

Expert Meeting on Possible Enhancements to Several National Institute on Aging Longitudinal Studies

Washington, DC

May 6, 2015

Meeting Summary

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TABLE OF CONTENTS

Acronym Definitions	iii
Meeting Summary	1
Overview of Study Designs and Methods	1
Health and Retirement Study.....	1
National Social Life, Health, and Aging Project.....	2
National Health and Aging Trends Study.....	3
Panel Study of Income Dynamics.....	4
Discussions	5
Alternative Modes and Multimodal Approaches.....	6
Sharing Resources Across Studies.....	7
Data Linkages.....	8
Optimizing Periodicity and Content.....	9
Incentives.....	9
Cost Tradeoffs.....	9
Appendix 1 Meeting Agenda	10
Appendix 2 List of Participants	11

ACRONYM DEFINITIONS

Acronym	Definition
AAPOR	American Association for Public Opinion Research
CMS	Centers for Medicare & Medicaid Services
CNSTAT	Committee on National Statistics
HRS	Health and Retirement Study
NHATS	National Health and Aging Trends Study
NIA	National Institute on Aging
NICHD	<i>Eunice Kennedy Shriver</i> National Institute of Child Health and Human Development
NLTCS	National Long Term Care Survey
NSF	National Science Foundation
NSHAP	National Social Life, Health, and Aging Project
PSID	Panel Study of Income Dynamics
SSA	Social Security Administration
SSN	Social Security number
VA	Department of Veterans Affairs

MEETING SUMMARY

On May 6, 2015, the National Academy of Sciences Committee on National Statistics (CNSTAT) convened an expert meeting to discuss possible enhancements to several longitudinal studies sponsored by the National Institute on Aging (NIA). The goal of the meeting was to identify methodological approaches that could reduce costs and respondent burden without adverse impact on data quality. Discussion focused on strategies that could be implemented broadly across multiple studies in the near term.

The meeting included an overview of four NIA-sponsored longitudinal studies: the Health and Retirement Study (HRS), the National Social Life, Health, and Aging Project (NSHAP), the National Health and Aging Trends Study (NHATS), and the Panel Study of Income Dynamics (PSID); and group discussions. The following emerged as promising avenues for future consideration:

- Adopt alternative modes and multimodal approaches, both for communication with study participants and for administration of interviews.
- Share information, lessons learned, survey questions or data structures, and personnel across studies.
- Expand the use of data linkages to both administrative and private sector data.
- Optimize the periodicity and content of current instruments.
- Offer more effective incentives to encourage study participation and reduce the number of contacts per respondent.

This document summarizes the presentations and discussions that occurred during the meeting. Appendix 1 contains the meeting agenda and Appendix 2 contains the list of participants.

Overview of Study Designs and Methods

Health and Retirement Study¹

David Weir, University of Michigan

The HRS is a nationally representative longitudinal study of adults over the age of 50 years in the United States that collects multidisciplinary data for public use. The NIA supports the HRS through a cooperative agreement with the University of Michigan and the Social Security Administration (SSA) provides additional support. Data collection began in 1992. Panel surveys are conducted every 2 years. Since 2009, approximately 120 peer-reviewed articles have used HRS data each year. The HRS has served as a model for similar studies around the world.

The HRS employs a steady state sample design in which cohorts are defined by birth years and refresher samples for younger age groups are added every 6 years. Couples are enrolled in the study together based on the age of the older spouse. With typical eligibility rates, screening and

¹ More information is available at the HRS website <http://hrsonline.isr.umich.edu/>

baseline interviews for a new cohort cost about four times as much as a typical panel interview. In 2016, the investigators propose to use commercial lists for area sample stratification, as recommended during a previous CNSTAT meeting, which is expected to reduce the cost to about three times the cost of a panel interview.

The HRS core interview is administered in person at baseline and for respondents ages 80 years and older. Approximately half of follow-up interviews are conducted via telephone, with the remainder conducted in person to allow for collection of biomarkers and a leave-behind self-administered questionnaire. The investigators have used internet as an ancillary mode since 2003 and are currently programming the entire instrument for internet administration. Full integration of internet mode interviews with other core modes is expected no earlier than 2018 due to limitations with Blaise software. The HRS follows respondents who enter nursing homes, seeks proxy respondents when the primary respondent is unable or unwilling to participate, and conducts exit interviews with next of kin of deceased respondents.

The HRS is a multidisciplinary study. The core content includes information on health, health services, labor force participation, economic status, family structure, and future expectations. Biomarkers are measured in alternative waves and DNA samples have been collected since 2006. The HRS maintains administrative linkages with the SSA, Centers for Medicare & Medicaid Services (CMS), Department of Veterans Affairs (VA), and others. The HRS has served as a platform for several supplemental studies on topics such as dementia, health care, and subjective wellbeing.

National Social Life, Health, and Aging Project²

Colm O'Muircheartaigh, University of Chicago

NSHAP is a study of the health and wellbeing of older adults in the United States that focuses especially on social connectedness and intimate personal relationships. The study includes a nationally representative sample of community-dwelling older adults. The first wave, conducted in 2005 to 2006, included approximately 3,000 adults between the ages of 57 and 85 years. The initial cohort was recruited using the HRS screener to select households not participating in the HRS. This cross-study collaboration yielded significant cost savings. Subsequent waves, which occur every 5 years, followed the initial cohort longitudinally and added co-resident romantic partners of any age, enabling analyses within dyads. Recruitment for a new cohort of participants ages 50 to 66 years old is planned for 2015 to 2016. Respondents receive an incentive of \$100 for participating in each wave.

The specific aims of NSHAP are to (1) describe the health of older adults, (2) evaluate the social pathways through which older adult interpersonal and intimate connections affect health, (3) identify the biological pathways through which social connectedness affects various aspects of health, and (4) examine disparities across groups in social connectedness and health. NSHAP data collection includes a 2-hour in-person interview and biometric assessment, a leave-behind

² More information is available at the NSHAP website <http://www.norc.org/Research/Projects/Pages/national-social-life-health-and-aging-project.aspx>

questionnaire, and, in waves 2 and 3, an actigraphy substudy, in which participants wear accelerometers for 72 hours to study their movements, providing objective measures of sleep.

A unique feature of NSHAP is the inclusion of multiple measures of social connectedness, including social networks, romantic partnerships and sexual activity, social engagement, and social resources of respondents. To examine social networks, interviewers obtain rosters that identify the primary individuals, including romantic partners, with whom respondents report discussing important topics over the last 12 months. The interviewers then ask follow-up questions to determine the nature of the relationships, including the content of the interactions, between the individuals named and the respondent. The investigators can compare social network rosters for individual respondents across waves.

Other NSHAP measures include parameters of relationship quality, mental health and personality, cognitive function, physical health, and biomeasures. In addition to self-reported health, performance assessments are used to evaluate frailty and cognitive function and samples of blood, urine, saliva, and vaginal swabs are taken to objectively measure health. Modifications from one wave to the next build on earlier findings, while many measures are preserved to allow for longitudinal analysis. The study includes a leave-behind self-administered questionnaire that covers topics on childhood background, social activities, bereavement, neighborhood, caregiving, thoughts and feelings, health, and fertility. Interviewer comments supply contextual information about the respondent and interview location. NSHAP administers a proxy interview to a close relative or friend of respondents from previous waves who have passed away or are otherwise unable to participate.

National Health and Aging Trends Study³

Vicki Freedman, University of Michigan

NHATS is a longitudinal study of disability trends and trajectories among Medicare beneficiaries ages 65 years and older living in any residential setting. Although data collection began in 2011, NHATS was preceded by the National Long Term Care Survey (NLTCs), which was established by CMS in the early 1980s and funded by the NIA from 1984 to 2004. The NLTCs was the first study to identify important declines in late-life disability.

NHATS emerged from the NIA's charge to design a long-term successor study to the NLTCs to facilitate research on (1) the causes and consequences of disability and disability trends and (2) disability dynamics and individual pathways to disability. The goal was to enable analyses by 5-year age groups to examine disparities and economic impact and to support development of intervention strategies. In designing the study, the investigators considered the optimal periodicity to evaluate trajectories and trends in disability, which populations to oversample, new measures of disability, and ways to bridge new data collected to the NLTCs to maintain comparability.

³ More information is available at the NHATS website <http://www.nhats.org/>

Rather than continue the NLTC panel, the NHATS investigators proposed to draw a fresh sample from the same frame as the NLTC. They also designed and validated a new, enhanced disability protocol that included an overlapping set of questions with the NLTC. The new sample design includes approximately 8,500 Medicare beneficiaries ages 65 years and older living in community, residential care, or nursing home setting. The study oversamples individuals whose race is listed as Black on the CMS enrollment file and older ages, which allows enough power to identify age- and race-specific trends. Data are collected annually from May through October and the sample is refreshed every 5 years.

NHATS interviews are conducted in person and include performance-based measures to distinguish capacity from environmental aspects of disability. Baseline interviews last approximately 2 hours and follow-up interviews last 90 minutes, including 30-40 minutes of performance tests. The investigators are presently considering with their scientific advisory panel whether there are ways to improve the efficiency of the protocol.

Most NHATS data are publicly available, with a small portion requiring data use agreements and other protections for access. Restricted NHATS data include linkages to CMS claims and geocoded files. There are presently more than 1,000 registered users of NHATS data.

The costs of data collection were highest in the first round, when the initial panel was recruited. Costs for follow-up are considerably lower and have remained relatively stable since round 2. Recently, the study adopted mobile technologies for use in the field in order to enhance the efficiency of fieldwork.

Panel Study of Income Dynamics⁴

Vicki Freedman, University of Michigan

The PSID is the world's longest running nationally representative household panel survey. The study began in 1968 with 4,800 families, including an oversample of families with low socioeconomic status, and was initially designed as a 5-year study to understand the causes and consequences of poverty in the United States. The PSID has grown over 39 waves of data collection into a family of studies with a core interview and several age- and content-specific supplements, modules, and linkages. Studies around the world also have replicated the study design of the PSID. Data from the PSID are used in about 150-175 academic publications annually.

The PSID is an ongoing longitudinal panel that allows prospective study of early- and mid-life factors on outcomes later in life. The study employs a genealogic design, whereby adult children of respondents become respondents themselves as they form independent households. In addition to natural growth of the sample, which now spans four generations, an immigrant refresher sample was recruited in 1997 and a second immigrant refresher cohort is proposed for 2017. The primary sponsors are the National Science Foundation (NSF), the NIA,

⁴ More information is available at the PSID website <https://psidonline.isr.umich.edu/>

and the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD).

The core interview involves one household informant who reports for the family unit. The periodicity, mode, and duration of interviews have evolved since the initiation of the study. At present, interviews are conducted biennially via phone and last approximately 60 to 80 minutes. The core interview content initially focused on income, program participation, employment, and housing and food security. Over the years, content has broadened to include topics that align with the priorities of the NIA and NICHD such as health status, behaviors, and expenditures; wealth, savings, and pensions; family composition; marriage, fertility, and newborn children; and details about education. The PSID also implements innovative modules and supplemental studies, which provide substantial value to the field, on topics such as early childhood health; family rosters and transfers; and disability, time use, and wellbeing.

The costs of data collection for the PSID core interview increase over time, in part because the sample grows naturally and in part because the average number of calls to reach and complete cases has been increasing. The PSID has increased the use of incentives for some groups and is introducing alternative modes of contact (e.g. email, texting). The Survey Research Center also is developing a multimode sample management system designed to facilitate implementation of complex contact protocols. The PSID's biennial periodicity allows the study to maintain full-time staff and to share field staff with the HRS, leading to substantial efficiencies.

Currently, available restricted PSID data include administrative linkages to the National Death Index, Medicare claims, school identifiers, federal housing assistance, and a geocoded file to facilitate linkages to geospatial data. The PSID is exploring additional administrative linkages (e.g. Social Security, the 1940 Census) as well as linkages to publicly available data (e.g. housing values and environmental data). Some of the challenges to establishing new administrative linkages are regulatory. Obtaining consent from respondents, when necessary, also can be challenging. The investigators have recently developed a framework to help guide decisions about implementation and use of linked data.

PSID investigators also are exploring issues involved in transitioning the core instrument to an internet-based option. They plan to pilot web-based administration of the core interview to a subset of respondents to determine the feasibility and impact on data quality, respondent burden, and costs. Challenges to internet mode interviewing include complexities of the PSID sample design and instrument, the need to balance ease of completion with data security, the length of the instrument, and programming and data processing issues. The potential for cost savings of internet interviewing remains unclear because not all respondents will be able to use this mode and there will be a greater need initially for post-production data processing to reconcile internet and telephone modes.

Discussions

The goal of the discussions was to identify potential near-term strategies for longitudinal studies to reduce costs and respondent burden without compromising data quality. It was

noted that the NIA-funded longitudinal studies already operate efficiently and have likely adopted any easily implemented cost savings measures that conserve data quality. Therefore, any new ideas were welcomed, including long-term strategies. The following is a combined thematic summary of the panel and open discussions.

Alternative Modes and Multimodal Approaches

Broader use of alternative modes and multimodal approaches both for administering interview instruments and contacting respondents was a major focus of discussion. Many studies already include a mail-based component and are exploring internet interviewing and email and text message communications. Still, opportunities exist to expand the use of these modes.

Communication Using Alternative Modes

Several participants noted that different modes are best suited for different purposes. For example, a primary advantage of the internet is as a mode of contact to stay in touch with respondents. Email could be particularly useful for contacting respondents who may not answer phone calls from unknown numbers. Even if respondents ignore initial emails, they may view the content of the subject line. Text messages could be used in a similar fashion. Although text messaging and internet usage are most prevalent among younger cohorts, technological fluency is increasing for all age groups.

The mode of initial contact does not need to be the same as the mode of response; respondents could receive a letter with a sample survey asking them to respond by the web. In this way, studies could build systems that provide more chances to communicate. Logical communication sequences across multiple modes, including partial communications to explain the needs of studies and garner interest, would be especially useful. Couples-based studies also could consider how different modes of communication might reach one partner or the other.

Data Collection Using Alternative Modes

Some participants suggested increased data collection via alternative modes. Greater use of mail and internet modes might be among the most promising strategies for achieving cost savings. For example, studies can screen for new participants via mail with response rates around 30 to 40 percent. Where these response rates are insufficient, selective face-to-face screening can serve as a follow-up method while maintaining cost effectiveness.

Internet mode can be used effectively for primary data collection; however, response rates may be lower than face-to-face and phone interviews, especially for older individuals. To maximize cost savings, studies could implement two-phase designs in which certain parameters (e.g., biomarkers) are measured face-to-face in a subset of respondents and proxy variables are identified to impute the rest based on internet responses. The two-phase design strategy might, however, reduce data quality. Any studies using multiple modes for data collection should aim to maximize compatibility of data fields across modes prior to implementation to minimize the need for post hoc reconciliation.

In addition to reducing costs, internet interviewing may have the potential to produce better quality data than in-person and telephone modes. Long interviews result in poor data quality

and lengthy instruments can be divided into shorter modules for internet administration. Moreover, well-designed internet mode surveys could reduce the incidence of protocol deviations by eliminating sources of human error during interview administration. Certain survey questions might also receive more accurate responses if visuals were provided to respondents, which internet mode could facilitate. With any interview mode, there are concerns that participating in longitudinal studies that involve repeated interviewing may affect participants and their responses. More research is needed on this topic.

Although most physical and biological measures must be conducted in person, some, such as saliva and actigraphy, can be completed by mail. For example, studies can mail accelerometers to participants with instructions for use and return by mail. The protocols for this approach need to be carefully considered so as to avoid activation of equipment at the wrong time. In addition to potential cost reductions, wearable accelerometers could reduce respondent burden by eliminating the need for time use diaries. Researchers opting to use such technology must investigate whether the devices will return data of sufficient detail and quality.

Sharing Resources Across Studies

Participants discussed achieving potential cost savings and quality improvements by increased sharing of resources across longitudinal studies, including sharing of information, lessons learned and best practices, survey questions or data identification structures, and personnel.

Information Sharing

Investigators from each longitudinal study have learned from past experiences; sharing these lessons across studies would be mutually beneficial. Participants suggested several venues that may be appropriate for sharing lessons learned and best practices for survey methods. These included:

- Annual meetings of relevant professional organizations, such as the American Association for Public Opinion Research (AAPOR), the International Field Directors and Technologies Conference, and the European Survey Research Association
- Meetings hosted by the NIA-funded Centers on the Demography of Aging and their respective networks
- Ad hoc meetings, potentially supported by the NSF Methodology, Measurement, and Statistics Program, for research coordination efforts

In addition to gathering the Principal Investigators of various longitudinal studies, it would be useful to include survey methodologists and field operations personnel in these discussions.

Sharing of Instruments or Data Structures

Improved coordination and collaboration between studies could lead to synergies and reduce redundancies. For example, many of the large longitudinal studies collect common data, particularly on demographics and economics. Although each study has unique features, sharing basic data could improve efficiency. One suggestion was to explore the creation of a national household panel that would serve as a master instrument to collect data across the life course. Then, investigators could add supplemental modules as needed to address specific questions.

Others cautioned against a centralized design because of the risk of restricting innovative ideas generated through the investigator-driven model.

Studies could share data in other ways, such as by creating a shared database of common measures or by establishing data linkages between studies targeting similar populations. Standardizing the data identification structures across studies would facilitate this type of data sharing. Without standard formatting, data sharing requirements could burden individual investigators.

Sharing of Personnel

Meeting participants commented on the importance of continuity of staff for efficient and high-quality data collection. Moreover, they acknowledged that several studies already share common personnel, especially for seasonal or intermittent fieldwork. Better coordination of fieldwork among different studies might help improve access of all studies to the best interview staff.

Data Linkages

Increased use of data linkages could reduce costs and increase data quality. Linkages to administrative data could facilitate efficient communication with respondents. Studies also could use data linkages to replace survey questions; for example, rather than asking respondents a lengthy series of questions about their health, studies could obtain consent to access electronic health records to gain potentially better-quality health data for lower cost. Before implementing this strategy, investigators must be confident about the accessibility and quality of the data linkage. Another consideration is the value of having both the data linkage and responses to survey questions because this combination can enable imputation of data for other individuals about whom investigators have partial information.

Although copious administrative data exist, their access is often limited by legislation. For example, tax data from the Internal Revenue Service are legally unavailable for research purposes except as defined in the tax code, which specifies several Census Bureau uses but generally restricts other applications to those bearing on tax administration. Over time, the Census Bureau has developed the ability to match 90 percent of its household survey respondents to their Social Security numbers (SSNs) using names, dates of birth, and addresses. Using its own unique identifier as a secure replacement for the SSN in both survey and administrative files, the Census Bureau is able to link databases with a high degree of success where such linkages are permitted by data use agreements and respondent consent. The technology for assigning SSNs cannot be shared with other agencies, however, because it relies on administrative data that are subject to the same legal restrictions as decennial census data. Broadening access to these and other administrative data requires legislative change.

Private data may represent a more expeditious opportunity for linkages compared to government-owned administrative data. Some studies have successfully obtained United States Postal Service data through private providers. Investigators could consider accessing private sector data on housing, payroll, personal finances, and electronic health records. Any linkages to private databases must consider potential selection biases based on the user population.

Optimizing Periodicity and Content

Studies could potentially achieve efficiencies by optimizing the periodicity of data collection and content of survey instruments. The need for frequent data collection is more important for some types of data than for others. Most studies follow the wave model, collecting data at regularly spaced intervals. Empirical tests are needed to determine whether continuous data collection might improve quality and cost effectiveness. In addition to optimizing the periodicity of collecting different types of data, investigators could consider optimizing the frequency of data collection for different groups of respondents. For example, the NSHAP investigators are considering abandoning the wave model altogether because they have recognized that respondents of different ages experience events of interest at different intervals. Thus, the investigators might decide to collect data on younger respondents much less frequently than on older respondents.

Improving the quality of questionnaires by eliminating redundancies could significantly increase the efficiency of many studies. Similarly, improving cross-sectional samples by implementing enhancements to sampling and screening processes, such as using commercial lists and information about target sample areas, could help reduce costs.

Incentives

Because the most expensive component of many studies is contacting respondents, developing incentives to encourage higher response rates while reducing time to response could achieve significant cost savings. One suggestion was to use partial incentives where respondents receive smaller and more frequent incentives with communication that takes place prior to the interview. This strategy might be more effective at keeping participants engaged than providing a single lump sum payment after completing the entire interview. Another suggestion was to find ways to make participating in the study a more positive experience for the respondent overall because respondents who enjoy their experience are significantly more committed to participating in the future. Small incentives, requests for feedback, and more frequent communication with respondents between waves might help.

Cost Tradeoffs

Finally, participants discussed how different tradeoffs in study design might affect costs of survey administration. For example, changing the periodicity of data collection, sample size, or the specific measures included clearly affects costs, but the cost function—or the mathematical formula that predicts survey administration cost based on study design parameters—is often unclear. Participants noted that cost information is typically proprietary but that an algorithm could be created if the underlying data could be obtained. One suggestion was for funders of longitudinal studies to implement requirements that awardees report a cost ratio. This could be obtained by asking survey companies to generate budgets for different study configurations.

APPENDIX 1 MEETING AGENDA

- 1:00–1:15** **Introductions and Welcome on Behalf of the National Academies**
Constance Citro, Committee on National Statistics
- 1:15–1:30** **Welcome on Behalf of the National Institute on Aging and Rationale for the Meeting**
John W. R. Phillips, National Institute on Aging
- 1:30–2:50** **Current Design of the Surveys and Updates on Any Current Methods Research**
- Health and Retirement Study
David Weir, University of Michigan
 - National Social Life, Health, and Aging Project
Colm O’Muircheartaigh, University of Chicago
 - National Health and Aging Trends Study
Vicki Freedman, University of Michigan
 - Panel Study of Income Dynamics
Vicki Freedman, University of Michigan
- 2:50–3:00** **Break**
- 3:00–4:15** **Opportunities and Tradeoffs for the NIA Longitudinal Studies**
- Discussion Topics:
- Integrating new data collection modes and new technologies
 - Expanding linkages to administrative data
 - Opportunities for innovation in the areas of survey/questionnaire design
- Discussants:
- Don Dillman (Chair), Washington State University*
John Czajka, Mathematica Policy Research
James House, University of Michigan
Colm O’Muircheartaigh, University of Chicago
Roger Tourangeau, Westat
- 4:15–5:00** **Discussion**
- 5:00** **Adjourn**

APPENDIX 2 LIST OF PARTICIPANTS

Invited Participants

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