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Forum

Building Survey Data Infrastructure on Aging: The Legacy of NIA

Emily M. Agree, MA, PhD* Amanda Sonnega, PhD[2], and Douglas A. Wolf, PhD[3]

[1]Department of Sociology, Johns Hopkins University, Baltimore, Maryland, USA.
[2]Institute for Social Research, University of Michigan, Ann Arbor, Michigan, USA.
[3]Maxwell School of Citizenship and Public Affairs, Syracuse University, Syracuse, New York, USA.
*Address correspondence to: Emily Agree, MA, PhD, E-mail: emily.agree@jhu.edu

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Abstract

The National Institute on Aging (NIA) has contributed to the remarkable growth in the field of gerontology. One of the many ways the NIA has contributed is through the creation and support of an extensive body of relevant data resources. This paper focuses primarily on NIA's support for the creation and use of these data sources in research, including mention of related documentation, archiving, harmonization, and dissemination/data access activities. Through all of these efforts, NIA-supported data have been used by researchers and policy analysts across a wide range of scholarly disciplines, producing a large body of research that provides a scientific foundation for policy and practice.

Keywords: Data infrastructure, Health and Retirement Study, National Health and Aging Trends Study

The 50 years of the National Institute on Aging (NIA)'s existence coincide with a period of remarkable growth in gerontology, whether measured by the volume of publications, membership in professional organizations, number of degree-granting institutions, or financial investments in basic and applied research. The NIA is both a reflection of and a contributor to this growth. One of the many ways the NIA has contributed is through the creation and support of an extensive body of relevant data resources. The development of this data infrastructure includes several distinct components: supporting the creation of both survey-based and clinically or administratively derived data collection; documenting and preserving data in various archives; supporting research that uses these data as inputs; and harmonizing data elements across data sources. This paper focuses primarily on NIA's support for the creation and use of these data sources in research, including mention of related documentation, archiving, harmonization, and dissemination/data access activities. Through all of these efforts, NIA-supported data have been used by researchers and policy analysts across a wide range of scholarly disciplines, producing a large body of research that provides a scientific foundation for policy and practice.

Data collection on aging had begun before the NIA was formally established, but efforts were scattered across existing institutes within NIH and were sometimes supported by outside foundations. Among the first efforts to understand aging more broadly was the National Survey on Aging (NSA), begun in 1957 and spearheaded by Ethel Shanas, Professor at the University of Chicago, and supported initially by the Health Information Foundation and later by the National Institute of Mental Health. The NSA was undertaken in response to a shortage of information on older people in the United States, especially on their health care needs and use of medical care. The survey also focused on the role of family members in providing financial support and care to them, as well as attitudes about family responsibility in American society (Shanas, 1962). According to Shanas, the motivation was to be holistic, "to study the total person, exploiting what was best in several disciplines" (Shanas & Achenbaum, 1996). The other primary focus for population-level data was on retirement, population-level data was on retirement and the economic security of older Americans. Funded by the Social Security Administration, the Retirement History Study collected information on the retirement transition as a function of work life and history between 1969 and 1979 (Ireland, 1972).

By the 1980s, more attention was being given to the long term, long-term care needs of the older population, and the need to understand functional health at older ages. This led the NIA to invest in multi-site studies like the Established Populations for Epidemiologic Studies of the Elderly (Coroni-Huntley et al., 1993). The Department of Health and Human Services (ASPE and HCFA) supported the 1982–1984 National Long Term Care Surveys, a national longitudinal study of older individuals with chronic disabilities later extended, at 5-year intervals, to 2004 with support from the NIA (USDHHS, 1982).

Although each of these efforts moved NIA's data infrastructure forward, they focused primarily on long-term care needs and hospitalization at older ages. By the mid-1980s, scholarship began to appreciate that a more multidisciplinary

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longitudinal approach was needed to understand aging as a cumulative process that incorporated health, economic, and social well-being. Recognition that aging is a process that unfolds over time, with substantial variation across individuals and groups in society, requires the development of population-level longitudinal data. Ideally, such information would be representative data collected from or about individuals over time at regular and frequent intervals and with attention to variability within the population. The policy priorities that had led to data collection on long-term care and retirement now suggested that both were intertwined and that late-life well-being was the result of historical opportunities and exposures. Systematic inequities in aging needed to be investigated, and samples needed to include women and minoritized populations in numbers that allowed comparative analysis.

Here we highlight two of the major longitudinal data resources that have been primarily supported by the NIA, the Health and Retirement Study (HRS) and the National Health and Aging Trends Study (NHATS), as case studies to illustrate the historical process and context in which these data infrastructure were developed. Other major surveys that are currently a part of NIA-sponsored data infrastructure in the NIA Longitudinal Studies of Aging Network are noted in Figure 1 (NIA, 2024).

A Spotlight on Two Major Data Resources

Health and Retirement Study (HRS)

In 1987, the NIA formed an ad hoc advisory panel to recommend priorities for data collection. The panel confirmed what many had already been arguing forcefully on their own and recommended that a new survey be implemented integrating multiple disciplines to study the economics and health of aging. The then director of the NIA, T. Franklin Williams, believed that a new study of this magnitude, which would represent an expansion of NIA's traditional scope, should be discussed at the Federal Interagency Forum on Aging Related Statistics, a coordinating organization jointly chaired by the National Center for Health Statistics, the Census Bureau, and the NIA.

The Director of NIA's Office of Behavioral and Social Research at the time, Richard Suzman, argued that independent scientists and peer review should chart the course for the study and focus on understanding the dynamics of aging, thus gravitating toward a longitudinal design. Advocacy by leaders in the research community generated increased support for such a survey more broadly within the NIA and in Congress. The 1990 House and Senate Appropriations bills for Labor, Health and Human Services and Education contained language recognizing the importance of initial funding for the longitudinal survey, including an acknowledgment that "*Data available are now 20 years old and do not reflect major changes in the Social Security and pensions systems and the participation of women in the labor force and changes in health and longevity.*"

In preparation for this undertaking, the NIA commissioned papers relevant to the study's design and content and held many widely attended meetings. The inclusion of academic researchers helped the study be responsive to the needs of the general scientific community. Input by interested federal agencies in a consultative role ensured that the study would be of value to the policy community. A 1988 report produced by the NIA's ad hoc advisory panel served as a blueprint for the HRS design (Phillips & Weir, 2023). Integrating multiple disciplines into one study was itself a pioneering step, and tests of innovative survey methods to improve data quality were built into the process.

The first HRS interviews took place in 1992, and since then, every two years, participants in the study have answered detailed questions on health, retirement, disability, resources, and family support. Over time, the study has grown in size, scope, and population coverage.

HRS data are also linked at the individual level to sources of administrative information including administrative records from the Social Security Administration, the Centers for Medicare and Medicaid Services, and the Department of Veterans Affairs (VA). At the employer level, information on employer-provided pension plans is obtained for businesses where respondents are or have been employed. Full details of the study design and content of the HRS are summarized elsewhere (Sonnega, 2024).

National Health and Aging Trends Study

By the 1990s, NIA's National Long Term Care Study (NLTCS), originally designed to focus on the needs of older Americans with chronic disabilities, produced major findings so at odds with prevailing views of late-life decline that they appeared on the front page of *The New York Times* (Barringer, 1993). Specifically, NLTCS data indicated that the prevalence of disability among the 65-and-older population had declined since 1982 (Manton et al., 1993). This finding, in turn, helped propel a wave of research on late-life disability trends based on several extant data sources, including the HRS. However, existing data provided limited and sometimes conflicting insights. Most nationally representative surveys differed in sampling strategies, relied on multi-year intervals between waves, and did not clearly separate functional capacity from the conduct of activities and use of accommodations (Freedman, 2018). These results provided an impetus for new data collection efforts devoted to the possible continuation of, and explanations for, the apparent downward trend in late-life disability at the end of the twentieth century, culminating in the launching of a new effort, the National Health and Aging Trends Study (NHATS).

NHATS was funded by the NIA in 2008 to guide efforts to reduce disability, maximize health and independent functioning, and enhance quality of life at older ages. From the beginning, it was designed to be a panel study that followed a cohort of Medicare beneficiaries aged 65 and older, with annual interviews and regular cohort replenishments. A successor to the NLTCS, NHATS was designed to "answer new

Americans' Changing Lives
Great Smoky Mountain Study
Health and Retirement Study
High School and Beyond Midlife Follow-up
Midlife in the United States
National Health and Aging Trends Study
National Longitudinal Study of Adolescent to Adult Health
National Social Life, Health and Aging Project
Panel Study of Income Dynamics
Project Talent
Understanding America Study
Wisconsin Longitudinal Study

Figure 1. Studies in the NIA longitudinal studies of aging network.

questions about how population-level disability trends change and how individual-level dynamics in late-life functioning unfold as the U.S. population ages. Additionally, the study facilitates investigation of differences in trends and trajectories for various at-risk subgroups and deeper understanding of the consequences of disability from age 65 through to the end of life (Freedman & Kasper, 2019). NHATS developed and validated a disability protocol that distinguishes between underlying physical, sensory, and cognitive capacity and changes in caregiving, use of devices, and the impact of the environment (Freedman et al., 2011, 2014).

Since 2011, NHATS has been conducting annual in-home interviews and performance tests with an initial sample of 8,245 older adults, replenished at regular intervals (see Freedman, Schrack, and Skehan, 2024). In addition to its primary community-dwelling sample, NHATS includes individuals living in residential care settings and nursing homes and collects information on these settings and the services they provide. Decedents are interviewed about the last month of life conducted with a knowledgeable informant. NHATS also includes a National Study of Caregiving (NSOC), initially funded by the Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation (ASPE) and later by the NIA. NSOC is a companion sample of family and unpaid caregivers to NHATS participants, which collects information from helpers on their experiences and perspectives (Freedman, 2022).

Expansion of Scope and Outreach

In addition to its primary sponsorship of the two large-scale studies just described, the NIA has helped build the infrastructure for aging-related research in a number of ways, a few of which we summarize in this section.

Data Resources for Studying Early Life Precursors

As our understanding of aging has grown, the need to look back earlier in life for precursors of late-life health and well-being has become apparent. For many years, NIA has supported long-term follow-up of cohorts such as the Wisconsin Longitudinal Study (WLS) of Wisconsin residents born around 1940 and the National Survey of Midlife Development in the United States (MIDUS), originally a MacArthur Foundation study of individuals age 25–75 in 1994/5. NIA has also supported the addition of aging-related content to longstanding surveys such as the Panel Study of Income Dynamics.

In recent years, NIA has extended its study of aging by following younger cohorts, such as the Study of Adolescent Health (now titled the Study of Adolescent and Adult Health), a nationally representative longitudinal study of over 20 000 adolescents in grades 7–12 in 1994–1995, as they enter middle age. Other school-based cohorts being followed include the National Longitudinal Study of the High School Class of 1972 (now EdShare), which follows a high school cohort that is presently about 70 years old; Project Talent (begun with over 400,000 high school students in 1960), and the High School and Beyond Midlife Follow-up (originally 10th graders in 1980).

NIA also has invested in linking many of its large-scale datasets (including the HRS and NHATS) to early life indicators from the 1940 census and soon from the 1950 census. This has allowed new research on early life precursors and early-life precursors but also enabled validation studies of retrospective data usually used in late-life surveys (Warren et al., 2022).

Finally, NIA has supported the IPUMS group at the Minnesota Population Center to create a new Multigenerational Longitudinal Panel (IPUMS-MLP). This panel will link publicly available historic complete count U.S. census data from 1850 to 1940 with public historical administrative data from Social Security, the military, and vital registration to construct life histories for individuals and families over multiple generations.

Facilitating Data Use

In addition to supporting the development of data resources, NIA has provided considerable support over the years to promote and facilitate the wide use of these resources through various initiatives. The NIA funds the National Archive of Computerized Data on Aging (NACDA) to curate data and documentation to promote effective research use, facilitate data sharing across the research community, and provide data user support for our hosted data collections.

Federal laws and regulations, as well as provisions for protecting human subjects of research, limit or rule out researchers' access to many of the external data sources listed in the preceding section. In addition to these privacy issues, the costs and technical issues associated with data linkages can inhibit data availability for many researchers with limited resources. To increase accessibility to these data, NIA has supported the development of data enclaves to securely share data and provide virtual infrastructure to allow users to work with restricted data through fully secure connections. MiCDA makes available restricted data from both HRS and NHATS. Another major asset that NIA has supported and that widens access to a broader array of potential users is the RAND versions of HRS data (Buligari et al., 2023). Researchers at the RAND Corporation have created user-friendly versions of much of the HRS public data. Derived variables covering a broad, though not complete, range of measures have been constructed and named consistently across waves. While the RAND contribution is a good starting place for new users, even seasoned users continue to use derived variables, such as total household income and wealth, which are very time-consuming to create.

International Investments

NIA has had a longstanding interest in comparative research on aging, providing support for the development of in-country studies around the world in both high-income countries and low- and moderate-income countries (LMICs). Initially, this involved helping to support population surveys being conducted separately in a wide variety of settings, such as the Aging in Asia studies in the 1980s and 90s (Hermalin, 2002) and the Mexican Health and Aging Study (MHAS). MHAS was one of the first international studies explicitly intended to be compatible with US data (HRS), with interviews of older Mexicans beginning in 2001 (Wong et al., 2017). In 2002, the first European companion study was undertaken—the English Longitudinal Study of Aging (ELSA)—with adults aged 50 and over who had participated in the Health Survey of England.

Eventually, these efforts led to a growing network of harmonized longitudinal aging studies designed to be comparable to U.S. data (HRS), supported by significant NIA funding and expertise. One of the most widely known is the Survey

of Health, Ageing and Retirement in Europe (SHARE), a pan-European effort launched in 2004 that now includes data for 140,000 people aged 50 or older from 28 countries.

The availability of comparably measured data across countries with different policy structures, social environments, and histories provides opportunities for comparative research to shed light on causal relationships that even longitudinal analysis in a single country cannot accomplish. With NIA funding, the HRS has led a global study of dementia in older populations, the Harmonized Cognitive Assessment Protocol, generating population-representative estimates of prevalence, providing longitudinal data for epidemiologic investigation, and gauging its impact on individuals, families, and the health care system. For those interested in conducting comparative research using these cross-national data, the NIA has also provided support for the development of the Gateway to Global Aging, a digital library of survey questions, a search engine for finding comparable questions across surveys, and identically defined variables for cross-country analysis maintained by researchers at the University of Southern California.

How NIA Data Infrastructure has Contributed to Knowledge

The kinds of analyses people can perform have expanded as a result of these investments in infrastructure. The range of research findings that have been produced using elements of the NIA-supported data infrastructure is vast. The HRS alone has generated over 8,000 publications since 1992, and NHATS has been used in almost 1,000 peer-reviewed papers since 2011. This large and growing body of work has contributed to new knowledge across various fields and brought attention to policy priorities as well. Rather than attempting to organize this body of scientific output according to discipline or topic, we have identified several salient features of the contents, design, and breadth of the data that comprise the infrastructure and have provided examples of studies that have used these features. In support of its data infrastructure, NIA has contributed to the growing body of aging-related research findings through investigator-initiated research grants, aging research centers, and the funding of doctoral and post-doctoral fellowships. Some of the studies cited in the following paragraphs can credit several of these mechanisms of support.

Lengthy Panels

The panel-data studies we have highlighted are, by their very nature, studies that track individuals over multiple time-periods. However, by the standards of past social science data collection efforts, both the HRS and NHATS cover impressively long periods. As noted, the HRS fielded its first interviews in 1992; as of 2024 (32 years later) interviewing continues, and a recent funding award extended the life of the HRS through 2029. NHATS, which began later, conducted its first interviews in 2011 and, like the HRS, is currently supported through 2029. Thanks to these long-time spans, the data can support powerful analyses of life-cycle and intertemporally dependent outcomes such as health and functioning trajectories (e.g., Zang et al. 2022), disease progression, mental and physical health consequences of major events such as the death of a spouse, and sequences of care needs and caregiving (Freedman et al., 2022). Another benefit of these long time-periods is the potential to support studies of the effects of policy changes that may occur in different settings, such as states, at different times, such as the adoption of paid family leave programs (Arora & Wolf, 2024).

Inclusion of Physiological and Physical Performance Measures and Biological Specimens

During the 1990s, there was growing interest in the idea that declining disability might be a harbinger of unanticipated extensions to the human lifespan. Two reports from the National Academy of Sciences, *Between Zeus and the Salmon: The Biodemography of Longevity* (National Research Council (US) Committee on Population, 1997) and *Cells to Surveys: Should Biological Measures Be Included in Social Science Research?* (National Research Council Committee on Population, 2001) reflected an interest in joining biological and genetic data to large multidisciplinary population surveys to study this question. The ability to collect biomarkers alongside the social, behavioral, and environmental histories of older adults was facilitated by the development of new less invasive methods that allowed the collection of these data outside of clinical settings (Kinsella et al., 2001).

HRS, NHATS, and several other survey efforts have collected biological and genetic data and anthropometric measurements. In 2006, the HRS added the collection of blood-based biomarkers and salivary DNA. In 2009, the NIH Director's Opportunity Award provided support for HRS to collect genetic data to estimate telomere length, candidate genes, polygenic risk scores, and DNA methylation (biological) clocks. In 2017, NHATS conducted blood-based assays for C-reactive protein, HbA1c, Cytomegalovirus, Interleukin (IL)-6, and genotyping.

An issue that has received much attention in recent years is the physical manifestation and measurement of the concept of geriatric frailty (Fried et al., 2001). Physical performance measures collected in NHATS, such as timed walking-speed tests and measures of hand grip strength, were incorporated into a measure of frailty reported in Bandeen-Roche et al. (2015), and accelerometry-based measures of physical activity are now available annually. Donahue et al. (2023) used NHATS to demonstrate that changes in peak expiratory flow predict the subsequent onset of dementia.

Studies using data such as these have also contributed to the growing body of multidisciplinary research in epigenetics and to recent NIA investments in linking their longitudinal population survey data to environmental information to examine the exposome (Wild, 2005). In 2022 NIA funded the HRS and the National Longitudinal Study of Adolescent to Adult Health, as well as other NIA-supported studies, to add exposome measures to better understand gene-environment effects on dementia and the effects of climate change on aging.

Linkages to Administrative Data

Applied researchers have long recognized the value of administrative data, such as earnings records supplied by employers to the Social Security Administration (SSA), for extending the scope and improving the accuracy of policy-relevant estimates. As noted earlier, the HRS took steps to create such linkages early on. In recent years, the number and types of external sources to which survey data have been linked have expanded to include, among others, Medicare and Medicaid claims files and employer pension plan features. Among the many examples of research that has made use of such linkages is Schmitz (2016), who used HRS data linked to SSA earnings records in her analysis of late-career employment contexts and self-rated health, or Mullins et al. (2023), who compared self-reported cancer onset to measures found in Medicare claims. They found that self-reported cancer diagnoses in the

U.S. HRS have poor validity for participants with cognitive impairment, dementia, or a proxy respondent. Kornblith et al. (2024) used HRS data linked to Medicare claims data to estimate the surprisingly high incidence of traumatic brain injuries among the older population and to investigate differences between population subgroups in the occurrence of these events. Researchers have linked NHATS and NSOC to Medicare claims data to show that more than half of older adults with probable dementia were undiagnosed and that a formal dementia diagnosis is integral to access support for family caregivers (Amjad et al., 2018; Burgdorf & Amjad, 2023). Ankuda et al. (2020) found that family and friends of NHATS decedents who were enrolled in Medicare Advantage programs reported lower quality of care in the last month of life compared with those who died while enrolled in traditional Medicare.

Creation of and Linkage to Contextual Data

The preceding examples illustrate the linkage of individual-level survey data to individual-level administrative records. However, geographically linked data that uses state-, county-, ZIP code-, or census tract-identified survey data are equally important, supporting a broad array of research on contextual influences on behavior and health outcomes or environmental exposures and their numerous consequences. Place-specific measures of contextual or environmental features have been created using a wide variety of sources including Census data, weather or climate information, governmental policies and programs, natural resource or industrial production figures, and physical features such as distance and travel times. Such data may describe the settings in which individuals make their decisions, adopt lifestyle behaviors, seek and obtain supportive resources, or experience the influence of peers. Linkage between individual-level survey data such as those produced in the HRS and NHATS can then be accomplished using place codes (e.g., Census Tract identifiers) or place names (e.g., of respondents' state or county of residence). A geographic linkages repository at the MiCDA enclave allows users access to contextual data resources developed for HRS and the National Neighborhood Data Archive (NaNDA), a publicly available data archive containing measures of the physical, economic, demographic, and social environment at multiple levels of spatial scale (e.g., census tract, ZIP code tabulation area, county).

An important type of contextual data are measures of public policy provisions, such as tax rates, safety-net programs, and requirements concerning service providers' availability or staffing. There is growing evidence that public policies can substantially affect health, well-being, mortality, and other outcomes (Montez & Grumbach, 2023). HRS-based research of this type includes studies of the health and employment consequences of an increase in the minimum wage (Jutkowitz et al., 2023) and Tipirneni et al (2021), who showed that increased access to Medicaid associated with the Affordable Care Act led to increased access to hospital-based care among low-income workers.

Conclusion

When NIA was founded in 1974, data documenting even the number of residents in long-term care institutions and the health and service needs of the older population was virtually unknown. Today, NIA has invested in building a vast resource of population data on aging and is expanding it to incorporate linkages to early life and contextual data and to understand the impacts of policy change on the older population. NIA investments have been used to promote global studies of aging and helped facilitate the investigation of novel questions by various researchers across disciplines.

As the population ages and the retirement of the Baby Boomers continues, NIA-supported data resources will continue to develop and are expected to grow to meet the need for data on these trends. In the coming years, by observing the dynamics of retirement and health and people's social and economic well-being following retirement, these data will provide powerful research tools for tracking and understanding important societal changes and potential policy responses.

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Conflict of Interest

None.

Data Availability

'This article does not report data and therefore the pre-registration and data availability requirements are not applicable.

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