

# Data Needs

**I**n preparing this report, the Federal Interagency Forum on Aging-Related Statistics (Forum) identified several areas where more data are needed to support research and policy efforts. The Forum's observations complement suggestions that were reported at a National Academy of Sciences' workshop on how to improve data on aging.<sup>42</sup>

## Extending the age-reporting categories

Although a respondent's age is almost always collected in single-year increments, it is often reported in categories. Typically, the standard age categories used by statisticians and researchers to describe and analyze the older population are 65 to 74, 75 to 84, and 85+. However, because the average age of the 85+ group has steadily increased over the past fifteen years, it is now necessary to consider extending the commonly used age categories to 65 to 74, 75 to 84, 85 to 94, and 95+. This may require sampling strategies to ensure an adequate sample size in these older age groups.

## Gathering information on older minorities

While the number of studies that oversample older minorities has been increasing, the amount and quality of data available to researchers are still limited. There is a lack of basic data about aging minority populations, largely due to the small sample sizes of these populations as well as to language barriers that prevent certain racial and ethnic groups from participating in surveys. The increasing number of older immigrants highlights the need to collect data on nativity and to analyze generational differences in health and well-being. Policy changes and cultural perceptions have brought increasing complexity to the definition and measurement of race and ethnicity. Currently, only the decennial census has adequate coverage to represent some of the smallest racial and ethnic groups, but even the census data lack critical information on health and disability that is

essential to adequately study the well-being of older minorities.

## Improving measures of disability

Information on trends in disability is critical for monitoring the health and well-being of the older population. However, the concept of disability encompasses many different dimensions of health and functioning, and complex interactions with the environment. Furthermore, specific definitions of disability are used by some government agencies to determine eligibility for benefits. As a result, disability has been measured in different ways across surveys and censuses, and this has led to conflicting estimates of the prevalence of disability. To the extent possible, population-based surveys designed to broadly measure disability in the older population should use a common conceptual framework. At a minimum, questions designed to measure limitations in Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), physical functioning, and other activities should use consistent wording and response categories whenever possible.

## Including the institutional population in national surveys

Because of the complex methodological issues involved with collecting data from people in institutions (along with the associated high costs), the institutional population is often not included in "nationally representative" surveys. According to the Census Bureau, the institutional population "Includes persons under formally authorized, supervised care or custody in institutions at the time of enumeration. Such persons are classified as 'patients or inmates' of an institution regardless of the availability of nursing or medical care, the length of stay, or the number of persons in the institution."<sup>43</sup> Because this definition includes people in nursing homes, psychiatric hospitals, and long-term care facilities, this becomes a critical issue for researchers who are interested in studying the entire older population.

### **Distinguishing between different types of long-term care facilities and the transitions that occur between them**

The use of assisted-living facilities, board and care homes, continuing-care retirement communities, and other types of facilities as alternatives to long-term care in a nursing home has grown over the last fifteen years. Current surveys and censuses that include information on the entire older population rarely distinguish between these types of “institutional” residences. As a result, there is a lack of information on the characteristics of older persons in different residential care settings and their service use and health care needs. Perhaps more importantly, there is little information on the costs, duration, and transitions into and between different long-term care settings. Researchers and policymakers should consider developing consistent definitions of residential settings and include these on surveys of the entire population.

### **Gathering national statistics on elder abuse**

The Institute of Medicine reports a “paucity of research” on elder abuse and neglect, with most prior studies lacking empirical evidence.<sup>44</sup> In fact, there are no reliable, national estimates of elder abuse, nor are the risk factors clearly understood. Most studies have been cross-sectional and have not investigated the natural history of abuse. The need for a national study of elder abuse and neglect is supported by the growing number of older people, increasing public awareness of the problem, new legal requirements for reporting abuse, and advances in questionnaire design.

### **Gathering information to understand the reasons for improvements in life expectancy and functioning**

One of the major successes of the 20th century is the increase in longevity and improved health of the older population. As life expectancy increases, the importance of effectively treating chronic diseases and reducing disability becomes ever greater. Understanding the underlying reasons for the improvements in longevity and functioning is a critical first step to further advances toward these goals. To this end,

information is needed to understand the long-term improvements in the health of the older population stemming from better nutrition, increased access to medical care, improvements in the public health infrastructure, changes in lifestyles, better treatment of chronic diseases through new medical procedures and pharmaceuticals, and use of assistive devices and other technology.

### **Improving the way data are collected to measure both income and wealth**

Collecting data on economic well-being is often a difficult task. Many survey respondents do not know their incomes or are unwilling to share this information with interviewers. This can result in missing data for a large proportion of respondents. A related problem with the collection of economic data is that most surveys use only income-based measures. This type of survey methodology does not capture the accumulated wealth (including the value of future pension payments) and assets on which many older persons rely. New methods to gather income and wealth data are coming into use and are being refined, and their use should be encouraged in surveying older people. These methods are aimed at providing a better understanding of the total financial picture of older Americans facing retirement and those already retired, specifically at including information on individual retirement accounts and 401(k) and Keogh plans.

### **Gathering information on the impact of transportation needs on the quality of life of older Americans**

While much is known about the safety issues of crash involvement and fatality rates of older people, more information is needed on the effects of transportation on the quality of life. The ability to move freely from place to place, while often taken for granted, is as crucial to the well-being of older people as it is to the rest of the population. For example, access to quality health care is effectively removed if an older person cannot get from his or her home to a medical facility. More data are needed on the number of trips older people take and the types of transportation they use. This critical information will aid policymakers in planning for the transportation needs of older Americans.

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