HAALSI, CHARLS, LASI, ESPS, KLOSA) have been completed (with data released for all but KLOSA) and five (SHARE, TILDA, NICOLA, CADAS, SAWA-L) have been paused due to COVID-19. Several countries (Brazil, Egypt, Nepal) are in the planning stages for HCAP projects. A number of studies also have funding and plans for a follow-up wave 2, some of which have been delayed because of COVID-19.

Future plans for the HCAP network include 1) coordinating and harmonizing strategies for addressing COVID-related delays and impacts on data collection; 2) facilitating fieldwork planning and implementation for studies that have not yet begun collecting data (SHARE, TILDA, NICOLA, CADAS, SAWA-L); 3) building comparable diagnostic data to support combined or comparative epidemiological work; and 4) creating comparable diagnostic status estimates and non-response adjusted weights to support comparable prevalence estimates in each of the main study full samples, not just in HCAP subsamples.

Project Updates from Selected Studies

Brief project updates were invited from 13 active projects (CHARLS, ELSI, AL-SEHA, SAWA-L, HAGIS, ELSE Uy, HAALSI, LASI, LASI-DAD, JSTAR, KLoSA, MARS, HART), with a focus on study highlights, current status, and funding.

The impact of COVID-19 on 2020 data collection and other aspects of study progress was a major focus of these presentations. Many countries either paused or delayed data collection. For those that have proceeded with data collection since the pandemic began in March, many have had to change from FTF interviews to telephone or video assisted interviews. Physical assessments and blood draws have largely been suspended. As for most of the long-standing HRS ATW projects, many new studies have also added or plan to add a COVID-19 module to their survey. Additional details about the updates from each new project can be found in the presentation slides, available in PDF on the <u>HRS ATW website</u>.

Stephen Tollman (HAALSI) gave a brief presentation on mortality in older South Africans that focused on the question of how HRS ATW studies follow up on deaths and cause of death. In HAALSI, all deaths (678/5059 participants) from 2015-2019 were confirmed by Verbal Autopsy (VA) interviews conducted with caregivers of the deceased 1-11 months after death. VA was used primarily because in rural South Africa 40-50% of deaths do not occur in a facility. As expected, overall mortality rates increased with age and males had a higher death rate than females. In addition to all-cause death counts, a computer algorithm is used to calculate cause-

specific mortality fractions. Such analysis revealed a prominence of cardiovascular causes, with men more likely to die from acute cardiac injury (such as myocardial infarction) and women more likely to die from stroke. Moreover, because South Africa has a high level of premature death and a substantial HIV survivor population, individuals are studied beginning at age 40, which is younger than in other studies. The team is now considering how to address COVID-19 and multiple causes mortality as outcomes. The ensuing discussion centered on the complexity of addressing this issue and differences among countries. A concern was raised about relying solely on the VA approach. For example, John Strauss cautioned that the World Health Organization (WHO) VA assigned many cases to causes which were considered questionable in China; combining VA results with exit interviews and reference to actual death certificates helped for validation but was not much help in ascertaining multiple causes. There was interest in considering mortality and cause of death as a subject for a future topic-focused meeting.

Additional Areas for Harmonization

Prior to their May 1, 2019 meeting, HRS ATW principal investigators ranked pollution, life histories (retrospective modules), and accelerometers as their top three areas to focus on for future harmonization discussions. Since that time, the significance and rapid implementation of studies focused on the COVID-19 pandemic also make harmonization of these studies a very timely and high priority area as this is critical for optimizing the design, execution, and analysis of these impactful studies. ELSA expressed interest for collaboration on the topic of elder abuse. The harmonization of both COVID-19 and accelerometer studies have been addressed in previous sections; presentations and discussion of harmonization considerations for studies about pollution, life histories, and elder abuse are summarized below.

Pollution

Jinkook Lee

The Air Pollution (AP) Initiative is one of the Gateway to Global Aging Data projects in the harmonization initiative supported by NIA. The AP team developed a "harmonized estimation strategy" that is built on a data integration model for air quality, called DIMAQ. The DIMAQ model estimates exposure to AP by combining data from ground measurements, satellite remote sensing, chemical transport models, land-use (roads, altitude), weather (temperature, wind), and other sources. This modeling of exposures provides more comprehensive information than a single measurement alone. The power and utility of the DIMAQ model is evidenced by its implementation by the WHO and Global Burden of Disease (GBD) group for estimating the burden of disease at a resolution of 10 km x 10 km for the entire world from 2010-2016.

Over the past couple of years, the AP team has made substantial progress in further developing this model. This includes increasing the spatial resolution to 1 km x 1 km in the United States, England, India, and South Korea from 2010-2016, estimating annual exposure to NO2 (nitrogen dioxide) for England from 2010-2016, and linking AP estimates to the survey data based on geographic information for the United States, England, and India. The AP team is also conducting a parallel analysis of the relationship between cognition and exposure to AP using baseline LASI data. Next steps for the AP initiative include further improving the spatial resolution (to 100 m x 100 m), improving the temporal resolution (from annual to monthly

estimates), expanding the time horizon (from 2010-2016 to 2000-2020), studying sourcespecific AP, and expanding AP studies to other countries, including China and Ireland.

The analysis of the relationship between cognition and AP has yielded several intriguing findings. A preliminary comparison of different emission sources of PM2.5 (particulate matter with diameters that are generally 2.5 micrometers) to cognition reveal that while overall cognitive scores are not correlated with aggregated AP, there is a strong negative impact of household AP and industrial AP derived from coal and industrial dust on cognition. These findings exemplify how much there is to be learned from this type of AP analysis and the importance of this project for understanding the consequences of AP for human physical and cognitive health.

Life Histories

Axel Boersch-Supan (SHARE)

Life histories have taken on increasing importance in light of the COVID-19 pandemic because we can condition COVID-19 survey responses against previous economic, social, and health conditions. Harmonization of strategies for building thorough life histories among studies is key to their utility for understanding the impacts of the pandemic. It is particularly useful to have a visual representation of a study participants' life history, known as a life grid.

The horizontal axis of the life grid is a timeline, broken down into years or quarters; the y-axis consists of various life domains. During the interview process, which takes at least 1 hour, the study respondent and interviewer work together to fill in the cells through addressing a series of questions. A key part of the design process entails understanding and exploiting results from cognitive research about the types of events that are easy for people to remember and those that are not. Such studies have shown that rare life events are easier to remember whereas health-related events are more difficult. Further, childhood and parental background variables are the most powerful. When building the life grid, these landmark episodes are used as anchors for asking questions about health and economic circumstances that surround that event.

SHARE has found that life histories have been a valuable resource for linking individual decisions to institutional background variables and for disentangling individual data from institutional context variables, such as government policies and other factors, to facilitate understanding causal relationships. Indeed, the real power of this life history approach comes from cross-country by time interactions. While this type of retrospective analysis is not as reliable as contemporaneous data, validation studies show that data quality is much better than expected, which suggests that life histories will be a valuable tool for understanding the impact of the COVID-19 pandemic on individuals and families. Interest in life histories data is indicated by the increase in data users after release of this data.

Elder Abuse

James Nazroo (ELSA)

Domestic and elder abuse is not an uncommon experience, with a 5-10% yearly prevalence, and has a substantial impact on health, wellbeing, and economic security. This topic is therefore a significant policy concern. However, while this topic has thus far received limited coverage by

HRS ATW, the panel, household, and interdisciplinary design of the HRS ATW surveys is an ideal format for investigating risk factors, prevalence, relationship dynamics, and the consequences of domestic and elder abuse. Ideally, issues such as neglect, psychological, physical, sexual, and financial abuse, as well as the context and history of the abuse would also be addressed. Because of the sensitive nature of this subject, ELSA considers it crucial to consider a priori harmonization <u>before</u> going into the field and Nazroo invited collaborators as thought partners in this area.

There are a number of ethical issues to consider when addressing domestic and elder abuse, particularly when the perpetrator is a partner or other family member. Half of abusers are partners, and these partners are usually participants in the survey and have shared knowledge of survey topic coverage. This fact alone may put respondents at risk and raises important considerations. Some of the ethical issues are related to privacy concerns, provisions of support for respondents, interventions for perpetrators, and the potential duty to disclose ongoing abuse. These issues also raise questions about the validity of the instrument, such as willingness to report, consequences of reporting, and accurate and full reporting. There are very well-established instruments for addressing these issues, though for HRS ATW these might require study modifications. Plans for further developing this approach to addressing domestic and elder abuse include holding workshops with academics, policy agencies, and advocates and pilot studies of the approach and questionnaire.

Closing Remarks

John Phillips (NIA)

The presentations and discussions throughout this meeting highlighted the wide-ranging effects of the COVID-19 pandemic on all aspects of HRS ATW studies – and on societies worldwide. While this unprecedented situation has posed numerous challenges for the HRS ATW network, it is also a time of unprecedented opportunities. John Phillips likened these developments to one of the great natural experiments of all time. HRS ATW is in a unique position because of the long-term longitudinal and broad multi-domain nature of the participating studies and the ability to compare across countries. He also underscored NIA's emphasis on facilitating protocol and data sharing, including consideration of tiered access to data to address data security issues, and ways to make available data more discoverable. By continuing to collect data throughout the pandemic, developing COVID-19 sub-studies, and focusing on ensuring the comparability and harmonization of data collection efforts, HRS ATW is well-positioned to make an invaluable contribution to our understanding of how the pandemic has and continues to affect many facets of the health and well-being of aging adults and their families throughout the world.

Next Steps for HRS Around the World Network

Discussion Leader: James Smith, Principal Investigator

One consequence of the COVID-19 pandemic is the increased to use videoconferencing meetings instead of in-person meetings. While many of the benefits of in-person meeting are lost in the virtual format, such as spontaneous and dynamic conversations, there are also some unanticipated advantages. These include the lower cost and time commitment to attend, which increases inclusivity and the rate of participation. This format also creates the opportunity to have more frequent and shorter meetings that are focused on specific topics and/or address timely or pressing issues. While meeting participants agreed that virtual meetings cannot and should not entirely replace in-person meetings once the latter can be resumed, there was a widespread consensus that HRS ATW should continue to utilize videoconference meetings to enable more frequent interactions among study teams and to focus on specific topics of interest.

Action Items

- Make plans to publish a special issue in a peer-reviewed journal and/or a set of publications about the impact of COVID-19 on aging adults and their families, with a focus on what has been learned from HRS ATW studies.
- Produce a list of desirable features that can be used for developing a videoconferencing software-based interviewing platform.
- Further develop strategies to increase the sharing of ideas, plans, protocols, and data with the goal of improving comparability and harmonization of COVID-19 focused substudies. Specifically:
 - Develop a list of common survey questions for ongoing and future COVID-19 substudies.
 - Compare the HRS saliva and French ELISA antibody testing protocols.
 - Share protocols for antibody testing to facilitate cross-country comparability.
- Compare accelerometry data obtained by the Axivity AX3 worn on the thigh and the wrist, by different wrist-worn accelerometers, and by using different software with the same accelerometers.
- Convene more frequent, shorter, topic-focused virtual meetings aimed at promoting increased interactions among project team members and more rapid study progress. Topics might focus on accelerometry, cause-of-death including coding deaths as COVID-19 and multiple causes, pollution, life histories, and the BRICS countries (specifically Brazil, India, China, and South Africa).

Appendix A: Meeting Agenda

National Institute on Aging HRS AROUND-THE-WORLD VIDEOCONFERENCE 2020 November 13 & 20

Rev. 11/16/20

Friday, November 13, 2020

1 – 3 PM (EST)

| 1:00 pm | Welcome and Introductions James Smith, Lis Nielsen, John Phillips |
|---------|--|
| 1:10 | 2020 Normal Data Collection: Summary of Approaches, Current Status, and What Should Be Done Discussion Leader: James Smith |
| 1:45 | Actions or Survey Additions Due to COVID-19 Discussion Leader: James Smith UAS COVID-19 Pulse Survey, Arie Kapteyn |
| 2:20 | Accelerometers The ELSA Experience: Andrew Steptoe The SHARE Experience: Axel Boersch-Supan |
| 2:40 | New Studies – Lightning Round (3 minutes each) China, Yaohui Zhao Brazil, M. Fernanda Lima-Costa Egypt, Mohamed Salama Lebanon, Carlos Mendes de Leon Scotland, David Bell Uruguay, Fernando Bertolotto South Africa, Stephen Tollman |

3:00 ADJOURN

Friday, November 20, 2020

| 1:00 pm | Welcome and Introductions James Smith, John Phillips |
|---------|--|
| 1:05 | Harmonized Cognitive Assessment Protocol (HCAP) Ken Langa |
| 1:10 | New Studies in Asia – Lightning Round (3 minutes each) India, David Bloom India-DAD, Jinkook Lee Japan, Hideki Hashimoto Malaysia, Norma Binti Mansor Thailand, Dararatt Anantanasuwong |
| 1:35 | Form of Future Meetings – Virtual and In-Person Discussion Leader: James Smith |
| 1:50 | Updated Discussion on all 2020 Normal Data Collection Issues <i>Discussion Leader: James Smith</i> |
| 2:10 | Updated Discussion on COVID-19 Discussion Leader: James Smith |
| 2:30 | Areas for Harmonization Pollution – Jinkook Lee Life histories – Axel Boersch-Supan Elder Abuse – James Nazroo Accelerometers – Arie Kapteyn Other? |
| 2:50 | Closing Remarks John Phillips |

3:00 ADJOURN

Appendix B: Meeting Attendees

National Institute on Aging HRS AROUND-THE-WORLD VIDEOCONFERENCE 2020 November 13 & 20

Rev. 11/20/20

| UNITED STATES | Health and Retirement Study (HRS) David Weir Kenneth Langa (also for HCAP) |
|--------------------------|--|
| BRAZIL | The Brazilian Longitudinal Study of Aging (ELSI-Brazil) M. Fernanda Lima-Costa Cesar Messias De Oliveira Fabiola Bof Elaine Thume |
| CHINA | The China Health and Retirement Longitudinal Study (CHARLS) Yaohui Zhao (11/13 only) John Strauss |
| EGYPT | A Longitudinal Study of Egyptian Healthy Aging (AL-SEHA) Mohamed Salama Victor Valcour (11/13 only) |
| ENGLAND | English Longitudinal Study on Ageing (ELSA) Andrew Steptoe (11/13 only) James Nazroo (11/20 only) |
| EUROPE (28 countries) | Survey of Health, Ageing and Retirement in Europe (SHARE) Axel Boersch-Supan |
| INDIA | Longitudinal Aging Study in India (LASI) David Bloom (11/20 only) T.V. Sekher Arunika Agarwal Jinkook Lee (LASI-DAD) |
| INDONESIA | Indonesian Family Life Survey (IFLS) John Strauss |

| IRELAND | Irish Longitudinal Study on Ageing (TILDA) Rose Anne Kenny Ann Hever |
|--------------|--|
| N. IRELAND | Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA) Frank Kee (11/13 only) Bernadette McGuinness (11/13 only) Charlotte Neville |
| JAPAN | Japanese Study of Aging and Retirement (JSTAR) Hideki Hashimoto (11/20 only) |
| S. KOREA | Korean Longitudinal Study of Ageing (KLoSA) Kyunghee Kim (11/20 only) Chonggak Shin (11/20 only) |
| LEBANON | Dementia and Related Health and Social Challenges in Lebanon: A Population Study (SAWA-L) Carlos Mendes de Leon (1-2 pm only) Monique Chaaya (11/20 only) |
| MALAYSIA | Malaysia Aging and Retirement Study (MARS) Norma Binti Mansor Halimah Awang |
| MEXICO | Mexican Health and Aging Study (MHAS) Rebeca Wong |
| SOUTH AFRICA | Health and Aging in Africa: Longitudinal Study of an INDEPTH Community (HAALSI) Stephen Tollman Thomas Gaziano Julia Rohr |
| SCOTLAND | Healthy Aging in Scotland (HAGIS) David Bell Elaine Douglas Anne Gasteen |
| THAILAND | Panel Survey on Health, Aging, and Retirement in Thailand (HART) Dararatt Anantanasuwong (11/20 only) Pailin Chuayok (11/20 only) |

URUGUAY

Study of Health and Aging in Uruguay (ELSE Uy)

Fernando Bertolotto Camila Estiben Sebastian Gadea Alejandra Marroig

NATIONAL INSTITUTE ON AGING

Lis Nielsen, Director, Division of Behavioral and Social Research (BSR) (Nov 13 only) John Phillips, Chief, Population and Social Processes Branch (PSP), BSR Georgeanne Patmios, Program Official, PSP, BSR

OTHER GUESTS

Arie Kapteyn, Director, Understanding America Study (Understanding America Study) Stanley Luchters, Aga Khan University, Nairobi, Kenya (11/13 only)

ROSE LI AND ASSOCIATES

James Smith, Principal Investigator Rose Maria Li, Project Manager Beth Finch, Senior Writer/Analyst Sabira Mohamed, Lead Meeting Coordinator Derek Smith, Meeting Coordinator