

Preface

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Preface: Expert Advice to Enhance Aging Research and the Health and Retirement Study

<https://doi.org/10.1515/fhep-2022-0021>

Received July 18, 2022; accepted July 26, 2022

This new issue of *Forum for Health Economics & Policy* brings five peer-reviewed articles that were commissioned in 2021 to shape the future of the Health and Retirement Study (HRS), a longitudinal panel study that surveys a nationally representative sample of approximately 20,000 people in America aged 50 and older, supported by the National Institute on Aging and the Social Security Administration.¹ Each article contains thoughtful recommendations from subject matter experts for the HRS team to consider as they develop plans for future data collection efforts, and the articles' content will also be of great interest for current and future users of HRS data. Wider still, these articles have high relevance for any cohort study now aiming to sustain its timeliness and vibrancy in future years. Users of data from cohort studies worldwide will find the articles' recommendations, analyses, cautions, and caveats very informative.

The Health and Retirement Study has evolved to become America's premier data source for science on social, behavioral, and more recently biological, processes of aging. Since its initial data collection in 1992, HRS data have generated more than 4000 peer-reviewed journal publications.² This significant scientific production is possible because HRS makes data sharing a priority: the number of data downloads by researchers worldwide has grown consistently since the study

1 Information about the Health and Retirement study can be found at <https://hrs.isr.umich.edu/about>.

2 HRS publication data over time are available at <https://hrs.isr.umich.edu/publications>.

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began, reaching close to 20,000 data downloads last year. The HRS data products go beyond the multidisciplinary core and off-year surveys to include blood-based biomarkers, contextual information about the environments participants live, genetic data, and administrative data from Social Security and Medicare. A recent sub-study capturing the pandemic-related experiences of participants included self-administered oral antibody tests to allow researchers to assess the near and long-term health and welfare impact of COVID-19. A proven model for studying aging, the HRS framework has been adopted by investigators in several countries around the world facilitating cross-national studies of aging in different cultural, social and environmental contexts.³ To further the study of Alzheimer's Disease, Alzheimer's Disease Related Dementias and dementia risk world-wide, the HRS team developed the Harmonized Cognitive Assessment Protocol (HCAP) a comparable collection of assessments employed across several HRS comparator studies around the world.⁴ This collection of data and studies is a powerful tool to study aging in the U.S. and around the world.

The HRS is directed by Dr. David Weir at the University of Michigan in collaboration with a multidisciplinary team of experts.⁵ The HRS is supported via a cooperative agreement, a type of federal assistance to produce public goods that assumes more substantial federal involvement in the conduct of project aims than a typical federal grant. In this case, substantial involvement is in the form of guidance from the **HRS Data Monitoring Committee** and engagement by NIA program staff tasked with both typical project administration as well as more direct input into the conduct of study aims. The committee, in concert with NIA and the HRS investigators, commissioned the articles in this issue ahead of the study's impending application for renewed funding, to inform priorities and plans for the next 6-year HRS funding cycle beginning in 2024. The aim was to identify ways that the HRS can markedly enhance its data collection without adding significantly to participant burden. Readers who are familiar with data collection on the scale of the HRS know that some of the recommendations made in the articles would, if adopted, entail inherent budgetary cost. However, the authors were instructed to make their most aspirational recommendations to improve the science, while not being overly constrained by budget considerations to allow the committee to assess their very best ideas, not necessarily their cheapest. The HRS investigators

³ A list of international HRS sister studies and user tools can be found at <https://hrs.isr.umich.edu/about/international-family-studies>.

⁴ See <https://hcap.isr.umich.edu/for> more information about the protocol and participating studies.

⁵ See <https://hrs.isr.umich.edu/about/co-investigators-committees> for a list of bios for the current investigative team.

and NIA will make use of this and other inputs to develop plans for potential continuation of the study based on peer review and institute funding practices.

We are grateful to the expert authors who prepared these commissioned articles, and appreciative of their many terrific ideas to enhance the HRS of the future. We are also grateful to the peer reviewers, who generously sent thoughtful and constructive reviews in a matter of weeks to ensure that FHEP was able to deliver these articles to you on a timely schedule.

Summaries

Response rates and their implications for data quality are the timely topics of the article by Dr. Joseph Sakshaug of the University of Mannheim. Response rates have been declining in the HRS as in most other cohort/panel studies, and increased levels of outreach have not been able to resurrect historically higher response rates. This article addresses challenges associated with sustaining population-based longitudinal datasets, and suggests innovative approaches to improving survey response. The article discusses selection bias in panel studies from the cumulative effects of participant nonresponse across waves, and from difficulties in linking participants to administrative databases. There is a focus on what to do to enhance response and consent rates ahead of data collection, and also on what to do to compensate for non-response after data have been collected. Strategies to increase rates of consent for high-value data, administrative records, and biological specimens are described. Linkage to administrative datasets can help to adjust for non-response bias, but the article notes ethical considerations when using administrative data for non-respondents who have not consented to linkage.

Contextual data to augment the reach of the HRS into exciting new areas of scientific interest is the topic of the article by Dr. Christopher Dick of Demographic Analytics Advisors. Linking contextual data to participants' locations through techniques such as geocoding can advance research on the impact of the physical and social environment on health and aging, including climate change and sustainability. The article considers nationwide contextual and neighborhood-level datasets that can be readily merged with HRS data. It suggests a major expansion of the existing HRS contextual resource to cover the impacts of both natural and human-induced disasters on participants and the resiliency of their communities. As examples, linkage can be accomplished to measures of a community's vulnerability to flooding, and a community's capacity to respond to weather-based disasters, pandemics, or other disasters.

Cognitive data in the HRS intended to support NIA research priorities on dementia have been enhanced via the inclusion of the Harmonized Cognitive Assessment Protocol (HCAP) and current plans include collecting a second wave of HCAP data. HCAP is a sub-study of HRS panel respondents who receive a set of established cognitive and neuropsychological assessments and informant reports to better characterize cognitive function in older adults designed to be comparable with other U.S. and international studies. Drs. Jacqueline M. Torres and Maria Glymour (University of California San Francisco) consider how HRS/HCAP can improve survey content to further facilitate the study of epidemiological effects, diagnostics issues, and comparisons across other international studies in the HCAP Network. The author's recommendations included prioritizing recruitment of racial/ethnic minorities and longitudinal assessments, phasing-in an HCAP baseline assessment for people under age 65 and adding blood and AD biomarkers.

Data on drivers of mortality rates can facilitate research on mechanisms that explain rising rates of working-age mortality in the United States as described in a recent report by the National Academies of Sciences, Engineering, and Medicine (NASEM) funded by NIA and the Robert Wood Johnson Foundation.⁶ Drs. Shannon Monnat (Syracuse University) and Ira Elo (University of Pennsylvania) consider the strengths and limitations of HRS data for supporting such research and discuss recommendations to enhance the HRS to study this high priority research area. Their recommendations include enhancements to the sample and content. Specifically, reducing the age of eligibility for inclusion in the sample to capture more of the "working-age" population, oversampling of rural residents, contextual data on structural determinants of health and new measures that capture drug use, gun ownership, and social media use. They note that the contextual data collection has the benefits of enhancing research opportunities in this area without increasing respondent burden.

Data on the changing nature of work is needed to support studies on recent trends in the US workforce such as contingent work and variation in the nature of work by demographic and socioeconomic groups on life course health, aging and dementia. The COVID-19 pandemic also effected employment differentially across occupations and could have significant impacts on future work and retirement. Dr. Kathleen Mullen (RAND Corporation) considers survey content needed to better enable research on recent trends in the US workforce using the HRS. Her paper provides an overview of the information on working conditions that is currently available in the HRS or can be added by merging information from occupational

⁶ See National Academies of Sciences, Engineering, and Medicine. (2021). *High and Rising Mortality Rates Among Working-Age Adults*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/25976>.

databases and explores the potential for new content on work arrangements with employers and occupational demands from respondent jobs. Beyond potential connecting to data sources such as O*NET and the Occupational Requirements Survey, she recommends collecting data on work flexibility and work scheduling, the “gig” economy, and technological changes to jobs.