

**National Institutes of Health
National Institute on Aging
Division of Behavioral and Social Research**

**2016 Data Infrastructure Review
Committee Report**

Revised November 29, 2016

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Committee Report

Introduction

The National Institute on Aging (NIA) Division of Behavioral and Social Research (BSR) supports a range of data infrastructure projects that serve as a platform for research studies by numerous individual investigators. In order to prioritize its investments in data infrastructure, BSR needs to maintain a clear vision of the research portfolio that would best advance its mission. Such a vision helps to guide future funding decisions. Emerging scientific and technological developments and funding constraints contribute to the need to continually reassess opportunities to ensure that BSR's data infrastructure investments optimally support its mission. With input from periodic reports, including those by the National Advisory Council on Aging (NACA), the National Academy of Sciences (NAS), and ad hoc expert review panels, BSR has developed a portfolio of data projects to meet evolving scientific priorities.

Trends that are especially evident in this century include the increasing linkage of self-report data to biomarkers and performance measures, incorporation of expanded cognitive and genetic data into ongoing studies, and expanding investigation of pathways through which the social environment affects health; clarification of how circumstances throughout the lifespan, including early life and adult development and even generational linkages, accumulate to affect aging outcomes; and harmonization of longitudinal microdata across countries to make possible comparative analyses of effects of individual and macro-level influences in very different environments. These trends reflect two recommendations from the report of the 2007 BSR Data Priorities Committee, which was co-chaired by Lisa Berkman and James Smith: (1) enhance efforts to understand the life-course and the role of cumulative exposures and (2) increase emphasis on integrating biological pathways and interactions into social, psychological, and behavioral models.

This report constitutes an assessment of the BSR portfolio of data infrastructure investments in 2016 to meet the scientific needs of the social and behavioral research community to further understanding of the aging process and aging outcomes in the coming decade.¹

In 2015, BSR convened an ad hoc Committee on Data Infrastructure to review its current portfolio and critical gaps, and to discuss future needs. Committee members, listed below, represent the range of fields for which data infrastructure is an abiding concern, including population studies, public health and epidemiology, psychology, economics, sociology, and demography.

¹ For the purposes of this review, BSR/NIA-funded data investments were categorized into tiers, with Tier I data resource projects being those for which data sharing is the main objective rather than an add-on to a particular research project as the primary focus. Designation as a Tier I study is a statement about the study's relevance for this review and does not imply greater scientific importance than projects not listed in Tier I. See Appendix A for a description of Tier I and Tier II projects.

Committee Members

Eileen Crimmins, Chair, University of Southern California
James Banks, University of Manchester and Institute for Fiscal Studies
Lisa Berkman, Harvard University
Constance Citro, National Academy of Sciences
William Dow, University of California, Berkeley
Maria Glymour, University of California, San Francisco
Scott Hofer, University of Victoria
James Jackson, University of Michigan
David Laibson, Harvard University
Terrie Moffitt, Duke University
Jonathan Skinner, Dartmouth College
James P. Smith, RAND Corporation
Arthur Stone, University of Southern California

Charge to Committee from NIA

The Committee was charged with providing input on the following questions:

1. Do the major data infrastructure investments managed by BSR provide an adequate basis for behavioral and social research on aging during the coming decade? In particular, does the infrastructure support the scientific priorities outlined in the 2013-2014 NACA BSR Review Committee Report,² which include:
 - a. Research that illuminates the pathways by which social, psychological, economic, and behavioral factors affect health in middle-aged and older adults.
 - b. Research aimed at understanding and modifying organizational or individual behaviors associated with positive and negative health outcomes in later life, including organizational and individual interventions in the health care system.
 - c. Research on factors that affect population aging, as well as the consequences of population aging, particularly in the context of demographic and epidemiologic transitions in progress and macro aspects about health, economics, and retirement.
 - d. Research that ameliorates the impact of disadvantaged position in society, including research that focuses on critical periods for reversing such effects and/or the optimal timing of intervention.
2. In what ways do the existing data infrastructure investments fall short, or fail to take advantage of new scientific opportunities?
3. Where does it appear there is unproductive redundancy, or areas that could be sacrificed for higher value scientific priorities?
4. What are the priorities for making data infrastructure investments more cost-effective?

² See Appendix B: Excerpts from the [2013 BSR Review Committee Report](#), National Advisory Council on Aging.

Committee Process

The Committee convened three times to complete its deliberations, including once in person, and reviewed background information during the interim periods. BSR staff compiled a list of major BSR data infrastructure investments, and with support provided by Rose Li and Associates, Inc. (RLA), drafted study briefs and assembled summary information on funding levels and data usage by outside investigators for each major data infrastructure project.

An initial teleconference was held on November 9, 2015, to discuss the charge to the Committee, review data infrastructure-related recommendations from previous reports, determine an approach to the review, and identify the resources and information from BSR to conduct the review. (The list of materials provided to the Committee in advance of the November 9 call is included as Appendix C). At this initial meeting, John Haaga stressed the importance of continuing BSR's emphasis on supporting integrative and interdisciplinary research, incorporating research across the lifespan, and representing both individual- and population-level perspectives. He also underscored that the Committee's review is separate and distinct from the NIH peer review process because the focus is not on the merit of individual projects but on how well the portfolio of projects serves the science now and in the foreseeable future.

Crimmins proposed that each member take responsibility for reviewing the portfolio for specific content areas and prepare a brief presentation for the in-person meeting. Assignments were provided as indicated in Table 1.

Each Committee member (or pair) was asked to address his or her topic in a 10-minute presentation during the February 5 meeting, including:

1. What are the scientific questions for the next 10 years?
2. How are the scientific foci of the next 10 years supported by the current data infrastructure?
3. What needs require what changes to the infrastructure?
4. Are we using administrative and Big Data appropriately?
5. What are the new approaches to data collection in this area, and how should they be integrated (e.g., internet, mobile devices, scans, evoked responses)?

Table 1. Committee Member and BSR Staff Content Assignments

Topic	Committee Member(s) Responsible	BSR Staff Resource Person
Economic behavior, support, work, and retirement	Banks	Phillips
Social and physical environment; participation and integration in family, neighborhood, community	Berkman	Haaga
Use of administrative and Big Data	Citro	Bhattacharyya
International studies including issues of consent, linkages to administrative records, release, etc.	Dow and Smith	Phillips
Aging bodies: mortality, disease, disability, and frailty	Crimmins	Patmios
Biosocial, biobehavioral influences on aging; integration of biology, genetics, etc.	Glymour	Gerald
Aging minds: cognition and decision making	Hofer	King
Health disparities by socioeconomic status, race, and ethnicity	Jackson	Patmios
Behavior change	Laibson	Onken
Life course influences (early, mid-life), reversibility, and resilience	Moffitt	Nielsen
Use and provision of health care, health care, policies, and programs	Skinner	Bhattacharyya
Subjective wellbeing and emotional health	Stone	Nielsen

In addition to these content-specific areas, several overarching themes were identified for consideration across the portfolio:

1. Study design and methodology (e.g., what is the future of representative longitudinal cohort samples, how do they relate to Big Data efforts and the Precision Medicine Initiative)
2. Data collection methods (e.g., new and possibly more cost-effective methods)
3. Data sharing and public use availability
4. Data usage
5. Design features affecting cost-effectiveness (e.g., periodicity, mode, sample recruitment)

BSR also solicited comments from the research community and received input during the December 2015 to February 2016 period from the Association for Psychological Science, The National Academies Committee on Population, the Society for Epidemiologic Research, and the Population Association of America/Association of Population Centers (see Appendix F).

At the February 5 meeting, members discussed the background materials, and each member presented a briefing on his or her assigned subject area. The meeting agenda was divided into two main components: (1) brief presentations from the Committee members identifying future data infrastructure needs in particular domains and (2) group discussion of principles for decision making (see Appendix D). The full list of participants is included as Appendix E.

RLA prepared an initial draft of the Committee’s report by documenting the review process and summarizing the discussion of emerging recommendations. The draft report was shared with program staff for factual accuracy and with the Committee Chair to ensure that all significant recommendations were adequately captured and properly interpreted. RLA coordinated with program staff and the Committee Chair to incorporate additional edits and assisted in preparing an updated draft Committee report for review and comments by the full Committee.

Follow-up teleconferences were held on September 22 and November 7, 2016, to discuss and finalize the recommendations in the committee report.

Overview of Current Data Infrastructure Supported by BSR

Background Material Supplied by BSR

BSR has a long tradition of seeking advice on data infrastructure investments from ad hoc panels of experts, beginning with a 1988 report, *Recommendations to the NIA Extramural Program on Priorities for Data Collection in Health and Retirement Economics*. The most recent review was conducted in 2006-2007, and its report was included in the background materials for this Committee. This review concluded that data collection was “one of the stellar-achievements of BSR over the last decade.” The timing of the last review was significant: it occurred two years after the end of the NIH appropriation increase, but before the Great Recession and the 2009 American Recovery and Reinvestment Act (ARRA) funds that allowed some significant, one time–only expenditures, augmenting the minority sample for younger cohorts in the Health and Retirement Study (HRS) and the genome-wide association study (GWAS) of HRS samples. The current Committee found that the progress made in building data infrastructure since the last review was again stellar and almost made that of the prior decade pale in comparison.

Budgetary Information and Climate

The Committee kept NIA budgets in the forefront of its thinking in making recommendations. The recent trend is one of roughly level NIA budgets in nominal terms (restored to levels before the 2013 sequester), with the significant exception of increments for research related to Alzheimer’s disease.

There is no set budget by NIA Division. The proportion of NIA research funds managed by BSR has nevertheless been fairly steady over the past decade, at about 20 percent. Likewise, within the research funds managed by BSR, there is no set budget for data infrastructure. The proportion devoted to what is labeled Tier I projects, those for which data sharing is the main point rather than an add-on to a particular research project, has grown slowly over the years to about 20 percent in FY14—two special supplements to the HRS in FY15 raised the proportion to slightly less than 25 percent (see Figure 1). Please see Appendix A for a list of Tier I projects.

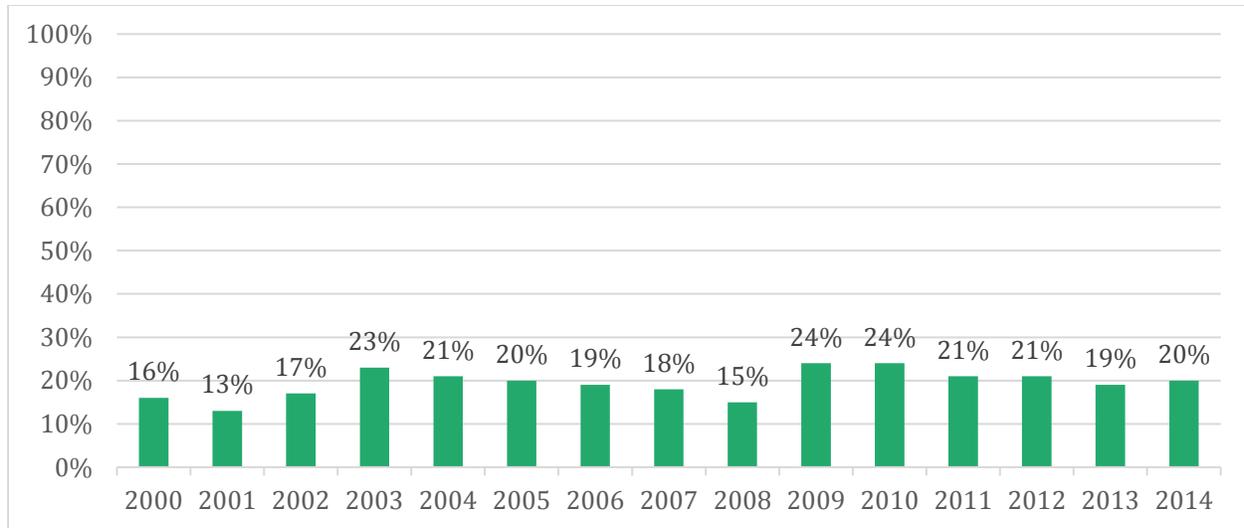


Figure 1. Tier 1 Data Infrastructure Spending as Proportion of BSR Research Funds, 2000-2014.

NOTES: Data do not include co-funding from ARRA, and include HRS, PSID, MIDUS II, NLTCS, NHATS, WLS, ELSA, CHARLS, LASI, Add Health Parents, and NSHAP. For some of these projects, data collection and analysis funding are mixed into the same grant mechanisms; BSR staff used an approximate but consistent method to remove the portion deemed to be for analysis to get a “data infrastructure” total comparable across projects and over time.

No other research funder is exactly comparable to BSR, but two funders cover some of the same territory: (1) the Population Dynamics Branch of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), which recently estimated that it devotes 16 percent of its research grant budget to analogous large data infrastructure and (2) the Economic and Social Research Council in the United Kingdom, which estimates that 15 percent of its budget is used to fund data infrastructure projects.

Decisions about data infrastructure—whether to accept an application in excess of \$500,000, how much to set aside for a Request for Applications (RFA), where to use BSR’s limited supplemental or discretionary funds—have to be made sequentially. But with help from the periodic advisory reports, BSR staff have managed to develop a portfolio that reflects a broad (though implicit) strategy, flexible enough to meet evolving needs.

Population Coverage and Study Niches

Figures 2 and 3 show the coverage of birth cohorts for the U.S.-based Tier I studies and the age at first contact (all these studies are continuing, so there is no explicit plan for an upper age limit). There are nuances peculiar to each study (e.g., HRS spouses might be below age 50; Wisconsin Longitudinal Study [WLS] siblings can be of any age; Add Health parents are representative not of all adults in their cohorts but of those who had children born in certain years); however, the figures provide a reasonable idea of the density of coverage in the portfolio of studies.

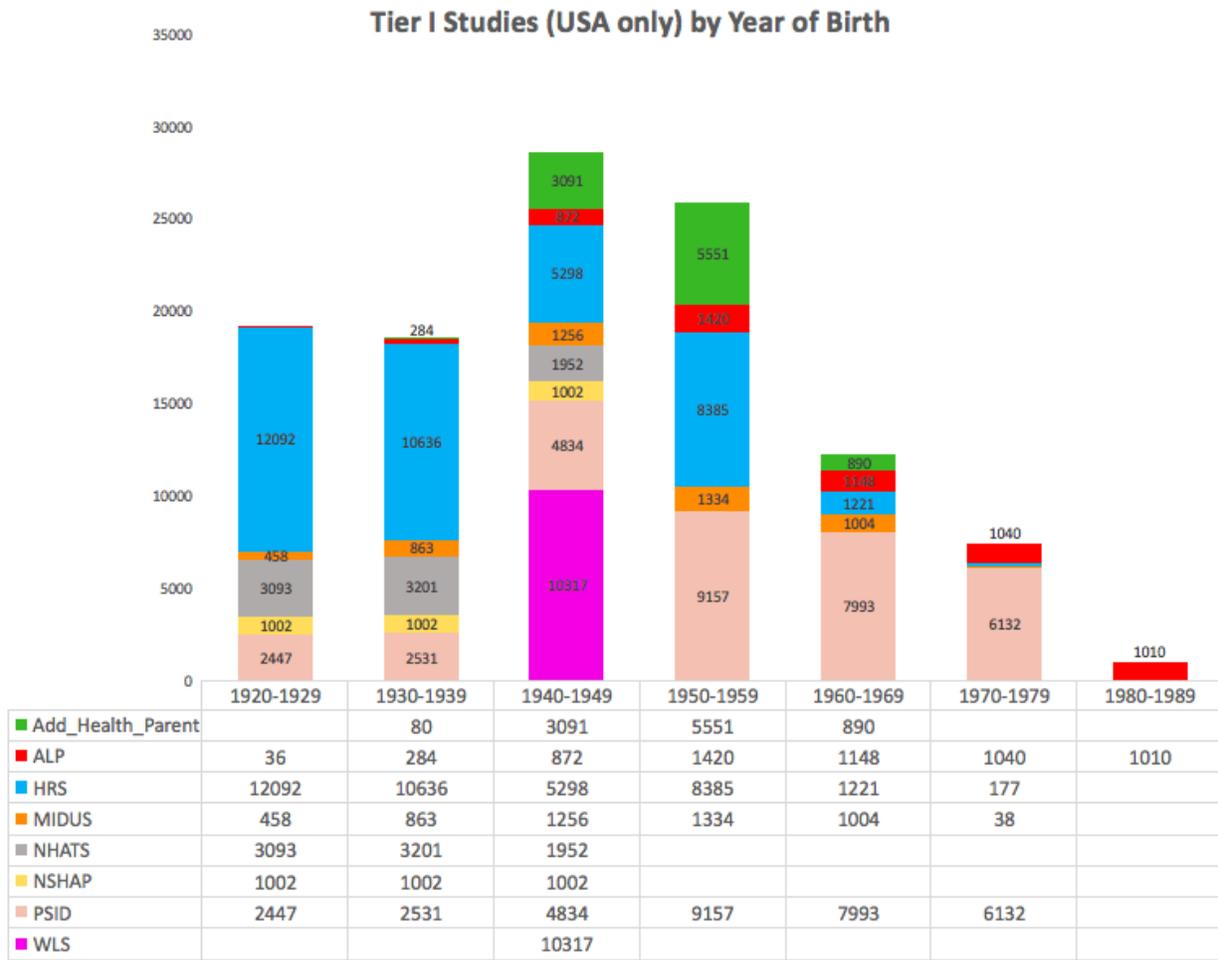


Figure 2. U.S.-based Tier I Studies; Number of Participants by Decade of Birth.

NOTES: These data are summarized to provide a basic overview and do not represent individual-level data from each study. Where necessary, individuals were proportionately assigned to the 10-year birth-year bands. For example, if the published study bands are 1925-1935 and 1936-1945, then 60 percent of the 1925-1935 and 40 percent of the 1936-1945 bands were assigned to the 1930-1939 band.

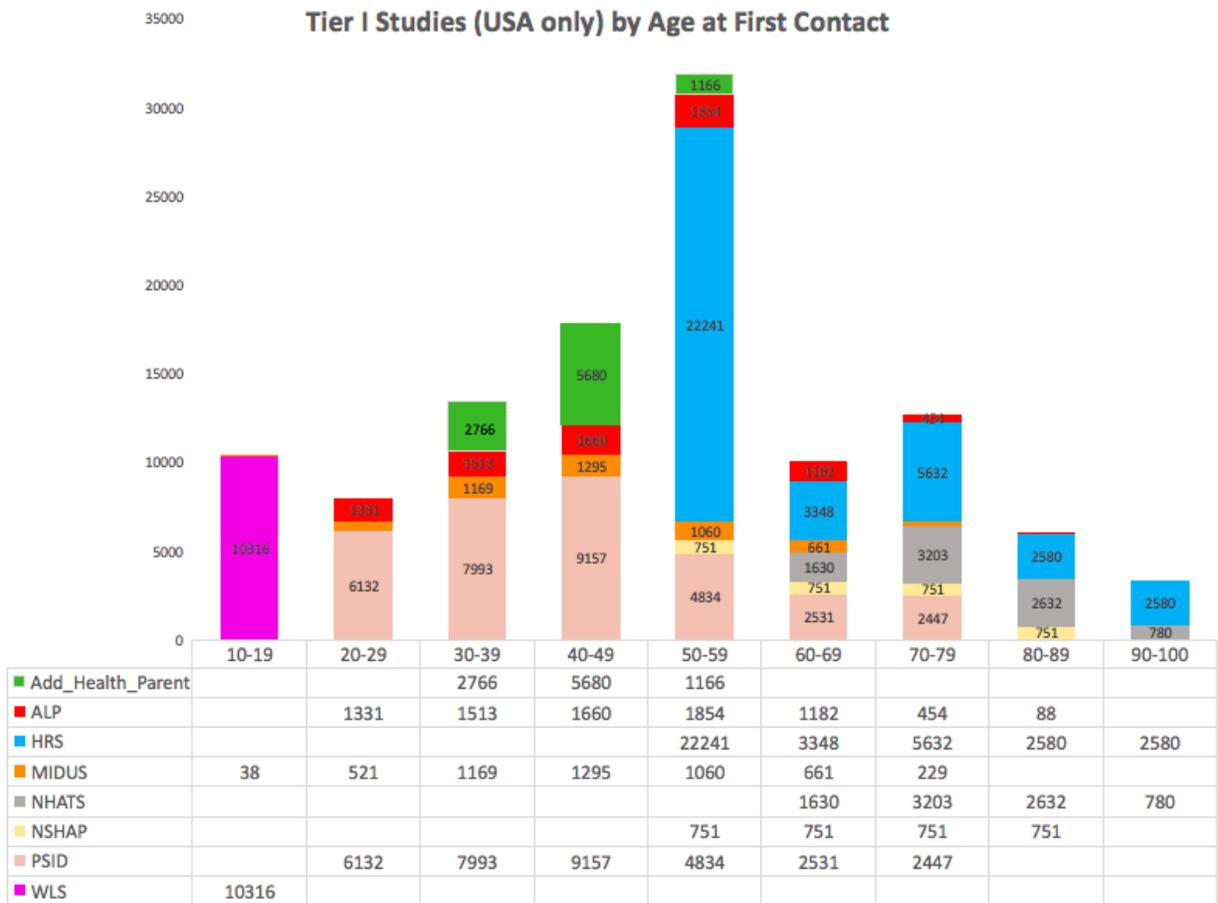


Figure 3. U.S.-based Tier I Studies; Number of Participants by Age at First Contact.

NOTES: These data are summarized to provide a basic overview and do not represent individual-level data from each study. Where necessary, individuals were proportionately assigned to the 10-year age bands. For example, if the published study age bands are 25-35 and 36-45 years, then 60 percent of the 25-35 and 40 percent of the 36-45 bands were assigned to the 30-39 year band.

Several of the major US studies in the portfolio fill a niche within the BSR data infrastructure portfolio. HRS is the platform that is representative for the entire population aged 50 and over, with periodic refreshment of birth cohorts newly reaching ages 50-54. The age cutoff was originally selected to enable following of people who were still working and still healthy through the full retirement period, as well as of people before onset of chronic diseases and disability until (and beyond) death. For cohorts entering HRS, including the first, only the noninstitutionalized population was sampled; however, HRS follows participants wherever they move, and so now includes a representative sample of older people in all living situations. Crucially for studies of disparities, HRS has a proportionate sample of people with low income and low educational attainment, and overrepresentation of African Americans and Hispanics.

Midlife in the United States II (MIDUS), as the name implies, starts with midlife (to which BSR advisory committees have consistently urged greater attention) and is BSR’s main source of

information on the pre-retirement age group apart from the more geographically restricted Wisconsin Longitudinal Study (WLS) and the Panel Study of Income Dynamics (PSID). MIDUS is especially rich in psychosocial and biological measurement, including measures taken at clinic visits and daily diaries.

The PSID is especially valuable for studies of family and household dynamics because it has followed family members since 1968 through moves and household formation and dissolution. It is not exclusively dedicated to aging and health, and NIA is only one of three major co-funders of the PSID, with the National Science Foundation and the NICHD.

The National Health and Aging Trends Study (NHATS) was designed as a successor to the National Long-term Care Survey (NLTC), which began under other auspices and was primarily funded by NIA through the 2004-2005 round. There were several concerns with the NLTC design, data availability, and documentation, which led to a decision (informed by participants at two NAS workshops) to hold an open competition for either a continuation or a replacement. NHATS draws its samples from Medicare beneficiaries aged 65 and over (oversampling the oldest old) and collects data annually from all participants. It specializes in assessment of disability, including innovative measures of the environments and assistive technology. In 2011 and 2015, the National Survey of Caregivers was conducted among caregivers for disabled NHATS participants with funding from the Office of the Assistant Secretary of Planning and Evaluation (ASPE).

The National Social Life, Health, and Aging Project (NSHAP) is especially adapted for study of intimate and social relations, and ego-reported (but detailed) social network data. It also has performance and biomarker data.

WLS is the long-term follow-up of a large sample of a defined cohort, Wisconsin high-school students in 1958, with various people connected to them (spouses and siblings). It is unusual in having rich, prospectively collected data from teenage years (and retrospective data for childhood collected after only a few years delay) for a birth cohort now in their 70s.

Internet surveys have added an element of flexibility and frequency of contact as well as a new survey mode. The first internet survey to receive support from BSR was the American Life Panel (ALP); more recently, the Understanding Americans Study has been added.

Add Health Parents is a new addition to the BSR portfolio. These are parents of the participants in the National Longitudinal Study of Adolescents and Adult Health (Add Health), a very widely used cohort study based on a multi-stage sample design such that whole high schools were included. NIA has already funded some harmonization of cognitive measures in Add Health (whose participants are now aged 34 to 42). The collection of data on the parents should open up possibilities for studies of intergenerational transmission and family dynamics in adult health.

The emphasis on international studies since the 2007 report has been on deepening and fostering comparability, rather than broadening the geographic range. “The 2007 Committee

report strongly endorsed NIA/BSR startup funding for HRS-like surveys around the world; ...vital to ensuring international data harmonization and sharing.” A major new development was the RFA for collection of harmonized data on cognition and dementia, which led to four awards covering HRS-like, nationally representative studies in England, India, and China and a small-area study in rural South Africa, which are much further along now. Both are adhering to the principles in the 2007 report, which include the ability to produce high-quality, comparable data and a commitment to making data available to researchers. The one significant territorial addition to the map since 2007 is the Health and Aging in Africa: Longitudinal Study of INDEPTH Communities (HAALSI).

BSR currently funds the [National Archive of Computerized Data on Aging](#), the [Gateway to Global Aging Data](#), and the [Integrative Analysis of Longitudinal Studies of Aging](#); these resources offer access for researchers to datasets and concordance of data across studies. BSR could consider providing additional support or resources to investigators seeking data generated from BSR-funded projects. This would serve a dual purpose: facilitating research using NIA-funded data while exposing potential violations of data sharing agreements. In the current environment, BSR may not be aware of all instances of investigators being unable to access data that are intended for public use. There may be additional opportunities for BSR to provide training and support to investigators both to share and to access data while reducing burdensome processes.

Data Usage

Table 2 shows counts of the numbers of NIH-funded analysis projects (mainly grants, but including components of program projects, contracts, etc.), active in October 2015, using data from one of the Tier I sources.³

³ These estimates are based on searches of awards completed in October 2015.

Table 2. Number of NIH-Funded Projects Using Data from Tier I Data Projects, October 2015

Health and Retirement Study (HRS)	127
Panel Study of Income Dynamics (PSID)	29
Midlife in the United States II (MIDUS)	24
American Life Panel (ALP); Understanding America (UAS)	11
The English Longitudinal Study of Ageing (ELSA)	11
National Health and Aging Trends Study (NHATS)	10
The Survey of Health and Retirement in Europe (SHARE)	10
China Health and Retirement Longitudinal Study (CHARLS)	8
Longitudinal Ageing Study in India (LASI)	6
National Social Life, Health and Aging Project (NSHAP)	6
Study of Global Ageing and Adult Health (SAGE)	6
Wisconsin Longitudinal Study (WLS)	6
Add Health Parents Study	[data collection in 2016]

Funding and Management

Funding is provided through cooperative agreements (e.g., HRS, NHATS) or grants (e.g., PSID, NSHAP, and MIDUS up to the current renewal application).⁴ The funding mechanisms typically cover some research aims as well as production and distribution of the data resource (with the exception of the HRS and NHATS; see the notes to Figure 1 for our method of separating out research expenditures from data infrastructure expenditures). NIA is the predominant, but not exclusive, funder of the HRS (the Social Security Administration provides approximately \$4 million per year); a partner in a consortium of funders for the PSID (with the National Science Foundation [NSF] and NICHD); and the almost exclusive funder of MIDUS II, NHATS, NSHAP, and WLS.

NIA has varying degrees of discretion over the funding for individual projects. The core funding for some large projects (HRS, NHATS, and, most recently, MIDUS) comes mainly through tailored RFAs, which announce the expected size of awards. Other projects are funded through investigator-initiated applications, which, when requesting more than \$500,000 in direct costs in one or more years, have to be approved in advance by NIA staff. Elements of some projects may be funded through smaller grants that were not pre-approved.

As an approximation to the relative proportions of BSR research funds devoted to data resources, Figure 4 shows the budget for one recent year (FY2015) broken down into four large, mutually exclusive categories:

1. Funds used to produce Tier I data resources
2. Funds used for analysis of Tier I data resources (some as entirely separate grants, some as a portion of the same grants or cooperative agreements funding creation of datasets)
3. Funds used for both creation and analysis of the Tier II data resources
4. All other BSR-funded research projects

⁴ Since the February 2016 Committee meeting, MIDUS was awarded a U19 cooperative agreement and is continuing work on a P01 grant in a no-cost extension.

BSR estimates that 25 percent of the BSR research budget was devoted to Tier I projects in FY2015, 13.5 percent of which was for the HRS. This was a high year because it counts two large supplements to the HRS, one for the Harmonized Cognitive Assessment Protocol (HCAP) dementia assessment and one for collection of venous blood, both of which were added in FY2015. The HCAP uses a special addition to NIA’s appropriation for Alzheimer’s disease research. Apart from those two supplements, the Tier I expenditures actually declined to below FY14 levels. A further 10 percent was used to fund analyses of Tier I data (7.5 percent for HRS analysis). Tier II projects (both production and analysis) accounted for just over 3 percent of BSR research expenditures. Other research funding amounted to just under 62 percent of the total of \$200 million.

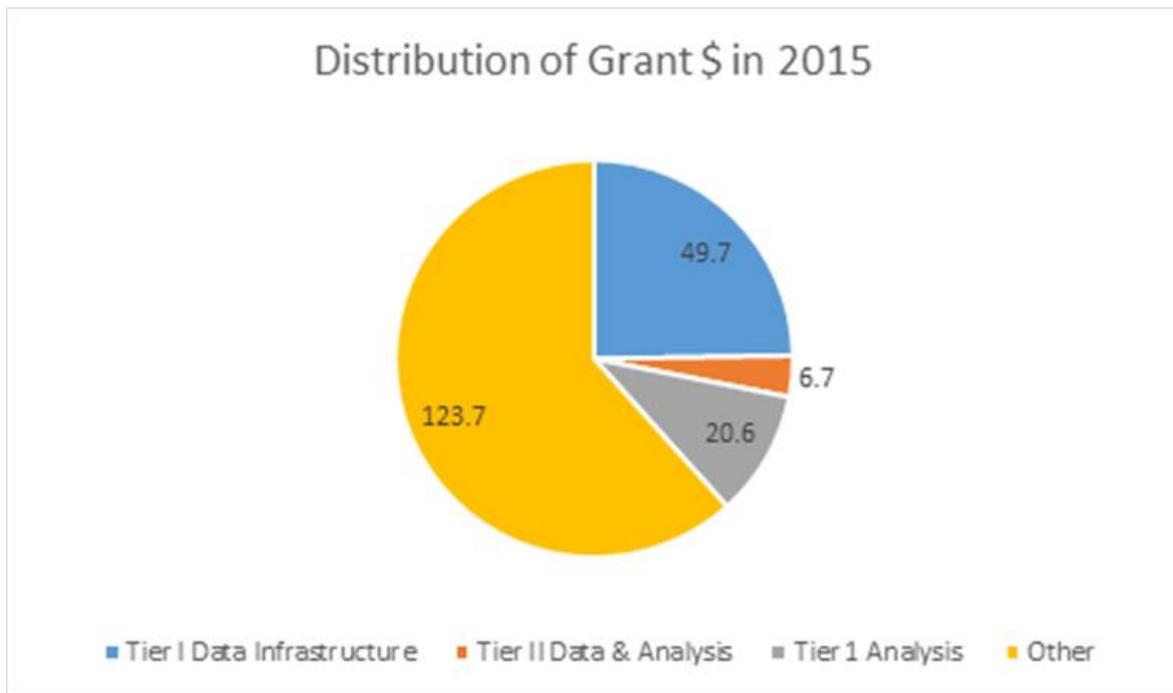


Figure 4. Distribution of BSR Grants Awards in FY2015.

Category	Grant \$M in FY2015	Percent
Tier I Data Infrastructure—HRS (\$27.1M, 13.5%)	49.7	24.76
Tier II Data & Analysis	6.7	3.33
Tier I Analysis—HRS (\$15.1M, 7.5%)	20.6	10.26
Other	123.7	61.65
Total	200.6	100.00

BSR is somewhat limited in its ability to manage across projects as a portfolio, for example, by deciding “if we are going to add accelerometry or neuroimaging for a subsample of participants,

to which studies should it be added?” or “to what extent do we want studies to use the same measures for comparability and to what extent do we want them to approach the same questions using different measures?” The program staff are also constrained by scientific review, which is sequential and decentralized. For example, if reviewers feel that some state-of-the-art enhancement known to exist in another data resource would improve the resource under review, they are free to say so, and score accordingly, whether or not BSR can afford the replication.

Several networks link the studies BSR funds and foster sharing of methodological and logistical information in ways likely to increase efficiency. These include the Biomarkers Network,⁵ harmonization efforts, and a new Network on Longitudinal Studies on Aging in the US⁶ that will foster creation and sharing of useful information across studies.

A relatively new data effort across the NIH is the Precision Medicine Initiative (PMI). This initiative intends to develop “big data” by enrolling volunteers and acquiring information from them and their electronic health records. It will not subsume any BSR study (because incorporation of existing research cohorts was explicitly rejected). But the value of BSR’s cohort studies as complementary resources, test beds, or replication datasets could grow as the PMI cohort starts to generate findings.

Committee Recommendations

The Committee considered the past decade to have been one of impressive developments in data infrastructure very much along the lines recommended in the 2007 data review report. The expansion of data collection to new areas, new ages, and new mechanisms was impressive and resulted in BSR being in an ideal position at this point to continue to support research that illuminates the pathways by which social, psychological, economic, and behavioral factors affect health in middle-aged and older adults; to support research that explains the disparities in aging by race, ethnicity, place of origin, and gender; and to support research aimed at understanding and modifying organizational or programmatic aspects or individual behaviors associated with positive and negative health outcomes in later life. The science has moved rapidly so that many of the mechanisms that will be the focus of investigations in the next 10 years were not even being considered 10 years ago. Many of the disparities and divergences in aging experiences have been brought to the forefront in the past 10 years but remain to be explained and ameliorated. The data have developed to provide considerable promise for promoting work at the scientific forefront on these issues. The Committee deliberations involved assessment of how to maintain the pace of scientific advances with scarce resources. The following recommendations resulted from Committee discussions.

⁵ <http://gero.usc.edu/CBPH/network/>

⁶ <http://micda.psc.isr.umich.edu/networks/>

Recommendation 1

BSR data infrastructure investments need to continue to evolve and develop in line with changing scientific focus and technical capability in order to promote research that illuminates the pathways by which social, psychological, economic, biological, behavioral, and medical factors affect health in middle-aged and older adults.

This field has matured markedly over the past decade, and the potential continues to grow for adding data that advances understanding of the aging process, which spans the lifecycle from beginning to end of life. There are also areas that have continued to be a challenge for current datasets and for which new approaches might be useful.

1.A. The integration of biological data into larger population-based studies—genetic and biomarker data—has been an important development of the past decade. Continued development of this approach should be encouraged to contribute to the growing scientific focus on molecular and cellular changes that reflect basic mechanisms of aging. This would include epigenetics and methylation. Additional areas not yet common in population research also show promise (e.g., the microbiome, neuroimaging, sensory functioning, body composition). Continued development of genetic data, including sequencing, will be needed to stay current with the science of aging. With growing interaction across fields, opportunities for integration of social and environmental data into what are considered biological data sets should be identified and encouraged where scientific progress could be extended in areas of BSR focus. Harmonization of concept measurement both biological and social will be important for research integrating biological and social data.

New biomarkers and other indicators of physiological deterioration will likely be a major scientific area of development over the next 10 or more years. BSR data allow unparalleled opportunity for clarifying the role of social and behavioral factors on biomarkers of the aging process. This will best be undertaken in longitudinal cohort studies with data on life circumstances over significant parts of the life cycle. NIA should consider cost-effective development of approaches for prioritizing integration of these types of data into studies. This could include validation of new measures in smaller studies, sub-studies, or nested cohorts and selection of the most promising measures for full-scale implementation in larger samples. This may mean not including all scientifically valuable approaches in all studies, but cross-walking and harmonizing measures across studies, using some studies to demonstrate the added value before including them in all studies.

Collection and storage of samples can often be an effective way to maximize the value of contemporary biospecimens collected from large cohort studies while minimizing current costs. This approach allows investigators to delay consumption of valuable biological samples until a better understanding of the most important assays emerges. It also allows funders to benefit from rapidly decreasing laboratory and analysis costs. This

does not mean all samples should be stored; immediate assays of some types may be required for scientific progress and for participant feedback.

1.B. BSR should encourage development of data that clarify the role of life experiences at different ages in affecting health and well-being at older ages. Understanding of the role of lifetime experiences in creating variability in aging outcomes has increased markedly in the past decade. With the increasing development of longitudinal datasets covering longer periods of life, questions of the resilience and reversibility of early-life effects can now be addressed. The life course perspective is essential for research on aging, but connecting accurate data on early-life circumstances to detailed data on later-life circumstances is a continual challenge. In the absence of a nationally representative set of birth cohorts followed to old age, other strategies may suffice. Research is needed to determine to what extent early-life exposures may be accurately collected with recall data, administrative or third-party data, or synthetic cohort methods, and how confidently such alternative sources can be used to approximate what would be available from a true prospective cohort study. None of these is ideal, but in combination these data can be triangulated for valid inference. It is also useful for NIA to pursue collaborations with funders of current cohort studies at earlier stages of the lifecycle to ensure that measures useful for life course studies across the aging years are incorporated at opportune times.

1.C. BSR should consider ways to reduce the significant obstacles faced by researchers in using medical care claims and encounter data. Use of medical care is a central mechanism through which disparities in health may arise. Linkages to data produced by the Medicare and Medicaid systems are essential for understanding health outcomes in longitudinal studies of aging. Facilitating the use of such data for the community of researchers is highly desirable. In addition, larger databases of use and claims linked to patient characteristics are needed for understanding geographic and diagnosis differentials in health outcomes. A growing challenge is the lack of accessible encounter data for an increasing proportion of Medicare beneficiaries enrolled in Medicare Advantage plans (currently 30 percent) and the difficulties with obtaining and using Medicaid data and data from private insurers. The coming decade should see growing research access to electronic health records, which should be encouraged and supported for research use. Administrative data linkages of many kinds could partially alleviate the lack of prior data in samples beginning recruitment at older ages; however, differences in conclusions reached from claims data and those gathered by self-report require further investigation.

1.D. BSR should further develop data to clarify how context affects the aging process, including end-of-life experiences. It is quite clear that social, familial, environmental, cultural, and policy contexts can influence the aging process. The development of cross-national datasets has greatly furthered understanding of contextual effects, and additional clarification of differences in cross-national programs and policies is encouraged. Data that develop our understanding of the role of social networks,

familial, work place, and environmental conditions should be encouraged both in terms of international comparisons and in investigation of the causes of differences in the United States. Data linkages that promote this strain of research should be promoted. In addition, novel methods of data collection of environmental influences should be considered.

1.E. BSR should continue its support of projects that clarify the causes and consequences of cognitive decline, impairment, Alzheimer’s disease, and dementia.

These are conditions that are most important in affecting the costs, social demands, and experience of aging. Understanding influences of early life in developing cognitive capacity is important, as is clarifying early markers and the period and speed of decline. Longitudinal designs with frequent assessment of neurocognitive function that permit accurate and early detection of within-person change are useful for observational studies and may help guide targeted intervention studies related to cognitive aging, Alzheimer’s disease, and dementia. Cohorts with early-life cognitive measures can be used to differentiate between individuals who have had lifelong low cognitive ability versus those who have age-related cognitive decline. Planned international comparisons should provide valuable information on the role of larger social and economic factors that may be important in predicting future trends. Alleviating the negative changes in quality of life for individuals and family members associated with Alzheimer’s disease remains a central issue for BSR research.

1.F. BSR should promote development of appropriate experimental and field studies.

Randomized experiments are valuable for determining cause and effect and effect size. They do not necessarily require a representative sample and may not be appropriate for embedding in an ongoing cohort; however, cohorts available to researchers for experimental studies could provide a useful resource. BSR should encourage researchers to think creatively about developing such cohorts. One possibility would be the designation of subsamples (i.e., sandboxes) for experimentation associated with larger studies, as is currently done with some internet panels—hybrids between the purely observational study and the experiment.

1.G. BSR should promote linkages of administrative data, programmatic data, and environmental context data to individual-level data sets. The addition of data from these sources can reduce respondent burden, increase accuracy of data, create opportunities for quasi-experimental studies, and provide information not known to the respondent. New methods for linking data collected for other purposes are being developed and should be evaluated and promoted where validity and reliability have been demonstrated. Linkage of existing administrative data from sources such as the National Death Index (NDI), Medicare, or electronic health records provide valuable extensions of survey data. Support for macro-level data collection can provide valuable contextual data for individual-level data sets as well as data in its own right (e.g., the Human Mortality Data Base).

Recommendation 2

BSR should continue its major investments in data infrastructure, preserving the capability for age, period, cohort, and cross-country population comparisons, while continuing to foster development of understanding of the mechanisms by which social, psychological, economic, biological, behavioral factors, as well as policies and programs, influence aging throughout the life cycle.

Over the past decade data have grown in scope both in terms of coverage of the life cycle, coverage of aging in different contexts, and content of indicators in datasets. These have been extremely positive developments, and the existing datasets supported by NIA grow significantly more valuable with the inclusion of these new dimensions and new populations. The high usage within the research community attests to their value. BSR should be congratulated for past performance and encouraged to maintain its scientific focus with consideration given to the following principles.

2.A. BSR should evaluate support for datasets, both new and existing, by their likelihood of adding significantly to the research findings on current scientific issues relevant to aging. New data collection can be an important way to advance science and BSR should be open to supporting new data infrastructure opportunities that will advance its scientific mission. It is also important to consider developing new approaches to collecting data to answer the primary scientific questions about mechanisms of aging and disparities of the experience of aging in the United States. Support for existing datasets should be contingent on their ability to continue to address emerging scientific issues and national priorities. Studies should be evaluated based on current scientific productivity (e.g., new findings, valuable replications, or tests of previous findings that impact public health; number of publications per year or per funding amount; data use and publications by researchers not associated with the project) and the extent to which scientific output aligns with the NIA mission.

Undertaking support for data collection or maintenance of existing cohorts that have not been developed for the study of aging but are now aging needs to be carefully considered and subjected to the same principles used for considering new data sets. Not every aging dataset is valuable to the study of aging. A convincing case that a cohort provides something new and important should be made before support is provided for aging cohorts. Cohorts need to provide evidence that their representativeness, loss rates, and content provide an appropriate basis for studying aging (i.e., evidence that inferences from these cohorts could be generalized to larger populations). Studies of specific populations and specific geographic locations need to be held to similar standards.

2.B. BSR should develop and document clear principles for sunseting and/or repurposing ongoing studies that are no longer addressing top priorities for evolving science. Studies may run their scientific course and continuation may not produce valuable science. Ending a study need not be an all-or-nothing decision. One potential strategy, which may continue to produce useful science, is to continue passive data collection by using existing or new linkages to administrative datasets, such as Medicare claims data and the NDI.

2.C. BSR should form a standing committee to provide advice to program staff on data infrastructure when needed for advice and information. BSR program staff may need to assess redundancy across studies, which is not obvious to study sections, and which could result in inefficient duplication. Because it is not possible for any single review panel to have knowledge of all ongoing data collection and how current requests fit into the overall portfolio, a committee could help BSR staff evaluate this. It is recommended that members of such a committee be asked to serve at BSR's discretion for a limited term of 2 or 3 years. It is also possible that such a committee could be of use to staff in thinking about duplication and harmonization of multiple studies. Some duplication is valuable, but not every study needs to have all of the most current scientific advances. Integrated planning across studies, harmonization, and cross-walking might be valuable for some major data infrastructure components. The standing committee's future evaluations of the BSR portfolio should be informed by metrics in addition to dollars spent, such as total number of publications, relative citation index, and publications and data use by parties other than the data infrastructure awardees.

Recommendation 3

BSR should continue to encourage the development of data that can be used to clarify the causes and paths to remediation of disparities in health by race, ethnicity, socioeconomic status, gender, immigration and migration status, and geography.

Health disparities exist across all of these dimensions, and many are not well understood. Disparities appear to be increasing along some dimensions, and the causes may vary across population subgroups. Understanding disparities in health requires sample sizes large enough to reliably investigate disparities. Data collection exercises should also be sensitive to incorporating information on varying mechanisms through which differentials arise and perhaps become levers for amelioration. BSR should promote research to explore what new content is needed in order to collect information on the unique experiences of racial/ethnic minorities, women, people living in different geographic areas, and immigrants and how these individually and interactively affect health statuses. Particularly important is greater attention to major acts of discrimination as well as micro-aggressions in daily lives that ethnic and racial minorities and immigrant groups may face over the life course. Other areas may include attention to disrupted education experiences, neighborhood and living quality differences, the role of family formation and fictive kin relationships, experiences of financial exploitation, and incarceration and criminalization.

Recommendation 4

BSR should encourage training opportunities for the use of newly available types of “big” data. Use of newly developed data of numerous types requires specialized knowledge. In order to have these data used by the wider multidisciplinary community, special training is required.

More opportunities for training researchers of all levels to use new methods or types of data are needed. Summer training programs may be a cost-effective way to establish a cohort of researchers who are well-versed in a particular type of data for use in future studies. BSR is also encouraged to explore alternative formats for training including sending trainers to PhD programs and medical schools, supporting webinars and online training sessions, and archiving video presentations for later viewing. Such alternative formats could be cost-effective and reach broader audiences.

Training programs can be an effective way to facilitate collaboration across disciplines. Data from biomarkers, genetics, neuroimaging, medical claims, sensors, smartphones, social media, etc., are currently difficult for many social scientists to use, and training directed at these topics will be useful and will require multidisciplinary input.

Recommendation 5

BSR should continue to support cross-national comparative research where it promotes scientific understanding of the aging process.

Support for international research offers unique opportunities for understanding the aging process. Studies in other countries may allow scientific investigation that is not possible with U.S. data. For example, studies of birth cohorts in other countries have followed participants through the life cycle and allow more direct and prospective assessment of the role of earlier life events than is possible with aging cohorts in the United States. Studies in other countries also can enable research on the effects of policy changes that happen more frequently in other countries, unique opportunities to capitalize on natural experiments that do not exist in the United States, and the opportunity to learn from unique data linkages that are not available in the United States. Other countries may have systems of administrative data that can be linked to better understand life cycle health than does the United States. Some countries offer study of unique aging experiences that are important to understand. As with U.S. studies, support for international studies and research should be determined by the scientific rationale and value in explaining the aging process. Support for infrastructure development or data collection should require the same expectations of data release to the international research community. Harmonization of data instruments that allow comparisons between the United States and other countries should also be a requisite of support.

International comparisons with U.S. data are extraordinarily valuable. The context in which people live is often set by their country of residence. Looking across countries can be akin to a natural experiment. For example, the existence of the HRS family of studies has enhanced U.S. aging research and the understanding of the U.S. aging experience in several ways. For

example, data collected in other studies have shown the value of a topic (e.g., life histories) and subsequently have been incorporated in U.S. studies. Having a sister study with similar social, behavioral, and health data as well as genetic data (e.g., ELSA) allows the publication of findings from the U.S. data, given that publishing genetic research often requires one sample for discovery and one for analysis. The HRS and ELSA serve this role for each other. Promoting harmonization among the international studies should be an important continuing goal for BSR because it underlies the ability to make valid cross-national comparisons that add to our understanding of the effects of policies, life circumstances while aging, and health disparities. The recent awards for harmonized cognitive assessment protocols are an excellent example of a productive approach to supporting cross-national analysis.

Current cross-national datasets will allow many useful comparative studies taking advantage of the wide variation in policies and programs (e.g., long-term care of the disabled elderly) across countries and subnational regions. Supporting research to compile and maintain a dataset documenting the most important policies and programs relevant to aging issues, and how they vary across space and over time for the regions covered by harmonized microdata, could be very cost-effective, because no such comprehensive resource now exists for research on aging.

The HRS family studies now cover a significant part of the world and adding additional countries may produce diminishing returns from a BSR perspective unless the study has a unique scientific aspect. In the past, BSR support for many international studies has been at the development phase (e.g., R21 awards) with study infrastructure generally funded by the host country. The approach of using supplementary awards that promote BSR priorities is desirable. BSR has an interest in being involved in the development of comparative studies in order to use its influence to encourage that international datasets adhere to accepted standards for harmonization, sampling, representativeness, and follow-up (i.e., including mortality). BSR also has a vested interest in supporting or continuing to support existing studies that have provided important data and research findings in the past. The presence of existing data, the existence of a developed research team, and past provision of public use data are factors to be considered in evaluating the overall return likely to be accrued from future support.

Recommendation 6

BSR should encourage methodological development to reduce respondent burden and study costs.

There are increasing problems with recruitment and retention in studies of all types. This trend appears to be pervasive, but it could be a particular problem for obtaining sufficient samples for analyses of health disparities among subpopulations defined by race, ethnicity, sex, education, wealth, and rural residence.

BSR should encourage continued investigation of methods of developing representative samples while maintaining or improving data quality. Important data infrastructure projects are often large and costly. A number of sampling strategies, if further developed, might reduce data infrastructure costs or improve data quality or sensitivity of detecting important events. These include targeted burst designs that trigger intensive data collection before, during, and after

important life events; the creation of new internet samples that can serve as platforms for experimental research; and the sharing of screened populations for complementary study samples.

Of course, not all samples need to be representative of the population in order to add value; there are circumstances in which it is acceptable to assemble a diverse sample that is not representative. Clarifying the value of representative and nonrepresentative samples is important to BSR in light of the PMI Cohort Program.

In general, more effort is needed to empirically determine the ideal frequency of various measurements (e.g., the optimal frequency of repeating frailty, biological, or cognitive measurements to detect change points that may indicate rapid declines in functioning and may predict death or other health outcomes) and to design cost-effective studies that collect data with the appropriate periodicity. It is possible that ideal periodicity will differ by indicator, which should be considered.

Connecting data across different studies and projecting results from smaller samples onto larger samples represents a potentially cost-effective way to incorporate new measures into large studies. Not all studies need to measure all variables. The Aging, Demographics, and Memory Study (ADAMS), which conducted detailed cognitive assessments on a subsample of HRS respondents and allows imputed results for the full sample, is a model for this approach.

Some new methods (e.g., social network assessments) significantly reduce assessment time. Development of additional methods that further reduce respondent burden while capturing detailed social network data, including occupational and intergenerational influences, is needed. For instance, data linkages to social media are worth exploring and offer potentially rich data with minimal participant burden.

Encouraging measurement of environmental influences both inside living units and in the neighborhood using sensors and novel measurement approaches should be considered to improve the scope of understanding of environmental influence. Validation of emerging methods in small studies or subsets of larger studies will bolster their credibility for broader use, potentially facilitating adoption of low-cost, high-reward research methods throughout the field. Large cohort studies could later adopt the most promising new methods for large-scale implementation.

Encouraging more systematic usage of administrative data and records that can be linked to individuals to clarify earlier life cycle conditions and environmental influences (e.g., neighborhood characteristics, housing characteristics) can both reduce survey burden and costs and/or add value to the data collected directly from survey respondents.

Recommendation 7

The Committee views current NIH data sharing requirements as not stringent enough. BSR should adopt more stringent data sharing requirements than current NIH policies require and facilitate timely data sharing by all projects that produce valuable data resources, whether or not the grant is over the \$500,000 threshold. BSR should also strengthen enforcement of data sharing requirements. The Committee recommends that all studies that are supported to produce data, regardless of dollar amount, should be required to share data publicly unless there are confidentiality or proprietary reasons not to.

Current NIH policy requires that investigators submitting an application seeking \$500,000 or more in direct costs in a single year include a plan for data sharing or provide justification of why data sharing is not possible (https://grants.nih.gov/grants/policy/data_sharing/). The NIH policy indicates that the data sharing policy can be addressed in RFAs or Requests for Proposals (RFPs). Program Announcements (PAs) may request data sharing plans for applications with direct costs of less than \$500,000 in any single year. The dollar limit seems arbitrary, and significant data resources can be produced by smaller awards. The Committee supports changing policy so that researchers need to make compelling arguments if they do not plan to share data publicly with the research community (e.g., confidentiality, proprietary, or the burden to a small study), in order to promote sharing by default unless the cost of making data public outweighs the benefit to the research community. A greater interest across the behavioral and social sciences (and across the NIH) in replicability of results will create new demand for open-access datasets; BSR and its grantees need to be part of the wider efforts of the NIH for reproducibility of research results. Greater focus in determining causes for differences across population subgroups and geographic areas also would benefit from making more data available.

Although most projects that are clearly data infrastructure projects produce public use data sets in a timely manner, BSR also funds many studies that produce datasets, sometimes spanning years and many rounds of data collection that are primarily intended to support the research aims of one grant or project. Data from many of these could be used more widely. Data sharing plans should specify how such data will be shared for replication studies or for use by qualified researchers for additional analyses, with the lowest prudent barriers to data access.

The Committee also supports a change in policy that makes the proposed data sharing plan a determination of scientific merit or priority score. BSR also might consider having researchers make their data-sharing plans public. Because the NIH requires a data-sharing plan in the application that is in compliance with the Funding Opportunity Announcement and is accepted by the Program Official, staff currently can set requirements for data sharing and can fully evaluate the proposed plan and clarify requirements as part of the Terms and Conditions of the award.

A grantee's declaration of good intentions should not suffice (as in "anyone who wants to use the data is welcome to apply, and if we are interested in what they want to do, we will invite

them to co-author papers with us”) nor should excuses such as “the amount of the grant was 18 percent below what we requested, so we will not archive or disseminate the data.” For data projects that have been funded for some years, consideration for renewal funding should be based, in part, on whether data actually have been used by researchers other than the original team of investigators. If they have not been, BSR should make it clear that the project has not demonstrated the value of the data and that a renewal application would be accepted only in unusual circumstances.

This encouragement should be accompanied by serious efforts by BSR to make it easy for grantees to obtain consultation on best current practices in the ethics of informed consent for data sharing, reduction of participants’ perceived or real risk of re-identification, data security, data curation, and funding an archiving service that can handle many or most of the tasks for high-value data resources. It is vital that appropriate informed consent be obtained at the start of studies if data are to be shared with the research community. BSR staff should also clarify for what reasons data sharing is not appropriate and guide people in making an effective case for exemptions.

It will be important to make this policy clear to potential applicants at an early stage, ideally before the award of the first data collection grant, that in addition to NIH formal review criteria, BSR staff will be looking for evidence of the actual, rather than theoretical, value of a data resource to the wider community when making funding recommendations for grant renewal to the NIA Director.

It is understood that certain types of data (e.g., sensitive and proprietary data) require appropriate safeguards and cannot be publicly released without restriction. BSR should continue to work with grantees and other organizations to take advantage of modern methods of making data accessible without posing a threat to confidentiality. This could include continued funding of efforts by the NAS and others to define and promulgate best practices, and funding of research and development for virtual data enclaves and other ways for safe reuse of potentially identifiable data.

Recommendation 8

BSR should encourage the development and dissemination of best practices for informed consent, reduction of participants’ perceived or real risk of re-identification, data security, and data curation.

With new types of data, and new types of data storage and distribution, there are potential new risks to participants who provide basic data infrastructure. BSR should regularly reevaluate the rights of research subjects and the responsibilities of researchers to make all efforts to protect the rights and safeguard data provided. This is becoming increasingly more complicated as data have implications not only for the respondent but also for family members and as new discoveries change the implications of existing data. BSR should encourage continued investigation of best practices for data development and dissemination.

Recommendation 9

NIA should develop a central repository for biological samples that allows for their retention after the period of support for the grant that collected them has ended. It should also consider developing a biorepository for ongoing studies.

9.A. A biorepository for ended projects with specimens is essential. Several BSR and other NIA studies collect many types of biological samples that have been saved for future use. Active support of these studies will end, and there may be a desire to preserve these samples for future use. Such a repository would not receive all samples. There will be complicated issues of establishing scientific value of the samples and rationale for sample use as well as approval from institutions and subjects, ownership, maintenance costs, etc. However, principles need to be developed before sources of valuable data are lost. We believe that it is wise for BSR to join with other NIA units to clarify issues, expectations, and plans for the future. It would be appropriate for project officers for individual studies to encourage planning for long-run storage even while support is ongoing or before support begins.

9.B. A biorepository for ongoing studies should also be considered. For some studies or samples, voluntarily placing specimens in a central facility might be best for current costs, future usage, and data preservation. Although there may be many complications to developing a biorepository, appropriate clarification of the standards, expectations, rules, etc. for future use should be considered now.

Recommendation 10

Although this Committee believes that population representativeness is usually desirable for investigating scientific questions about health and aging, the PMI Cohort Program may present unique opportunities to study questions relevant to the BSR mission, depending on its ultimate design and implementation. Where appropriate, BSR should encourage use of representative data to inform the PMI, and it should use results from the PMI to encourage attention to scientific questions that would be better addressed in defined cohorts.

The PMI aims to establish a cohort of more than 1 million volunteer Americans to serve as a platform for observational and experimental studies examining the biological, environmental, and behavioral influences on common and rare diseases.⁷ Population scientists generally believe representative samples are required to understand general population health and see the volunteer nature of the PMI as a long-term weakness. However, close and early involvement of social scientists in the design of the PMI Cohort Program would maximize its ability to contribute to the understanding of the social and behavioral determinants of health, disease, and the aging process. Considerable scientific value can be offered by research on methods to draw valid comparisons between the PMI cohort and established representative cohort studies and evaluations of the implications of sample representativeness for generalizable inferences on determinants of health. The value of BSR's cohort studies as

⁷ More information about the PMI Cohort Program is available on the website: <https://www.nih.gov/precision-medicine-initiative-cohort-program>

complementary resources, test beds, or replication datasets could grow as the PMI cohort starts to generate findings.

Recommendation 11

BSR should continue to realize cost-effective opportunities to further its mission through collaboration with other funders and other branches within NIA, when appropriate.

BSR has interests complementary to that of other funders, NIH Institutes, Centers, and Offices and other Divisions within NIA. Some of the major BSR data infrastructure projects have significant co-funding from other sources—for example, the Social Security Administration co-funds the HRS, and the NSF and NICHD co-fund the PSID. Such collaborations can be demanding in staff time, but as the needs of behavioral and social research grow more complex, opportunities also grow, yet budgets remain constrained. Growth in this field is likely to come from selective new collaborations. This is a time when the science across NIA Divisions seems to be increasingly integrated, and data infrastructure in BSR will be improved with growing collaboration.

Appendix A: Tier I and Tier II Data Projects

For the purposes of this Data Infrastructure Review, Tier I projects include data resources meant to be useful for multiple research studies, many of which will be implemented by investigators other than those involved in the parent project. The grants or cooperative agreements funding these projects often include specific aims relating to the research of the project team, so for those cases BSR staff removed a proportion of the funding deemed to be for analysis rather than creation of the data resource.

This designation is a statement about the study's relevance for this review and does not imply greater scientific importance than projects not listed in Tier I.

Tier I U.S.-based Data Projects

- Health and Retirement Study (HRS)
- Midlife in the United States II (MIDUS)
- Panel Study of Income Dynamics (PSID)
- National Social Life, Health and Aging Project (NSHAP)
- National Health and Aging Trends Study (NHATS)
- Wisconsin Longitudinal Study (WLS)
- American Life Panel (ALP)
- Add Health Parents Study

Tier I International Data Projects

- The English Longitudinal Study of Ageing (ELSA)
- The Survey of Health and Retirement in Europe (SHARE)
- Study of Global Ageing and Adult Health (SAGE)
- China Health and Retirement Longitudinal Study (CHARLS)
- Longitudinal Aging Study in India (LASI)

Additional sets of studies, considered as groups:

- Other international studies modeled on, and to greater or lesser extents harmonized with, the HRS (e.g., Health and Aging in Africa: Longitudinal Studies of INDEPTH Communities [HAALSI], Indonesian Family Life Survey, Mexican Family Life Survey, Mexican Health and Aging Study, Japanese Study on Aging and Retirement)
- Cognitive Studies (Integrative Analysis of Longitudinal Studies of Aging [IALSA] consortium, which includes some studies listed here separately, and many not funded by NIA)
- Twin Studies (Interplay of Genes and Environment across Multiple Studies [iGEMS] consortium and several studies funded directly by NIA)

Although they do not represent pure infrastructure investments to the same degree as Tier I projects, the Committee may also consider Tier II studies as producing infrastructure. Data collection in these projects is primarily to support a specific research project. Many are

supported by grants awarding less than \$500,000 in direct costs in each year and thus do not require pre-approval for applications. They typically cover one birth cohort; they are often not nationally representative; and are not expected to continually refresh cohorts. Some are not supported by an active NIA grant, although they have been in the past and future applications from the investigators may succeed and provide support in the future. Many of these projects have multiple sources of funding.

BSR encourages—and for large grants, requires—data sharing from Tier II studies. These projects provide useful resources, and contribute significantly to the goals of data sharing, although they are not reviewed primarily on that basis and support for them is not predicated primarily on their value outside the parent project.

Tier II Data Projects (examples—not all currently have NIA grants supporting them)

- Hispanic Established Populations for the Epidemiologic Study of the Elderly (HEPESE)
- Collaborative Perinatal Study long-term follow-up of New England cohorts
- Terman Study long-term follow-up
- Project Talent
- Los Angeles Family and Neighborhood Study (LA FANS)
- Taiwan Social Environment and Biomarkers of Aging Study (SEBAS)
- Cebu Study (Philippines)
- Study of the Tsunami Aftermath and Recovery (STAR) in Indonesia
- Midlife in Japan (MIDJA) Comparison Study to MIDUS
- Dunedin cohort
- Union Veterans
- Tsimane Study
- Social Network Study (Fischer)
- Seattle cohort
- Victoria cohort
- Long Beach cohort
- Americans Changing Lives
- Longitudinal Study of Generations

Appendix B: Excerpts from Previous Reports

The [2013 BSR Review Committee Report](#), National Advisory Council on Aging

Page 1 of Executive Summary

This report does not purport to be comprehensive about all the areas that BSR should support. Rather, the Committee sought to highlight the areas meriting particular attention, both in the overview and in the discussion of scientific topic areas, given the state of the science today. In this spirit, the Committee recommends four integrative research areas that merit high-priority support:

- Research that ***illuminates the pathways*** by which social, psychological, economic, and behavioral factors affect health in middle-aged and older adults.
- Research aimed at understanding and ***modifying organizational or individual behaviors*** associated with positive and negative health outcomes in later life, including organizational and individual interventions in the health care system.
- Research ***on factors that affect population aging, as well as the consequences of population aging***, particularly in the context of demographic and epidemiologic transitions in progress and macro aspects about health, economics, and retirement.
- Research that ***ameliorates the impact of disadvantaged position in society***, including research that focuses on critical periods for reversing such effects and/or the optimal timing of intervention.

The Committee also recommends a number of actions related to...data infrastructure... [including]:

- BSR should continue to emphasize the integration of biological, social, and behavioral science. BSR has been a leader in developing infrastructure for data sharing and should continue to strategically allocate resources devoted to this important effort and demand timely data sharing by grantees. Moving forward, BSR should review on a regular basis its priorities for data collection to ensure the greatest value from its investments and should sunset studies with declining marginal returns.
- The Committee endorses BSR's efforts to balance and integrate or iterate where possible randomized controlled trials with existing observational studies to maximize the utility of current studies

Reconvening of the Data Priorities for Behavioral and Social Research on Aging Committee, December 2013. Notes from this meeting provide recommendations for overarching criteria for evaluating studies:

- Alignment with the scientific priorities of the NIA/BSR;
- Productivity and impact of ongoing studies;
- Cost-effectiveness; and
- Balance of the entire BSR portfolio in terms of short- and long-term investments, funding mechanisms, and content.

Appendix C: Background Materials

List of Materials Provided to the Committee Prior to the November 9, 2015, Teleconference

- November 9 Teleconference Agenda
- Overview Memo
- Charge to the Committee Memo
- Committee Report on Data Priorities for Behavioral and Social Research on Aging, November 2007
- Summary of a Reconvening of the Data Priorities for Behavioral and Social Research on Aging Committee, December 2013
- BSR Review Committee Report, National Advisory Council on Aging, 2013-2014 Review
- Report from Expert Meeting on Possible Enhancements to Several NIA Longitudinal Studies, Committee, convened by the National Academy of Sciences Committee on National Statistics, May 2015

List of Materials Provided to the Committee Prior to the February 5, 2016, Meeting

- Meeting agenda
- Plans for meeting memo
- Background memo
- Overview table of characteristics of Tier I data resources
- Tier I project briefs
- Supplementary memos
- Major current investments in longitudinal studies of cognition
- International studies in the network on harmonization to the HRS
- Twin studies funded by NIA/BSR
- Comments received from professional organizations
- Detailed spreadsheet of characteristics of Tier I data resources

Appendix D: February 5, 2016, Meeting Agenda

Revised 2-2-16

Friday, February 5, 2016		Gateway 525C
9:00 a.m.	Welcome	Eileen Crimmins John Haaga
	WHAT IS NEEDED FOR THE FUTURE	
9:15	Aging Bodies: Mortality, Disease, Disability, Frailty	Eileen Crimmins
9:25	Use and Provision of Health Care	Jonathan Skinner <i>(remotely)</i>
9:35	Biosocial and Biobehavioral Influences on Aging	Maria Glymour
9:45	Q&A and Discussion	
9:55	Aging Minds: Cognition and Decision Making	Scott Hofer
10:05	Health Disparities	James Jackson
10:15	Subjective Well-being and Emotional Health	Arthur Stone
10:25	Q&A and Discussion	
10:35	BREAK	
10:50	Economic Behavior, Support, Work, and Retirement	James Banks
11:00	Life Course Influences, Reversibility, Resilience	Terrie Moffitt
11:10	Social and Physical Environment Participation/Integration in Family, Neighborhood, and Community	Lisa Berkman
11:20	Q&A and Discussion	
11:30	Behavior	David Laibson
11:40	International Studies	James Smith William Dow

11:50	Administrative and Big Data	Constance Citro
12:00 p.m.	Q&A and Discussion	
12:10	LUNCH	
1:10	Precision Medicine Initiative: How Ought NIA data projects relate?	John Haaga
1:30	PRINCIPLES FOR DECISION MAKING Principles to Guide Decision Making in the Next Few Years <ul style="list-style-type: none">• BSR scientific priorities from 2013 NACA review• How well do/should we cover life before age 50?• What is the right balance between national representativeness and smaller-area, more intensive studies?• Principles for deciding which existing (orphan) cohorts to adopt• Principles for deciding when and how to allow a cohort to sunset	Eileen Crimmins John Haaga
3:30	BREAK	
3:45	Principles and Priorities for Cross National Comparative Research and Harmonization	John Phillips
4:15	Next Steps—Staff and Committee Assignments	
5:00	ADJOURN	

Appendix E: February 5, 2016, Meeting Participant List

Data Infrastructure Review Committee Members

Eileen Crimmins, Chair, University of Southern California

James Banks, The University of Manchester and Institute for Fiscal Studies

Lisa Berkman, Harvard University

Constance Citro, National Academy of Sciences

William Dow, University of California, Berkeley

Maria Glymour, University of California, San Francisco

Scott Hofer, University of Victoria

David Laibson, Harvard University

Terrie Moffitt, Duke University

Jonathan Skinner, Dartmouth College (via web conference)

James P. Smith, RAND

Arthur Stone, University of Southern California

Division of Behavioral and Social Research

John G. Haaga, Acting Director

Partha Bhattacharyya, Program Director, Population and Social Processes Branch

Prisca N. Fall, Research Program Analyst, Population and Social Processes Branch

Melissa Gerald, Program Director, Individual Behavioral Processes Branch

Jonathan King, Program Director, Individual Behavioral Processes Branch

Lisbeth Nielsen, Chief, Individual Behavioral Processes Branch

Lisa Onken, Program Director, Individual Behavioral Processes Branch

Georgeanne Patmios, Acting Deputy Director

John W. R. Phillips, Chief, Population and Social Processes Branch

Contractor Staff

Chandra Keller-Allen, Project Coordinator, Rose Li and Associates, Inc. (RLA)

Rose Maria Li, Senior Advisor, RLA

Samuel Thomas, Science Writer, RLA

Appendix F: Comments Solicited from the Research Community

January 19, 2016

John G. Haaga, PhD
Acting Director, Division of Behavioral and Social Research
National Institute on Aging
Gateway Building, Suite 533
7201 Wisconsin Avenue
Bethesda, Maryland 20892

Dear John,

On behalf of the Association for Psychological Science (APS) I appreciate the opportunity to comment on the National Institute on Aging Division of Behavioral and Social Research (BSR) program of data resources to support aging research in the behavioral and social sciences. APS is a 26,000-member U.S.-based international organization that advances scientific psychology in research, education, and the improvement of human welfare. APS members are involved in the full range of areas represented in the diverse field of psychological science, from basic biology and neuroscience to social and organizational studies, and promoting the integration of these diverse scientific perspectives is one of APS's most important goals.

APS recognizes BSR as a national leader in the management of data resources and the practice of data sharing. Collecting valuable data on lifespan development is both time- and resource-intensive. BSR's careful dedication to building an infrastructure for aging research helps maximize the impact of that research while improving efficiency. This dedication is typified by BSR's successful review of data priorities in 2007.

Specifically, APS would like to underscore the value of BSR's current data initiatives. These initiatives support research on important topics such as midlife, time use, and retirement. APS also recognizes the importance of collecting and maintaining data describing populations outside of the U.S.

Beyond existing programs, APS believes future data initiatives could consider the importance of "big data" and build ties to other existing data initiatives when possible. Working to connect with research on the other end of the lifespan -- child development -- may also be an important goal. APS too believes that recent BSR-related events exploring "reversibility" and pathways to healthy aging may hold ideas for establishing new data priorities.

APS also continues to promote open data and open research practices, and we value our partnership with NIA in advancing these issues. I know that NIA's involvement was shaped significantly by the visionary leadership of the late Richard Suzman, and many of the activities in the field continue to reflect his efforts and those of BSR more broadly. As you may know, authors who publish in our journal *Psychological Science* are awarded badges for making their data and materials accessible to other scientists and the public. APS is also a signatory on the Transparency and Openness Promotion Guidelines, which help guide standards in the scientific community. APS urges BSR, in its data resource efforts, to continue to be a leader in NIH- and science-wide discussions on research transparency.

In sum, APS commends BSR for its data sharing initiatives, and we look forward to continuing to work together to strengthen the development of, and access to, data resources relating to aging. I would be pleased to provide additional information and hope you will continue to view APS as a resource for expertise and support in these efforts.

Sincerely,



Sarah Brookhart
Executive Director

The National Academies of
SCIENCES • ENGINEERING • MEDICINE

DIVISION OF BEHAVIORAL AND SOCIAL SCIENCES AND EDUCATION

Committee on Population

Date: January 27, 2016

To: John Haaga, Acting Director, Division for Behavioral and Social Research, NIA

From: Peter J. Donaldson and Kathleen Mullan Harris, Committee on Population

Subject: BSR Data Resources Investments

In response to your request for input from the Committee on Population (CPOP) for your review of BSR's data resources and infrastructure to support aging research in the behavioral and social sciences, we convened a telephone conference call with CPOP members on January 18, 2016. The following members participated: Jere Behrman, Vicki Freedman, Kathleen Mullan Harris (Chair), Mark Hayward, Hillard Kaplan, Sara McLanahan, Emilio Parrado, and John Wilmoth. Interim CPOP director Peter Donaldson also participated as did rapporteur Kristen Schorpp.

Our discussion was structured according to the following questions: 1) What are the pressing issues and scientific questions in aging research within the behavioral and social sciences that NIA should support in the coming decades? 2) What kinds of data resources and research infrastructure are needed to address these issues and questions? and 3) Given our assessments under 1 and 2, what suggestions should we make to the Division of Behavioral and Social Research for either maintaining or acquiring new data resources or infrastructure?

We decided that our discussion should focus on principles and priorities for aging research in behavioral and social sciences and not on specific datasets or studies (though we do mention some studies relevant to our discussion points).

We summarize the conclusions or suggestions from the conference call on pages four and five. Because our discussion on items 1 and 2 above motivated these suggestions, we have also included a summary of our main discussion points for your reference. The Committee on Population and the community of researchers that it represents value greatly the data resources and infrastructure for aging research that NIA supports. We hope that our input will be useful to BSR during this important review.

Meeting Summary

What are the pressing issues and scientific questions in aging research within the behavioral and social sciences that NIA should support in the coming decades?

Committee members discussed priorities for aging research:

1. Conceptualization of education and its impacts on population aging.

- a. The meaning and heterogeneity of educational experiences has changed and its impact on the kinds of outcomes (e.g., social, economic, health) that matter for aging has changed (and continues to change) across time. What does education mean for aging? How are the impacts of education on aging changing over time?
2. The implications of health care (ACA and Medicare) for aging.
 - a. As baby boomers hit retirement age, health care and strain on health care systems will become an important issue for older adults and the cohorts that follow.
3. The effects of population-level issues/change on individual health and disease.
 - a. The next decades will see continuing aging of baby boomers and shifting population structure, which have implications for individuals, patterns of disability, and their families as caregivers.
 - b. How does the macro (population structure, environment, economy) interact with the micro (individual health, biomarkers, genetics)?
 - c. Why do women suffer from higher morbidity and disability rates compared to men?
4. The influence of early life conditions on the emergence, severity, and heterogeneity of aging-related disease.
 - a. The aging process begins before age 50. Data are needed that connect early and mid-life to late adulthood. This life course perspective provides insight into aging processes before disease is manifest to intervene to slow the aging and disability process and improve health
 - b. There is substantial heterogeneity in the old age population; understanding pre-disease pathways across early life may reveal insights about “successful aging.”
 - c. There is a need to look at cohort processes. Cohorts face different epidemiologic environments across time.
5. Changing family dynamics, late life health, and the availability of caregiving.
 - a. Family forms continue to change—age of marriage, number of children, prevalence of divorce, unions, etc. This has implications for social support and integration in old age. What will happen to the aging population with these more varied family forms?
 - b. How do family processes in early and middle life impact aging processes?
6. The effects of the destandardization of retirement on aging.
 - a. Timing of retirement has changed. Older adults are retiring later, phasing into retirement, and coming out of retirement.
 - b. What are the consequences of different patterns on health and cognition?
7. The interaction of access and constraints (structural factors) with behavioral choices in shaping health gradients.
 - a. Are health behaviors driven by structural opportunities and limitations, behavioral choices based on cultural norms and values, or both? Need to examine interaction of the two to understand health gradients across social strata and aging processes.
8. The continued coordination with international work to understand both U.S. and cross-national issues in aging.
 - a. Issues of aging in U.S. are related to aging in other societies.

- b. Globally, the aging of the population is going to occur more quickly than institutional change to support the population can happen. This is going to be especially true in less developed countries, and has implications for migration and other population patterns.
9. Identifying the structural and behavioral factors that lead to selection processes and differential mortality, as well as the implications for health issues of the surviving population in late life.
- a. Structural and behavioral factors lead to differential mortality, which affects the structure of the older population.
 - b. How do socioeconomic conditions and behavioral factors interact to shape mortality, and how does this affect the compositional structure of older adults and the risk factors that these survivors face?

What kinds of data resources and research infrastructure are needed to address these issues and questions?

Committee members discussed developments in data resources and research infrastructure that would be necessary to address the above priorities:

1. Need continued focus on existing panel studies.
 - a. Current data resources are good, especially HRS and its international sister studies.
 - b. Need to continue regular follow-ups of panel study participants.
2. Need to incorporate data featuring younger cohorts, such as Add Health and Fragile Families, within an aging context.
 - a. As cohorts age, these data will inform our understanding of aging processes.
 - b. Only with rich multilevel data from early periods of the life course can researchers test current theories about the causes of health and disease in aging populations.
3. Need more methodological development on the determinants of behavior.
 - a. Requires stronger causal modeling techniques.
 - b. A behavioral economics approach to health would be useful, and would create incentives for new directions in health and aging research.
4. Need to address broad methodological issues.
 - a. Harmonizing measures across populations.
 - b. Address sampling and response bias across study populations for comparison and pooled analyses.
 - c. Enhance efficiency of data collection.
5. Need to increase the availability and use of big data.
 - a. New data sources exist that include social, economic, and health information, but little of these data are utilized.
 - b. Need training or collaboration to develop analytic methods that are suited for big data.
6. Need to make existing, traditional data sources more research user-friendly.

- a. Traditional sources of demographic information, such as the US Census, vital statistics, IPUMS, and the Human Mortality/Fertility Databases should be made more accessible.
7. Need to make data linkages available and easier to complete.
 - a. For example, linkage of CPS and NDI, NHIS and NDI.
 - b. Doing so will enhance understanding of inequality and aging.
 8. Need to incorporate epidemiological approaches to health measurement in studies.
 - a. Studies such as CARDIA, ARIC, MESA are stronger than demographic studies in their collection of health data and biomarkers, but are limited in their demographic data and representativeness.
 - b. Include epidemiologists on design teams of demographic health studies.
 9. Need intervention studies that build on findings from panel studies.
 - a. Established findings from observational and panel studies should be further investigated using intervention studies. This will strengthen causal inferences and have direct applications for policy initiatives.
 10. Need to implement theoretical and methodological approaches that place greater emphasis on context and social networks.
 - a. Resources and behavioral choices affect surrounding networks (partner, family, peer).
 - b. Need methodological tools to account for network/clustered nature of social and economic resources.
 - c. Need study designs that allow for network approach, such as clustered designs and network data.

CPOP members' suggestions to the Division of Behavioral and Social Research for their review of the program to create data resources to support aging research in the behavioral and social sciences.

1. Continue national panel studies as a priority. To the extent that international studies will aid in the production of cross-national research on aging, continue to coordinate with international work.
2. Incorporate panel studies that feature younger cohorts into NIA-supported data resources and infrastructure to study earlier life individual and environmental causes of chronic disease and disability in aging populations.
3. Pay greater attention to methodological issues, including (1) causal inference, (2) harmonization of measurement across studies, (3) design discrepancies in cross-national studies due to differences in eligibility requirements, (4) efficiency of data collection given developments in communication technologies, (5) incorporation of big data in aging research, (6) usability of existing population data, (7) linkage of data sources, and (7) incorporation of higher-level social phenomena and network information into panel studies.

These methodological issues can be addressed through funding projects to address data needs, as well as the formation of expert panels to develop recommendations for efficient data collection, comparability across databases, etc.

4. Improve the health data available in demographic studies by incorporating epidemiological approaches to the collection and measurement of biological and health data.
5. Develop intervention studies to further test established findings from panel studies. Use of intervention studies will strengthen causal inferences from panel studies, and will have direct applications for policy initiatives.

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February 3, 2016

Dr. John Haaga
Acting Director
National Institute on Aging
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7201 Wisconsin Avenue
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On behalf of the Population Association of America (PAA) and Association of Population Centers (APC), we are pleased to provide the following report to the National Institute on Aging (NIA) regarding its ongoing data infrastructure review. We hope these recommendations assist the NIA staff and the review committee members as they undertake this ambitious activity.

We wish to recognize the primary authors of this report: Dr. Robert A. Hummer, University of North Carolina, Chapel Hill; Dr. Robert A. Moffitt, Johns Hopkins University; Dr. Rebeca Wong, University of Texas Medical Branch; and, Ms. Mary Jo Hoeksema, Population Association of America/Association of Population Centers.

Thank you for accepting our organization's comments. Please do not hesitate to contact us if you need further information.

Sincerely,

Judith A. Seltzer
President, Population Association of America

Pamela Smock
Vice President, Association of Population Centers



Introduction

In 1988, and again in 2006, the Population Association of America (PAA) and Association of Population Centers (APC) submitted reports to the National Institute on Aging (NIA) Division of Behavioral and Social Research (BSR), laying the groundwork for a significant, focused investment in data infrastructure on population aging issues. The reports' recommendations influenced the design and implementation of groundbreaking studies, which have generated many years of invaluable data on the decisions and challenges facing older people on issues such as health status and health care, economic security, work and retirement, housing, and family support for the elderly. Today, policymakers rely on these data to inform potential programmatic changes to entitlement and social service programs. Likewise, scientists rely on NIA-sponsored datasets as an essential resource in their own research projects.

PAA and APC are pleased that NIA is, once again, undertaking a thorough review of its data collection and dissemination efforts and soliciting suggestions from the broader research community. Unprecedented technological, methodological, and scientific innovations have occurred in the last decade, making 2016 an ideal year for the Institute to consider future data needs and research directions, particularly in the context of uncertain fiscal constraints. PAA and APC hope this document assists the Institute and members of the 2016 NIA Data Infrastructure Review Committee with accomplishing their ambitious task.

Underlying Principles

The traditional subjects of demographic research—fertility, mortality, and migration, three fundamental forces that together determine the size, age structure, and spatial distribution of populations—along with less purely demographic phenomena as marriage and divorce, household composition and labor force behavior, remain central to the field. These forces heavily influence the health status of the older population.

In recent decades, these traditional emphases have evolved substantially into broader areas of scientific inquiry, including the study of kin structures and the intra-familial resource flows that occur within them, the influence of early life course exposures on later life outcomes, and the association between health and mortality. In addition, research on other topics such as health disparities, economic inequality, and the interactions between population processes and public policy have expanded. A “micro” orientation towards individual- and family-level dynamics, including recognizing the importance of unobserved as well as



observed sources of heterogeneity, has grown up alongside the more traditional “macro” orientation characteristic of the discipline of demography.

Enhanced interdisciplinary research collaborations, with fields such as biology, genetics, epidemiology, psychology, neuroscience, and medicine, as well as the longer-established collaborations of demographic research within the social-science fields, especially economics and sociology, have increased dramatically as well. More complex data collection efforts, including longitudinal tracking of individuals, linkages of individuals to others with whom their behavior interacts—i.e. family members, fellow students or employees, or neighbors—and supplementation of survey responses with programmatic information, spatial data, and biological and genetic data has facilitated this evolution of enhanced interdisciplinary research. The NIA has contributed in many important ways to these data collection and interdisciplinary activities that have advanced the science

Our review of the NIA’s current data-collection and dissemination efforts reflects the contemporary field of population science, with its emphasis on interrelated outcomes in multiple domains, within family and intergenerational interdependencies, and its recognition of the value of interdisciplinary approaches to research. Our recommendations for new initiatives also reflect this point of view.

Underlying all of the following recommendations is our organizations’ strong endorsement of investigator-initiated research. The PAA and APC strongly support the basic principle that the best scientific ideas are researcher-initiated and that the current system of scientific peer review is the best mechanism for evaluating those ideas. The starting point for good science starts with the creativity of individual researchers and the best of those ideas are the backbone of good science.

Recommendations

#1. HRS is a central and invaluable resource for the social and behavioral scientific research community that NIA should continue supporting, while also expanding to include more diverse subpopulations.

The Health and Retirement Study (HRS) is one of NIA’s most important initiatives. The principal objectives of the HRS are to monitor economic transitions to work, income, and wealth, as well as changes in many dimensions of health status, and to allow researchers to investigate the principal ways that the domains of family, economic resources, and health interact. The HRS began as a cohort study in 1992, subsequently adding new cohorts to fill out and



maintain its over-age-50 population representation, and has fielded follow-ups every two years.

The HRS has been an unquestioned success. It has generated over three thousand scholarly articles in peer-reviewed professional journals and has generated major health research advances and how health is associated with the work to retirement transition. It has generated articles in multiple disciplines and has had an impact on research across a wide range of domains. It has drawn many new researchers into the field who are attracted by the excellence of its data and the ability to study important scientific and policy questions. NIA should continue to improve the HRS. One area where it could be improved is by the inclusion of more diverse subpopulations, defined by geographic, race-ethnicity, immigration status, and other attributes. HRS sample sizes are often inadequate to study health and aging in important subpopulations, and an expansion of the sample size would make such studies more feasible. In addition, continued efforts should be made to link the HRS to important administrative data sets as described more fully below.

By limiting its sample to individuals aged 50 and over, the HRS focuses on the transition to retirement and the health antecedents and consequences of that transition. However, the health and well-being of the older population are influenced by factors that begin well before age 50, and this includes traditional demographic forces such as marriage, divorce, and intergenerational linkages and their strengths. Researchers attempting to combine the HRS with other data sets to conduct analyses that chart life course trajectories seamlessly from pre-50 to post-50 often have difficulty doing so. NIA should consider an overall data infrastructure portfolio that makes it easier for researchers to conduct those types of analyses. Our next topic follows on this recommendation.

#2. NIA should increase its investment in key aging-related surveys and research activities focused on ages prior to 50 that help complete its population-based research portfolio by supporting studies on health and aging within younger cohorts.

Innovative scientific work over the past couple of decades has made it abundantly clear that there are very important early life precursors of later life health, wellbeing, family life, and socioeconomic attainment. For example, health at birth and in early childhood, early life socioeconomic advantages/disadvantages, and adolescent friendship networks are just a few of the critical factors that have been shown to be strongly associated with adult disease patterns.



Of particular concern among newer cohorts of US adults are the highest ever recorded rates of obesity; rates of death from drug poisonings, suicide, and liver disease that are rapidly increasing and perhaps just the tip of the iceberg in comparison with related overdoses, addictions, and levels of depression; and very high levels of social and economic inequality. A 2013 report from the National Research Council and Institute of Medicine (NRC/IOM) showed that US children and young adults up to age 50 have the highest mortality rates and generally among the worst physical health profiles of any high-income country in the world. Even more recently, a 2015 report from the NRC/IOM documented surprisingly poor health among US adults aged 18-26.

As recent cohorts of children, adolescents, and young adults begin to age into middle adulthood and beyond, the population aging research community will need to increase its attention to the early life biological, contextual, social, economic, and psychological factors that influence the health, health behavior, work lives, family lives, and socioeconomic attainment of US adults as they age. Longitudinal data sets on younger cohorts with rich multi-level social, economic, contextual, biomarker, genetic and psychological measures from early in the life course – such as Add Health and Fragile Families – provide great potential for understanding these key issues of health, wellbeing, family life, and socioeconomic resources prior to age 50. Developing a portfolio that exploits multi-cohort designs or facilitating the crosswalk among specific cohort designs will enhance knowledge of period and environmental effects on healthy aging.

#3. NIA should give increased attention to the intergenerational transmission of health and socioeconomic attainment.

Beyond improved understanding of the individual- and contextual-level early life, adolescent, and early adulthood factors related to the health and wellbeing of middle-aged and older adults in the US, it is also important to better understand how the intergenerational transmission of health and socioeconomic resources influences the health and wellbeing of aging Americans. Indeed, very few population-based data sets of aging Americans include enough information on two or more generations of related individuals to understand intergenerational patterns of health and socioeconomic transmission. Yet, such patterns of transmission within families – both downward and upward – may be particularly important for best understanding the health and wellbeing of aging Americans.

Of perhaps greatest concern are: the intergenerational patterns of health and socioeconomic transmission that occur within low-income and minority families (in comparison with higher income and white families); questions regarding the general direction of transmissions (upward or downward); and, the potential for



individuals in vulnerable structural positions to pass on advantages to their adult children. These issues are very important and not well understood. Population-based longitudinal data sets that include extensive information on two or more generations of individuals within the same family, and particularly those that have adequate coverage of racial/ethnic minority groups and low SES families, are urgently needed to address such questions.

#4. NIA should continue to support surveys focused on disability, particularly the National Health and Aging Trends Study (NHATS).

Clearly, the scientific and policy communities have learned a great deal about older age disability patterns, trends, causes, and consequences within the U.S. population based on data collection efforts supported by NIA. It is extremely important to continue such efforts. These data provide scientists, policymakers, and others with timely information on: changing patterns of disability and functioning in the U.S. elderly population; how individuals, families, and social institutions are adapting to the changing resources and needs of an aging population; when and why individuals move into and out of nursing homes; and, disability trends, which are important for informing potential entitlement program changes.

Most recently, the longitudinal National Health and Aging Trends Study (NHATS) has been instrumental in providing the scientific and policy communities with greatly enhanced knowledge of disability patterns, processes, and disparities in the US population. NHATS is employing innovative and updated measures of functioning and disability to understand patterns, trends, and causes and consequences of disability in the U.S. older adult population. Given worsening trends in middle-aged disability among cohorts of Americans who will soon age into older adulthood, it is very important that NIA continue to support studies such as NHATS that provide the scientific and policy communities with crucial information related to population-level functioning and disability in the United States.

#5. NIA should continue to support strongly studies in which survey data – HRS and others – are linked to existing survey data sets and administrative datasets, including financial records and electronic medical records, but also residential areas and environmental exposure records.

NIA has made major efforts to link its survey data sets (HRS, NHATS, PSID) to administrative records and to pursue data linkages and data sharing arrangements with the Veterans Administration and Social Security Administration—efforts we applaud. These linkages are difficult to achieve, but



given the tremendous payoff for the research community, we urge NIA to continue pursuing such arrangements. For the HRS, linkages to Social Security data have been important, and efforts to link to the VA have been valuable, as have those that obtained private pension information. At the same time, linkages to more data sets not only for the HRS but also for the NHATS, PSID, and other data sets supported by NIA-BSR should be pursued. These include linkages to state Medicaid records, which, though probably infeasible for all states and jurisdictions, could be attempted for a subset. Further, we urge NIA to continue its efforts to link more quickly to National Death Index.

Another recent and promising area of research has involved linking survey data to private firm data. For example, there have been a number of uses of private financial record data which more accurately record asset and other financial information (NIA has supported some of these efforts). Another type of linkage that might be explored on a trial basis are linkages to electronic medical records (EMRs). While such linkages have a number of barriers, other major initiatives within NIH such as ECHO and PMI, are moving vigorously in that direction. Any progress NIA makes to enhance survey data linkages could complement those efforts.

Yet another area where additional linkages should be pursued are linkages to local geographic information on neighborhoods, communities, and environmental exposure. The last of these could also furnish a research link to ECHO, for example. Social and behavioral scientists have increasingly realized the key importance of local and environmental influences on healthy aging. NIA should reflect this trend in its own priorities.

#6. NIA should continue to encourage other disciplines to emulate the population research community's practices of making data accessible to scientists while protecting sensitive data.

NIA and many other behavioral and social scientists at the NIH have led the way to make data publicly available. This development is a hallmark of good science and serves to move the field further, not only by allowing other researchers to validate the research of others, but also by allowing others to extend it in new directions by using the data to explore additional research questions. NIA should continue to prioritize putting NIA-funded data as quickly as possible in the public domain. NIA should require its grantees to comply with data availability requirements and to assist them in placing their data into high-quality data archives, which can professionally curate the data for future use.



Special issues arise when the data have the potential to identify individuals and when survey data are linked to administrative data that are licensed or otherwise protected for restricted use by data sharing agreements. As noted above, linkages to such data are increasingly common in the social and behavioral sciences, and this trend is likely to continue. Licensing agreements, which allow such data to be preserved and curated by professionals, should be sought. In addition, wherever possible, access to those data by other researchers, under proper confidentiality safeguards spelled out in a formal data use agreement, should be pursued.

#7. NIA should continue facilitating and encouraging the development of international datasets, especially in developing countries, as well as the development of innovative methods to enhance cross-national comparisons.

NIA's exemplary and effective leadership has stimulated research conducted in other countries, and the Institute should continue to lead population aging research efforts around the globe. The understanding of aging of the human race is vastly enhanced by studies conducted in other national settings in which U.S. researchers and the NIA play an important collaborative role. Comparable data sets are crucial to perform complementary studies across multiple countries, and major strides have occurred over the last two decades. More than 30 countries have ongoing data collection studies closely based on the HRS model of longitudinal, multi-disciplinary, with national representation, and open-access data. The well-established studies in England, Mexico, and more than 20 countries in Europe through SHARE, as well as the more recent addition of China, India, Brazil, and others over the last decade, are a testament to NIA's leadership.

Efforts to augment the coverage of these studies, particularly in developing countries, should continue. Many regions of the world are not sufficiently covered by comparable data sets. The model set by the HRS in cross-national collaborative efforts should be pursued with other leading studies with which NIA can offer similar leadership, in the areas of disability with NHATS, for example. International comparisons in the area of disability are also needed.

#8. NIA should continue its strong support of the collection of biological measures (e.g., genetic, gene expression, microbiome, biomarker, brain) in population health surveys and make these data usable and accessible to behavioral and social scientists.



The collection of biological data in population health surveys over the past decade has brought about a revolution in how demographers and other population scientists study and understand health outcomes and disparities in the U.S. and around the world. The integration of biological data – genetic, gene by environment, biomarker, microbiome, and more – with population health surveys has also facilitated much closer collaboration between social and biological/health scientists.

Future NIA-sponsored data collection efforts should continue to encourage the collection of biological data in an effort to facilitate future integration of the social and health/biological sciences and to most effectively push scientific frontiers in the study of human health and wellbeing across the life course. Measures that are comparable to those collected by biomedical researchers should also be pursued as an avenue to providing research bridges between those researchers and population scientists.

#9. NIA should expand its data collection programs to cover health in all its many dimensions, especially mental health, mental disability, and cognition.

NIA has been a leader in supporting research on physical health in old age and longevity, including a well-deserved attention to the life course approach. However, there is less emphasis on mental health over the life course and the derived consequences for old-age physical health and longevity. Addictions and over-consumption of food or substances damaging to health such as tobacco, alcohol, and illegal drugs are closely related to mental health. The NIA data collection efforts should emphasize aspects of mental health that can help understand the origins of these addictions in old age and their consequences for quality of life and longevity.

Over the last decade, NIA has supported important research on cognitive aging combining multiple disciplines such as neuroscience, human development and social sciences. NIA programs to support innovative data collection and interdisciplinary research on cognitive aging should continue. Moreover, as the global costs of dementias are expected to increase with rising longevity around the globe, how social and cultural contexts shape cognitive aging are fundamental areas of research. Population-based studies supported by NIA, like the HRS, can provide a platform to launch innovative ancillary studies in cognitive aging. These ancillary studies on cognitive aging are a good example of the type of studies that can be successfully launched by a cross-national network of research collaborations that have been encouraged and supported by NIA.



#10. NIA should develop data resources and sub samples to enhance understanding of socioeconomic, racial/ethnic, immigrant status, and gender-based health disparities.

As part of the NIA mission, studies with multiple purposes have enabled understanding of health disparities in aging. Many of the advances have been enabled by the successful surveys with national representation. However, a common shortcoming of the studies with national representation is that they lack large enough samples to learn from the minority groups defined by socioeconomic, racial/ethnic, immigrant status and other diversity criteria. These minority groups are important to advance in the study of health disparities in the US population.

In order to support further scientific advances, NIA should consider developing data resources that are sub-samples, even if these are observed with lower frequency than the national samples, but that can help advance the knowledge on the sources of unequal old-age health and longevity in the U.S. population. For example, a recent National Academy of Sciences Report documents a growing gap in life expectancy among groups defined by income and education. However, research on the sources of these gaps can only be examined in detail if sufficient groups with low income and education are covered by the data collection studies NIA supports.

#11. Through the data collection efforts it supports, NIA should strive to keep pace with the advances other federal agencies and data providers are making to develop newer methods of collection, including web-based surveys, mobile device response mechanisms, satellite imagery, and spatial indicators.

Both federal statistical agencies and private data collection efforts are rapidly developing enhanced uses of electronic methods for obtaining data. These include web surveys, tablet surveys, and surveys using mobile devices, including data collected under a “Big Data” nomenclature, which involves collecting large amounts of data from secondary sources, usually electronic. There are many challenges in obtaining data in this way as well as using it for research, especially as issues of representativeness are paramount.

For better or for worse, it is clear that this is the wave of the future, and other federal agencies, such as the Census Bureau, Bureau of Economic Analysis, and the Bureau of Labor Statistics, are seriously working on the issues these forms of data collection present. The transition from a model where data are only

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collected in traditional survey methods with in-person or telephone interviews to some kind of mixed-mode data collection is going to take several years, as both survey questions will need to be written and technological, sampling, and other statistical issues will need to be resolved. NIA and its grantees should be on the frontier of these efforts.

Conclusion

PAA and PAC congratulate NIA for the visionary and bold steps it has taken to develop a reputable data collection and dissemination program. Undoubtedly, the agency's support has transformed current understanding of the scope of population aging and its implications for our society. The Institute, with leadership from the Division of Behavioral and Social Research, will move the field in exciting, innovative, and promising research directions. The PAA and APC look forward to continuing our partnership with NIA to accelerate scientific discovery and, ultimately, to improve the health and well-being of older people worldwide.



December 7, 2015

John G. Haaga, PhD
Acting Director
NIA Division of Behavioral and Social research

Dear John,

As President of SER I am writing on behalf of the SER officers. I want to express appreciation for your asking SER for a response to its data resource program to support aging research in the behavioral and social sciences. We discussed this request, and we decided we could not make a formal organizational response for two reasons. The first is that we are reluctant to advocate for specific resources or directions that might seem to advantage some of our membership relative to others. The second reason is a broader one: SER has historically avoided taking positions which related to policy, preferring to focus largely on our mission of advancing all types of epidemiologic research.

Having said that, we did want to offer some general comments and enthusiasm for the current portfolio, especially those studies that include biomarkers. Historically, epidemiologists have more often relied on primary data collection in their research, but there has been increasing use of secondary data sets such as these. That is in part due to changing funding issues, but there are other reasons also. We very much appreciate that these study populations were constructed to be representative, generally, of the national population. For epidemiologists, the increased inclusion of biomarkers, stored samples and objective functional or behavioral measures are of particular interest.

I hope this is somewhat helpful. We realize there must be a trade-off between keeping these large data collections running and supporting smaller investigator-initiated projects. While I am sure each of us individually has an opinion on that, we are reluctant to make comment at the organizational level.

Sincerely,

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Cc: Sue Bevan, SER Administrative Director