

# **Expert Meeting on the Future of the National Long-Term Care Survey: Data Needs for Disability Policy Making and Research for the Future\***

**National Institute on Aging Meeting Summary  
The National Academies, Keck Center  
October 7, 2005**

The expert meeting on the future of the National Long-Term Care Survey (NLTCs), convened on Friday, October 7, 2005 at The National Academies, and chaired by Burton Singer, was organized as part of the first steps in addressing a major concern of the Behavioral and Social Research Program (BSR) within the National Institute on Aging (NIA); namely, that all BSR-sponsored data-collecting activities be reviewed in order to ensure support of an optimal mix of national and international data collection and data analysis projects in the BSR portfolio. As a similar data review that was conducted 20 years ago proved useful in redefining the scope and specificity of select influential projects in the area of health and retirement, BSR believes this inquiry to be both timely and of significant importance for the future direction of the program and the aging field. After a brief overview of the history, design, content, uses, and contributions of the NLTCs, meeting participants were invited to comment on the perceived strengths and weaknesses of the NLTCs based on their own academic and/or policy-based research, and on next steps. As such, this meeting of experts was not convened with an expectation of generating formal recommendations, but as an impetus for progress through critical assessment.

In his opening remarks, Richard Suzman addressed the NIA's main concern that while the NLTCs is a panel study, only a few articles and books have capitalized on this feature. Suzman raised several options to resolve the situation, including (1) terminating the study and issuing a Request for Applications (RFA) to solicit alternative study designs or a new cohort to study disability among the elderly; (2) integrating the NLTCs into the Federal statistical system and combining it with data from earlier samples to stimulate interaction between the research community and the Federal statistical system, and (3) continuing the NLTCs with several modifications to assure clearer focus and specificity. In the latter case, attention must be given to the continued tracking of functional disability, especially in the very old, and to a greater focus on the dynamics of disability and family structure, health conditions and genetics, and long term care issues, including transitions between these settings based on changes in health status.

There was general support for continuing to address long-term care and disability questions from both academic and policy quarters. The NLTCs has offered a unique resource for understanding the disability and functioning of the American elderly population. However, the discussion raised a number of issues for further consideration, including the advisability of collecting biomarkers and associated implementation strategies, increasing the periodicity, collecting more detailed data on the living arrangements of older adults with chronic disability, collecting information to understand the environmental components of disability separate from the functional components,

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\* The expert meeting was hosted by the Committee on National Statistics and the Committee on Population, The National Academies, and sponsored by the National Institute on Aging. This meeting summary was prepared by Virginia Lerch and Rose Maria Li, Rose Li and Associates, Inc. (rose@roseliassociates.com).

and adding to the screener questions to collect more information about individuals without chronic disability (frequently called screen-outs) in order to better assess incidence. The meeting also raised the visibility of the contributions of the NLTCS in the policy arena, which previously had been less appreciated in part because NLTCS data and associated analyses that have informed policy decisions generally are not published. Participants endorsed establishing regular meetings involving stakeholders from both the academic and policy arenas so that the NLTCS can benefit by interactive feedback from its strongest user bases, ensuring as well that research questions have policy relevance and policy questions are informed by the best available research. Additionally, participants encouraged the NIA to consider a funding consortium to include federal policy agencies.

The following report highlights the main themes from the meeting presentations and discussion. The meeting agenda and roster of participants are included as Appendices A and B.

### **Overview of the History and Uses of the NLTCS<sup>1</sup>**

In the 1980s, several projects were implemented to address the critical gap in national data concerning health and functioning changes in later ages, an area of great concern in light of the post-1968 increase in life expectancy and the resulting threat to the fiscal basis of the Social Security system. At that time, it was unknown whether life expectancy was increasing due to improved health or if the increase was a result of improved medical treatment, keeping the very sick and disabled elderly alive for longer periods of time. The NLTCS was first fielded in 1982 as a cross-sectional survey of health and long-term care (LTC) needs of the elderly by the Health Care Financing Administration (HCFA), now the Center for Medicare and Medicaid Services (CMS), with input from the Office of the Assistant Secretary for Planning and Evaluation (ASPE). A follow-up in 1984 assessed improvements, as well as declines, in functional status of all community residents chronically disabled in the 1982 survey.<sup>2</sup> Additionally, 44 percent of persons who screened out in 1982 as not chronically disabled were rescreened to determine incident cases of disability, while 77 percent of those deceased between 1982 and 1984 had their health statuses assessed through next-of-kin (NOK) interviews. These NOK interviews proved to be especially useful in studying institutionalization and Medicaid spending, and efficient in tracking continuous changes in health aspects over time while maintaining low respondent burden. A detailed institutional survey also was implemented in 1984.

Following the 1984 follow-up, HCFA decided against conducting a third round of the NLTCS due to funding constraints, which spurred the submittal of an application to the NIA for funding by Duke University, with Kenneth Manton as the Principal Investigator. The third wave of the NLTCS was fielded in 1989, establishing a 5-year interval period that was based on a consideration of the age-specific disability incidence and mortality rates from previous NLTCS rounds and availability of funding. Although funding was provided primarily by the NIA, the NLTCS adhered to its purpose of examining the operation of the Medicare and Medicaid programs and their effects on beneficiaries.

Following the publication of a suggested small decline in chronic disability prevalence yielded by the analysis of 1982 to 1989 data,<sup>3</sup> a group convened by the National Academies recommended that the NLTCS be conducted in 1994 to investigate further the reliability, scope,

and nature of the decline.<sup>4</sup> The 1994 wave of the NLTCS confirmed the decline in the prevalence of chronic disability seen from the 1982 to 1989 survey data and affirmed that the rate of decline could reduce future Social Security and Medicare expenditures, as well as LTC costs, significantly.<sup>5</sup> The 1999 wave of the NLTCS included an innovative pilot study to collect blood and buccal wash cell samples that offers potential for studying the relation of genetic traits (e.g., APOE alleles) and disability, mortality, and morbidity. The collection of this data could be useful in the future design of Medicare reimbursements of various diagnostic and treatment options, the design of more cost effective drug prescriptions, and side effects related to pharmacogenetics.<sup>6</sup>

Several findings of note ultimately resulted from analyses of the 1982 to 1999 NLTCS data and the linkages to prior NLTCS and Medicare files. These findings include a significant decline in both Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) measures of disability, a significant acceleration of the rate of decline from 1994 to 1999,<sup>7</sup> a significant decline in cognitive impairment from 1982 to 1999,<sup>8</sup> and an absolute decline in the size of the nursing home population.<sup>9</sup> Additionally, slower rates of increase in Medicare costs for nondisabled persons aged 65 to 84, as compared to disabled persons of the same age group, were detected.<sup>10</sup>

After the NLTCS-Medicare data were found by study principals to be more reliable than the underlying Medicare files alone, the utility of the linked data was investigated in several studies of health states, active life expectancy, and transitions.<sup>11</sup> Data collection as part of the 2004 NLTCS concluded in March 2005; the preliminary estimates of disability prevalence are expected in late 2005. Thus, there have been six waves of the NLTCS conducted to date (1982, 1984, 1989, 1994, 1999, and 2004).

Manton highlighted the analytic productivity and use of the NLTCS data for policy research. As a result of monitoring mortality, morbidity, and disability trends of the elderly in the United States, the NLTCS is being used to assess the relation of health changes to Medicare expenditures, service use, and diagnoses.<sup>12</sup> The survey also has been utilized to evaluate the impact of biomedical research and research support on health changes in the elderly.<sup>13</sup> Additionally, the NLTCS has allowed for the examination of health change and service use in the extreme elderly population (aged 95 and older),<sup>14</sup> and provided state and federal agencies, as well as Congressional staff and private LTC actuaries, with data regarding reductions in institutional use, changes in informal care giving patterns in LTC, and patterns of changes in disability prevalence by age and sex from 1982 to 1999.

With regard to future uses of the NLTCS, Manton suggested several possible new applications of the data, as well as continued studies of previous patterns and findings. One of the newest uses of the NLTCS longitudinal data is the application of frailty indices to track changes in disability. The construction of the indices from a battery of 30 measures of disease and disability (i.e., “deficits” as substituted for ADL and IADL measures) from the 1999 NLTCS has been shown to be strongly predictive of time to death while controlling for age and gender. The logic behind these indices reflects the most recent conception of frailty as the accumulation of multiple small deficits and insults.<sup>15</sup> Likewise, another area of potential future use includes assessing physiological change underlying longitudinal health trends using biomarkers for genomic,

proteomic, and service-use studies.<sup>16</sup> Additionally, Manton suggested that expanding the lower age range to identify markers of earlier turning points in future trends in disability, possibly by crosswalking with other ongoing surveys (e.g., National Health Interview Survey, National Health and Nutrition Examination Survey) likely will be proposed in future iterations of the NLTCS.

Manton also discussed the linking of NLTCS and Medicare files to Medicaid records and veterans' health status data in the U.S. Department of Veterans Affairs (VA) health data system in order to create actuarially-based forecasts of demand on the VA system by the elderly population. A veteran-status variable was added to the 2004 NLTCS screener, which resulted in an increase in the number of veterans (approximately 9,100 in total across all years) identified in the samples who can be linked back to the VA health service use records. While the VA attempted to link a telephone survey used to periodically assess short-term changes in veterans' satisfaction with VA services, the data from the telephone survey could not be reconciled with measures conforming to HIPAA standards from the NLTCS. This problem has been addressed by the VA, and a coordinated NLTCS-VA instrument has been designed and will be available for future analyses of veterans' satisfaction with LTC review details. Collaboration with the VA on linking NLTCS data to Medicaid records is currently ongoing with records for all 50 states now drawn for 1999, 2000 and 2004. In addition the NLTCS files are being linked to administrative and patient assessment records for home health care (OASIS) and for nursing home use (Minimum Data Set). These linkages previously had not been possible because Medicaid data have not been previously available from all fifty states. Thus future linkage of these datasets would allow for the study of both informal and formal LTC service use by individuals who survive to later ages – ages at which LTC and Medicaid costs tend to dominate Medicare costs for acute care.<sup>17</sup>

In addition to needed improvements in data documentation (which are currently being addressed), Manton acknowledged that the NLTCS has been criticized for being resistant to change. He argued that the survey has accommodated a number of changes in its history, including the addition of ASPE-funded informal care supplements in 1989, 1999 and 2004, the addition of a health insurance module in 1989, the above-mentioned addition of a veterans status question to the screener in 2004, and a series of changes over time in the design of the survey (e.g. a change in the institutional interview respondent in 2004 from nursing home caregiver to the sample person to parallel the community interview). These small changes and additions were said not to have compromised the data collection, but Manton suggested that changing core disability and morbidity questions and altering the core sample design could compromise comparisons over time and among cohorts. The uniqueness of the NLTCS' stable sample structure and core questionnaire content over a 20-year period allows for the measurement of the underlying phenomenon without regard to outside forces, a feature that is critical when assessing effects from changes in Medicare policy. However, changing the periodicity of the survey in focused ways (e.g. more frequent contact with very elderly persons) could be useful for future analyses and for more carefully tracking changes in disability.

Overall, the NLTCS design features (e.g., sample size, list sample from CMS administrative records, face-to-face interviewing, high response, and 100-percent linkage to Medicare records) are noteworthy and have been well received in reviews.<sup>18</sup> There is no gap in coverage, as both

institutional and community populations are represented. The NLTCS also features long-term measurement stability, a mixed cross-sectional and longitudinal design, detailed disability and informal care assessment, enhanced samples of oldest-old (aged 85 and older) and extreme elderly (aged 95 and older), and low respondent burden.

In the discussion following Manton's assessment of past and future uses of the NLTCS, Alan Garber noted that the use of the NLTCS has extended much further beyond the scope that was envisioned at the beginning of the survey. Nevertheless, in the opinion of many NLTCS users, one of the most serious limitations with using data from the NLTCS is the need to combine it with data from other sources for certain analyses of interest. For example, the absence of nursing home admission and discharge dates is a significant flaw when considering one of the NLTCS' principal intended uses to examine nursing home and hospital utilization.<sup>19</sup> While the NLTCS is unique in its ability to track the disabled population and many questions can only be addressed by it, a number of participants suggested that small changes or additions to the screener instrument might yield large benefits, as was the case with the addition of the question about veteran status, and address current limits to analysts' ability to study incidence and prevalence issues. Garber believed that many of the existing shortcomings can be remedied. Although more questions could be added to the screener to collect specific information, it was recognized that doing so would increase respondent burden and survey costs.

## **The Role of the NLTCS in Policy Analysis**

### ***Department of Veterans Affairs***

In his discussion of the effect of the NLTCS on VA operations, Bruce Kinoshian described past discussions within the VA concerning whether data analyses should focus on all veterans or only on those veterans enrolled in the VA system. The addition of veteran status on the NLTCS screener at the VA's request has made it possible to obtain nationally representative data on all veterans, and their transitions in and out of the VA system. The latter is extremely important for projecting future LTC needs for this population. The addition of a Veteran Status question to the screener also enabled definitive identification of all veterans included in prior waves of the survey who were still alive, creating a cohort of more than 9,000 veterans from the 5 waves of the survey. This cohort is the basis for the current revision of VA's Long Term Care Planning Model. In addition, the VA now administers the NLTCS functional status screener questions to its entire Survey of Enrollees (N=50,000), creating a powerful but efficient survey strategy to determine and validate the functional status of the enrolled veteran population. Kinoshian noted that compared to the prior VA LTC Planning Model, the first revision, based on the 1999 NLTCS, produced substantially more accurate estimates of demand for nursing home and home and community-based care, and focused attention on key planning areas (such as enrollment rates for the oldest (aged 85+) veterans. Kinoshian concluded his remarks by categorizing the NLTCS as a rich source to model health states and health changes over time.

### ***Office of the Assistant Secretary for Planning and Evaluation***

William Marton and Pamela Doty, representatives of ASPE, summarized some of the many applications of the NLTCS data for analyzing trends in disability and associated policy implications. ASPE has used the NLTCS data not only to track aggregate trends, but to examine dynamic factors that have driven these trends and to hypothesize about the implication of these

patterns on health and LTC expenditures. In addition to LTC analyses, ASPE has relied on the NLTCs data to inform the development of policies related to caregiver supplements, private LTC insurance tax credits, and tracking of home health expenditures, as well as the development of microsimulations, which require very detailed information about the population.<sup>20</sup> While the NLTCs has proven useful in policy research, Marton noted perceived weaknesses of the survey, which include the 5-year interval between survey waves, and limited information on transitions between disability states and settings. However, two major strengths of the survey result from its list sample and its ability to detect the use of quasi-institutional care (e.g., assisted living facilities which emerged 1999 to 2004) and major changes in informal caregiver patterns between 1994 and 1999 which other surveys had not captured. These findings led to the redesign of the 2004 NLTCs caregiver survey.<sup>21</sup> Marton praised the NLTCs as unique in utilizing Medicare files as the sampling frame and emphasized that although it is not a perfect survey; its ability to permit examination of the dynamics of disability and specific programs has been extraordinarily useful from the policy perspective, with no ready substitute. He further suggested that the proposed enhancements to the NLTCs (e.g., increased periodicity) would make it even more useful to ASPE, and perhaps to other policy offices.

### *Centers for Medicare and Medicaid Services*

Carol Kelly of the CMS acknowledged that the NLTCs contains unique information on informal care and environmental factors that contribute to disability, and that this information could be valuable for strategic planning. Kelly also asserted that, although the NLTCs is not the only survey available to study the important issues of trends in disability prevalence and the settings where people with disabilities reside, it is useful to have multiple data sources to replicate research findings. However, the Office of Policy at CMS has not used the NLTCs to date and relies primarily on internal data sources (e.g., Minimum Data Set, Medicare Current Beneficiaries Survey) to administer their programs. Kelly echoed concern with the 5-year data collection interval, citing that this length of time is far from optimal for public policy formulation given the immediacy of public policy debates.

### *Statistics Canada*

Michael Wolfson offered the perspective of disability assessment through the lens of Statistics Canada, contrasting it to the U.S. federal statistical system. Citing the strong legal foundation for national surveys that is reinforced by Canada's Constitution, Wolfson emphasized how the mandate allowing for the collection and compilation of data enables researchers to analyze and guide the overall statistical system with relative ease. The surveys issued by the centralized National Statistics Office contain standardized questions regarding education, family structure, income, and disability; this feature supports a broader range of analyses encompassing multiple surveys due to coherent concepts and definitions. As well, the statutory authority of Statistics Canada (combined with respondents' consent) greatly facilitates linkage of survey and administrative data. On the other hand, the disadvantages of the Canadian statistical system include its high costs and sometimes poor timeliness in the reporting of actual findings. Wolfson also noted that while rich, crosslinked data sets exist, the skills in the research community for fully utilizing the power of longitudinal data (as compared to repeated cross-sectional data) are limited, and relative to the United States, policy demand for quantitative analysis, as well as comprehensive and longer term projections of disability, is weaker in Canada. However, there is

generalized appreciation by senior officials of the need to understand disability (and many other issues) within a broader context, e.g. social determinants of health.

With respect to the NLTCS, Wolfson noted the challenges of cross cultural comparability of questionnaire items (e.g. Spanish versus English native speakers) which may not have been adequately addressed, and the obsolescence of ADL and IADL questions in the face of the International Classification of Functioning, Disability and Health (ICF) and recent work on international summary health status measures undertaken by the Washington Group on Disability Measurement.

## **The Role of the NLTCS in Research**

In his invited comments, Dana Goldman addressed what he thought to be a fundamental question: What would be the ramifications if the NIA redirected money for the NLTCS to oversample the elderly disabled in the Medicare Current Beneficiary Survey (MCBS)? The long-term followup associated with the NLTCS highlights the key limitations of surveys like the MCBS, although the MCBS collects data with much higher frequency, three times per year. The MCBS also is not as strong as the NLTCS on content related to LTC, particularly LTC not paid by Medicare, and informal support. Goldman suggested that the NLTCS could go in novel directions, such as including biomarkers and harvesting information from medical records. The NLTCS principals also appear to be receptive to supplementing and updating questions regarding health and disability, and the use of assistive devices and equipment, thus offering clear advantages to the research community.

Vicki Freedman noted that the NLTCS has been used to answer a broad range of important policy and research questions related to late-life chronic disability including: trends in disability and cognition, Medicare costs by age and disability, age-specific incidence rates for major disease groups, mortality of the oldest old, and care giving for those with chronic disability. She suggested, however, that since the survey's inception, the framing of disability research issues has been influenced by three contextual changes: (1) a shift from a strictly medical definition of disability to an ecological understanding that disability exists in a social and environmental context; (2) a growing array of support systems and technological innovations that help people with disabilities participate in school, work, and leisure activities and to live independently; and (3) a variety of newer federal assistance programs and policies that emphasize legal protections and the removal of barriers to participation in work, health care, and leisure. With these changes in mind, she identified a variety of current and emerging research questions on late-life disability at the population level (e.g., tracking improvements in active life expectancy and their implications, causes and consequences of disability decline, changing patterns of LTC arrangements) and at the individual level (e.g., disability incidence and transitions, accommodations to functional loss, and effectiveness of interventions). After reviewing the strengths and weaknesses in the design of the NLTCS for the purposes of identifying national trends in disability,<sup>22</sup> Freedman noted that the current design and content did not allow for in-depth treatment of many of the emerging issues. She offered several suggestions to enhance the measurement of disability that build on innovations highlighted at a May 2005 workshop held at the Urban Institute.<sup>23</sup> Particularly salient opportunities for the NLTCS include the (1) collection of physical performance measures, (2) expansion of measures of assistive technology and the

physical environment, (3) collection of time use and participation data for older adults, and (4) if respondent burden issues can be adequately addressed, addition of vignettes to facilitate comparisons of the subjective components of disability measures across culturally distinct groups.

Vincent Mor also offered his opinions of the key points regarding the research value of the NLTCs. While the NLTCs is focused on people with disabilities and LTC, Mor highlighted several areas that he considers not to have been addressed sufficiently. First, the built environment and implantable environment (e.g., cochlear implants) and residential arrangements are different now than when this survey began. This change has led to differences in what are now considered “needs” and “difficulties.” In order to be most effective, the NLTCs must disentangle the nature of the built environment and assistive technology and the nature of participants’ responses. Second, although relevant information is included in the dataset, the NLTCs has not been used to look meaningfully at “supply side” issues related to LTC except perhaps by state Medicaid programs interested in design of benefit programs. For example, the influences of change in state health policy on payments and reimbursements at the individual level have been documented over the past 10 to 15 years through the NLTCs but have not been used to look at care changes. The NLTCs does not facilitate this type of research also because of less detailed economic data on the demand side from survey participants as compared to the Health and Retirement Study, although there is ample information about informal support. Finally, Mor stressed that compiling administrative data to create a residential history file to track movement in and out of entities such as assisted living and daycare, in conjunction with the NLTCs, would increase the value of the survey by accounting for the dynamic quality of transitions in the population. Dates in and out of assisted living, daycare, etc. therefore are critical to know because though they are contained in Medicare administrative records, there is significant care covered by Medicaid and other sources.<sup>24</sup>

As an anatomic pathologist, George Martin is interested in the genetic basis of extraordinarily well-preserved structure and function, not only successful aging but what he termed “elite” aging which includes environmental and genetic components. Martin was drawn to the NLTCs because it is a population-based structure that is longitudinal as well as cross-sectional, has functional measures (although he would prefer better sensitivity and more dynamic range of functional measures), and its linkages to Medicare data give pathologists specific histological diagnoses, as well as actual or estimated age at onset of specific diseases or conditions. He encouraged Duke principals to go beyond buccal swabs or mouthwashes for DNA to collection of peripheral blood which is potentially very powerful because it permits long-range biological experiments with living cells that can be cryopreserved indefinitely, with the possibility of immortalizing subsets of cells. One also can undertake biochemical studies, isolate DNA for genetic studies, examine RNA and gene expression, save serum and plasma depending on collection method, and store the specimens at locations in different parts of the country to diversify storage risks. Martin would love to see the NLTCs begin in middle age, and suggested starting at age 40 because the evolutionary biological theory of aging predicts that declines in structure and function begin in very early middle age, and physiological studies have confirmed this depiction. Such a population does not suffer from inordinate comorbidities and complications, and provides opportunities for sibling analyses. Martin also expressed interest to see more sensitive and objective assays with large dynamic range. He suggested collecting data



from perhaps a subset of individuals in early middle age and looking at concordant and discordant sibling pairs to help find meaningful genes.

## **Design, Content, and Methodology Issues**

Robert Groves summarized the key points of design, content, and methodology for the NLTCs. In addressing these issues, he suggested that the first process is to (1) compare the NLTCs to other surveys and begin to set priorities and identify competitive advantages (essentially, the goal of this meeting), (2) formally address the current user base to assess resource allocations, (3) assess any gaps that exist, and (4) analyze the cost implications to determine any options for budget partners. The second process addresses the issue of viewing the NLTCs as an entity within a coordinated system. This “system” can be defined by the NIA or may include the scope of the federal statistical system. Although some thought needs to be given to alternative coordination models, Groves emphasized that a family-of-surveys model is essential in expanding the user base of the NLTCs. Finally, the third process requires defining both a substantive and methodological agenda to stimulate innovation within the survey.

Groves continued by highlighting the comments of meeting participants with specific regard to the NLTCs. While there was general acceptance of the advantages of a CMS list sample, which allows for quick identification of the target population as well as the ability to link data, there was discussion about the entering age of survey participants. Lowering the age of entry would allow for more extended longitudinal observations of the population but could create sampling frame discrepancies and linkage problems.

Several participants encouraged the addition of new questions in future screeners to broaden the applicability of NLTCs data. While no conclusions were drawn, it became apparent that expanding the set of screener questions for certain subpopulations of the survey (i.e., in addition to those screened in and screened out for the detailed disability questions) should be considered.

Groves suggested that Medicare records could be used between waves to trigger followup interviews on major health transitions more quickly. The advantages of observing more transitions must be weighed against the disadvantages of increasing respondent burden and creating higher survey costs. Kenneth Wachter asserted that increased periodicity could interfere with the ability of study principals to spur innovation in research because attention would be diverted away from scientific questions in order to meet the burden of data collection demands. Of course, no one suggested that lengthening the intervals would result necessarily in greater innovation. Issues of nonresponse also were addressed, with the sense that while the NLTCs has impressively low losses to follow-up, this may be achieved at the cost of higher proxy measurements, and there has been little careful study of possible biases introduced by proxy responses.

Discussion also arose regarding blood draws and justification for the collection of biomarkers in a nationally representative population, particularly in numbers deemed too small for examining polymorphisms. Others expressed the view that the collection of biomarkers should not be for the purpose of gene hunting but to control for already-known correlations. A number of participants underscored the need for clearly articulated hypotheses that take account of the

broader data context (e.g., the National Health and Nutrition Examination Survey) and the comparative advantages of the NLTCs cohort (including sample size). There also was concern that the emphasis on genetics belied the importance of broader determinants of health and health care, and that the world has moved beyond genetic determinism. Some voiced the need to collect biomarkers for more than just those screened in as disabled in order to answer many of the most interesting research questions. A suggestion was made to collect and store DNA samples, and then to run tests later to take advantage of future DNA array technology that is declining drastically in cost over time. Despite the relatively low analytic use of the initial genetic samples collected to date, several participants were convinced that useful information can be gained from the broader collection of this data, although the effects that it could have on nonresponse generates a delicate situation. If there is a risk of disproportionate attrition, one participant suggested consideration of subsampling schemes to diversify this risk rather than jeopardizing the entire study. It was noted that, ultimately, current social science has limited ability to analyze biomarkers for relevant data at this time.

Several participants addressed the construct measurement gap issue that occurs because disability is not a binary but a continuous or scaled phenomenon, and involves physiological, psychosocial, and ecological components. Wachter considered it an important task to tie the NLTCs in with assistive technology and the changing concept of disability. One participant suggested that disability as conceptualized in 1982 may no longer be the most appropriate framework for understanding disability today. Because the definition of disability has and will continue to evolve, studying it longitudinally is challenging. Stephen Fienberg described his efforts to develop longitudinal profiles of disability, and the enormous heterogeneity that is added to profiles over time with each additional wave. He cautioned against drawing causal conclusions from longitudinal models or profiles over time.

A number of participants questioned the lack of significant insights based on the longitudinal aspect of the NLTCs, and supposed that some studies (e.g. trends in compression of morbidity) could have been undertaken through repeated cross-sectional analyses and did not really require a longitudinal survey.<sup>25</sup> At least one participant called for more rigorous justification for continuing the NLTCs, and believed the question needs to be asked whether it would be more cost effective to supplement another ongoing survey (e.g., the National Health Interview Survey [NHIS]) to monitor disability among the elderly and answer some of the questions that the NLTCs seeks to address. Suzman noted that prior discussions with the National Center for Health Statistics (NCHS) did not instill confidence that the tracking of long term care would be accorded a high priority even with supplemental funds from the NIA.

Finally, discussion focused on the perceived lack of users analyzing NLTCs data. While documentation issues and difficulty of use were mentioned as possible factors contributing to low user rates, a formal analysis of the user space and a critical assessment of how to increase the latent user pool were considered to be essential.

## **Concluding Remarks**

In his concluding remarks, Manton expressed interest in the possibility of having a consortium of experts from both policy and research fields to assess the NLTCs critically. He acknowledged

that creative and constructive thinking for moving forward must include the reconciliation of many of the issues mentioned at the meeting, including the role of biomarkers in LTC research, the issue of the 5-year periodicity, and including younger individuals in the survey. Overall, Manton thought that the meeting was very helpful in addressing the existing and emerging issues of the NLTCS.

Richard Kulka also expressed interest in the consortium idea. He stressed the uniqueness of the NLTCS, which started out as a federal statistics survey and transitioned into an academia-based endeavor known for its focus on declining disability. In terms of priorities, Kulka emphasized several key issues, including (1) deciding what “disability focus” means by examining all of the different surveys and the specific phenomena that they address, (2) making a formal assessment of which measures are essential, (3) taking advantage of the low respondent burden while strategically adding useful measurements, and (4) determining which measures are most useful to both the policy and research communities. Kulka believed that by focusing on these priorities, both the demand for and usability of the NLTCS would increase greatly.

Suzman stated unequivocally that the NLTCS would not be continued without demonstrated improvements in data documentation and ease of use, which are expected with the 2004 data release. Funds have been provided in the current bridge funding for this activity. In comparison to other surveys undertaking the collection of similar information, the NLTCS is distinguished by its large population size, continuity over two decades, low attrition, and detailed information about disability. Suzman considered the need to track disability and to understand the dynamics and interaction of disability, health, and health care settings as the most essential reason for the continuation of the NLTCS. He was somewhat surprised, although heartened, by the level of support from many thought to be critics of the NLTCS. At the same time, he was aware of the amalgam of interests and perspectives that the survey pulls together and thought that a priority list of components would be very rudimentary at this time. In conclusion, Suzman considered it a significant indicator of the NLTCS’ utility that no one in the policy or research community expressed any interest in terminating the NLTCS and continuing with passive monitoring of the NLTCS sample through Medicare and National Death Index linkages. Also, there seemed to be little sentiment for trying to have the official statistical agencies “take back” the NLTCS. It was unclear if there were interest in starting a fresh NLTCS-II.

Burton Singer reiterated that the distinguishing features of the two major communities (research and policy) taking advantage of the NLTCS are that they have limited interactions and rarely communicate with each other. In terms of planning for the future, Singer observed a consensus calling for regular meetings of the research and policy communities in order to establish common ground and priorities for the future of the NLTCS and to consider possible cofunding arrangements, as well as the possibility of transferring responsibility for future waves of the NLTCS to a professional survey organization. While agenda differences may ensue, a consortium of research and policy experts would enhance the utility and overall importance of future waves of the NLTCS. The NIA encouraged focus on applied questions that will push forward basic research, which should in turn translate into useful applications.

**Appendix A  
Meeting Agenda**

**Expert Meeting on the Future of the  
National Long Term Care Survey (NLTC)**

**Data Needs for Disability Policy-Making and Research for the Future**

Friday, October 7, 2005  
Hosted by the Committee on National Statistics and the Committee on Population  
The National Academies  
Keck Center – Room 204  
500 5<sup>th</sup> St, NW Washington, DC

- 8:00 am Continental breakfast available
- 8:30 *Opening remarks/introductions*  
**Burt Singer, Chair**  
**Richard Suzman, NIA**
- 8:45 *Measuring Disability at the National Level: The NLTC & Other Surveys*  
**Ken Manton, Duke**
- Brief overview of the history, design, content and uses of the NLTC
  - What were the motivations for, and the original objectives of, the NLTC?
  - To what extent has the NLTC fulfilled its original goals?
  - Can the Medicare Current Beneficiary Survey (MCBS), together with other extant surveys, fulfill the same objectives?
  - What can NLTC contribute to policy and research in the future?
  - What are some future visions for NLTC (2 or 3 alternatives)
- 9:15 *The Role of the NLTC in Analysis of Policies for Long-Term Care and Other Federal Programs Affecting the Disabled Population*
- How has the NLTC been used for policy analysis in the past?
  - What are the key current and emerging questions for federal policy-makers with respect to long-term care and disability?
  - How well can the NLTC address those questions?
  - What are the comparative advantages of NLTC vis-à-vis other data sources, such as the MCBS; Health and Retirement Survey (HRS); and the National Health Interview Survey (NHIS)?
  - What are the needs for cross-sectional analyses? Longitudinal analyses?
  - What is the value for policy analysis of continuing the NLTC?
- Discussion leaders: Mark McClellan, CMS [tentative]; Bruce Kinoshian, VA; William Marton, ASPE; Alan Garber, Stanford**

- 10:30 Coffee break
- 10:45 *The Role of the NLTCs in Research on Disability Trends in the Context of Other Data on Disability and Aging*
- How have the NLTCs data been used in research?
  - What are the current and emerging research questions on disability?
  - What is the role and need for cross-sectional versus longitudinal analyses?
  - What are the comparative advantages and weaknesses of NLTCs vis-à-vis other data sources?
  - What is the value of continuing the NLTCs for disability research?
  - What changes in design or content could improve its value?
- Discussion leaders: Dana Goldman, RAND; Vicki Freedman (by phone), UMDNJ**
- 12:00 noon Lunch (in room 1024)
- 1:00 pm *Design, Content, and Methodological Issues for the NLTCs to be Most Useful for Disability Policy and Research*
- Design issues
- Should the NLTCs field a 7th wave similar to the previous waves or should it change the design and, if so, in what ways?
  - Should the NLTCs lower the age to capture such phenomena as body part replacement at younger ages?
  - Should the NLTCs field the survey at a shorter time interval than 5 years so that it can better capture transitions in disability status? (In that regard, what are the implications of managed care for reducing the data available from Medicare files?)
- Content issues
- What are the priority assessments to include in addition to ADLs and IADLs?
  - What overlaps in content with other surveys should be built into or eliminated from the NLTCs?
  - What important gaps in content might a 7th wave fill?
  - Where could the NLTCs cut back given the strengths of other data sources?
- Methodological issues
- What methodological research (on question content, incentives, or other aspects) should be built into the NLTCs?
- Discussion leaders: Steve Fienberg, Carnegie Mellon; Ken Manton, Duke; Ken Wachter, Berkeley**
- 2:10 *Perspective from Statistics Canada: Pros and cons of disability assessment Through the federal statistical system*
- Michael Wolfson, Statistics Canada**
- 2:30 Coffee break

- 2:45 Review of the Previous Sessions
- Key points regarding the policy value of the NLTCS.  
**Carol Kelly, CMS**
  - Key points regarding the research value of the NLTCS.  
**Vincent Mor, Brown**
  - Key points regarding design, content, and methodology issues for the NLTCS.  
**Bob Groves, Michigan**
- 3:30 Comments from NLTCS Principal Investigator and Co-Principal Investigator  
**Ken Manton, Duke; Richard Kulka, Duke**
- 4:00 Wrap-up/Summary  
**Burt Singer, chair; Richard Suzman, NIA**
- 4:30 Adjourn

## **Appendix B Participant Roster**

**Burt Singer**, Chair, Princeton University  
**Stephen Bronars**, Unicon Research Corporation  
**David Cutler**, Harvard University  
**Pamela Doty**, Office of the Assistant Secretary for Planning and Evaluation  
**Stephen Fienberg**, Carnegie Mellon University  
**Vanessa Flint**, Centers for Medicare and Medicaid Services  
**Vicki Freedman**, University of Medicine and Dentistry of New Jersey  
**Alan Garber**, Stanford University  
**Dana Goldman**, The RAND Corporation  
**Robert Groves**, University of Michigan  
**John Haaga**, National Institute on Aging  
**Carol Kelly**, Centers for Medicare and Medicaid Services  
**Miriam Kelty**, National Institute on Aging  
**Bruce Kinosian**, VA Medical Hospital  
**Richard Kulka**, Duke University  
**Ken Land**, Duke University  
**Virginia Lerch**, Rose Li and Associates, Inc.  
**Rose Maria Li**, Rose Li and Associates, Inc.  
**Jim Lubitz**, National Center for Health Statistics  
**Ken Manton**, Duke University  
**George Martin**, University of Washington  
**William Marton**, Office of the Assistant Secretary for Planning and Evaluation  
**Tom Miller**, Office of the Vice Chairman of the Joint Economic Committee  
**Vincent Mor**, Brown University  
**Georgianne Patmios**, National Institute on Aging  
**Kristen Robinson**, Federal Forum on Aging Related Statistics  
**Eric Stallard**, Duke University  
**Richard Suzman**, National Institute on Aging  
**Ken Wachter**, University of California, Berkeley  
**Robert Wallace**, University of Iowa  
**Maxine Weinstein**, Georgetown University  
**David Weir**, University of Michigan  
**Robert Willis**, University of Michigan  
**Michael Wolfson**, Statistics Canada

### **NAS Staff:**

**Connie Citro**, Committee on National Statistics  
**Barney Cohen**, Committee on Population  
**Michael Feuer**, Division of Behavioral and Social Sciences and Education  
**Caryn Kuebler**, Committee on National Statistics  
**Michael Siri**, Committee on National Statistics  
**Myron Straf**, Committee on National Statistics  
**Gooloo Wunderlich**, Committee on National Statistics

## Endnotes

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- <sup>1</sup> The overview summarizes the presentation by Kenneth Manton which was based on the background paper prepared for the meeting. See Manton KG. NAS Briefing Paper on the NLTCS for the October 7, 2005 Expert Panel, September 26, 2005.
- <sup>2</sup> Manton KG. A longitudinal study of functional changes and mortality in the United States. *Journal of Gerontology* 43:S153-S161, 1988.
- <sup>3</sup> Manton KG, Corder LS, Stallard E. 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 Social Sciences* 48 (4): S153-S166, 1993.
- <sup>4</sup> Freedman V, Soldo B. *Trends in Disability at Older Ages*. Washington, DC: Committee on National Statistics, 1994.
- <sup>5</sup> Singer B, Manton KG. The effects of health changes on projections of health service needs for the elderly population in the United States. *Proceedings of the National Academy of Sciences USA* 95 (26): 15618-15622, 1998. Also, see Manton KG, Corder L, Stallard E. Chronic disability trends in the United States populations: 1982 to 1994. *Proceedings of the National Academy of Sciences U.S.A.* 94 (6): 2593-2598, 1997.
- <sup>6</sup> Manton KG, Gu XL, Huang H, Kovtun M. Fuzzy set analyses of genetic determinants of health and status disability. *Statistical Methods in Medical Research* (Landau S, Leese M, Eds.), Volume 13 (5): 395-408, 2004.
- <sup>7</sup> Manton KG, Gu XL. Changes in the prevalence of chronic disability in the United States black and nonblack population above age 65 from 1982 to 1999. *Proceedings of the National Academy of Sciences, U.S.A.*, 98, 6354-6359, May 8, 2001.
- <sup>8</sup> Manton KG, Gu XL, Ukraintseva SV. Declining prevalence of dementia in the U.S. elderly population. *Advances in Gerontology* 16: 30-37, 2005.
- <sup>9</sup> Manton and Gu, 2001.
- <sup>10</sup> Manton KG, Gu XL. Disability declines and trends in Medicare expenditures. Oxford Institute of Aging, *Ageing Horizons*. Kenneth Howse, Ed. Issues 2: 25-34, 2005.
- <sup>11</sup> Manton, Gu, and Ukraintseva, 2005.
- <sup>12</sup> Manton and Gu, 2001; Manton, Gu, and Ukraintseva, 2005; Manton KG, Gu XL. Change in physical and mental function: Prospects. Chapter in *New Dynamics of Old Age: Individual, Environmental, and Social Perspectives*. Wahl, HW, Tesch-Romer C, Hoff A, Eds. Society and Ageing Series (Hendricks J, Series Ed). Baywood: Amityville, NY, 2004.
- <sup>13</sup> Pardes H, Manton KG, Lander ES, Tolley HD, Ullian AD, Palmer H. Effects of medical research on health care and the economy. *Science* 283 (5398): 36-37, 1999; Manton KG, Corder LS, Stallard E. Monitoring changes in the health of the U.S. elderly population: correlates with biomedical research and clinical innovations. *FASEB Journal* 11(12): 923-930, 1997.
- <sup>14</sup> Manton KG, Gu XL. Disability declines and trends in Medicare expenditures. *Ageing Horizons* (House K, Ed.) 2: 25-34, 2005.
- <sup>15</sup> Mitnitski AB, Graham JE, Mogilner AJ, Rockwood K. Frailty, fitness and late-life mortality in relation to chronological and biological age. *BMC Geriatrics* 27: 2(1): 1-8, 2002; Mitnitski AB, Song X, and Rockwood K. The estimation of relative fitness and frailty in community-dwelling older adults using self-report data. *The Journal of Gerontology, Series A, Biological Sciences and Medical Sciences* 59 (6): M627-32, 2004; Mitnitski, AB, Mogilner A, and Rockwood K. Accumulation and deficits as a proxy measure of aging. *Scientific World Journal* 1:323-36, 2001.
- <sup>16</sup> Huang H, Patel DD, Manton KG. The immune system in aging: Roles of cytokines, T cells and NK cells. *Biodemographic Effects of Genome-Proteome Interactions*, *Frontiers in Bioscience* 10:192-215, 2005.
- <sup>17</sup> Spillman B and Lubitz J. The effect of longevity on spending for acute and long-term care. *The New England Journal of Medicine* 342:1409-1415, 2000.
- <sup>18</sup> Freedman V, Martin L and Schoeni R. Recent trends in disability and functioning among older adults in the United States: a systematic review. *Journal of the American Medical Association* 288: 3137-3146, 2002.
- <sup>19</sup> This feature of the NLTCS predates the involvement of the Duke investigators. It is compensated in part by the Skilled Nursing Facility (SNF) data on the Medicare files and by the use of the NOK survey. However, these two sources of data are hardly adequate to compensate for the important omissions in nursing home admission and discharge dates in the NLTCS. As Medicare SNF information is limited to Medicare-financed admissions, it represents a small fraction of all nursing home utilization, though not necessarily a small fraction of all admissions.



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The NOK survey, at least in the past, was based on recall with the attendant problems of poor accuracy. Note that nursing home admission date is included in the institutional questionnaires.

<sup>20</sup> Congressional Budget Office. Financing long-term care for the elderly. Washington, DC: 1-37, 2004.

<sup>21</sup> Manton KG, Gu X. Changes in the prevalence of chronic disability in the United States black and nonblack population above age 65 from 1982 to 1999. *Proceedings of the National Academy of Sciences, U.S.A.* 98: 6354-6359, May 8, 2001.

<sup>22</sup> Freedman VA, Martin L, Schoeni, R. Recent trends in disability and functioning among older adults in the United States: a systematic review. *Journal of the American Medical Association*, 288 (24): 3137-3146, 2002.

<sup>23</sup> Freedman VA, Waidmann T, Spillman B. Opportunities to improve survey measures of late-life disability: Part II. Workshop Summary. Report prepared for the Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation, July 2005.

<sup>24</sup> It is hoped that many of these concerns will be addressed with the Medicaid linkages.

<sup>25</sup> Subsequent to the meeting, a number of references were provided by Manton to demonstrate the use of the NLTCs in longitudinal studies. These include the following: Manton KG, Singer BH, Suzman RM (Eds.) *Forecasting the Health of Elderly Populations*. New York: Springer-Verlag, 1993; Manton KG, Stallard, E, Singer BH. Projecting the future size and health status of the U.S. elderly population, *International Journal of Forecasting* 8: 433-458, 1992; Manton KG, Land KC. Active life expectancy estimates for the U.S. elderly population: a multidimensional continuous-mixture model of functional change applied to completed cohorts, 1982 to 1996. *Demography* 37(3): 253-265, 2000; Laditka SB. Modeling lifetime nursing home use under assumptions of better health. *J Gerontol B Psychol Sci Soc Sci* 53 (4): S177-87, July 1998. The NLTCs data also have been used to analyze the incidence and course of Alzheimer's disease over a 15-year period using a longitudinal Grade of Membership model, which found costs to be lower than generally had been accepted in the early disease stage, and greater at later stages. The strength of the NLTCs for this analysis was its linking of actual clinical measures (such as cognitive tests) with Medicare claim files, overcoming limitations in most administrative data. See Kinoshian BP, Stallard E, Lee JH, Woodbury MA, Zbrozek AS, Glick HA. Predicting 10-year care requirements for older people with suspected Alzheimer's disease. *J Am Geriatr Soc* 48 (6): 631-8, June 2000.