



## Improving Data on America's Aging Population: Summary of a Workshop

Deborah Carr, Anu Pemmarazu, and Dorothy P. Rice,  
Editors; Committee on National Statistics, National  
Research Council

ISBN: 0-309-52353-2, 64 pages, 6 x 9, (1996)

**This free PDF was downloaded from:**  
<http://www.nap.edu/catalog/5481.html>

Visit the [National Academies Press](#) online, the authoritative source for all books from the [National Academy of Sciences](#), the [National Academy of Engineering](#), the [Institute of Medicine](#), and the [National Research Council](#):

- Download hundreds of free books in PDF
- Read thousands of books online for free
- Purchase printed books and PDF files
- Explore our innovative research tools – try the [Research Dashboard](#) now
- [Sign up](#) to be notified when new books are published

Thank you for downloading this free PDF. If you have comments, questions or want more information about the books published by the National Academies Press, you may contact our customer service department toll-free at 888-624-8373, [visit us online](#), or send an email to [comments@nap.edu](mailto:comments@nap.edu).

This book plus thousands more are available at [www.nap.edu](http://www.nap.edu).

Copyright © National Academy of Sciences. All rights reserved.

Unless otherwise indicated, all materials in this PDF file are copyrighted by the National Academy of Sciences. Distribution or copying is strictly prohibited without permission of the National Academies Press [<http://www.nap.edu/permissions/>](http://www.nap.edu/permissions/). Permission is granted for this material to be posted on a secure password-protected Web site. The content may not be posted on a public Web site.

# Improving Data on America's Aging Population

---

## Summary of a Workshop

Deborah Carr, Anu Pemmarazu, Dorothy P. Rice,  
Editors

Committee on National Statistics  
Committee on Population  
Commission on Behavioral and Social Sciences and Education  
National Research Council

NATIONAL ACADEMY PRESS  
Washington, D.C. 1996

NOTICE: The project that is the subject of this report was approved by the Governing Board of the National Research Council, whose members are drawn from the councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine. The members of the committee responsible for the report were chosen for their special competences and with regard for appropriate balance.

This report has been reviewed by a group other than the authors according to procedures approved by a Report Review Committee consisting of members of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

The National Academy of Sciences is a private, nonprofit, self-perpetuating society of distinguished scholars engaged in scientific and engineering research, dedicated to the furtherance of science and technology and to their use for the general welfare. Upon the authority of the charter granted to it by the Congress in 1863, the Academy has a mandate that requires it to advise the federal government on scientific and technical matters. Dr. Bruce M. Alberts is president of the National Academy of Sciences.

The National Academy of Engineering was established in 1964, under the charter of the National Academy of Sciences, as a parallel organization of outstanding engineers. It is autonomous in its administration and in the selection of its members, sharing with the National Academy of Sciences the responsibility for advising the federal government. The National Academy of Engineering also sponsors engineering programs aimed at meeting national needs, encourages education and research, and recognizes the superior achievements of engineers. Dr. William A. Wulf is interim president of the National Academy of Engineering.

The Institute of Medicine was established in 1970 by the National Academy of Sciences to secure the services of eminent members of appropriate professions in the examination of policy matters pertaining to the health of the public. The Institute acts under the responsibility given to the National Academy of Sciences by its congressional charter to be an adviser to the federal government and, upon its own initiative, to identify issues of medical care, research, and education. Dr. Kenneth I. Shine is president of the Institute of Medicine.

The National Research Council was organized by the National Academy of Sciences in 1916 to associate the broad community of science and technology with the Academy's purposes of furthering knowledge and advising the federal government. Functioning in accordance with general policies determined by the Academy, the Council has become the principal operating agency of both the National Academy of Sciences and the National Academy of Engineering in providing services to the government, the public, and the scientific and engineering communities. The Council is administered jointly by both Academies and the Institute of Medicine. Dr. Bruce M. Alberts and Dr. William A. Wulf are chairman and interim vice chairman, respectively, of the National Research Council.

This workshop was supported by funds from the National Institute on Aging through grant No. SES 9116694 by the National Science Foundation to the National Academy of Sciences for support of core activities of the Committee on National Statistics.

ISBN 0-309-05633-0

Additional copies of this report are available from National Academy Press, 2101 Constitution Avenue, N.W., Lock Box 285, Washington, DC 20055  
Call 1-800-624-6242 or 202-334-3313 (in the Washington metropolitan area).

This report is also available on-line at <http://www.nap.edu>

Copyright 1996 by The National Academy of Sciences. All rights reserved.

Printed in the United States of America

**COMMITTEE ON NATIONAL STATISTICS  
1995–1996**

NORMAN M. BRADBURN (*Chair*), National Opinion Research Center,  
University of Chicago

JOHN E. ROLPH (*Vice Chair*), Department of Information and Operations  
Management, School of Business Administration, University of Southern  
California

JULIE DAVANZO, RAND, Santa Monica, California

WILLIAM F. EDDY, Department of Statistics, Carnegie Mellon University

JOHN F. GEWEKE, Department of Economics, University of Minnesota,  
Minneapolis

JOEL B. GREENHOUSE, Department of Statistics, Carnegie Mellon  
University

ERIC A. HANUSHEK, W. Allen Wallis Institute of Political Economy,  
Department of Economics, University of Rochester

NICHOLAS JEWELL, Program in Biostatistics, School of Public Health,  
University of California, Berkeley

CHARLES F. MANSKI, Department of Economics, University of Wisconsin,  
Madison

WILLIAM NORDHAUS, Department of Economics, Yale University

JANET L. NORWOOD, The Urban Institute, Washington, D.C.

EDWARD B. PERRIN, Department of Health Services, School of Public  
Health and Community Medicine, University of Washington

KEITH F. RUST, Westat, Inc., Rockville, Maryland

FRANCISCO J. SAMANIEGO, Division of Statistics, University of California,  
Davis

MIRON L. STRAF, *Director*

MICHELE L. CONRAD, *Division Administrator*

**COMMITTEE ON POPULATION**  
**1995–1996**

- RONALD D. LEE (*Chair*), Department of Demography, University of California, Berkeley
- CAROLINE H. BLEDSOE, Department of Anthropology, Northwestern University
- JOSE-LUIS BOBADILLA, World Bank, Washington, D.C.
- JOHN BONGAARTS, The Population Council, New York
- JOHN B. CASTERLINE, The Population Council, New York
- LINDA G. MARTIN, RAND, Santa Monica, California
- ROBERT A. MOFFITT, Department of Economics, Brown University
- MARK R. MONTGOMERY, The Population Council, New York
- W. HENRY MOSLEY, Department of Population Dynamics, School of Hygiene and Public Health, Johns Hopkins University
- ALBERTO PALLONI, Department of Sociology, University of Wisconsin, Madison
- JAMES P. SMITH, RAND, Santa Monica, California
- BETH J. SOLDI, Department of Demography, Georgetown University
- MARTA TIENDA, Population Research Center, University of Chicago
- AMY O. TSUI, Carolina Population Center, University of North Carolina, Chapel Hill
- JOHN HAAGA, *Director*

## WORKSHOP ON PRIORITIES FOR DATA ON THE AGING POPULATION

### Participants

- DOROTHY RICE (*Chair*), Institute for Health and Aging, University of California-San Francisco
- RONALD ABELES, National Institute on Aging, National Institutes of Health, U.S. Department of Health and Human Services
- CLYDE BEHNEY, Division of Health Care Services, Institute of Medicine
- RICHARD BURKHAUSER, Center for Policy Research, Maxwell School, Syracuse University
- ROBERT CLARK, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services
- STEVEN CLAUSER, Health Care Financing Administration, U.S. Department of Health and Human Services
- STEVEN COHEN, Agency for Health Care Policy and Research, National Institutes of Health, U.S. Department of Health and Human Services
- DAVID CUTLER, Department of Economics, Harvard University
- LILY ENGSTROM, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services
- JACOB FELDMAN, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services
- DOROTHY GILFORD, Commission on Behavioral and Social Sciences and Education, National Research Council
- NANCY GORDON, Demographic Programs, Bureau of the Census, U.S. Department of Commerce
- JONATHAN GRUBER, Department of Economics, Massachusetts Institute of Technology
- HOLLY HARVEY, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services
- ROBERT HAUSER, Department of Sociology, University of Wisconsin, Madison
- RICHARD HAVLICK, National Institute on Aging, National Institutes of Health, U.S. Department of Health and Human Services
- SANDRA HOFFERTH, Institute for Social Research, University of Michigan
- MICHAEL HURD, Department of Economics, State University of New York, Stony Brook
- DAVID JOHNSON, Bureau of Labor Statistics, U.S. Department of Labor
- THOMAS JUSTER, Institute for Social Research, University of Michigan
- ROBERT KANE, Institute for Health Services Research, School for Public Health, University of Minnesota

- ROBERT KOMINSKI, Population Division, Bureau of the Census, U.S.  
Department of Commerce
- MARION EIN LEWIN, Institute of Medicine
- JENNIFER MADANS, Division of Epidemiology, National Center for Health  
Statistics, Centers for Disease Control and Prevention, U.S. Department of  
Health and Human Services
- KENNETH MANTON, Center for Demographic Studies, Duke University
- NADINE MARKS, Department of Child and Family Studies, University of  
Wisconsin, Madison
- MARY McCARTHY, Bureau of Labor Statistics, U.S. Department of Labor
- FAITH MITCHELL, Commission on Behavioral and Social Sciences and  
Education, National Research Council
- MARILYN MOON, The Urban Institute, Washington, D.C.
- ROBERT MOORE, Bureau of Data Management and Strategy, Health Care  
Financing Administration, U.S. Department of Health and Human Services
- RANDALL OLSEN, Center for Human Resources Research, Ohio State  
University
- JAN OLSON, Social Security Administration
- GEORGIANNE PATMIOS, National Institute on Aging, National Institutes of  
Health, U.S. Department of Health and Human Services
- DEBORAH PHILLIPS, Commission on Behavioral and Social Sciences and  
Education, National Research Council
- WILLIAM RAUB, Office of the Assistant Secretary for Planning and  
Evaluation, U. S. Department of Health and Human Services
- PHILIP RONES, Bureau of Labor Statistics, U.S. Department of Labor
- TIMOTHY SMEEDING, Metropolitan Studies Program and Economics  
Department, Syracuse University
- BETH SOLDI, Department of Demography, Georgetown University
- ROBYN STONE, Office of the Assistant Secretary for Planning and  
Evaluation, U.S. Department of Health and Human Services
- MICHAEL STOTO, Division of Health Promotion and Disease Prevention,  
Institute of Medicine
- RICHARD SUZMAN, Office of Demography, National Institute on Aging,  
National Institutes of Health, U.S. Department of Health and Human  
Services
- BARBARA BOYLE TORREY, Commission on Behavioral and Social  
Sciences and Education, National Research Council
- JOAN VAN NOSTRAND, National Center for Health Statistics, Center for  
Disease Control and Prevention, U.S. Department of Health and Human  
Services
- ROBERT WALLACE, Department of Preventive Medicine and Environmental  
Health, University of Iowa

WORKSHOP PARTICIPANTS

vii

KATHERINE WALLMAN, Office of Information and Regulatory Affairs,  
U.S. Office of Management and Budget  
ROBERT WILLIS, Institute for Social Research, University of Michigan  
GOOLOO WUNDERLICH, Division of Health Care Services, Institute of  
Medicine

**Staff**

DEBORAH CARR, *Rapporteur*  
AGNES GASKIN, *Senior Project Assistant*  
JOHN HAAGA, *Director, Committee on Population*  
ANU PEMMARAZU, *Research Assistant*  
MIRON L. STRAF, *Director, Committee on National Statistics*





# Contents

PREFACE	xi
INTRODUCTION	1
AMERICA'S AGING POPULATION: TRENDS AND UNCERTAINTIES	5
Projecting the Elderly Population: How Many?, 5	
Health and Disability, 6	
Long-Term and Acute Care Arrangements, 9	
Work and Retirement Patterns in Later Life, 11	
Income, Wealth, and Quality of Life, 12	
Living Arrangements and Family, 14	
Residential Patterns, 15	
Summary, 16	
IMPROVING DATA SOURCES	17
Oversampling Subgroups of the Elderly, 17	
Cross-Agency Coordination and Data Integration, 19	
Ethical Challenges, 21	
Attention to Statistical Methodology, 23	
Data for State-Level and Local-Level Estimates, 24	
Accurate and Standard Concepts and Measures, 26	
CONCLUSIONS	29

REFERENCES	33
APPENDIX A: AGENDA, WORKSHOP ON PRIORITIES FOR DATA ON THE AGING POPULATION	39
APPENDIX B: DATA SOURCES FOR STUDYING AGING: SURVEY CHARACTERISTICS AND LINKAGE CAPACITIES	43

## Preface

In March 1996 the Committee on National Statistics and the Committee on Population convened a group of experts for a two-day workshop on priorities for data on the aging population. The workshop provided a vehicle for serious brainstorming among a group of policy analysts, principal investigators for the major surveys, academic and other researchers, and others interested in aging-related statistics from many perspectives.

The purposes of the workshop were to explore how the population at older ages in the next few decades will differ from the older population today, to understand the underlying causes of those changes, to anticipate future problems and policy issues, and to suggest how future data needs can be met for the purposes of research; for understanding the social, economic, and health conditions of the older population; and for informing public policy.

Participants reviewed developments on statistics for the aging population since publication of the Committee on National Statistics report *The Aging Population in the Twenty-First Century* (Gilford, 1988) and major trends in the population at older ages, identified policy issues for which data may be needed, described current data collection efforts, and suggested changes to more effectively meet future data needs.

Funding for the workshop was provided by the National Institute on Aging, and we thank its director, Richard Hodes, and Richard Suzman, director of the institute's Office of Demography, for their interest in and support of this project. A number of staff of the National Research Council contributed time and expertise to the workshop and the production of this report. Miron Straf, John Haaga, and Anu Pemmarazu organized the workshop. Agnes Gaskin was the project

assistant. In addition, Deborah Carr of the University of Wisconsin at Madison served as rapporteur. Editorial assistance was provided by Eugenia Grohman.

We are especially grateful to the chair Dorothy Rice and workshop participants for their time and effort to this task. The report that follows is a summary of their presentations and discussion.

Norman M. Bradburn, *Chair*  
Committee on National Statistics

Ronald D. Lee, *Chair*  
Committee on Population

## Introduction

The Committee on National Statistics (CNSTAT) has had a continued interest in the adequacy of statistical information and methodology for studying the aging population. In the report of CNSTAT's Panel on Statistics for an Aging Population, the adequacy of current statistical information and methodology was examined, particularly in the area of health and medical care, for an aging population. The panel's report, *The Aging Population in the Twenty-First Century: Statistics for Health Policy* (Gilford, 1988), focused on the data required during the next decade for policy development and research on health care for the elderly.

Recommendations emphasized modifications to existing national statistical programs and surveys in light of the budgetary constraints faced by the federal agencies at that time. A systematic review of administrative and survey data sets led to a large number of recommendations to improve existing surveys and to make better use of administrative records required for health policy analysis in the next decade.

In the 8 years since the report was issued, many of its recommendations have been enacted. The most substantial progress has been made in three main areas: federal data collection, data linkages, and mechanisms for data dissemination. Several new data sets, including the longitudinal Health and Retirement Survey (HRS), the Assets and Health Dynamics Among the Oldest-Old (AHEAD) survey, and the Medicare Current Beneficiary Survey, address the report's call for data that describe health and functional transitions of old Americans.

Several data linkage and integration projects have also been completed or are now in progress. One milestone is a tracking system by the U.S. Department of

Health and Human Services (HHS), in which all National Center for Health Statistics surveys will be linked to the National Death Index and data from the Health Care Financing Administration.

New data dissemination mechanisms have also been established. The Federal Interagency Forum on Aging-Related Statistics—a congressionally mandated organization—was established in 1986 to encourage cooperation among federal agencies in the development, collection, analysis and dissemination of data on the older population. One of the forum's projects is the biannual publication of *Data Base News in Aging*, which highlights the content of government-sponsored surveys and products containing information about the older population. In addition, most federal statistical agencies have developed—or are currently developing—procedures for researchers to access their data bases through the Internet, particularly, the World Wide Web.

Despite these strides, the National Institute on Aging (NIA) believes it is important to continually reassess the current data collection environment and to develop general guidelines for the collection of additional data on aging. In the coming decades, the nation's decision makers will be challenged by changing demands for social and health services due to the anticipated rapid rate of growth of the elderly (65 years or older) and especially of the oldest old (85 years or older). At the same time, national policy makers are contemplating a major shift in responsibility for many social programs from the federal to state government level. Such a shift would place even greater demands on the capacity of statistical systems to track and publish up-to-date information about the number, health status, economic well-being, employment behavior, living arrangements, and service utilization patterns of the elderly.

It is in this context that the Committee on National Statistics and the Committee on Population, at the request of the NIA, convened a workshop in March 1996 to discuss data on the aging population that address the emerging and important social, economic, and health conditions of the older population. The purposes of the workshop were to identify how the population at older ages in the next few decades will differ from the older population today, to understand the underlying causes of those changes, to anticipate future problems and policy issues, and to suggest future needs for data for research in these areas. The scope of the workshop was broader than that of the 1988 CNSTAT report, including not only data on health and long-term care, but also actuarial, economic, demographic, housing, and epidemiological data needs for informing public policy.

Workshop participants included members of the two committees, investigators for the major NIA-funded surveys on the aging population, officials of relevant federal agencies, and other experts on economics, biodemography, public policy, and the social aspects of aging. The workshop format was informal in order to facilitate discussion; see agenda, Appendix A.

The workshop began with a brief review of the findings and recommendations of the 1988 CNSTAT report, but the purpose was not to assess systemati-

cally the degree to which each of the 1988 recommendations had been implemented. Rather, participants discussed and identified issues pertaining to trends in the population at older ages: consequences of baby boomers facing retirement; health, disability and functional status of the older population; trends in long-term care; health care delivery, organization, and financing; and longevity and quality of life. They also focused on identifying important data needed to understand these issues and to inform public policies. Specifically, participants assessed how current and future data collection activities might meet some of these needs. Important data gaps were identified, and the likely future environment of data collection was considered.

This report is a summary of the workshop proceedings and discussions. As such, it does not provide a comprehensive review of data collection efforts or empirical research focusing on the old population. Rather, it reflects the concerns and areas of expertise of the workshop participants. The discussions focused primarily on the economic, social, and health trends affecting the aging population. A variety of related topics, important in their own right, were not covered in detail: such topics include the effects of macroeconomic trends on health, health policy evaluation, and disease diagnoses, as well as health informatics (the combination of computer science, information science, and medical science; Connick, 1994).

The first section of this report reviews the information presented at the workshop regarding economic, social, and health trends affecting the aging population. The second section highlights the common themes that emerged at the workshop. Finally, broad guidelines for assessing the merits of relevant data sources are provided, and suggestions for future projects are described.





## America's Aging Population: Trends and Uncertainties

### **PROJECTING THE ELDERLY POPULATION: HOW MANY?**

Over the past 25 years, the number of persons aged 65 and older in the United States has risen at an unprecedented rate (Manton and Stallard, 1994). More recently, in the 10-year period between 1980 and 1990, census data show an increase in the number of persons aged 65 and older from 25.5 million in 1980 (11.3 percent of the total U.S. population) to more than 31 million in 1990 (12.5 percent of the total U.S. population). During the same time period, the population of those aged 85 and older grew even more markedly: from 2.2 million in 1980 (1 percent of the total U.S. population) to 3.0 million in 1990 (1.2 percent of the U.S. population) (Bureau of the Census, 1996).

The proportion of the total U.S. population over age 65 will continue to increase dramatically in the coming decades. According to the Census Bureau's "middle series" population projections, the population aged 65 and older will make up 20.4 percent of the U.S. population in 2050, an increase from 13.3 percent in 2010 and 12.5 percent in 1990 (Bureau of the Census, 1996).<sup>1</sup> Under the same assumptions, the oldest old (those aged 85 and older) are projected to

---

<sup>1</sup>The middle series population projections assume a total fertility rate in 2050 of 2.15, life expectancy at birth in 2050 of 79.7 years for males and 85.6 years for females, and an ultimate net migration of 880,000 per year. In contrast, under the "high life expectancy" series of projections, the proportion of Americans aged 65 and older is expected to be 22.7 percent in 2050. The high life expectancy series assumes the same total fertility rate and ultimate net migration as the middle series, but assumes a life expectancy at birth of 83.8 years for males and 91.1 years for females (Bureau of the Census, 1996).

account for 4.8 percent of the U.S. population in 2050, up from 2.0 percent in 2010 and 1.2 percent in 1990.

The minority elderly, who differ significantly from the white (non-Hispanic) older population in terms of wealth and poverty status, will be growing at a considerably faster rate than the older population as a whole. Minority persons aged 65 and older accounted for 13 percent of the elderly population in 1990; they are expected to account for 16 percent of the elderly population in 2000, 22 percent in 2020, and 33 percent by 2050 (Bureau of the Census, 1996). Consequently, future cohorts of the elderly are expected to be much more heterogeneous than earlier cohorts in terms of race, ethnicity, and socioeconomic status.

Uncertainty looms around such projections, however; population projections are based on a series of assumptions about the future of fertility, mortality, and net immigration that may not necessarily hold in the future. For example, the Social Security Administration's projections of mortality imply a sharp slowing of the rates of decline of mortality at all ages, relative both to the previous two decades and to longer run historical trends back to 1900. (These results are inherent in their methodology, which extrapolates rates of decline in age-specific death rates for specific causes of death over the previous 20 years—see Lee and Skinner, 1996; Singer and Manton, 1993.) Projections by other researchers (e.g., Lee and Carter, 1992) extrapolate the rates of decline in age-specific mortality rates observed over the 20th century (not disaggregated by cause of death), which have been fairly steady despite periods of faster and slower progress. Hence, such projections imply a larger elderly population than do the SSA projections (or those developed by the Census Bureau).

Projections about future numbers of the “oldest old” are particularly uncertain. Not only are data scarce on the relatively small cohorts of people who have survived to age 85 and older, but data on the oldest old likely suffer from greater measurement error (Taeuber and Rosenwaike, 1992). The simple extrapolation methods often relied upon in making official projections may be neither adequate nor appropriate (Suzman, Manton, and Willis, 1992). Changing life expectancy at older ages, some would argue, is the largest source of uncertainty in Social Security Trust Fund solvency. It is crucial that researchers and policy makers be able to estimate the number of elderly persons in the future population, especially when developing legislation to ensure the fiscal stability of the Social Security system.

## HEALTH AND DISABILITY

Whether widely reported increases in life expectancy have been accompanied by changes in the prevalence of chronic disability remains unclear.<sup>2</sup> Studies

---

<sup>2</sup>Chronic disability is most frequently measured in surveys by indicators of activities of daily living, or ADLs (Katz and Apkom, 1976) and instrumental activities of daily living, or IADLs

using data from the 1970s and early 1980s point to modest increases in the prevalence of disability at older ages (Crimmins, Saito, and Ingegneri, 1989; Riley, 1990; Verbrugge, 1989). More recent evidence suggests, however, that this pattern may have reversed itself since the mid-1980s, with a decline in reported functioning problems among the old (Crimmins and Ingegneri, 1992; Manton, Corder, and Stallard, 1993; Yeas, 1987). An analysis of data from the 1982, 1984, and 1989 National Long-Term Care Surveys showed that both preservation of functioning in the nondisabled population and increased life expectancy for disabled persons occurred: overall, the analysis showed a significant improvement in the functional status of older cohorts at the end of the 1980s, compared with those who belonged to older cohorts at the beginning of the 1980s (Manton, Corder, and Stallard, 1993). It is possible that current cohorts of persons aged 65 and older have reaped the benefits of such improvements as better nutrition, water quality, and hygiene that occurred when they were young.

Another explanation posited for the decline in poor health and disability at older ages is that recent cohorts of elderly are and will continue to be better educated than past cohorts of elderly, and higher education is associated with better health and positive health behaviors. While more than 45 percent of those aged 75 and older in 1994 had not graduated high school, this figure falls to 32 percent among those aged 65-74 and drops to less than 15 percent for those aged 45-54 (Bureau of the Census, 1995). The relationship between education and mortality, morbidity, and health behaviors has been demonstrated across numerous studies. For example, an analysis of National Longitudinal Mortality Study data showed that if educational differentials among people who died of heart disease were eliminated, the excess mortality of those with 0-8 years of schooling, relative to those with some college, would be reduced by 57 percent for males aged 65 and older and by 67 percent for women aged 65 and older (Rogot, Sorlie, and Johnson, 1992).

The explanations posited for the relationship between education and health are numerous. People with higher levels of education, in general, have higher potential income levels and are thus able to purchase more health-enhancing goods and services. Education is also associated with a variety of risk factors and health behaviors. Shea et al. (1991) examined educational differentials for a variety of risk factors in a 1989 New York state sample and found that better educated people are significantly more likely than less educated people to engage in aerobic exercise and to know their blood pressure and less likely to smoke or to be overweight. Similarly, an examination of 1979-1986 data from the Stanford

---

(Lawton and Brody, 1969). ADL measures encompass items describing an individual's ability to perform basic self-care activities, such as bathing, dressing, and feeding oneself (Katz and Apkom, 1976). IADLs assess independence in activities requiring adaptation to the environment, such as shopping, preparing meals, and carrying out household chores (Lawton and Brody, 1969).

Five-City Project showed that level of schooling is significantly associated with cigarette smoking, hypertension, serum cholesterol, body mass index, weight and health knowledge (a 17-item scale of knowledge about cardiovascular risk factors): in all cases, the risk factor distribution of poorly educated people was more adverse (Winkleby et al., 1992). Dramatic strides in medical knowledge and technology during the 1980s also may have had an effect on disability levels over the decade. Advancements such as hip replacements, lens replacements for people with cataracts, angioplasty for heart diseases, antihypertension drugs, and exogenous estrogens to reduce postmenopausal symptoms are among the developments credited with reducing elderly disability (Studies of Left Ventricular Dysfunction Investigators, 1991; Nabulsi et al., 1993).

Macrolevel social and economic trends may also play a role in determining the health of current and future generations of the old. Evidence from other nations illustrates such relationships. The decline in the economies of Eastern Europe since World War II has been associated with a decline in the health status of the populations, while the improved prosperity of Japan during the same time period has been associated with a marked improvement in health status (Frank and Mustard, 1994). A recent analysis for the World Bank concluded that the quality of the social environment in which families live and work—in addition to deterioration in the physical environment—was a major factor in explaining the decline in health status in Eastern Europe (Hertzman and Ayers, 1993). In contrast, the improvement in the health of the Japanese is associated with economic prosperity and an apparent ability to sustain reasonable income equity and the quality of social environments throughout the society (Marmot and Davey-Smith, 1989).

An understanding of the health of future cohorts of elderly is crucial. Projections of the elderly disabled population are used by a number of federal agencies with responsibilities for disability benefit programs, and by policy makers interested in modifying programs and proposing new services for this population (Freedman and Soldo, 1994). Projections vary considerably, however, depending on how the underlying survey defines disability and on what criteria are used by researchers when they analyze disability. Surveys of the aging population generally focus on a person's ability to carry out activities essential to maintaining independence. However, researchers may add further stipulations to their definitions of disability, such as duration of one's disabled condition.<sup>3</sup> The accuracy of such projections may have major fiscal ramifications. For instance,

---

<sup>3</sup>For example, projections of the future disabled elderly population using data from the 1984 National Long-Term Care Study define disabilities as conditions that last at least 90 days (Manton, 1989). In contrast, projections of the future disabled elderly population based on data from the 1984 National Health Interview Survey Supplement on Aging do not specify whether a disability has lasted or is expected to last at least 90 days (Zedlewski et al., 1990).

delayed mortality—accompanied by continued declines in disease and disability prevalence—may have major negative implications for the Social Security Trust Fund. Alternatively, better health of older cohorts might affect the Medicare Part A Trust Fund positively: although larger cohorts of elderly persons may become dependent on programs such as Medicare in the future, their better all-around health may result in lower costs or lower cost increases. Effective planning for medical, rehabilitation, and social services requires reliable estimates of the number and characteristics of current and future disabled people.

### LONG-TERM AND ACUTE CARE ARRANGEMENTS

One of the most crucial issues for the quality of life of aging Americans is the cost and availability of acute medical and long-term care. Although the elderly make up roughly 12 percent of the U.S. population, they account for more than 33 percent of total health expenditures (Waldo et al., 1989). Researchers are only beginning to collect data on the diverse care arrangements that elderly Americans are selecting. Moreover, the distinctions between “acute care” and “long-term care” are increasingly clouded, with funding sources—rather than the site or type of care—becoming the main point of differentiation (Kane and Kane, 1990).

Acute care is generally defined as including hospital care, physician services, and prescription drugs. Long-term care, in contrast, has evolved from an emphasis on purely institutional care to a broad range of services in both institutional and community settings. Under this broader definition, homemaker services, nutrition programs, congregate housing, and visiting nurse services are all part of long-term care (U.S. Senate Special Committee on Aging, 1992). The increasing size of the old population and the fact that health clearly declines with age suggest that an increasingly large number of people will seek long-term care as part of the continuum from independent living to assisted living at home to institutional care (Kane and Kane, 1990).

Long-term care and acute care will continue to place financial pressures both on families and public funds. Long-term care arrangements are seldom covered by private insurance or Medicare.<sup>4</sup> Total expenditures for long-term care in 1993

---

<sup>4</sup>Medicare and Medicaid cover different expenses. Medicare, authorized under Title XVIII of the Social Security Act, is a federal health insurance program that serves almost all elderly and some disabled persons. The Medicare program has two parts: Part A, the hospital insurance (HI) component, and Part B, the supplemental medical insurance component. Part A pays for hospital care, some skilled nursing facility care, limited amounts of skilled home health care, and hospice care. Part B covers physician services, hospital outpatient services, and a variety of other medical and health services, such as laboratory and diagnostic tests. However, Medicare does not cover prescription drugs and only minimal long-term care and mental health services. Consequently, in 1987 Medicare paid less than one-half (45 percent) of the total health care expenditures for the elderly, but two-thirds of their hospital and physician costs (Waldo et al., 1989). Medicare spending amounted to roughly 18 percent of nursing home and home-care expenditures in 1993 (Wiener and Illston, 1996).

reached \$75.5 billion—\$54.7 billion for nursing home care and \$20.8 billion for home care—yet only \$13.7 billion was paid by Medicare. Roughly two-thirds of the total bill was paid by out-of-pocket spending (\$33.5 billion) and Medicaid (\$26.0 billion) (Wiener, Illston, and Hanley, 1994). Still, the demand for noninstitutionalized long-term care is high. While Medicaid long-term care expenditures increased by 8.6 percent from 1993 to 1994—roughly equal to overall Medicaid expenditure growth—Medicaid spending for *noninstitutional* care grew by 26 percent, from \$6.7 billion to \$8.4 billion (Stone, 1996).

Just as long-term care expenditures have risen, the burden on the elderly to finance their own health care has also increased. Consumer Expenditure Survey data show that more of the total budget of those aged 65 and older now is consumed by out-of-pocket health care expenditures than was the case in the 1980s (Hitschler, 1993). Between 1980 and 1990, health insurance as a share of total health expenditures expanded from 37 percent to 48 percent for those aged 65-74 and from 26 percent to 45 percent for those aged 75 and older. As health care costs rise, older persons are paying higher health plan premiums, deductibles, and copayments, and more older persons are buying commercial supplements to Medicare, which is causing a shift in health expenditure shares from medical services to health insurance for both age groups.

Among the future policy concerns related to health care are questions about whether Medicare and Medicaid funding will be reduced drastically, whether proposed health care reforms will lead to increased reliance on managed care, and the degree to which federal policy shifts decision making to the state level. Moreover, policy makers increasingly are interested in quality assurance and health outcomes. Quality assurance issues pertinent to long-term care include consumer risk-taking related to quality of care; whether and how quality standards and assessments should differ depending on care setting; whether and how standards and assessments should differ on the basis of the consumer's degree of cognitive impairment; and the rights and perquisites of the long-term care labor force. Likewise, it is expected that consumers may search for less costly, better quality care alternatives, including subacute care, home health care, and assisted

---

Medicaid spending is primarily for long-term care services. In 1993, 62 percent of government spending for nursing home and home care for the elderly was accounted for by Medicaid (Wiener, Illston, and Hanley, 1994). Medicaid benefits include payment of Medicare Part B, and when applicable, Part A premiums, and cost-sharing for Medicare-covered services. Medicaid also provides certain acute-care benefits not available through Medicare, primarily prescription drugs, eye and dental care, and preventive and rehabilitative services. Generally, Medicaid benefits for the elderly are for the "categorically needy," those who meet the strict income and asset eligibility criteria of the Supplemental Security Income (SSI) program, the cash welfare program for the aged, blind, and disabled. In 1992, there were slightly fewer than 4 million "dual eligibles" (i.e., those who were both Medicare and Medicaid beneficiaries). In 1992, about 30 percent of Medicaid expenditures and 88 percent of Medicare expenditures were for the elderly (Coughlin, Ku, and Holahan, 1994).

living. Long-term care insurance is expected to attract more interest in the future: as of 1992, however, only about 350,000 long-term care insurance policies had been sold (Health Insurance Association of America, 1993), and these policies remain unaffordable to most elderly (Wiener, Illston, and Hanley, 1994).<sup>5</sup>

### WORK AND RETIREMENT PATTERNS IN LATER LIFE

Most American men and women are healthy and active long after they pass their 62nd birthday—the earliest age of eligibility for Social Security retirement benefits. Ironically, though, labor force participation rates of older men and age at retirement have declined at precisely the time that the health of older Americans has improved. A trend toward early retirement was rapid and dramatic from 1950 through the mid-1980s, but this trend, as well as declining labor force participation rates of older men, has recently stabilized (Quinn and Burkhauser, 1994; see also Lumsdaine, 1996).

Government and corporate policies that discourage work at older ages have started to change during the last decade. Recent legislation has outlawed mandatory retirement, banned the cessation of service year credits in pension calculations after a certain age, and increased the Social Security credit for delayed retirement after the age of 65. The age of “full benefits” (100 percent of the primary insurance amount) is scheduled to increase from 65 to 66 between the years 2000 and 2005 and then from 66 to 67 between 2017 and 2022.

Moreover, employer pension coverage has undergone a shift away from defined-benefit to defined-contribution plans, and this shift may complicate researchers' understanding of how cohorts reaching old age in the future will experience retirement (Uhlenberg and Miner, 1996).<sup>6</sup> The growth of defined contribution plans relative to defined benefit plans may reduce incentives for early retirement, may accentuate the already significant role of pensions in creating income inequality within cohorts in later life, and may lead to increasing uncertainty about future pension incomes in retirement (Paine, 1993; Quinn and Burkhauser, 1994).

The retirement behavior of future cohorts is equally uncertain. Part-time employment and self-employment have emerged as new forms of early retirement. Older workers are now reducing their hours rather than completely severing their ties with the labor force. Whether or not older workers remain with their employers beyond age 62 depends on many factors, including Social Security,

---

<sup>5</sup>The average annual premium for high-quality policies sold by the leading sellers in 1991 was \$2,525 for people aged 65 and \$7,675 for those aged 79 (Health Insurance Association of America, 1993).

<sup>6</sup>Defined benefit plans provide actuarial benefits for retiring early; defined contribution plans do not. Defined contribution plans are actually savings accounts with tax advantages so they are age neutral with respect to retirement age (Quinn and Burkhauser, 1994).



private retirement policies, private pension plans and health benefits, and contemporaneous labor market conditions (Quinn and Burkhauser, 1994). Individual workers make their retirement decisions on the basis of the financial incentives they face, while employers must assess whether it is in their best interest to retain older workers. Future research will necessitate data collection at the individual, employer, and benefits-provider level to address such questions.<sup>7</sup>

### INCOME, WEALTH, AND QUALITY OF LIFE

Older Americans as a group have made impressive gains in their economic well-being over the past 30 years. At the same time, the economic position of nonelderly persons aged 18-64 has declined somewhat, and the economic position of children has eroded considerably. Poverty rates for the elderly and nonelderly were nearly identical in 1994<sup>8</sup>—11.7 percent and 11.9 percent, yet these rates are parts of very different patterns. The proportion of elderly living in poverty declined substantially, from 25 percent in 1970 to 16 percent in 1980 to 12 percent in 1990, while the proportion of persons aged 18-64 living in poverty increased slightly, from 9 percent in 1970 to 10.1 in 1980 to 11 percent in 1990 (Bureau of the Census, 1996).<sup>9</sup>

Despite the economic strides made by the elderly during the past 30 years, relative to children and adults aged 18-64, not all segments of the older population have shared equally in these gains. Elderly blacks and Hispanics are two to three times more likely than non-Hispanic whites to be poor. The proportion of persons aged 65 and older who were poor in 1994 was 10.2 percent among whites, 27.4 percent among Hispanics, and 22.6 percent among blacks (Bureau of the Census, 1996).

---

<sup>7</sup>An in-depth study of these issues is being conducted by the Committee on National Statistics Panel on Retirement Income Modeling. The panel was established to review the state of the art and make recommendations to inform policy making on retirement income security. The panel's work considers what data, research, and models exist and what are needed to estimate the short-run and long-run implications of current retirement-income-related policies and proposed changes to them. Products of the panel include an interim report published in July 1995 (Committee on National Statistics, 1995), a volume of commissioned papers published in August 1996 (Hanushek and Maritato, 1996), and the panel's final report (Citro and Hanushek, 1997).

<sup>8</sup>Official poverty guidelines are based on the assumption that the elderly require fewer resources to maintain a suitable standard of living (see Citro and Michael, 1995). For instance, by the official 1994 definition, the poverty level was an annual income of \$7,108 for a person aged 65 or older living alone and \$8,967 for an older couple household; in contrast, the poverty line was an annual income of \$7,710 for an adult aged 18 - 64 living alone and \$9,976 for a nonelderly couple household (Bureau of the Census, 1996).

<sup>9</sup>Perhaps an even more telling contrast is the economic status of children versus the elderly during the period from 1970 to 1990. The proportion of persons under 18 classified as poor increased from 15 percent in 1970 to 18 percent in 1980 to 21 percent in 1990.

Poverty rates among the elderly also vary widely by sex and living arrangement. Elderly white persons in married-couple families were less likely in 1992 to be in poverty (5.2 percent) than comparable black (19.6 percent) or Hispanic (12.7 percent) families. Women living alone were particularly subject to poverty: among women who did not live with relatives in 1992 ("unrelated individuals" in census terminology, most of whom live alone), poverty rates were 24 percent for white women, 50.7 percent for Hispanic women, and 57.5 percent for black women. The economic disparities seen within the U.S. older population are even more striking when compared with other industrialized nations. Elderly couples in the United States have the highest income and wealth in the OECD (Organization for Economic Cooperation and Development) world, according to findings from the Luxembourg Income Study, but the average income of older women living alone in the United States ranks below all other major industrialized countries except Australia (Holtz-Eakin and Smeeding, 1994).

The sources of income that the elderly rely on also vary widely, especially when age of recipient is considered. Only 30 percent of the total income of those aged 65-69 comes from Social Security, but this figure increases to more than 50 percent for those aged 80 and above. Conversely, private pensions or annuities account for more than 10 percent of the total income of those aged 65-69, but only 6.3 percent for those older than 85 (Hurd, 1996).

The elderly population, as a whole, is in a privileged position in terms of assets—especially if home values are considered. The elderly have had longer to accumulate their assets, and aggregate levels of elderly net worth reflect this. An analysis of data from the Survey of Income and Program Participation (SIPP) showed that from 1988 to 1991 real median net worth for all households fell from \$41,172 to \$36,623, while the median net worth of the elderly remained around \$88,000 (Eller, 1994). However, wealth, like income, varies widely among the elderly by age and marital status. According to 1993 data from the AHEAD survey, the median nonhousing wealth of married persons aged 70-74 was \$60,000, more than three times that for unmarried persons (\$18,000) of the same age. The disadvantaged position of the unmarried elderly is underscored when homeownership is examined. Homeownership rates range from 75 percent (for those aged 85 and older) to 90 percent (for those aged 70-74) among the married elderly; these rates are roughly 50 percent higher than the homeownership rates of the unmarried, which range from 48 percent (for those aged 85 and older) to 65 percent (for those aged 70-74) (Hurd, 1996).

Accurate assessment of the economic future of the elderly is contingent on the availability of data that contain detailed and accurate information on respondents' assets, income from all sources and that permit analyses of relevant subpopulations. Moreover, the economic status of future cohorts of the older population is much more likely to be influenced by income from occupational (private) pensions, from assets and wealth, and from part-time earnings, than is the current generation of elderly. These sources of income all reflect increased reliance on

individual decision making by older persons and are thus more difficult to predict than are formula-driven sources of income, such as Social Security or Supplemental Security Income (SSI) (Smeeding and Torrey, 1996).

In addition, the older the population, the more important are measures of wealth (such as net worth) and consumption in determining their economic status, along with the nature and size of intergenerational transfers of wealth, both during their lifetimes and at death. The life-cycle hypothesis of saving posits that assets increase during the working years of the life cycle and decline after retirement as savings are spent to finance daily life, yet evidence on whether households accumulate or decumulate wealth during the retirement years is mixed. Economic theory assumes newly retired persons would avoid using savings as long as possible, given that most people are relatively healthy on retirement but still face significant uncertainties about future health and longevity. However, a large number of persons reach retirement with little or no savings. Some indirect evidence suggests that inheritances may substantially increase the wealth of baby boomers as they enter the young old ages, with research indicating that most inheritances go to householders in their 50s and 60s (Greenwood and Wolff, 1992). Thus, a shift in emphasis from income to wealth and consumption measures in data is needed if an accurate picture is to be drawn.

### LIVING ARRANGEMENTS AND FAMILY

Families have undergone a transformation in the last 30 years: divorce rates have increased, fertility has declined, and marriage and childbearing have been postponed to later ages. Although these trends may have little effect on the living arrangements and support networks of today's elderly, they could very well have important implications for the lives of baby boomers as they reach old age. Declines in birth rates during the past 30 years may mean that the elderly baby boomers will have fewer children who are a potential source of care. As women's labor force participation rates gradually approximate men's, it is uncertain whether working women will continue to be a source of care for their aging parents.

The availability of family members to provide care is an important factor in the lives of elderly Americans. Evidence from current cohorts of elderly people shows that families continue to be the mainstay of support for older, impaired persons: 70 percent of older persons who have a disability and live in the community (i.e., not in institutions) rely on family members as their sole source of care; another 23 percent use some combination of family and formal (paid) providers. The majority of unpaid caregivers of the disabled are women, usually wives, daughters, or daughters-in-law (Stone, Cafferata, and Sangl, 1987). Only 7 percent use formal care arrangements exclusively (Wolf, 1994; Soldo and Freedman, 1994).

The living arrangements of the elderly vary widely by gender, due largely to

the gender gap in mortality. In 1994, more than twice the proportion of elderly women lived alone or with nonrelatives (42 percent) than elderly men (19 percent), likely due to the fact that many more women than men are widowed. Moreover, future cohorts of elderly are likely to have even more diverse living arrangements, given trends in divorce, remarriage, and blended families (Smeeding and Torrey, 1996).

## RESIDENTIAL PATTERNS

Policy makers are interested not only in with whom the elderly live, but where they live. The older population is distributed very unequally among the 50 states. In 1994, persons aged 65 and older accounted for 12.7 percent of the U.S. population overall, but they accounted for more than 15 percent of the population in five states: Florida (18.4 percent), Pennsylvania (15.9 percent), Rhode Island (15.6 percent), and Iowa and West Virginia (15.4 percent each) (Bureau of the Census, 1995). The elderly are also distributed very unequally by urban or rural region: in 1990, about 23 million elderly Americans lived in metropolitan areas and only 8.2 million lived outside metropolitan areas. The elderly represented a higher proportion of nonmetropolitan residents, however: 15 percent in nonmetropolitan areas and 12 percent in metropolitan areas. The agglomeration of older populations will have significant effects on service delivery patterns and demands for various tax-financed local goods, such as recreational facilities and long-term care services.

To the extent that living costs and living patterns are different among states, having geocoded data about the elderly will be increasingly important. To the extent that health conditions vary by climate, projections of future health status would benefit from taking into account the unequal geographical distribution and growth rates of the elderly. Finally, a better understanding of the effects of growing concentrations of older persons on local service delivery and demands is needed (Longino, 1990), which suggests a need for data on local fiscal patterns, such as taxation and service provision, as well as household data.

Migration, and the accompanying growth in the size and share of the older population, also has important implications for the tax base and service programs of state and local governments. States and local areas that receive large numbers of elderly migrants may fare better than areas without this type of growth. The concentration of older persons in a specific area is not due only to the in-migration of retirees, however. Elderly persons who move long distances tend to be younger, healthier, better educated, and wealthier than those who do not move (Bean et al., 1994; Longino, 1990). Moreover, migration often carries with it substantial amounts of retirement income transfers. In 1989, Florida was estimated to have received a net \$6.5 billion in transferred income due to interstate migration of the population aged 60 and older, while New York lost a net \$3.3

billion to other states, with more than one-half of that loss (\$1.9 billion) going to Florida (Longino, 1995).

Certainly, states whose populations are disproportionately made up of older persons will shoulder relatively larger financial responsibilities for Medicare and other state and locally funded programs. This situation can be exacerbated if the area is also losing its working-age and tax-paying populations (Bean et al., 1994).

### SUMMARY

Future generations of persons aged 65 and older will differ markedly from the older population today, in terms of their size, characteristics, and behaviors. Consequently, researchers cannot simply rely on characteristics of the current generation of elderly to predict behaviors and outcomes for future generations of older Americans.

Although it is relatively certain that the United States will experience a "boom" in the absolute size and growth rate of the elderly population, as well as increased diversity and an increased proportion of the oldest old (85 and older), some characteristics of the elderly of tomorrow are less predictable. The health and disability status of future cohorts of the elderly may vary widely, depending on individual characteristics such as educational attainment, socioeconomic status, and race and ethnicity. Medical advances or unforeseeable macroeconomic and social shifts may also influence the health of future cohorts of the aged. Older persons' preferences for medical care and the ability of individuals and social programs to shoulder the bill for such care also are not well understood. Whether older, healthy workers will retire at older ages also is unknown; ongoing changes in government and corporate policies will play a role in molding labor force participation rates of older Americans.

The size and characteristics of the older population will have important social and economic implications. An understanding of the aging population and its social ramifications is contingent on the availability of thorough and detailed data on current and future cohorts of the elderly, as well as the development of appropriate methodology for studying the aging population.

## Improving Data Sources

Over the course of the workshop, the discussion converged on important implications for data collection, and the participants made numerous suggestions—some highly detailed and others more general—for improving data sources on the elderly and aging. Participants agreed that current data collection efforts are highly fragmented and are administered by different agencies and investigators, each with its own substantive interests, distinctive histories, and constituencies.

Furthermore, budget constraints make it impossible for surveys to capture every desirable piece of information on elderly health, employment and economic status, care arrangements, family structure, and the like. Therefore, participants suggested both priorities for data collection efforts and strategies for achieving greater efficiency and coordination among existing data sets. With these shared concerns about fragmentation and resource constraints as a source of departure, six common themes regarding problems and suggestions for improving data on older Americans emerged from the workshop discussions.<sup>10</sup>

### **OVERSAMPLING SUBGROUPS OF THE ELDERLY**

The changing demographics of the elderly population, as well as shifting policy concerns, warrant inclusiveness in data collection efforts. In particular,

---

<sup>10</sup>Of course, not all participants agreed with each and every priority; for instance, some urged for detailed data collection at the state and local levels, while others called for more effective use of available data.

workshop participants noted that new strategies for oversampling currently underrepresented subgroups of older men and women would be valuable. The older population is growing increasingly diverse, and these diverse subgroups experience their later years in very different ways. As noted above, economic status varies widely by race, ethnicity, gender, and residential pattern. Workshop participants also pointed out that while gains in health and life expectancy at older ages are expected to continue in the aggregate, this optimistic scenario might not hold true for all populations, especially less educated and poor people. Most national surveys contain samples that are too small to be statistically representative of older age groups by sex and race or ethnicity.

Several participants noted that the subgroups one wishes to use for analytic purposes may not necessarily be defined by the traditional demographic characteristics of race, ethnicity, or gender. Rather, characteristics such as residential status, urban or rural location, or early disability status may be important correlates of the outcome variables of interest. Other participants suggested that factors such as regional climate conditions, support for local services, and social interactions with younger populations may be important correlates of physical and emotional health. Therefore, where possible, oversampling the older population—and especially underrepresented subgroups—may be needed. Similarly, participants noted that sufficient numbers of new immigrants may not be captured in current data sets. One proposed solution is for longitudinal studies to periodically replenish their samples, so that “new” Americans can be included in the analyses. Appendix B lists populations that are oversampled in existing data sets used for the study of aging.

Another dominant theme at the workshop was that data should be collected on multiple cohorts and that data should be collected at multiple points in time for each cohort. Participants noted that between-cohort comparisons can be more useful than simply studying the experience of one birth cohort. Moreover, social change can be assessed by contrasting the experiences of diverse cohorts. Caution must be taken in extrapolating from the experience of earlier cohorts, however; each birth cohort arguably has unique characteristics, and newer cohorts of the old, especially the post–World War II baby boomers, may have very different health, education, work history, family arrangement, and benefits profiles than earlier cohorts.

Participants who called for detailed cohort data also noted that many characteristics of the elderly—especially mental and physical health, disability, and the demand for health services—are the result of cumulative experiences throughout life. For example, cohort studies by Elo and Preston (1992) demonstrate that susceptibility to certain diseases is established early in life and persists throughout adulthood. Since a poor health environment in childhood is often associated with low levels of schooling and occupational attainment, the direct effects of schooling and occupational status on adult health status can be overestimated

without proper data on earlier experiences. To understand such connections would require that longitudinal data be obtained on multiple cohorts.

For these reasons, workshop participants stressed the importance of repeated panel data and longitudinal data on different cohorts of the old, sufficiently large to capture diversity. Such efforts are currently under way; HRS, for one, will add members of the 1924-1930 birth cohort during its next wave of data collection (Juster and Suzman, 1995). These data, combined with HRS data on the birth cohorts of 1931-1941 and the AHEAD data on cohorts of 1923 and earlier, will ensure the coverage of every cohort of the current elderly population. This coverage will allow for between-cohort comparisons and will allow researchers to study the effects of period effects—such as economic conditions—on the elderly.

### CROSS-AGENCY COORDINATION AND DATA INTEGRATION

The need for improved cross-agency planning and coordination, as well as coordination and data integration across multiple data sources, emerged frequently as a point of discussion.<sup>11</sup> Since the early 1980s, the availability of large longitudinal and cross-sectional data sets on aging has increased dramatically. In the last 15 years, NIA has invested heavily in new data collection efforts, and various governmental departments have either supplemented existing surveys or developed new surveys to track the aging population. The burst of activity included the development of new NIA-funded data sets such as the AHEAD and the National Long-Term Care Survey, the introduction of questions on functional status of the elderly to the 1990 census, and the addition of the Supplement on Aging to the National Health Interview Survey (NHIS) of the National Center for Health Statistics (NCHS).<sup>12</sup>

As statistical data on the elderly population have accumulated, the data bases from which these data derive have become increasingly specialized in nature. Furthermore, even within single federal agencies, supplements, topical modules, and new surveys have proliferated. Integrating or linking data from various sources offers the advantage of increasing the utility of existing data bases at a relatively modest cost (Agency for Health Care Policy and Research, 1991). In particular, six kinds of data integration or linkages were discussed:<sup>13</sup>

---

<sup>11</sup>A report by the Committee on National Statistics Panel on Retirement Income Modeling (Citro and Hanushek, 1997) discusses the needs for improved cross-agency planning and coordination and for integration of data sources on topics that relate to retirement income security.

<sup>12</sup>This is a very abbreviated listing of the numerous data collection efforts that have occurred in the last decade. A detailed list of data sets for studying the aged is provided in Appendix B.

<sup>13</sup>The six kinds are not necessarily mutually exclusive: for instance, firm- and employer-level data can also be considered a private data source.



- (1) integration of public and private data sources, such as data collected by the Robert Wood Johnson Foundation;
  - (2) integration of large national survey data with local-level data;
  - (3) integration of population-level data sources with administrative record data, such as those maintained by the Health Care Financing Administration (HCFA) and Social Security Administration;
  - (4) integration of population-level data with firm- or employer-level data;
  - (5) integration of population-level data with (benefit) provider-level data;
- and
- (6) integration of population-level data with demonstration data, such as those from the Social Health Maintenance Organization.<sup>14</sup>

Linkages between data sets can be accomplished either through matches of records on the same individuals from different data bases, known as exact matches, or through matches of records on different individuals who are identified as identical or similar in important respects, known as statistical matches (see Gilford, 1988). Both types of matches serve to provide a broader set of data on individual cases—without undertaking new data collections—by merging two or more data sets that supply different sets of characteristics.

Many strides have been made in the last 10 years, yet workshop participants noted that data linkage systems, for the most part, are still in their formative stages. The most successful linkages have occurred through the horizontal integration of multiple population-level data sets and the integration of population-level data sets with administrative record data.

The use of data linkages can be enhanced by active coordination among agencies. One such program is currently under way. In 1995 NCHS launched the HHS survey integration plan, a major effort to restructure the health surveys sponsored by HHS in an effort to fill major data gaps, improve analytic utility, and create greater operational efficiencies. The plan addresses a range of linkages and consolidation approaches, including the integration of survey samples. A cornerstone of the plan is the restructuring of HHS health surveys so that the redesigned NHIS is the sampling “nucleus” for most HHS population surveys. The 1996 Medical Expenditures Panel Study, for one, will use the 1995 NHIS as a sampling frame, thus enhancing the NHIS data by providing detailed data on expenditure-related topics such as insurance and utilization.

---

<sup>14</sup>The Social Health Maintenance Organization (SHMO) is a demonstration project funded by HHS that combines the delivery of acute and long-term care with adult day care services and transportation. Medicare beneficiaries pay slightly higher monthly premiums than elsewhere; Medicaid recipients pay nothing. The SHMO demonstration will help test whether comprehensive health services, linking acute and chronic care under an integrated financing scheme, can be provided at a cost that does not exceed the public costs of Medicare and Medicaid.

The availability of health care provider-level data, insurer-level data, and employer-level data and the capacity to link population-level data with such sources are limited, however, according to many workshop participants. Efforts have been under way at HHS to remedy several of these limitations. The department has begun to build on and coordinate three surveys on health care providers: the National Nursing Home Survey, an NCHS survey; the National Nursing Home Expenditure Survey, a survey of the Agency for Health Care Policy and Research (AHCPR); and the Medicare Current Beneficiary Survey, a HCFA survey. In addition, plans are under way to integrate the National Employer Health Insurance Survey and the Health Insurance Provider Survey, both of which obtain insurance information from employers. Plans are also being made for restructuring all HHS provider-based surveys. Participants stressed the importance of obtaining data from detailed insurance claims records and characteristics of insurance and pension plans, as well as the cost, type, and effectiveness of medical and personal care being provided to individuals. They also acknowledged, however, that protecting individuals' privacy must be an equally important objective. Some participants noted, however, that reliance on Medicare data for information on expenditures and utilization may be thwarted by the growth of managed care, a system that does not provide the same level of detailed data.

Progress on linkages between individual-level and employer-level data has been less substantial. Workshop participants noted that employer-level data are crucial for understanding the labor force behavior of future cohorts. Factors such as employers' willingness to retain older workers and the type of health benefits afforded to early retirees will be critical for policies related to retirement age and eligibility for Social Security benefits. Several participants said that more employer-level data should be collected and linked to population-level data.

Private foundations and corporations were frequently mentioned as potential data "partners" of large population-level surveys. For example, the Robert Wood Johnson Foundation, a national philanthropy devoted to health and health care research, is collecting extensive data on health care systems in 60 communities. One way to expand the utility of such data sets is to sample respondents from the same primary sampling units as used in "partner" population-level data sets. Although privately funded and collected data sources can provide valuable information on health care providers and characteristics of the care recipients, ethical and procedural issues surrounding the integration of public and private data sources have not yet been resolved.

Perhaps the greatest strides in linkages have occurred with the integration of individual-level survey data with administrative data. Administrative records are invaluable sources of data: for example, the National Death Index provides information on the date, location, and cause of death, while Social Security Administration records provide detailed information on individual earnings. A tracking system has been developed whereby all NCHS surveys will be linked to National Death Index and HCFA data bases. Many federally funded surveys

currently have, or will have, the capacity to be linked to administrative records, including the National Death Index and Social Security Administration earnings data (see Appendix B). Linkages of administrative data with survey data could provide a powerful mechanism to explore the relationship between services provided and resulting health status in the geographic area served by health services organizations, for instance (Newacheck and Starfield, 1995). Workshop participants cautioned, however, that in cases of statistical uses of administrative records, particular care must be taken to safeguard traditional assurances of confidentiality of statistical data.

### ETHICAL CHALLENGES

Throughout the workshop, participants grappled with the conflict between maximizing the usefulness of data sources and abiding by the ethics of confidentiality and informed consent. Moreover, participants noted that a host of ethical uncertainties surround newly developing data collection practices, such as genetic testing on the physiological samples (usually blood) obtained from survey participants, linking population-level data with local-level data, and integrating public and private data sources.

Data bases that draw samples directly or indirectly from the decennial census (e.g., the Current Population Survey), must comply with U.S. Code Title 13, which prohibits the release of any microdata that theoretically could result in identification of respondents. For instance, SIPP, which uses an address list that derives from the decennial census, has “confidential” files that include linked administrative data that can only be analyzed by designated Census Bureau employees. Linkage to local-level data runs the risk of violating the federal rule that no data will be available in “identifiable form,” defined as “any representation of information that permits information concerning a specific respondent to be reasonably inferred by either direct or indirect means” (U.S. Office of Management and Budget, 1996: 2878).

Definitive solutions to the tension between data linkage and the use of small-level and administrative data have not yet been found. One action has been proposed by a working group formed under the National Information Infrastructure: the idea of a “privacy ombudsman” or “czar.” Survey respondents would have access to a central person who could answer their questions and provide additional information and assurance about the confidentiality of their responses.

Researchers are only beginning to tackle the ethical issues involved with the collection and analysis of genetic data. Among the ethical and consent issues raised during the workshop were informed consent for future genetic studies not yet planned; the ownership of genetic information; the disposition of genetic material and registry data, as well as implications for commercial processes; notification of study participants of new or unexpected findings; the implications for family members of genetic findings; the access of insurance companies to

research findings; and resolving whether participants really understand the “informed” consent information (see Clayton et al., 1995, for a review of related issues).

Representatives from NCHS presented workshop participants with a current ethical dilemma. As part of the extensive phlebotomy protocol of the National Health and Nutrition Examination Survey (NHANES III), a small sample of blood was collected that could be used for analysis of DNA and cell lines. Since the avalanche of genome information expected to accrue over the next decade has led to concerns regarding the potential misuse of such information, this situation requires resolution of complex privacy, informed consent, and related ethical issues. Options range from completely anonymous testing to recontacting and obtaining additional information from NHANES III respondents. For an anonymous research design, data on a limited number of categories—such as age (grouped by broad categories), race or ethnicity, gender, and education—could be identified so that a randomly chosen subset of each cell could be selected, assigned a new random identification number, and tested. Using these limited variables, anonymous testing can provide information on the frequency of genotypes in target populations or case-control studies. A recontact, on the other hand, would allow researchers to obtain additional informed consent, thereby allowing genetic information to be linked to the remaining, extensive NHANES III observations. Longitudinal and family medical history data could also be obtained through recontact. As of the time of the workshop, NCHS had not determined what course of action to take.

Yet another set of concerns about ethics and procedural issues surround the proposed practice of integrating national, public survey data with privately collected data sources, such as the Robert Wood Johnson Foundation data on health utilization patterns at the community level. Questions about the possible loss of nonprofit tax status, and the possibility of private, for-profit organizations using publicly funded surveys for market research or for-profit purposes were among the concerns raised. Participants agreed that innovative data linkages and data collection efforts will inevitably continue to raise new ethical challenges.

### ATTENTION TO STATISTICAL METHODOLOGY

Although most discussions at the workshop focused on data collection efforts, participants agreed that data collection is only the first step in successfully studying the aging population. The need for research and policy-oriented analysis on patterns of aging and their consequences was also underscored. Such investigations will require sophisticated use of existing statistical methodology and, in some cases, the development of new methods. For instance, the collection of additional longitudinal data may be most fruitful when accompanied by the further development and assessment of stochastic models for temporal processes. Moreover, projections of population characteristics based on traditional assump-

tions about the aging process—especially continued declines in morbidity—will have to be dealt with cautiously.

Suggestions were also made for additional model building, with an emphasis on interactions among changes in health status, economic status, and living arrangement. Actuarial, economic, demographic, and epidemiologic models are among the tools available to forecast the health and behavior (e.g., service utilization, benefit levels, etc.) of future cohorts of the elderly (Manton, Singer, and Suzman, 1993). In general, federal government programs have employed actuarial forecasting methods, which traditionally have been used to anticipate the future fiscal risk of programs based on well-defined past experiences, while academic researchers have developed more sophisticated models of health, functioning, and life expectancy that describe such outcomes as a function of individual states and characteristics (Freedman and Soldo, 1994).

Workshop participants also observed that important factors in many projections concerning population size, composition, and health status are the future levels of age-specific mortality. Projections should not be based solely on optimistic assumptions about aging and life expectancy; a reverse in life expectancy gains is also a possibility, especially given the anticipated heterogeneity among future cohorts of the elderly.

Participants also noted that American researchers could benefit from examining cross-national comparative data. Such an effort is important for understanding how similarities and differences in both initial conditions and policy responses in the United States compare to those in other nations. For example, because most western European nations are experiencing an aging population similar to that in the United States—albeit at a slightly earlier time—data from these nations may inform predictions and assumptions about the U.S. aging population.

### **DATA FOR STATE-LEVEL AND LOCAL-LEVEL ESTIMATES**

Recognizing the current debate about a move toward block grants, the state and local locus of many policies and programs for the elderly, and growing interest in the effects of state variation in benefit levels, service structures, and other key features of social policy programs, workshop participants noted the critical need for data at the state and local level with respect to nearly every policy area discussed at the workshop. For example, most major federal health data bases were originally designed to provide national or regional estimates, but state-level data will be critical in evaluating health care reforms since reform is likely to be implemented differently in each state (and perhaps only in selected states). Consequently, state-level data represent a key component in studying health and health care of the elderly.

All states maintain vital records, and many maintain data collection systems for hospital discharge information. Although claims payment systems are main-

tained by every state Medicaid agency, not all such systems lend themselves to analysis. Moreover, there are large state-level differences in Medicaid funding: the dollar expenditure per recipient varies by a factor of three between the highest and lowest paying states. Consequently, participants stressed the need for data collection and retrieval to be coordinated so that data collected at the local level can be aggregated to state and national levels and so that data collected at state and national levels can be related to data collected at local levels: doing so may permit comparison of effects across communities and states. Pressing needs include the selection of primary sampling units that are consistent with state-level estimation, inclusion of a sufficient number of cases for each state to permit accurate estimation, and making better use of claims data and other administrative records. The value of linking qualitative and local data to national health surveys in order to interpret local health care trends, processes, costs, and effects on the elderly was also discussed throughout the workshop.

Several efforts are under way to both enhance local-level data and link state-level data with national population surveys. One part of the HHS data integration project involves the development of a modular design that will facilitate state-level estimates and provide a mechanism for states to “buy into” national survey efforts to meet their own needs. The Centers for Disease Control is taking the lead in establishing baseline data at the state level; its plans include the development of a comprehensive, integrated, and flexible state-level telephone survey that can provide ongoing interviewing infrastructure to address a variety of issues, including access to care.

Participants expressed concern about the ethical issues and inherent tension between data linkage and the use of small-area data. Clearly, available data sources would be enhanced by appending neighborhood or regional-based data, especially those variables measuring local resources, economic opportunities, aggregate poverty levels, and other local-area characteristics. Likewise, understanding the effects of health care reforms requires outcome data that can be aggregated at the patient-provider, plan, or system of care and community levels.<sup>15</sup> At the same time, however, the confidentiality of respondents’ reports must be assured. Participants also expressed caution about the use of local-level data when studying the elderly. When elderly survey respondents live in nursing homes or institutions, it is unlikely that the economic and social characteristics of

---

<sup>15</sup>One source that provides county-level data on health care services availability is the Area Resource File (ARF), maintained by HHS’s Bureau of Health Professions. The ARF is a county-based file summarizing secondary data from a wide variety of sources into a single file to facilitate health analysis. The file contains over 7,000 elements for most counties in the United States (except Alaska). Data elements include county descriptor codes, and data on the number of health professionals in the county, health facilities, population, the training of health professionals, medical expenditures, hospital expenditures, Medicare enrollments and reimbursements, and economic characteristics of the county.

the surrounding neighborhoods are significant for the elderly residents themselves.

### ACCURATE AND STANDARD CONCEPTS AND MEASURES

As progress is made in studying the aging process, researchers have begun to develop more precise and applicable measures of elderly health status, living arrangements, and care arrangements. Workshop participants pointed out that progress needs to continue in measuring each of the following: the timing, severity, and progression of chronic and acute health conditions; functional status, including ADLs and IADLs; psychological variables, such as denial and proclivity toward help-seeking behavior; and long-term care settings and characteristics. Measurement can be improved by calibrating survey measures and by striving for item comparability across surveys.

It was emphasized that single-time measures of the presence of illness are inadequate. Rather, longitudinal data sets should be used to time the onset of diseases and to track the course of one's illnesses and health conditions. Also, longitudinal studies need to obtain information on events and conditions that occur during the time period between the data collection times, not just at the two times. While acute conditions, such as heart attacks or strokes can be dated, it is much more difficult to ascertain the onset of chronic conditions, such as high blood pressure, bronchitis, or Alzheimer's disease. Tracking health and illness should begin prior to old age; data sets with information on people at midlife should be used to focus on at-risk subgroups, such as the disabled and the poor. Moreover, survey items should capture the severity of illness, measured by indicators such as the degree of interference in a person's daily life imposed by the illness.

Participants debated the utility of the ADL and IADL measures as indicators of disability. Some argued that these measures are good broad demarcators of independence and dependence status and relatively robust predictors of later mortality. Others countered that the ADL and IADL measures are not appropriate for predicting a broad range of outcomes and do not capture the broad continuum of disability status. An additional limitation of the ADL and IADL questions is that the question wordings sometimes confound supply of care with need for care. Specifically, some IADL and ADL questions ask sample members whether they received help with a variety of tasks. An affirmative response could reflect the availability of care providers *in addition to* a need for personal care.

The difficulty of disentangling the need for health care and access to health care was discussed at several times during the workshop. Participants pointed to numerous studies that showed that an increase in the availability of health care services was accompanied by an increase in reported ill health. It was cautioned that survey data could erroneously reveal decreases in morbidity if future genera-

tions of older persons have reduced access to health care. Consequently, some workshop participants noted, there is a need to improve measures of the effects of not receiving the health care one needs.

Participants called for improved measures of psychological characteristics and more fine-grained measures of care arrangements. Emotional or subjective health measures, such as “denial” about one’s health status, might be good predictors of seeking and following medical care and advice. Likewise, measurements of care arrangements warrant elaboration and improvement. AHCPR representatives reported that long-term care settings are changing and will continue to change. These settings now include subacute care, home health care, assisted living, and integrated care; both the level and type of care provided vary widely among these diverse settings. Moreover, the sociodemographic characteristics of persons utilizing these services vary widely. Current data do not differentiate among these arrangements. Participants called for longitudinal data on long-term care: care arrangements vary by cost, intensity, and setting over time, and such changes need to be captured if researchers are to adequately understand long-term care arrangements.

Finally, general suggestions were offered to improve measurement in surveys. Suggestions included standardization of items across surveys and calibration of survey measures—when possible. Standardization of survey items was raised as a possible goal, yet one that may not be applicable to all research topics. For example, questionnaire items obtaining information on “health insurance provider” may not lend themselves to standardization over time and across surveys, as shifts occur in insurance provision arrangements. A decade ago, the majority of health insurance was provided by fee-for-service indemnity plans; now, health maintenance organizations (HMOs)—and more generally, managed care providers—are becoming the most common health insurance provider. Participants noted that with the increasingly widespread use of computer-assisted personal interviewing and computer-assisted telephone interviewing techniques, researchers may be able to easily and effectively arrange questionnaire items using a sequence of “unfolding” questions, which are contingent on answers to prior questions.





## Conclusions

Future generations of persons aged 65 and older will be marked by two distinct characteristics: their size and diversity. Consequently, policy makers will require accurate data on the number, health status, economic well-being, employment behavior, living arrangements, and service utilization patterns of the elderly. Large, national, population-level data sets alone will not be sufficient to understand future generations of elderly, however. National policy makers currently are contemplating a major shift in responsibility for many social programs from federal to state governments. Such a shift will place even greater demands on the capacity of statistical systems to obtain local-level data on the aging population.

Workshop participants agreed that data collected at the employer, insurer, and service-provider level are also essential to developing a comprehensive understanding of the aging population. Data collection can also be enhanced by integration and coordination among data sets. In the last 15 years, NIA, HCFA, AHCPR, and NCHS, among others, have invested heavily in new data collection efforts, as well as supplements and spinoffs to existing surveys. Many of these data collection efforts focus on distinct substantive questions, and on different segments of the old population. Moreover, the data collection efforts are administered by different agencies and investigators—each with its own approaches. Furthermore, budget constraints make it impossible for surveys to capture every possible piece of relevant information on the elderly. Therefore, participants suggested the need for both priorities for data collection efforts and strategies for achieving greater efficiency and coordination among extant data sets.

Participants provided specific suggestions for data integration efforts, in-

cluding the integration of public and private data sources (such as data collected by the Robert Wood Johnson Foundation); integration of large national survey data with local-level data sources; integration of population-level data sources with administrative record data, such as those maintained by HCFA and the Social Security Administration; integration of population-level data with firm and employer-level data; integration of population-level data with (benefit) provider-level data; and integration of population-level data with demonstration data, such as Social Health Maintenance Organization data. Participants acknowledged, however, that as new and innovative data collection and integration strategies are developed, appropriate ethical guidelines must be delineated to safeguard confidentiality of individuals' information.

The workshop concluded with participants suggesting steps for achieving the goals of promoting collaborative meetings, continuing to examine the fit between the information needs of decision makers and the available data, and improving the underutilization of existing data. One suggestion was to hold future meetings among principal investigators of major NIA-funded surveys. Other participants added that the aging process can best be understood from a life-course perspective; therefore, future meetings should benefit from the input of investigators who study childhood and midlife—as well as the older population.

Many participants agreed that information about data sets and data dissemination should be made more widely available and accessible, and they noted a variety of efforts that are currently under way. For instance, the Federal Interagency Forum on Aging-Related Statistics produces the twice-annual report *Data Base News in Aging*. Federal agencies that produce and distribute aging-related data products are invited to contribute current information about the electronic data files and hard-copy data products and reports available from their organizations. In addition, most federal statistical agencies have developed—or are currently developing—procedures for researchers to access their data bases through the Internet. Moreover, under the auspices of the Interagency Council on Statistical Policy, the U.S. Office of Management and Budget has formed a Task Force on One-Stop Service for Federal Statistical Data Users. The task force is primarily responsible for designing and developing easy World Wide Web access to a broad range of federal statistics.

Over the course of the workshop, an ambitious set of suggestions was made for improving existing data sets, enhancing data linkages, and developing new data sets. Participants also concluded that some general guidelines could be developed to determine whether a new data collection effort or existing data set is cost-effective and useful, and they proposed 10 questions to consider when assessing a data collection effort:

1. Does the data source fill important information gaps? For example, does it address topics such as family, housing, and outcomes and effectiveness of care?

Are there redundancies? If so, what are the advantages and disadvantages of the redundancies?

2. Do the data help to answer important policy questions?
3. Are there statistical models to turn the data into useful information?
4. Can the data help to anticipate future changes in the populations of interest?
5. Can the data be linked or integrated with other sources (e.g., clinical research, provider and patient data, state- and local-level data)? What constraints does the need to protect confidentiality place on data linkage and integration?
6. Do the data provide for state-level estimates and estimates for smaller geographic areas?
7. Is the data collection design efficient and effective? For example, does it provide longitudinal data when they are required either for inferences or an efficient design?
8. Are the survey measurement methods relevant, valid, advanced, and innovative?
9. Are dissemination modes provided for the data? Is the availability of data made widely known?
10. What research opportunities do the data provide for other related areas?

Participants agreed that “there is no one data source for all seasons;” no single survey can address the data needs of all researchers and policy makers. Rather, the burden is on researchers and funding agencies to determine whether a new data collection effort or existing data set is cost-effective and useful. Encouraging greater access to existing data sets, unifying and integrating the existing data sets with administrative records, and assessing the merits of new data collection efforts are crucial for fostering and enhancing research on current and future generations of the aging population.



## References

### Agency for Health Care Policy and Research

- 1991 *Report to Congress: The Feasibility of Linking Research-Related Data Bases to Federal and Non-Federal Medical Administrative Data Bases*. AHCPH Publ. No. 91-0003. Rockville, MD: Agency for Health Care Policy and Research, U.S. Department of Health and Human Services.

### Bean, Frank D., George C. Myers, Jacqueline L. Angel, and Omer R. Galle

- 1994 Geographic concentration, migration, and population redistribution among the elderly. Pp. 319-354 in *Demography of Aging*, edited by Linda G. Martin and Samuel H. Preston. Committee on Population, National Research Council. Washington, D.C.: National Academy Press.

### Bureau of the Census

- 1995 *Statistical Abstract of the United States*. Washington, D.C.: U.S. Department of Commerce, Economics, and Statistics Administration.
- 1996 *65+ in the United States*. Current Population Reports, Special Studies, P23-190. Washington, D.C.: U.S. Department of Commerce.

### Citro, Constance F., and Eric A. Hanushek, eds.

- 1997 *Assessing Policies for Retirement Income: Needs for Data, Research, and Models*. Panel on Retirement Income Modeling, Committee on National Statistics, National Research Council. Washington, D.C.: National Academy Press.

### Citro, Constance F., and Robert T. Michael, eds.

- 1995 *Measuring Poverty: A New Approach*. Panel on Poverty and Family Assistance, Committee on National Statistics, National Research Council. Washington, D.C.: National Academy Press.

### Clayton, E.W., K.K. Steinberg, M.J. Khoury, E. Thomson, L. Andrews, M.J. Kahn, L.M. Kopelman, and J.O. Weiss

- 1995 Informed consent for genetic research on stored tissue samples. *Journal of the American Medical Association* 274(22):1786-92.

Committee on National Statistics

- 1995 *Toward Improved Modeling of Retirement Income Policies: Interim Report*. Panel on Retirement Income Modeling, Committee on National Statistics, National Research Council. Washington, D.C.: National Academy Press.

Connick, M.

- 1994 *Issues in Health Informatics: Nursing within Health*. Centre for Strategic Human Services 1(5). Griffin University.

Coughlin, T.L., L. Ku, and J. Holahan

- 1994 *Medicaid Since 1980: Costs, Coverage, and the Shifting Alliance Between the Federal Government and the States*. Washington, D.C.: Urban Institute Press.

Crimmins, E.M., and D.G. Ingegneri

- 1992 Health trends in the American population. Pp. 259-78 in *Demography and Retirement: The 21st Century*, edited by A.M. Rappaport and S.J. Scheiber. Westport, CT: Greenwood.

Crimmins, E.M., Y. Saito, and D. Ingegneri

- 1989 Changes in life expectancy and disability-free life expectancy in the United States. *Population and Development Review* 15: 235-267.

Eller, T.J.

- 1994 *Household Wealth and Asset Ownership: 1991*. Current Population Reports, P70-34, Bureau of the Census, Washington, D.C.: U.S. Department of Commerce.

Elo, Irma, and Samuel Preston

- 1992 Effects of early life conditions on adult mortality. *Population Index* 58(2):186-212.

Frank, John W., and J. Fraser Mustard

- 1994 The determinants of health. *Daedalus* 123(4):1-19.

Freedman, Vicki A. and Beth J. Soldo, eds.

- 1994 *Trends in Disability at Older Ages: Summary of a Workshop*. Committee on National Statistics, National Research Council. Washington, D.C.: National Academy Press.

Gilford, Dorothy M., ed.

- 1988 *The Aging Population in the Twenty-First Century: Statistics for Health Policy*. Panel on Statistics for an Aging Population, Committee on National Statistics, National Research Council. Washington, D.C.: National Academy Press.

Greenwood, Daphne T., and Edward N. Wolff

- 1992 Changes in wealth in the United States, 1962-1983. *Journal of Population Economics* 5:261-288.

Hanushek, Eric A., and Nancy L. Maritato

- 1996 *Assessing Knowledge of Retirement Behavior*. Panel on Retirement Income Modeling, Committee on National Statistics, National Research Council. Washington, D.C.: National Academy Press.

Health Insurance Association of America

- 1993 *Long-Term Care Insurance in 1991*. Washington, D.C.: Health Insurance Association of America.

Hertzman, Clyde, and Wendy Ayers

- 1993 Environment and Health in Central and Eastern Europe. Report No. 12270-ECA. World Bank, Washington, D.C.

Hitschler, Pamela B.

- 1993 Spending by older consumers: 1980 and 1990 compared. *Monthly Labor Review* (May):3-13.

Holtz-Eakin, Douglas, and Timothy Smeeding

- 1994 Income, wealth and intergenerational economic relations of the aged. Pp. 102-143 in *Demography of Aging*, edited by Linda G. Martin and Samuel H. Preston. Committee on Population, National Research Council, Washington, D.C.: National Academy Press.

Hurd, Michael

- 1996 The Baby Boomers face retirement. Presentation at the Workshop on Priorities for Data on the Aging Population, Committee on National Statistics, National Research Council. March 4, 1996. Department of Economics, State University of New York, Stony Brook.

Juster, F. Thomas, and Richard Suzman

- 1995 An overview of the Health and Retirement Study. *The Journal of Human Resources* 30 (Supplement 1995):S1-S56.

Kane, Robert L., and Rosalie A. Kane

- 1990 Health care for older people: Organizational and policy issues. Pp. 415-437 in *Handbook of Aging and the Social Sciences, Third Edition*, edited by Robert H. Binstock and Linda K. George. New York: Academic Press.

Katz, S., and C.A. Apkom

- 1976 A measure of primary sociobiological functions. *International Journal of Health Services* 6:493-508.

Lawton, M.P., and E.M. Brody

- 1969 Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist* 9:179-186.

Lee, Ronald D., and L. Carter

- 1992 Modeling and forecasting the time series of U.S. mortality. *Journal of the American Statistical Association* 87(419):659-671.

Lee, Ronald D., and Jonathan Skinner

- 1996 Assessing Forecasts of Mortality, Health Status, and Health Costs During Baby Boomers' Retirement. Pp. 195-243 in *Assessing Knowledge of Retirement Behavior*, Eric A. Hanushek and Nancy L. Maritato, eds. Committee on National Statistics, National Research Council. Washington, D.C.: National Academy Press.

Longino, Charles F., Jr.

- 1990 Geographic distribution and migration. Pp. 45-63 in *Handbook of Aging and the Social Sciences*, edited by Robert H. Binstock and Linda K. George. San Diego, CA: Academic Press.

- 1995 *Retirement Migration in America*. Houston, TX: Vacation Publications.

Lumsdaine, Robin L.

- 1996 Factors Affecting Labor Supply Decisions and Retirement Income. Pp. 61-122 in *Assessing Knowledge of Retirement Behavior*, Eric A. Hanushek and Nancy L. Maritato, eds. Committee on National Statistics, National Research Council. Washington, D.C.: National Academy Press.

Manton, K.G.

- 1989 Epidemiological, demographic, and social correlates of disability among the elderly. *The Milbank Quarterly* 67(2):13-58.

Manton, K.G., and S. Corder, and E. Stallard

- 1993 Estimates of change in chronic disability and institutional incidence and prevalence rates in the U.S. elderly population from the 1982, 1984, and 1989 National Long- Term Care Survey. *Journal of Gerontology* 48:S153-66.

Manton, K.G., B.H. Singer, and R.M. Suzman

- 1993 *Forecasting the Health of Elderly Populations*. New York: Springer-Verlag.

Manton, K.G., and E. Stallard

- 1994 Medical demography: Interaction of disability dynamics and mortality. Pp. 217-278 in *Demography of Aging*, edited by Linda G. Martin and Samuel H. Preston. Committee on Population, National Research Council. Washington, D.C.: National Academy Press.

Marmot, Michael G., and George Davey-Smith

- 1989 Why are the Japanese living longer? *BMJ: British Medical Journal* 299:1547-1551.



- Nabulsi, A.A., A.R. Folsom, A. White, W. Patsch, G. Heiss, K.K. Wu, and M. Szklo  
1993 Association of hormone-replacement therapy with various cardiovascular risk factors in postmenopausal women. *New England Journal of Medicine* 328(15): 1069-1075.
- Newacheck, Paul, and Barbara Starfield  
1995 Monitoring changes in health care for children and families. Pp. 156-191 in *Integrating Federal Statistics on Children: Report of a Workshop*. Board on Children and Families, Committee on National Statistics, National Research Council and Institute on Medicine. Washington, D.C.: National Academy Press.
- Paine, T.H.  
1993 The changing character of pensions: Where employers are headed. Pp. 33-40 in *Employer Pensions in a Changing Economy*, edited by R.V. Burkhauser and D.L. Salisbury. Washington, D.C.: Employee Benefit Research Institute.
- Quinn, Joseph F., and Richard V. Burkhauser  
1994 Retirement and labor force behavior of the elderly. Pp. 50-101 in *Demography of Aging*, edited by Linda G. Martin and Samuel H. Preston. Committee on Population. Washington, D.C.: National Academy Press.
- Riley, J.C.  
1990 The risk of being sick: Morbidity trends in four countries. *Population and Development Review* 16:403-432.
- Rogot, E., P.D. Sorlie, and N.J. Johnson  
1992 Life expectancy by employment status, income, and education in the National Longitudinal Mortality Study. *Public Health Reports* 107(4):457-461.
- Shea, S., A.D. Stein, C.E. Basch, R. Lantigua, C. Maylahn, D.S. Strogatz, and L. Novick  
1991 Independent associations of educational attainment and ethnicity with behavioral risk factors for cardiovascular disease. *American Journal of Epidemiology* 134(6):567-582.
- Singer, Burton, and Kenneth G. Manton  
1993 How many elderly in the next generations? *Focus* 15(2)(Summer and Fall):1-10. Institute for Research on Poverty, University of Wisconsin-Madison.
- Smeeding, Timothy M., and Barbara Boyle Torrey  
1996 Major Demographic and Social Trends in the Population at Older Ages. Paper presented at the Workshop on Priorities for Data on the Aging Population, Committee on National Statistics, National Research Council. March 4, 1996. Washington, D.C. Center for Policy Research, Syracuse University.
- Soldo, Beth J., and Vicki A. Freedman  
1994 Care of the elderly: Division of labor among the family, market and state. Pp. 195-216 in *Demography of Aging*, edited by Linda G. Martin and Samuel H. Preston. Committee on Population, National Research Council. Washington, D.C.: National Academy Press.
- Stone, R., G.L. Cafferata, and J. Sangl  
1987 Caregivers of the frail elderly: A national profile. *Gerontologist* 27:616-626.
- Stone, Robyn  
1996 Trends in Long-Term Care. Presentation at the Workshop on Priorities for Data on the Aging Population, Committee on National Statistics and Committee on Population, March 4-5, 1996. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, Washington, D.C.
- Studies of Left Ventricular Dysfunction Investigators  
1991 Effect of Enalapril on survival in patients with reduced left ventricular ejection fractions and congestive heart failure. *New England Journal of Medicine* 325(5):293-302.
- Suzman, Richard M., Kenneth G. Manton, and David P. Willis  
1992 Introducing the oldest old. Pp. 3-16 in *The Oldest Old*, edited by Richard M. Suzman, David P. Willis, and Kenneth G. Manton. New York: Oxford University Press.

- Tauber, Cynthia, and Ira Rosenwaike  
1992 A demographic portrait of America's oldest old. Pp. 17-49 in *The Oldest Old*, edited by Richard M. Suzman, David P. Willis, and Kenneth G. Manton. New York: Oxford University Press.
- U.S. Office of Management and Budget  
1996 Order Providing for the Confidentiality of Statistical Information; Notice. *Federal Register* 61:2876-2879.
- U.S. Senate Special Committee on Aging  
1992 *Aging America: Trends and Projections*. Washington, D.C.: U.S. Government Printing Office.
- Uhlenberg, Peter, and Sonia Miner  
1996 Life course and aging: A cohort perspective. Pp. 208-228 in *Handbook of Aging and the Social Sciences, Fourth Edition*, edited by Robert H. Binstock and Linda K. George. New York: Academic Press.
- Verbrugge, Lois M.  
1989 Longer life but worsening health? Trends in health and mortality of middle-aged and older persons. *Millbank Memorial Fund Quarterly/Health and Society* 62:474-519.
- Waldo, D.R., S.T. Sonnefeld, D.R. McKusick, and R.H. Arnett III  
1989 Health care expenditures by age group, 1977 and 1987. *Health Care Financing Review* 10(4):111-120.
- Wiener, Joshua M., and L. H. Illston  
1996 The financing and organization of health care for older Americans: Organizational and policy issues. Pp. 427-445 in *Handbook of Aging and the Social Sciences, Fourth Edition*, edited by Robert H. Binstock and Linda K. George. New York: Academic Press.
- Wiener, J.M., Illston, L.H., and R.J. Hanley  
1994 *Sharing the Burden: Strategies for Public and Private Long-Term Care Insurance*. Washington, D.C.: Brookings Institution.
- Winkleby, M.A., D.E. Jatulis, E. Frank, and S.P. Fortmann  
1992 Socioeconomic status and health: How education, income, and occupation contribute to risk factors for cardiovascular disease. *American Journal of Public Health* 82(6):816-820.
- Wolf, Douglas  
1994 The elderly and their kin. Pp. 146-194 in *Demography of Aging*, edited by Linda G. Martin and Samuel H. Preston. Committee on Population, National Research Council. Washington, D.C.: National Academy Press.
- Yeas, M.A.  
1987 Are the eighties different? Continuity and change in the health of older persons. Pp. 57-61 in *Proceedings of the 1987 Public Health Conference on Records and Statistics*. Hyattsville, MD: National Center for Health Statistics, U.S. Department of Health and Human Services.
- Zedlewski, Sheila R., Roberta O. Barnes, Margaret R. Burt, Timothy D. McBride, and Jack A. Meyer  
1990 *The Needs of the Elderly in the 21st Century*. Washington, D.C.: Urban Institute Press.



# Appendix A

## AGENDA

Workshop on Priorities for Data on the Aging Population

Committee on National Statistics  
Committee on Population

4-5 March 1996

National Academy of Sciences  
Room 130  
Green Building  
2001 Wisconsin Avenue, N.W.  
Washington, D.C.

*Monday, March 4*

### **Part I Introduction**

9:00	Welcome and Opening Remarks	Dorothy Rice Richard Suzman Barbara Torrey
9:15	Purpose and Goals of Workshop	Dorothy Rice
9:25	Discussion of Findings and Recommendations of the 1988 CNSTAT Report, <i>The Aging Population in the Twenty-First Century: Statistics for Health Policy</i>	Dorothy Rice

*(The chair will begin the discussion with a brief overview of the major findings and recommendations of the report. Commentary and discussion will follow.)*

## Part II How Will the Future Population at Older Ages Be Different?

*This session will present the major scenarios for the aging population. The designated leader will begin with 10-15 minutes of commentary, and the discussion will then be opened up for other participants to provide their comments and views. Discussions will focus on the important policy issues and the needed data to inform policy making. The goal of this part of the workshop is to take a visionary look toward anticipating what we need to know. Discussion will not be just about fairly immediate program-related needs, but more importantly about long-range data needs that will address major policy and research questions.*

9:45 a.m. Major Demographic Trends in the Population at Older Ages Timothy Smeeding

*(What are the major demographic, economic, and other social changes we will see as the population ages—in education, health, income and wealth, household composition, and living and income sharing arrangements?)*

11:00 a.m. Health, Disability, and Functional Status Longevity and Quality of Life Beth Soldo

*(What do we need to get better projections, as well as a better understanding of the forces underlying trends and racial and social differences?)*

1:30 p.m. Trends in Long-Term Care Robyn Stone

2:30 p.m. Health Care: Delivery, Organization, and Financing Marilyn Moon

*(Discussion topics will include trends in managed care, block grants for Medicaid, proportion of family budgets spent on health care, and health utilization and expenditures.)*

3:45 p.m. The Baby Boomers Face Retirement: Health, Wealth, and Demography Mike Hurd

*(What changes do we expect, for example, in labor force participation of the elderly, in savings of the future elderly, and in inter-generational transfers as the low-fertility high-divorce cohorts age?)*

4:45 p.m. Research Opportunities with Current and Potential Surveys Robert Wallace

*(Topics to be covered include lineages, genetic markers, tertiary prevention.)*

5:30 p.m. Adjourn

*Tuesday, March 5*

9:00 a.m. Rapporteur's Review of Major Issues and Identified Data Needs Deborah Carr  
Anu Pemmarazu

### **Part III Taking Stock of Current Surveys to Meet Future Needs**

9:45 a.m. How Current Surveys or Modifications to Them Meet the Needs Dorothy Rice

*(HRS, AHEAD, NLTCs, LSOA, SOAII, NHIS, and other surveys)*

*This session will be structured as a roundtable discussion. Specifically, the chair will call upon each of the survey representatives to speak about their respective surveys in the context of Part II and the important needs that are fulfilled by the survey, how the survey can be used as an instrument to meet future data needs and inform policy, and what the potentials are for data linkage.*

### **Part IV Methods to Fill the Gaps**

11:00 a.m. The Future Environment for Data Collection

The Federal Statistical System Katherine Wallman  
Organization and budgets  
Confidentiality and data sharing  
Consolidation of household surveys  
Continuous measurement  
Interagency collaboration  
New responsibilities for states

- 1:00 p.m. Suggestions for Improvements in Data Collection Robert Hauser

*(This session will cover data linkages, models, collection methodologies, administrative records, consolidation of surveys, continuous measurement.)*

*This discussion will be structured similarly to Part I: the leader will begin with 10-15 minutes of introductory comments, and the discussion will then be open for comments from participants.*

## **Part V Conclusions**

- 2:00 p.m. Summary and Conclusions Dorothy Rice

*(This session will review of population trends and policy issues, identified data needs, and current or potential data sources.)*

# Appendix B

## Data Sources for Studying Aging: Survey Characteristics and Linkage Capacities



## Appendix B Data Sources for Studying Aging: Survey Characteristics and Linkage Capacities

Survey	Sample	Oversamples
Asset and Health Dynamics Among the Oldest-Old (AHEAD) Survey	National panel study of cohorts born 1923 and earlier; 7,477 respondents aged 70+ in 1993	Blacks, Hispanics, and Florida residents
Consumer Expenditure Survey (CEX)	Nationally representative sample of 5,000 households; rotating panel	None
Current Population Survey (CPS)	Rotating national sample of 57,000 households	None
Decennial Census	All persons and housing units in the U.S. and its territories	None
German Socio-Economic Panel (GSOEP)	National sample of 5,921 households in (former) Federal Republic of Germany; 2,179 (former) East German households added in 1990	None
Health and Retirement Survey (HRS)	Nationally representative sample of 7,700 households (over 12,600 persons) of those age 51-61 in 1992 and their spouses; will introduce new (younger); cohort every 5 years	Blacks, Florida residents, and Mexican-Americans
Longitudinal Survey on Aging (LSOA)	National sample of 7,541 persons aged 70+ in 1984; drawn from NHIS sample.	None

Planned Periodicity	Planned Linkage Capacities	Dissemination and Information Contact (as of 8/96)
1993, 1995; biennial interviews planned	Medicare records, NDI, state Medicaid files, SSA earnings & benefits files	Cathy Terazas 313-763-9794 ahead.ask@umich.edu <a href="http://www.umich.edu/~hrswww/index.html">http://www.umich.edu/~hrswww/index.html</a>
Decennial, pre-1980; ongoing since 1980; each new panel is interviewed for five consecutive quarters, then replaced	No linkage	Stephanie Shipp Bureau of Labor Statistics 202-606-6900 shipp_s@bls.gov
Monthly; households are in sample for 4 months then out of sample for 8 months, then in sample for 4 months	No linkage	Ron Tucker Bureau of the Census 301-457-3806 pop@census.gov
Decennial	No linkage	POP/SIS 301-457-2422 pop@census.gov <a href="http://www.census.gov">http://www.census.gov</a> <a href="http://www.psc.lsa.umich.edu/aging/census.html">http://www.psc.lsa.umich.edu/aging/census.html</a>
Annual, since 1984	No linkage	elke.holst@diw-berlin.d400.de burk@maxwell.syr.edu <a href="http://www-cpr.maxwell.syr.edu/demogctr/demogctr.htm">http://www-cpr.maxwell.syr.edu/demogctr/demogctr.htm</a>
Baseline interview in 1992; follow-ups by mail or phone or every other year for 12 years	Medicare records, NDI, SSA earnings data	hrsquest@isr.umich.edu <a href="http://www.umich.edu/~hrswww/index.html">http://www.umich.edu/~hrswww/index.html</a>
1984, 1986, 1988, 1990	Medicare claims records; NDI	Harold Lentzner 301-436-7035, ext. 172 HRL1@NCHS07a.em.cdc.gov

Appendix B Continued

Survey	Sample	Oversamples
Luxembourg Income Study (LIS)	Data for more than 25 countries for one or more years; data bank has more than 60 data sets covering from 1968-1992	None
Medicare Current Beneficiary Survey (MCBS)	A rotating panel of a representative sample of 12,000 Medicare enrollees	None
Medical Expenditure Panel Study (MEPS): Household Component	National sample of 10,500 households and 23,000 individuals, selected from 1995 NHIS	Starting in 1997: adults and children w/ functional or activity limitations; persons with incomes <200% of poverty level; persons who anticipate high levels of medical expenses
Medical Expenditure Panel Study (MEPS): Nursing Home Component	National sample of 800 nursing homes with 5,500 residents	None
National Ambulatory Medical Care Survey (NAMCS)	National sample of 3,000 physicians in office-based practices. Covers 45,000 patient visits	None
National Health and Nutrition Examination Survey (NHANES III)	Nationally representative sample of 30,000 persons aged 2 months and older; data sources include survey, physical exam, and lab tests	Blacks, Mexican-Americans
NHANES I Epidemiologic Followup Survey (NHEFS)	Nationally representative sample of 14,407 people aged 25-74, from 1971-1975 NHANES I sample	Poverty areas, women of childbearing age, elderly
National Health Interview Survey (NHIS)	Nationally representative sample of 41,000 households	Blacks, Hispanics

Planned Periodicity	Planned Linkage Capacities	Dissemination and Information Contact (as of 8/96)
Varies by nation	No linkage	LISAA@maxwell.syr.edu <a href="http://www-cpr.maxwell.syr.edu/lis_part/lisintro.htm">http://www-cpr.maxwell.syr.edu/lis_part/lisintro.htm</a>
Three interviews per year: Access to Care files available for 1991-93. Calendar Year Cost & Use files available in 1995	Medicare claims data	Information Analysis Branch, Decision Support Division, Bureau of Data Management & Strategy, HCFA 410-597-5083
Annual, since 1996	HCFA records	Karen Beauregard 301-594-1400 kbeaureg@cghsir.ahcpr.gov dpotter@cghsir.ahcpr.gov
First survey in the field in August 1997	No linkage	Karen Beauregard 301-594-1400 kbeaureg@cghsir.ahcpr.gov dpotter@cghsir.ahcpr.gov
Annual, since 1975	No linkage	Cathy Burt 301-436-7132, ext. 175 cwb2@nch9a.em.cdc.gov
Periodic, with longitudinal follow-up	Will be part of the HHS Plan for Survey Consolidation	Vicki L. Burt 301-436-7080, ext. 116
Special cohort study; Data were collected in 1982-1984, 1986, 1987, and 1992.	NDI and Medicare data	Chris Cox 301-436-5979, ext. 115 csc3@nch7a.em.cdc.gov
Annual	NDI, HCFA records, Medicare state-based data	Dr. Gerry Hendershot, 301-436-7085, ext. 142 nchsquery@nch10a.em.cdc.gov

Appendix B Continued

Survey	Sample	Oversamples
National Health Interview Survey on Disability	Phase I screens 50,000 households, phase II is a follow-up of persons with moderate to severe disabilities; about 20,000 households per year	None
National Home and Hospice Care Survey (NHHCS)	National sample of 1,500 home health agencies and hospices, with 9,000 current patients and 9,000 discharged patients	None
National Hospital Ambulatory Medical Care Survey (NHAMCS)	National sample of 600 hospitals with 90,000 patient visits	None
National Hospital Discharge Survey (NHDS)	National sample of 542 hospitals and 250,000 discharges; sample updated in 1991 to include new hospitals	None
National Longitudinal Survey (NLS) of Older Women	National sample of 5,083 women aged 30-44 in 1967	Blacks
National Long-Term Care Survey (NLTC)	Sample drawn from Medicare administrative files; 6,393 interviewed in 1982; more than 20,000 observations as of 1996	400-500 persons aged 95+; 1,200 persons identified as nondisabled.
National Nursing Home Survey (NNHS)	National sample of 1,500 nursing homes with 6,500 residents and 7,800 discharges	None
National Survey of Ambulatory Surgery (NSAS)	National survey of 800 facilities, and 192,000 patients; surveys are completed by facility staff	None
National Survey of Families and Households (NSFH)	National sample of 13,008 including main cross-section sample of 9,637 age 19+	Blacks, Mexican-Americans, Puerto Ricans, HHs of single-parent families, stepfamilies, recently married and cohabiting couples

Planned Periodicity	Planned Linkage Capacities	Dissemination and Information Contact (as of 8/96)
A special two-year study	NDI, HCFA records, Medicare state-based data	Marcie Cynamon 301-436-7085, ext. 118 mlc6@nch8a.em.cdc.gov
Annual, since 1992	No linkage	Evelyn Mathis 301-436-8830, ext. 159 esm3@nch9a.em.cdc.gov
Annual, since 1992	No linkage	Cathy Burt 301-436-7132, ext. 175 cwb2@nch9a.em.cdc.gov
Annual, since 1965	No linkage	Bob Pokras 301-436-7125, ext. 184 rop1@nch9a.em.cdc.gov
Periodic. 17 interviews from 1967-1994	No linkage	usersvc@pewter.chrr.ohio-state.edu
1982, 1984, 1989, 1994; plans for 1999 and 2004	Medicare data, Part A and B service use records, 1982-1994	<a href="http://cps.duke.edu">http://cps.duke.edu</a> , then go to NLTC files
1977, 1985, and 1995	No linkage; will be part of HHS Survey Integration Plan	Evelyn Mathis 301-436-8830, ext. 159 esm3@nch9a.em.cdc.gov
Annual	None	Bob Pokras 301-436-7125, ext. 184 rop1@nch9a.em.cdc.gov
Baseline survey in 1987-88; follow-up in 1992-94	No linkage	nsfhhhelp@ssc.wisc.edu <a href="http://www.ssc.edu/cde/nsfhw/home.htm">http://www.ssc.edu/cde/nsfhw/home.htm</a>

Appendix B Continued

Survey	Sample	Oversamples
National Survey of Midlife Development in the United States (MIDUS)	National sample of 7,240 adults aged 25-74 in 1995, 4,240 from general population, 1,000 siblings, 1,000 twin pairs	Men, older persons
Panel Survey of Income Dynamics (PSID)	National sample of 4,800 households, beginning in 1968; 8,700 households in 1996	Blacks; Hispanics in 1990-1995, with Cubans and Puerto Ricans oversampled relative to Mexican-Americans
Second Supplement on Aging I (SOA II)	National sample of 10,000 persons aged 70+ in 1994, from NHIS	Elderly persons living in Black households
Survey of Income and Program Participation (SIPP)	National sample of 14,000 to 20,000 households. Each longitudinal panel lasts 30-36 months	None
Wisconsin Longitudinal Study (WLS)	Wisconsin high school graduates from the class of 1957 and their siblings; 10,317 in 1957; 9,400 in 1975; 8,500 in 1992-1993. 2,000 siblings in 1977; 5,000 siblings in 1992-1993.	Twins

NOTE: HCFA - Health Care Financing Administration  
 NDI - National Death Index  
 SSA - Social Security Administration

---

Planned Periodicity	Planned Linkage Capacities	Dissemination and Information Contact (as of 8/96)
1995, 2000 (planned)	No linkage	Dr. Orville Gilbert Brim, Life Trends 407-778-8899
Annual, since 1968	Medicare records, NDI, PSID geocode; does not have SSN; links via address	bressan@umich.edu <a href="http://www.umich.edu/~psid/">http://www.umich.edu/~psid/</a>
Special cohort study in 1994-1995; a follow-up is planned for 1997-1998	Ongoing record matches with NDI and HCFA Medicare records	Harold Lentzner 301-436-7035, ext. 172 HRL1@NCHS07a.em.cdc.gov <a href="http://www.cdc.gov/nchswww/nchshome.htm">http://www.cdc.gov/nchswww/nchshome.htm</a> <a href="http://www.cdc.gov/nchswww/aging.htm">http://www.cdc.gov/nchswww/aging.htm</a>
New panel introduced annually. A 48-month panel of 36,700 households planned for 1996	No linkage	Michael McMahon Bureau of Census 301-457-3819
1957, 1975, 1992-1993; in-depth interviews and medical data to be collected for 200 in 1996-97	SSA earnings data, NDI	wls@ssc.wisc.edu <a href="http://dpls.dacc.wisc.edu/WLS/wls_archive.html">http://dpls.dacc.wisc.edu/WLS/wls_archive.html</a>

---



