Expert Meeting on the Future of the National Long-Term Care Survey[*]

National Institute on Aging Meeting Summary
The National Academies, Main NAS Building
February 14, 2006

I.   Introduction

The expert meeting on the future of the National Long-Term Care Survey (NLTCS), convened on Tuesday, February 14, 2006, at The National Academies and chaired by Burton Singer, was organized as a follow-up to the October 7, 2005, expert meeting held at the National Academies to advise the National Institute on Aging (NIA) on data needs for disability policy and research for the future.[1] At the previous meeting, it was apparent that the NLTCS enjoys general support from both academic and policy quarters because of its large population size, continuity over two decades, low attrition, and detailed information about disability. Research and policy experts were encouraged to convene regularly to enhance the utility and overall significance of future waves of the NLTCS. The February meeting was one step in this direction, as it sought to address priorities and concerns from both perspectives, as well as to understand what design modifications to the NLTCS would be welcomed by both researchers and policymakers.

The following report highlights the main themes from the meeting presentations and discussion. Particular emphasis is placed on future priority areas rather than on accomplishments of the past. The meeting agenda and roster of participants are included as Appendices A and B.

II.   Opening Remarks

In his opening remarks, Richard Suzman noted that when Kenneth Manton first proposed taking over the NLTCS, his initial goal was to examine disability and its impact on changes in terms of elder care and living arrangements. This occurred when the Behavioral and Social Research Program (BSR) within the NIA was beginning its initiative on the oldest old (aged 85 and above), for which the survey was rich in sample size. A data review was conducted in the late 1980s that proved useful in redefining the scope and specificity of influential projects in the area of health and retirement. BSR currently is undertaking a similar data review, organized by John Haaga, to guide investments in data collection and archiving for the next decade. BSR intends for the future development of the NLTCS to fit into an overall strategy for producing the infrastructure for behavioral and social research on aging.

While influential findings have derived from the NLTCS, the survey has not yielded as much as hoped on changes in disability and care settings, in part because of the 5-year period between rounds. Suzman expressed a concern that the survey data have been analyzed for the most part as

if they were repeated cross-sections, without taking advantage of the longitudinal design. The NLTCS has also been underused for analysis of the economic costs of disability and the savings associated with disability decline. The survey lags behind comparable studies in terms of methodological innovation. Although the NLTCS has embraced revolutionary approaches such as proposed genetic and proteomic data collection, it has not done much methodological research on how well the questions measure disability. Despite these weaknesses, Suzman noted that there was little support for the possible course of action that he put before the previous workshop, namely discontinuing the NLTCS and starting an entirely new cohort. The NLTCS is too important to end abruptly.

For the first time in 30 years, the NIA budget has declined in real and current dollars, and diminished purchasing power has created an environment in which it is difficult to begin a major new study or expensive modifications to existing studies. This difficulty is compounded by the fact that, after this year, the NLTCS will not have a base in the NIA budget. While the Institute has not made any decisions on funding, any modifications to the NLTCS will need to be cost-effective. The NIA will entertain cofunding arrangements and consider supporting a streamlined version of the NLTCS, perhaps without many special features. Suzman further challenged participants to consider the costs and benefits associated with having the Census Bureau continue to conduct the fieldwork.

III.   Policy Uses for a New Round of the NLTCS

A. Office of the Assistant Secretary for Planning and Evaluation[2]

Pamela Doty and William Marton, both from the Office of the Assistant Secretary for Planning and Evaluation (OASPE), identified six high priority areas for which the NLTCS can be used to understand and evaluate policy options:

- Long-term care financing and service delivery, with the NLTCS providing a comparative advantage in its ability to address multifaceted issues due to its large sample size drawn from Medicare administrative records;
- The provision of home- and community-based services (as alternatives to institutionalization) for older Americans with chronic disabilities;
- Family caregiving—In combination with the Caregiver Supplement to the NLTCS, the data can be used to analyze the amount of time informal caregivers devote to chronically disabled elders, thereby addressing another key policy goal of ensuring that family caregivers are not overburdened by their responsibilities;
- Improving the quality of long-term care—The NLTCS can be used to measure the quality of long-term care by using respondents' self-reports of unmet and under-met need for help with ADL/IADL tasks. However, there are no measures of consumer satisfaction with formal services (publicly or privately funded) in the NLTCS. One possibility would be to merge the institutional NLTCS sample with nursing home information contained in the Online Survey, Certification and Reporting (OSCAR) system;
- Coordination/integration of acute health and long-term care among those dually eligible for Medicare and Medicaid, and effective continuity of care, which is enhanced by the ability to merge NLTCS data with Medicare and Medicaid claims and administrative data; and

- Emerging issues such as the implementation of Medicare Part D and access to medication among the elderly population.

Doty called for more responsive collaboration from the Centers for Medicare and Medicaid Services (CMS) through more efficient data linkage methods and protocols. These requests underscore the importance of the NLTCS for truly timely input into policy debates in addition to research interest.

B. The Department of Veterans Affairs[3]

Bruce Kinosian of the Department of Veterans Affairs (VA) summarized some survey enhancements that could increase the value of the NLTCS to the VA. These suggestions included:
- Filling gaps (e.g., 20 percent of Veterans Health Administration [VHA] nursing home residents excluded due to age, 6 percent of VHA enrollees aged 65 and older excluded due to non-Medicare status, and inability to identify overlap services other than in the year and month of the survey);
- Adding Minimum Data Set (MDS) data to help detail transitions into and out of nursing facilities;
- Including a supplemental sample of the population between ages 50 and 65 to permit more accurate projections of current demand and project future nursing home demand;
- Matching Census data with the NLTCS data to better estimate disability among veterans at the county and market-sector levels, facilitating the development of needs-based targets; and
- Adopting a shorter interval between rounds (e.g., 2 years) for researchers to examine functional status transitions and health service use.

Thomas Edes also suggested several enhancements that would be useful to the VA. These include more detailed data on disability measures to capture the clinical complexity of patients' needs; more detailed classification of patients that would tell us about the burgeoning population with complex diseases; additional longitudinal data on the population with complex diseases; and projected health care utilization. Such data are needed to facilitate performance analysis and to evaluate outcome measures when implementing policies. Edes also discussed the need for more refined data to guide strategies to support caregivers, which involve gender, age, and lifestyle transition factors. Finally, he provided an example of the usefulness of the NLTCS in understanding end-of-life care. About 1,500 veterans die every day, comprising about 25 percent of all deaths in the United States. He noted that approximately 25 percent of those who die in VA facilities are not Medicare eligible. Analyses relying on NLTCS data revealed that only 5 percent of veterans were utilizing hospice care compared to 20 percent of Medicare decedents. Within two years, the VA tripled the percentage of veterans with access to hospice care.

C. Congressional Budget Office

Stuart Hagen explained that the Congressional Budget Office does not conduct basic research, but it uses research from the NLTCS and similar surveys. The CBO has relied almost exclusively on research from the NLTCS for projecting disability prevalence, as well as for projecting the use of various types of long-term care services. Hagen expressed his hope of making better projections for Medicare in the future by again using NLTCS data.

Hagen suggested that the presentation, reporting, and marketing strategies of the survey be modeled after those of the Economic Research Initiative on the Uninsured,[4] as well as the Medical Expenditure Panel Survey[5], which he characterized as having very interactive and user-friendly Web sites that facilitate data access. Hagen suggested that to encourage usage of the NLTCS among policy users, marketing and presenting research findings to the policy community must be considered.

Discussion
Discussion highlighted the importance of linking the NLTCS data with administrative data to address questions about expenditures that are central to policymaking. It also was noted that private financing should not be overlooked, including issues related to the measurement of total out-of-pocket costs, asset decumulation, and reverse mortgages (these require data collected from households rather than administrative data linkages). The NLTCS provides invaluable data on segments of the population not covered in other surveys. It lacks fine-grained data from state-level initiatives related to consumer direction, assisted living facilities, and nursing facility transitions. End-of-life care is an area that could benefit from greater attention.

IV.   Research Uses for a New Round of the NLTCS

In their paper, Vicki Freedman and Robert Schoeni identified six priority areas for research and made suggestions for approaches to enhance the NLTCS:[6]
- Identifying and understanding the causes and consequences of declines in disability and any underlying disparities;
- Identifying interventions to promote disability decline in the future;
- Describing and evaluating settings in which individuals with chronic disability live;
- Monitoring changes in the provision of care and implications for caregivers and recipients' well-being;
- Illustrating the cost and cost-effectiveness of various long-term care and rehabilitation strategies; and
- Understanding how a variety of behaviors influences disability pathways.

To explore these priority areas, they suggested that five key areas for enhancement must be addressed:
- Explicating and expanding disability measurement (e.g., physical performance measures, assistive technology and physical environment measures, time-use data, and vignettes);
- Expanding measures of underlying disease processes and treatments;
- Assessing well-being;
- Systematically identifying long-term care settings and services; and
- Expanding linkages to administrative data.

Freedman and Schoeni argued that dramatic changes in technology, rehabilitation sciences, the socioeconomic and demographic composition of the older population, and public policies regarding disability and long-term care are all compelling reasons to consider new content areas for the NLTCS.

Vincent Mor considered how to meet the multiplicity of user needs. He echoed the call for more modern measures of disability, including perhaps some measures of performance-based disability. The NLTCS may consider obtaining additional information from an event-contingent subsample of individuals who experience a common event (e.g., hospitalization) that then triggers a series of additional survey questions. There must be proper crosswalk with retrospective measures in the full sample to facilitate intersections between micro- and macrovariables, and close to real-time linkage with administrative data to be meaningful. Mor also cautioned that while expanding content on assets, income, private financing, and mortgages would be valuable, there would likely need to be discussion of trade-offs in terms of questionnaire length.

Discussion
Doty reported that the OASPE has been able to analyze the 1999 NLTCS sample linked to the MDS and Outcome and Assessment Information Set (OASIS) data, so such linkages are feasible. These linkages should have taken three weeks to complete, but ultimately took a year. Doty attributed the delay to bureaucratic obstacles. There was discussion about the policy value of linking the NLTCS to Medicaid data (a linkage OASPE has not yet performed). Although certain linkages have been done, the linked data have not been put into the public domain and it is difficult for the research community to access them. Researchers would like an easy process to do these linkages in the future. Katherine Wallman acknowledged the separation between what is available within a federal agency and for public use. She noted that there are mechanisms to permit access, for example, the swearing-in of researchers as has been done by the Census Bureau and the National Center for Education Statistics. Suzman was optimistic that collaboration with CMS is improving that will make linkages easier, and noted a number of approaches that can be tried in the meantime, including the use of secure enclaves and multiple imputation approaches for developing synthetic files.

V.   Design and Content Options

In his remarks, Stephen Fienberg outlined several design and content options that he felt would enhance the utility of the NLTCS.[7] While he stressed the importance of keeping the core design of the questionnaire consistent across survey waves for intercohort and time-based comparisons, he argued for improving the comparability of NLTCS findings with other surveys. His suggested enhancements included improving comparability with the main disability and morbidity questions in other national surveys, such as the National Health Interview Survey and the Medicare Current Beneficiary Survey (MCBS). Fienberg also suggested that utilizing identical questions in the screener and detailed interview could provide an opportunity to address the short-term dynamics of disability, in cases when there are time lags between the interview components. He argued that both of these suggestions could be undertaken while incurring minimal additional costs and changes to the survey.

Fienberg also argued that while the NLTCS measures individuals' disabilities at discrete points in time, many research questions can be addressed only by continuous-time models for disability. While increasing the frequency of the entire survey (periodicity) would present a budgetary challenge and perhaps still be insufficient to track certain changes, Fienberg suggested four alternative data collection approaches for the NLTCS:

(1) Add a new cohort of subjects less frequently, that is, every eight years, while collecting data every two years. Increasing the frequency of data collection would enable investigators to understand rapid changes in disability and other transitions that may not be identified over longer time intervals, while enrolling fewer new subjects would help to balance the cost.

(2) Add a new cohort of subjects less frequently, that is, every eight years, while resampling every two or four years depending on the prior level of disability. Assign higher probabilities of sampling in two years to those who were ADL-disabled in the previous wave.

(3) Consider Option 2 but also assign higher probabilities of sampling in two years to screened-in subjects who had presented no ADL/IADL disabilities in the previous wave.

(4) Add a small new cohort of subjects every five years (the current plan) and resample more disabled respondents halfway through the 5-year cycle.

Fienberg also suggested that supplemental questions be included on individuals who became "healthy" in certain waves (and who, therefore, are considered at less of a risk for disability than those who are consistently disabled), and on those who are at a high risk of dying in the next few years. These data would be very informative for better understanding and predicting the cost of end-of-life medical care. Finally, Fienberg questioned the practicality of using survey weights as part of estimating longitudinal trajectories and also the usefulness of biological markers within the study; however, there was no consensus among participants on these issues.

Before delineating his ideas for design and content options for a new round of the NLTCS, Robert Groves first addressed the issue of cost and the many ways that it impacts design options. He emphasized that cost is not based merely on sample size, but is also affected by the mode of data collection, frequency of measurement, number of waves, the between-wave interval, and the decision between cross-sectional vs. longitudinal. Groves stressed that cost is respondent-rule driven and pointed out that it is unclear whether proxies are managed under a controlled process. Cost is also affected by modularization of measurements. Modules result from (1) pressure to include new variables in the research design, (2) the desire to collect timely policy- and research-relevant information for a subgroup of interest, and (3) an interest to test new questions and stimulate innovation. Adding modules increases costs, though they can be more cost-effective than changing the instrument for the entire sample. Groves noted that survey methodology is advancing at such a rate that current measures become quickly outdated; therefore, there is a growing need for longitudinal designs to include built-in tools for innovation.

While he agreed with many of the options outlined by Fienberg, Groves added four design options for the NLTCS:

(1) Status quo: The NLTCS must be assessed to determine the types of research for which it is useful and the information that can be gleaned accurately from its implementation.

(2) A smaller, richer NLTCS: This option would resonate with researchers wanting new measures of disability with more detailed data vectors. Such a study design might include specialized modules specific to the interest groups funding the study. It would however have a smaller sample and thus potentially not be useful for sub-group analyses.

(3) Continuous monitoring: Data collection would increase in frequency toward end of life. In this design, everyone eventually would get the same survey treatment, but monitoring would be triggered by disability-related events that would call for more frequent contact.

(4) Event-informed monitoring based on administrative records: This would inform the frequency and content of the measurement. As this would also mean that the frequency of measurement would vary across participants, a base design giving equal probability to the cross section would be established and then enhanced by a trigger event(s). This type of informed sampling would provide longitudinal analysts with the transitions and microlevel longitudinal records that are currently lacking.

Discussion

The NLTCS and MCBS share two major features—they are both based on Medicare list samples and both allow linkages to Medicare, MDS, and OASIS data. While the MCBS has very detailed information on medical expenditures and conducts quarterly interviews, follow-up is truncated at four years for each subject. The two studies were designed for different core purposes, and can be seen as complementary. The NLTCS has a comparative advantage in measuring transitions because of low respondent burden and high response rates. Nevertheless, it is important to consider overlap issues in the portfolio of federal survey activities.

The options for mode of data collection must be considered carefully. The radical idea of instantaneous monitoring is very appealing but would require a very nimble data collection organization. Other modes available include Internet interviewing, which allows for much more rapid and less expensive responses, and interactive voice response for limited data. Varying modes and the use of mixed modes also need to be considered. The challenge is in capturing the same information over time, which may require new wording. Asking the same question over time does not necessarily ensure comparability, since the meaning of questions changes over time.

Fienberg emphasized that continuous monitoring approaches that are event driven require a sound understanding of the statistical models that will be used to ensure that the final outcomes sought are estimable. Groves clarified that record-informed sampling could be based on probabilities of observing an event rather than on occurrence only. Dana Goldman raised a key concern regarding event-based modeling, which is whether the initiation of events or the follow-up of events once they are initiated matters more. Until the relative weighting of research questions is determined, it is not clear why one would select such a complicated design. Another approach could be to oversample healthy respondents to observe transitions in disability status, although such an approach likely would have large cost implications. Joshua Weiner expressed frustration with the minimal information available on the nondisabled population from the screener, which makes it difficult to compare the nondisabled to the disabled population. Richard Kulka believed that enhancing the screener content could be addressed quite easily.

Alan Garber stressed that it is difficult to evaluate the different options suggested for enhancing the NLTCS without knowing how much the various proposed design features would cost. One of the most important issues to resolve, in his view, is the need to put resources into enabling linkages to administrative data.[8] He also suggested that consideration be given to making minor

modifications to the MCBS that would make it more useful for research purposes, as the MCBS currently cannot compare to the depth and detail of the NLTCS.

Participants then turned to a discussion of what the major goals of the NLTCS should be, since design decisions cannot be made intelligently without some idea of the core questions of interest. For example, focusing specific aims on transitions from three ADLs to nursing homes may undermine the ability to understand the onset of disability. Jennifer Madans believed that the focus of the NLTCS should be on longitudinal questions, because there are many other surveys available for cross-sectional research. However, Manton pointed out that the NLTCS contains cross-sectional information not available in other national surveys.

Michael Wolfson offered two examples of topics that could dictate NLTCS focus: (1) Earlier starting age of observation (e.g., beginning at 40 years of age) to be able to document earlier differences in disability trajectories; and (2) Continuity of care—Interest in transitions among primary care, home care, assisted living, and nursing homes means that a national sample design is not the answer. He also advocated oversampling those most likely to experience rapid changes in their disability trajectories.

As the discussion about design issues must be conditional on research emphasis, Singer asked participants to identify the top priority areas that they would like the NLTCS to address. This was an effort to prioritize among the dozens of research questions suggested. The following priorities were raised, some of which require more frequent observations as well as linkages to administrative data:
- Disability and consequential care needs, disability care optimization, quality of care for disabled older individuals, and long-term care intersections with care provisions. The focus was suggested to be the disability process that generates need for care.
- Cross-sectional estimates of caregiving.
- Exposures in the past (e.g., education, military service) and how they affect outcomes.
- How changes in disability over time by age and sex impact Medicare/Medicaid costs and services (mix, level, intensity) in the aggregate and how spending affects disability over time.
- Long-term consequences of medical or policy interventions on costs, life expectancy, active life expectancy, and well-being, which would require more economic data and a large number of chronically disabled.
- Whether a relatively small set of disability trajectories categorizes the bulk of the population in one form or another; interactions among points on those trajectories, long-term care, and medical events.
- Generating functions for trajectories, with trajectories tied to specific diseases.
- Linking to longitudinal information from Medicare claims files.
- Better indicators of the types of residential long-term care settings in the screener.

VI.   Field Options for a New Round of the NLTCS

Enrique Lamas offered his insights on some of the key features of the 2004 NLTCS from the data-collection perspective. He presented comparative data on total nonresponse rate for the entire sample (screener and detailed interview), documenting favorable results for the NLTCS

with about an 89-percent response rate in the screener and about a 95-percent response rate in the detailed interview [though some argue that the high response rate is due to use of proxies]. Although the NLTCS compares favorably on initial contact refusal rates, all surveys have seen an increase in initial contact refusal rates over time.

Lamas recognized the staffing benefits from increased survey frequency, as the current 5-year interval between surveys disrupts the continuity of interview teams that must be dispersed to handle other projects in the interim. Lamas suggested that a core set of questions be used in every interview and that any supplement to the core should be determined by answers to previous interviews. He expressed support for event-based sampling, particularly when matching CMS files over time, which would trigger the administration of a set of follow-up questions. This approach would be especially feasible in light of advances in the computer data collection environment.

Graham Kalton also addressed the issue of event-based sampling, commenting that events will be spread over time. He suggested that a complex event-driven survey instrument is feasible given advances in computer-assisted methodologies. Likewise, various modes and mixed modes of collection (which he considered to be inevitable in future data collection) could be managed adequately. One of the biggest difficulties with panel surveys is processing the imputations due to the extensive cost and time requirements; for this reason, high-quality, detailed datasets are a necessity. If many questions will focus on transitions among disability states and the process of disability in relation to care, then a shorter time period between surveys would be ideal. He emphasized that the real issue with increased frequency would be respondent burden.

Proxy data were seen as contributing to the NLTCS' high response rate, and one could question if proxy data are informative, especially with respect to measurements of attitudes and functionality. Fienberg contended that the extremes of these characteristics would be reliable (e.g., independent versus institutionalized), but assessments of events in the middle of the spectrum would have lower reliability. However, Colm O'Muircheartaigh defended proxy reports based on validation data from other surveys, which suggest that proxies can be as reliable as self-reports. Manton clarified that proxies were used only if there were no other option, for example, when the subject was cognitively impaired. However, it does not appear that the NLTCS used a standard assessment to determine cognitive ability.

VII.   Conclusions

In his concluding remarks, Suzman observed that the NLTCS has become more, not less, important with respect to Medicare and the older population. However, given NIA's tight budget, it is likely that the NLTCS would need to grow in stages, starting with a more basic survey that maintains the trend data, and then gradually building up over time. Suzman stated that unless the survey were anchored in major chronic diseases and health conditions, the NLTCS would have little chance of obtaining further funding from the NIA.

He argued that the meaning of disability is now sufficiently varied that we need new measures beyond ADL/IADL to be useful for research purposes. Multiple measures and methodologies must be considered in future studies, including performance tests, measures that work across

racial/ethnic/SES classes, and proxies. Suzman expressed optimism that record linkages will become more efficient with time, which will improve the ease with which NLTCS data can be used. Nested, more intense substudies (similar to the ADAMs dementia substudy in the Health and Retirement Study (HRS) on Aging, Demographics, and Memory) also could be considered as prominent features in future iterations of the NLTCS. He emphasized the need to observe the impact of various interventions, for example, in health services.

Participants recognized that it is not possible for the NLTCS to meet the needs of all users, but priorities should be set to address both research and policy questions. Suzman qualified this assessment by highlighting that the NIA is a science organization and its main goal is research, not policy analysis. As a result, research projects are reviewed primarily for scientific relevance and secondarily for policy import. Therefore, for research questions that integrate policy and scientific issues, partnerships between the NIH and other policy agencies such as the Social Security Administration, CMS, VA, and OASPE may be the most appropriate.

Another recurring point of contention was whether emphasis should be on longitudinal or cross-sectional analyses; there was no consensus on this point. Manton argued that the reason the NLTCS became a longitudinal survey was because the study questions lent themselves to a longitudinal design. It was recognized that design decisions must be driven by the research emphases selected. For example, an emphasis on transitions and intersection with care would argue for shorter interval periods. Thomas Gill has documented (in the Precipitating Events Project) frequent and clinically meaningful transitions in intervals much shorter than two years and called for strategies to capture the complexity of occurrences over shorter time periods. The value of nested samples with different intensity of content, as well as test-bed samples to encourage innovation, would dictate different designs. The importance of including built-in measures to test the reliability and quality of data also was noted. New content areas and updated measures of disability must be included in future studies of national long-term care, especially for research, and to facilitate comparisons to other surveys.

Data collection must prove to be useful and must weigh the utility of information collected against the burden of collection. The importance of linking the NLTCS to administrative data was stressed repeatedly, and several participants commented that they hoped this would become more common with the improved ease and speed of linking in the future. A final sentiment that recurred throughout the discussion was that, unquestionably, the NLTCS is rare in its ability to cover both institutionalized and noninstitutionalized populations and assisted-living environments.

VIII.   Next Steps

Following these comments, Suzman discussed the next steps that would include deliberations by the NLTCS Data Monitoring Board on major research priorities, as future design decisions ultimately are dependent on the core questions of interest. The NIA then may consider issuing a Request for Applications and will explore the possibility of obtaining cofunding from agencies such as the OASPE, VA, and CMS, with the condition that cofunding be relatively stable and amortized over a 5- to 6-year period. Suzman concluded by welcoming any further comments and suggestions.

Endnotes

[1] A summary of the October 7, 2005, meeting is available at: http://www.nia.nih.gov/NR/rdonlyres/AF0997F6-0C16-4A76-96C0-D3780F00E6D4/8642/NASMtgonNLTCSReportFinal112805.pdf

[2] For more details about this section, see Pamela Doty and William P. Marton, "How the National Long-Term Care Survey Can Address Policymakers' Disability and Long-Term Care Questions." Paper prepared for presentation at the Expert Meeting on the Future of the National Long-Term Care Survey, organized by the Committee on National Statistics, The National Academies, February 14, 2006.

[3] For more details about this section, see Bruce Kinosian, "The Department of Veterans Affairs Long-Term Care Planning Model and the National Long-Term Care Survey." Paper presented for presentation at the Expert Meeting on the Future of the National Long-Term Care Survey, organized by the Committee on National Statistics, The National Academies, February 14, 2006.

[4] The Economic Research Initiative Web site can be accessed at http://www.umich.edu/~eriu/

[5] The Medical Expenditure Panel Survey Web site can be accessed at http://www.meps.ahrq.gov/

[6] For more details about this section, see Vicki A. Freedman and Robert F. Schoeni, "Disability, Long-Term Care, and Rehabilitation: Emerging Questions and Data Needs." Paper presented for presentation at the Expert Meeting on the Future of the National Long-Term Care Survey, organized by the Committee on National Statistics, The National Academies, February 14, 2006.

[7] For more details about this section, see Stephen E. Fienberg, Jason T. Connor, and Elena A. Erosheva, "Towards a Restructuring of the National Long-Term Care Survey: A Longitudinal Perspective." Paper presented for presentation at the Expert Meeting on the Future of the National Long-Term Care Survey, organized by the Committee on National Statistics, The National Academies, February 14, 2006.

[8] Manton clarified that the NLTCS has a Data Use Agreement in place with the CMS for Medicare data linkages; however, the linkages have not yet been performed due to a lack of resources.

Appendix A

Expert Meeting on Design Options for a New Round of the National Long Term Care Survey (NLTCS)

Agenda

February 14, 2006
Hosted by the Committee on National Statistics and the Committee on Population
The National Academies
Lecture Room, Main NAS Building, 2101 Constitution Ave., NW, Washington, DC

8:00 am   Continental breakfast available

8:30   *Opening Remarks/Introductions*
                    Burton Singer, Chair; Richard Suzman, NIA

9:00   *Policy Uses for a New Round of the NLTCS*
                 - What are the key current and emerging questions for federal policy-makers with respect to long-term care, disability, and rehabilitation?
                 - What new/modified content does the NLTCS need to address those questions?
                 - How important is longitudinal analysis vis-à-vis cross-sectional analysis?
                 - What core content should be retained to facilitate longitudinal analysis and repeated time series estimates?
                 - What other design changes would facilitate policy use of the NLTCS?
                 - What degree of overlap should the NLTCS have with the Medicare Current Beneficiary Survey (MCBS) or other data sources that are used for policy?

               *Thought piece prepared jointly by **ASPE/DHHS** and **CMS** and by **Bruce Kinosian, VA** addressing the above questions, identifying no more than 10 priority policy questions, and indicating priorities within the context of different cost levels for a new round of the NLTCS.*

               Discussion leaders: **Pamela Doty/William Marton, ASPE; Bruce Kinosian, VA**

9:40   *Research Uses for a New Round of the NLTCS*
                 - What are the current and emerging research questions on long-term care, disability, and rehabilitation?
                 - What is the role and need for cross-sectional versus longitudinal analyses?
                 - What new/modified content does the NLTCS need to address those questions?
                 - What core content should be retained to facilitate longitudinal analysis?
                 - What other design changes would facilitate policy use of the NLTCS?

- What degree of overlap should the NLTCS have with the MCBS and other surveys used by the research community?

*Background materials: Thought piece prepared by **Vicki Freedman, University of Medicine and Dentistry of New Jersey,** and **Robert Schoeni, University of Michigan** (see description of policy thought pieces above)*

Discussion leaders: **Vincent Mor, Brown [by phone]**

10:15   Coffee break

10:30   *Design and Content Options for a New Round of the NLTCS*
- 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 for some or all of the sample so that it can better capture transitions in disability status?
- Should the NLTCS use event-based sampling from Medicare records to capture transitions from nondisabled to disabled status? (In that regard, what are the implications of managed care for reducing the data available from Medicare files?)
- What are the priority assessments of disability 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 should a new wave fill?
- Where could the NLTCS cut back given the strengths of other data sources?
- What questions in the NLTCS need substantial cognitive research to validate and revise them as needed?

*Background materials: Thought piece addressing the above questions prepared by **Stephen Fienberg and Jason Connor, Carnegie Mellon University,** and **Elena Erosheva, University of Washington***

Discussion leaders: **Robert Groves, University of Michigan, and Nancy Mathiowetz** [*unable to attend*]**, University of Wisconsin—Milwaukee**

12:00 noon   Lunch

1:00 pm   *Continued Discussion of Design and Content Options*

Discussion leaders: **Alan Garber, Stanford [by phone];**

2:00	*Field Options for a New Round of the NLTCS*

2:00   *Field Options for a New Round of the NLTCS*
- What are the requirements for successful data collection and management—for example, ability to field different questionnaires for subsamples, use event-based sampling, process data for both cross-sectional and longitudinal use?
- What are the advantages/disadvantages of continuing to have the Census Bureau collect the data?
- What are the advantages/disadvantages to having another organization collect the data?
- What methodological research (on question content, incentives, or other aspects) should be built into the NLTCS?

Discussion leaders: **Howard Hogan and Enrique Lamas, Bureau of the Census; Graham Kalton, Westat**

2:45   Coffee Break

3:00   *Recap of Previous Discussions*
- Should a New Round of NLTCS Favor Policy and/or Research Uses?
- What Are the Most Promising Design Options?
- What Are the Most Promising Areas for New/Modified/Deleted Content?
- What Are Key Data Collection Requirements?

Discussion leader: **Michael Wolfson, Statistics Canada**

4:00   *Wrap-up/Summary*
    Burton Singer, Chairperson; Richard Suzman, NIA

4:30   Adjourn

Appendix B

Expert Meeting on Design Options for a New Round of the National Long Term Care Survey (NLTCS)

Participant Roster

February 14, 2006
The National Academies
Lecture Room, Main NAS Building, 2101 Constitution Avenue, NW, Washington, DC

Burton Singer (Chairperson), University of Wisconsin and Princeton University

Jason Connor, Carnegie Mellon University

Brenda Cox, Battelle Centers for health Care Research and Evaluation

Pamela Doty, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health & Human Services

Thomas Edes, Department of Veterans Affairs

Elena Erosheva, University of Washington

Luigi Ferrucci, National Institute on Aging

Stephen E. Fienberg, Carnegie Mellon University

Vanessa Flint, Centers for Medicare and Medicaid Services

Vicki Freedman, University of Medicine and Dentistry of New Jersey *(via phone)*

Alan Garber, Stanford University *(via phone)*

Thomas Gill, Yale University

Dana Goldman, The RAND Corporation

David Greenberg, Centers for Medicare and Medicaid Services

Robert Groves, University of Michigan

John Haaga, National Institute on Aging

Catherine Hawes, Texas A & M University *(via phone)*

Howard Hogan, U.S. Census Bureau

Graham Kalton, Westat

Miriam Kelty, National Institute on Aging

Bruce Kinosian, VA Medical Hospital, Philadelphia and University of Pennsylvania

Richard Kulka, Abt Associates

Enrique Lamas, U.S. Census Bureau

Virginia Lerch, Rose Li and Associates, Inc.

Rose Maria Li, Rose Li and Associates, Inc.

Jim Lubitz, National Center for Health Statistics

Jennifer Madans, National Center for Health Statistics

Temina Madon, Office of Senator Edward M. Kennedy

Kenneth Manton, Center for Demographic Studies, Duke University

William Marton, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health & Human Services

Vincent Mor, Center for Gerontology and Health Care Research, Brown University *(via phone)*

Colm O'Muircheartaigh, National Opinion Research Center / Harris School of Public Policy, University of Chicago

Georgeanne E. Patmios, National Institute on Aging

Susan Schechter, Office of Management and Budget

Robert Schoeni, University of Michigan *(via phone)*

Eric Stallard, Duke University

Richard Suzman, National Institute on Aging

Robert Wallace, University of Iowa

Katherine Wallman, Office of Management and Budget

David Weir, University of Michigan

Joshua Wiener, RTI

David Willis, Columbia University

Michael Wolfson, Statistics Canada

National Research Council Staff:

Constance Citro
Barney Cohen
Caryn Kuebler
Michael Siri
Miron Straf
Gooloo Wunderlich