National Invitational Conference on
LONG TERM CARE DATA BASES

Summary of Proceeding Sponsored by
The Office of the Assistant Secretary for Planning and Evaluation
United States Department of Health and Human Services
Ritz-Carlton Hotel * Washington, D.C. * May 21-22, 1987

Office of the Assistant Secretary for Planning and Evaluation

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In particular, DALTCP addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This report--which summarizes a national conference held at the Ritz-Carlton Hotel, Washington, D.C. on May 21-22, 1987--was prepared by the Office of Social Services Policy with the U.S. Department of Health and Human Services. For additional information, you may visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the Office of Disability, Aging and Long-Term Care Policy, Room 424E, H.H Humphrey Building, 200 Independence Avenue, SW, Washington, DC 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The DALTCP Project Officer was Robert Clark.

NATIONAL INVITATIONAL CONFERENCE ON LONG TERM CARE DATA BASES:

Summary of Conference Proceedings

Office of Social Services Policy
U.S. Department of Health and Human Services

1988

Prepared for
Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services

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CHAPTER I. INTRODUCTION/WELCOME

Robert B. Helms, Ph.D., Department of Health and Human Services

It is certainly a pleasure to welcome all of you. It is amazing that we could get this kind of turnout for a Conference on Long Term Care Data Bases. It speaks to the importance of this issue.

This Conference is jointly sponsored by my office, the Office of the Assistant Secretary for Planning and Evaluation, or ASPE, as we usually call it, and the Office of the Assistant Secretary for Health, or OASH. We work very closely with Bob Windom, Steve Grossman, and their staffs.

I sometimes tell people that ASPE is the Secretary's Policy Shop. We are engaged in a kind of a long range planning and so on, but the real reason we exist is to provide a job for Mary Harahan. I want to first of all thank Mary in particular, and the people in the Division of Disability, Aging, and Long Term Care, for their hard work in setting up this Conference.

There are three reasons for holding this Conference. **First**, it is the formal follow-up to Secretary Bowen's Catastrophic Illness Study. In his report to the President, the Secretary underscored the importance of "improving the knowledge and understanding of Americans regarding the risk of needing long term care, and the options for financing it."

The analysis of large valid and reliable long term care data bases can help significantly to expand our knowledge and understanding about who needs long term care, how much it costs to provide care, and the impact of various financing proposals on public and out-of-pocket costs.

In my judgment, a thorough exploration of how best to maximize private insurance and other private financing options is one of the most critical research priorities of this Department.

Second, over the past several years, the Department of Health and Human Services (DHHS) has undertaken a number of major data collection efforts pertaining to long term care.

As a result there has been considerable improvement in the breadth and quality of data available to examine the use and cost of long term care services. In this Conference, we are deliberately focusing on data bases that are or soon will be publicly available.

Third, long term care continues to attract the attention of Congress, advocacy groups, insurance carriers, and others within our political and economic system. It will remain an area of national policy and significance in the foreseeable future.

The appropriateness of public policy responses and private sector initiatives depend largely on the development of a body of high quality research derived from the best available data.

I believe that our Department has a major responsibility, not only to collect data relative to public policy, but to assure that public use files are made available as quickly as possible for the use of researchers, policy analysts and private sector organizations.

I do not say that lightly. That is something that the government has not always had a good record in. This Conference is intended to acquaint you with the current supply of long term care data bases, and frankly to stimulate the demand for that data.

The audience for this Conference includes researchers, private sector representatives, with emphasis on the insurance industry, federal agency and Congressional staffs, nonprofit association members, and others.

We anticipate that the cross-section of interests represented in this audience will contribute some valuable synergy to the proceedings.

We hope that the Conference achieves several objectives. One objective is to share technical information on the construction, documentation, and availability of large, long term care data bases.

It is important that not only researchers, but policy analysts and other users become familiar with the strengths and the limitations of these data bases and the kinds of issues they are best suited for.

Another objective is to provide a forum for acquainting ourselves with ongoing and completed analytical work that makes use of these data bases.

Many of you in this audience may be able to contribute information regarding your analytical needs and plans during the Conference sessions. Most importantly we want to examine the potential of these data bases for assisting employers, insurance carriers, continuing care retirement communities, nursing home operators, federal and state agencies, and nonprofit groups in projecting long term care service needs and costs.

As occurs in many conferences, the chief benefit may simply be the opportunity provided for a group of people concerned with the long term care needs of the nation's elderly and disabled population to meet and exchange ideas informally as well as formally.

If that occurs to a significant degree, we can count this Conference a success. Again, I wish to welcome you. I hope that your participation in this Conference on long term care data bases proves to be both rewarding and productive.

Arnold R. Tompkins, Department of Health and Human Services

I would like to add my welcome to all of you as we begin this Conference.

My office, which is a part of ASPE, has had a longstanding interest in long term care issues. Much of our work is carried out in conjunction with other components of DHHS.

For example, the National Long Term Care Channeling Demonstration, which ended last year, was jointly funded and managed by our office, the Health Care Financing Administration, and the Administration on Aging.

We also provided considerable support to the Secretary's Catastrophic Illness Study, particularly the Technical Work Group on Private Financing of Long Term Care, chaired by Steve Grossman, our next speaker.

Several things have become clear as we grapple with the issues surrounding long term care. **First**, from a policy perspective, long term care is a hot topic. While acute care attracts the bulk of attention on Capitol Hill these days, long term care will inevitably become part of any resulting discussions.

Whether we are talking about the early discharges under the Medicare Prospective Payment System (PPS), the likelihood of an added Medicare Part B premium to offset catastrophic acute care expenses, or the expansion of home health care benefits, we are inevitably faced with the effects on the long term care system.

Above all, it is clear that the public sector alone cannot adequately address these issues. Private sector initiatives, like long term care insurance, and new financing mechanisms, like individual medical accounts, and home equity conversions are much needed.

Second, in spite of some exemplary research done to date, there is a great deal yet to be learned about the long term care system, including its beneficiaries, its services, and its payors.

We need ongoing research with respect to at least the following areas: the characteristics of persons with long term care needs, especially the disabled elderly; the changing patterns in the supply and use of long term care services; the particular characteristics of different types of nursing home residents, for example, short stayers, long stayers, and the terminally ill.

The use of home and community-based services; current and projected patterns in informal care long term care costs; and ways of addressing catastrophic long term care costs.

Third, in recent years, our capacity to examine the long term care system has grown significantly with the public availability of national long term care data bases, plus a number of demonstration programs and state and local surveys.

As Dr. Helms stated, we consider it critical to create and make available public use files from data collected under the sponsorship of the Department. This Conference is an outgrowth of all these developments.

Steven A. Grossman, Department of Health and Human Services

First, on behalf of Dr. Robert Windom, the Assistant Secretary for Health, and myself, we would like to welcome you to this Conference. Long term care, and you will hear this in different ways, is, in my opinion, the big intellectual planning challenge for health care in America for the next 40 years.

The demographics are there, and hopefully, for a change, unlike the school boom of the 1960's and other pieces of demographics, we have learned our lesson. We know that demographics without study and demographics without action is courting disaster.

You will learn a lot not only about the basic demographics, but what we know about things that can be projected into the future.

There is not an obvious solution or even sufficient insight to know exactly how to make that future work for all of us who will eventually have long term care needs. That is the job that did not start here, but to which we hope this Conference will be a big boost, and which will carry each of you forward into providing additional insight through your research, through your activities in insurance companies and in health care providers, to make sure that the long term care system meets our nation's needs.

Our system, as all of your know, is expensive. It is heavily oriented to institutional care. Most of all, it is confusing. It is confusing in a policy way. We need to change the way the consumer approaches the long term care system. We do not have all the information we need, not by a long shot.

It is also important to emphasize that the long term care field right now Is a public/private partnership. About 50 percent of long term care funding in this country, at least of the nursing home portion, is paid through public dollars. It is primarily Medicaid, but it is also Medicare; it is also Older Americans Act programs, Veterans Administration (VA), Social Services Block Grants, and a variety of other initiatives.

The federal government is a partner; the state governments are partners; local governments are partners through the programs.

The governmental dollar, as I say, approaches 50 percent. The problem that we faced when we looked at catastrophic costs as part of the Secretary's initiative was therefore the private dollar.

We all acknowledge that those public dollars may be able to be spent better, and that is a worthy subject for investigation, research and analysis.

Our study looked at the private dollar. It is half of the dollars flowing into the field; it is not, however, keyed the way any other social good is paid for in this country. Insurance is not the primary form of private long term care dollar. Out-of-pocket expenditure is. That is not how people protect against fire losses; that is not how they protect against Ill health. The report that the Secretary asked my group to do, and which would not have been possible to do without the leadership of Arnold Tompkins, Mary Harahan and their staff, was to look at those private dollars and try and say, is there a better way? Can we help people plan for their long term care needs so that whatever needs they have for public dollars will be secondary and only if their own resources fail them?

In the report we said that we need more savings mechanisms, more insurance mechanisms, and most of all, consumer education.

Those are all fair game for research. We need the answers in those areas. We need to look at family structure. There are already built into those demographics some ways in which that family structure will change. The largest proportion of all long term care in this country is provided free by families and friends. I will risk speaking on behalf of the Department, even though this is not in any way clear, and say that there will be no "solution" to the long term care needs in this country that does not support that system, because that is the system that is the most humane, that every study says that the elderly themselves want.

Whatever structures we need to deal with those who cannot stay at home, we need to make sure that we do not create Incentives that are counter to encouraging people who want to be at home to make use of that opportunity.

I welcome you all. There is a big challenge before you. The challenge is in the next day and a half, but it is also in the next 50 years. There is lots of opportunity for contribution, and I ask each of you to do what you can to take that opportunity.

CHAPTER II. OVERVIEW OF THE 1982/1984 NATIONAL LONG TERM CARE SURVEYS

Kenneth Manton, Ph.D., Duke University

The 1982/1984 National Long Term Care Survey (NLTCS) is an extremely rich data base; not only was there a longitudinal follow-up of the 1982 sample in 1984, but we have complete cross- sections in both 1982 and 1984. There is also a linkage to administrative records. There is currently a proposal to replicate this survey with a longitudinal component in 1988.

We are looking approximately at the 10 year period of 1980-1989. The first survey was July 1982, then the replication 2 years later in July 1984, and now the proposed replication after 4 years.

You also have to think in terms of a continuous collection of Medicare Part A service records that are linked to all individuals in the various survey populations. We are currently discussing the possibility of us linking into Medicare Part B, but that is a tentative plan.

In 1982, there was the NLTCS of the community disabled. A total of 36,000 individuals were drawn in from the Health Insurance Master File (HIMF), there was a telephone screen and also a personal visit screen for those who could not be contacted by telephone.

This picked out individuals who either had or were expected to have either an activity of daily living (ADL) or an instrumental activity of daily living (IADL) limitation of 90 days or more duration. From that screen of 36,000 individuals, 6,393 individuals were identified as having a chronic disability. They were delivered a detailed community survey, which had a large number of questions in terms of their disability, the type of personal services and equipment used to meet these limitations, as well as questions on other types of service use.

There was no institutional survey in 1982. There was a Informal Caregivers Survey (ICS) of 1,925 individuals who were caregivers to people in the NLTCS. Interviewers talked to about 1,625 individuals for those who were in continuing care, and about 300 individuals who discontinued care, and asked them about the nature and burden of care, the number of hours that were spent, and--for those 300 who quit--the reasons for ceasing.

The 1982 round was the basis for a series of projections on the long term care population. You could also trace those through to the number of individuals in the national population who were responsible for delivering care to those individuals. You could project those numbers out as well as from the ICS to get some estimate of the number of hours per week that the informal caregivers were delivering care and the types of care.

In 1984, there was both a longitudinal component and an aging component. By an aging component, I mean individuals who in 1982 were age 63-64 and did not qualify were also sampled. In 1984 you have a complete cross-section as well as a longitudinal follow-up of about 20,000 individuals who were there in 1982.

For all individuals in both samples, you had the continuous Part A service use so that you could find out about their acute care use of hospitals, their use of Medicare-funded skilled nursing facilities (SNF's), and also the use of home health. The bill gives the dates of services, the number of episodes, and the reimbursement amounts.

In the 1982 survey, we have 25,541 individuals who are identified as non-disabled by the telephone or personal visit screen. Then you have a people who are followed through to 1984, decomposed by where they ended up in one of four statuses.

The disabled 65+ noninstitutionalized population were the target of the community survey. The institutional sample, 1,992 individuals, were both people who were identified as being in institutions on the April 1 freeze date for the sample population, plus people who became institutionalized between April 1 and the beginning of the survey operations.

The 1,992 individuals were not interviewed in 1982 so we do not have the detailed information on their institutional use, but we can identify that component of the population to identify transitions between 1982 and 1984.

There were 4,916 individuals aging in for 1984, who were 63-64 in 1982. We have only a 47.4 percent sample of people who were non-disabled in 1982 that were followed up and screened again in 1984. This produces the 14,130 individuals in that non-disabled block for the 1984 component.

The 6,182 individuals who received the detailed community instrument in 1984 were automatically brought into the survey population. We can took at the status of individuals reporting chronic disability in 1982, but improved in their functional and health status. There did seem to be a significant group of individuals who reported chronic disability but yet showed improvement in functional and health status on the long term basis over a 2 year period.

In 1984, there was a short institutional questionnaire, which got somewhat of a retrospective history of nursing home service use, and there are about 1,870 individuals. There was a deceased questionnaire, a next-of-kin survey describing something of the characteristics of health service use for those individuals who died over the 2 year period. Of the 3,219 individuals who died over the 2 year period, 970 individuals died out of the non-disabled group and 1,383 died out of the disabled and 65+ noninstitutionalized group.

Potentially, with the 1988 round, you have a time-frame of recovering a large number of changes and reimbursement of policies and analyses looking at some service substitution of facts over at least the 1982-1984 changes.

One of the missing components is Medicaid institutional service use. The instrumentation in the survey itself is similar to the instrumentation in a number of the major demonstration projects. Here you have a nationally representative data file, and potentially you have the health and functional measures, and certain outcome measures to relate it to the outcomes of various demonstration data sets where you might either have interventions or more intensive Medicaid service use records. By crosswalking between the nationally representative data and the slack population in the demonstration data sets, you can tell something about how well the demonstration results might translate to a national level.

Surveys looking at particular target populations where you can specialize the instrumentation and focus your samples are cost-effective. Think of three major surveys, the NLTCS linked to its Medicare service use, the Longitudinal Study on Aging (LSOA) with the Supplement on Aging (SOA) in 1984 and again in 1986, and the National Nursing Home Survey (NNHS).

There is potential coordination of these surveys that can reflect on different aspects of the elderly population. In the sample design one of those gaps in the NLTCS is the non-chronically disabled, community dwelling elderly; the SOA will give you information on that group.

The institutional samples about 1,800 individuals in 1984 and in 1988 we project to be 1,600. That gives you transitions or changes from 1982-1984, but it is nowhere near as detailed a survey as, for example, the NNHS.

One can think of a coordinated analytic strategy with the NLTCS being one component fitting in with these other two surveys, and then also think intentionally about the various demonstration studies that might be coordinated to analysis of the surveys.

For the highly disabled, very elderly population, there were over 2,000 individuals age 85+ in each of the 1982 and 1984 survey dates. The diagnosis of senility was made on the basis of proxy response. There is a high proportion of full individual surveys but, as you would expect, with disability levels, the number of proxy respondents increases.

There is the information under Medicare service use linked in. In 1984, you have a next-of-kin report on health service use among the deceased, an institutional instrument for the institutionalized person, and as of the 1984 survey date the detailed community service use.

You can follow people who were disabled by various levels here, e.g., those individuals who only had IADL impairments, and those who had different levels of ADL impairment.

You can now identify an institutionalized component from 1982, and look at their status in the 1984 survey. In 1984, you can look at the deceased and at individuals who report chronic disability of 90 days duration but who even at very high levels of disability were community dwelling. There is a reasonably sizable proportion of these individuals who are improving somewhat in functional status, about 25 percent. It is interesting, as well, that the mortality of this particular group is nearly as high as the institutionalized group, 37 percent.

Of survivors to 1984, about 35 percent got better to some degree on the long term basis, suggesting that, at least, at that level of functional disability, you might have two sub- populations--one with an acute problem, perhaps hip fractures or something on this order, but also one which has a 2 year long term improvement even at very profound levels of disability.

We have constructed simple life table measures out of the 12 month service use window about the 1982 and 1984 survey dates. On this life table are survival curves, where down the left-hand side you have the proportion of all people. On the hospital service use table, if you look at 100 percent of people entering a hospital during a 12 month window associated with the 1982 service date, and then look at a 12 month window of eligibility in the 1984 service date, for those episodes you can see how rapidly people were discharged.

Associated with each of these curves are statistics like mean length of stay or median length of stay for the sub-populations. Obviously, from the survey itself you could start looking for the community disabled population, the discharge and hospital service uses, a function of disability level, and a number of other co-variates. This allows you to perform some very detailed analyses of the interrelationship of chronic functional Impairment and acute service use**,** and allows you to start looking at the systemic effects or the interaction.

SUMMARY OF BREAKOUT SESSIONS

Kenneth Manton, Ph.D., Duke University
Korbin Liu, Sc.D., Urban Institute

KENNETH MANTON: We want to give you a sense of how the various data elements fit together when you are referring to the NLTCS.

For example, in 1982 of the ICS, there are 1,926 caregivers, both continuing and a small sample of people who discontinued care.

Then in 1984, we have quite a different group of surveys, the community-based survey, the next- of-kin survey (for people who were deceased in the 2 year interim period), and the institutional questionnaire (for people who were institutionalized on the date of which the survey was delivered).

The projected 1988 survey would not do the next-of-kin survey, but would do the community and institutionalized surveys. A four year follow-up would be a long period over which to rely upon next-of-kin recall on health services. The other component is the Part A data, which is the acute hospitalization use, and home health use.

Currently the files are linked from 1980 through the end of 1985 with some trail-off information through three quarters of 1986.

The public use tapes that will be generated will be composed actually of two sets of tape files: a rectangularized form of the survey data and the longitudinal file structure. This is integrated on the sample person so that you will have one very large record with all the information tied to that from the various record types on the public use tape that the Bureau of the Census released. The second set of tapes will be the individual Part A bills with a survey respondent identifier so that there will be multiple bills for each individual. You will be able to link the survey response information on the other tape file, with the detailed Part A bill information for that entire period 1980 through the end of 1985 with some information through 1986.

QUESTION: Will the information from the 1982 survey be included in the longitudinal file?

KENNETH MANTON: The full longitudinal sample, of roughly 25,000 individuals that were in the 1984 sample, will be in the file.

A total of 36,000 people drawn off the HIMF formed the sample frame for 1982. The 25,000 people who formed the longitudinal core will be together on the file both with 1982 and 1984 information in a rectangularized format. On the same person records, you will have the 1982 and 1984 information.

The work on the documentation and the files is essentially done, so it is a matter of clearance and then integration into the National Technical Information Service (NTIS) system.

QUESTION: Can you talk about some of the types of questions in the different surveys?

KENNETH MANTON: The documentation package has a series of appendices, background documentation on the survey, both the interviewer instructions for 1982 and 1984, and the community instrument. That tells you a lot about certain questions.

You would have the interview survey manuals, and then there would be a code book for the survey files themselves for the rectangularized file, with the information on them.

The community survey instrument asks about both chronic and current medical events. There are 29 conditions up front and broken down into things that occurred in the past 12 months versus chronic conditions that were experienced over a longer period of time.

There is a very extensive set of questions on ADL, IADL, and what I call IADL-II, functional limitation measures which have to do with physical functioning like holding packages or climbing stairs.

With each of those questions, there are a number of detailed questions that go along with what type of personal care or informal care, who might be delivering certain types of services to deal with those functional impairments, and the type of equipment that might be used. There can be up to 25 questions associated with particular ADL or IADL measures.

There is a lot of information on income and assets. There are some things on housing characteristics. There are questions on behavior. There are questions on health service use, visiting physicians, and other types of health service professionals.

There are various types of general questions on program entitlement in terms of Medicaid use.

KORBIN LIU: The NLTCS was designed, in part, to be a backdrop for the National Long Term Care Channeling Demonstration data. You will find fairly similar Items between domains of information between the NLTCS and Channeling.

There was a major concern about who provided what level care, what types of care, and what types of providers, in terms of whether they were family members or were formal paid providers, and in terms of costs.

For example, if somebody receives assistance in bathing, the questions are: who provided that care; was it a member of the family; was it an outsider; if it was an outsider, was it paid care. There are some dollar amounts associated with out-of-pocket payments.

On the income information, they ask sources of income, such as Social Security, Veterans Administration (VA), dividends and interest income, and so forth. They ask this for not only the sampled person but other members of the family living in the household.

In 1982, they basically had eight questions about home ownership and the market value of the home. There was no information in 1982 on liquid assets. On the other hand, there were questions about the income derived from liquid assets, so one might be able to estimate the liquid assets.

In 1984, for the community survey, the survey designers added a few more asset questions, such as stocks, bonds, CD's and so forth. As time went on, the amount of information on types of financial status improved.

In the 1982 community survey, they asked about institutional history, such as: Did you spend any time In a nursing home? When was the first time? When was the second time?

For each nursing home episode, they would also ask, how many days, weeks, or months did you spend there? For those people in the community in 1982, you have information on their prior nursing home use.

Part of that 1984 sample was the 1982 sample. They again asked in 1984: Over the last 2 years, did you spend any time in a nursing home? How many times did you enter a nursing home? How many days did you stay in a nursing home?

In some preliminary tabulations, we estimated that about 15 percent of community disabled population in 1982 went into a nursing home at some point in time in those 2 years. By 1984, 7 percent were still in nursing homes.

For these sample members, you had the community characteristics in 1982, and then you had the information about what kind of nursing home history they had over the 2 years. By 1984, you had the information on what their payment source was at admission, and their payment source at the current time.

A particular focus was the Medicaid transition. For private pay patients, there were specific questions and an institutional questionnaire about payment source at admission. There is some information there on spend-down phenomena.

Most of you are aware that the nursing home length of stay distribution tends to be bimodal, from the standpoint of having short and long stay patients. I think we are able to see that kind of phenomenon between 1982 and 1984 with this survey.

The other strength of this particular data base right now is that we have also got the Medicare bills attached to them, and the Medicare bills include not only the hospital but also the Medicare SNF, and the home health bills.

QUESTION: When will the public use tape be available.

KENNETH MANTON: It will be available through the NTIS. Herb Silverman from the Health Care Financing Administration (HCFA) might want to say something.

HERB SILVERMAN: Because of the sensitivity about the release of information, the government has put a lot of safeguards on the public availability of survey data, so there are a lot of little hurdles that have to be jumped before we can release it.

We have our Freedom of Information Officer who will have to review the documentation on the nature of the information, and make sure that the provisions for public notice have been met.

Every data file that is potentially available to the public is recorded in the Federal Register, so we have to make sure those requirements are met.

The most conservative statement on availability is before the end of 1987.

KENNETH MANTON: I think when Korbin was going through the instruments, we covered a little bit the community instrument, the institutional instrument, and a next-of-kin instrument for the deceased.

You also have the information on the Part A bill files. The bill file records obviously are contingent upon the Freedom of Information Officer clearance. They would contain an edited version, i.e., eliminating redundant bills and going through the standard editing procedures.

In the ICS for 1,926 individuals, they asked caregivers questions that reflected on the psychological motivation and the acceptance of the burden of care.

There are actually four or five survey instruments that were used. The community-based for the chronically disabled is the most detailed.

We linked them all to the person-based record so you did not have to crosswalk among four or five record types.

Regarding the disabled, 65+ noninstitutionalized, those who were given the detailed instrument in 1982, what happened to them In 1984? How did they sort out? A total of 409 became non- disabled; 4,114 ended up in the disabled component; 487 were institutionalized; and 1,383 died over the 2 year interval.

You have four donor states, and four receptor states telling you where people shifted back and forth between 1982 and 1984. You have to be careful about this since what is in 1984 Is not a proper subset of what is in 1982.

They did not go back to all 25,000 individuals who were non-disabled in 1982; they pooled a 47 percent sample of those because of budget constraints and did telephone screens of that 47 percent sub-sample. Then they brought in the 5,000 individuals who were 63-64 in 1982.

By the time you get to 1984 in one sense, you have looked at 36,000 plus 5,000 individuals who have been somehow touched upon in the two survey dates, but they have sub-sampled the group that was non-disabled in 1982.

For the institutional block, there was not an instrument in 1982, whereas there was in 1984.

The 1,992 is based on two components. In one, 1,708 people who on the April 1 freeze date for the sample who were in institutions, and there are about 280 people who became institutionalized by the time the instrument was delivered.

QUESTION: A person who was non-disabled in 1982, and non-disabled in 1984 would not be interviewed?

KENNETH MANTON: That is right.

QUESTION: Was the 1982 sample a cross-section of the whole population over age 65, or was there some kind of stratified sampling going on there where you took a smaller sample of the non-disabled population?

KENNETH MANTON: The total sample frame was the Medicare eligible population.

It is the vast majority of those 65+, taken out of the HIMF. From that they pulled out 55,000 individuals, because they did not know what their yield rate was going to be for the disabled. They had blocks of cases, which they would screen to see, in a given block, how many were disabled. They roughly wanted a target number of 6,000.

They worked backwards from the 55,000 and at 36,000 they identified the 6,393. The design effect in terms of this survey is relatively mild because it was not strongly clustered. The Census statisticians agreed that the sample design effects were less major for the 1984 survey.

One approach to the variance adjustment procedure which is normally done by the survey statisticians says, because of clustering effects and other things I have got a higher variance. When I go to a spatial cluster of cases, I do not have independent responses, so I do not have as many degrees of freedom as I might think. I need to adjust and increase my variance for that. They have various different models for randomizing effects to increase their variance estimate.

Another approach is to say that clusters in these other effects are important. If I were looking for local area effects, and I had a clustering in my sample design, I might be worried about a confounding between the spatial clusters and the sample design in my local area effects if I was looking for local market conditions.

I might want to go with the model-based approach where I build in the stratification and cluster effects as part of my model for analyzing that data. There is a larger discussion between sample statisticians and other people over this finite population approach versus model-based approach.

QUESTION: I did not hear mentioned the availability of insurance coverage for long term care, probably because in 1982, and even in 1984, such was not widely available.

Was there a question in 1984, and is one intended in 1988, for discriminating between utilization patterns on insured versus non-insured individuals?

KORBIN LIU: There was not a specific question on whether you had long term care insurance. In that section where they were asking about helpers, in that whole series of questions, they did ask, is it paid for by Medicare, by Medicaid, or other? That is probably as close as we can get with the 1982.

The designers for the survey were aware of a small prevalence of private long term care insurance, and I think it is one of those compromises that we had to make in terms of keeping the questionnaire within bounds, but clearly it seems like any future surveys are going to have a bigger interview section asking about long term care insurance.

We know some of the financial information can be improved, probably unlike the assets, and there is a scientific advisory group that is supposed to make recommended changes in content.

One person you can conceivably talk to is Bob Clark from the Office of the Assistant Secretary for Planning and Evaluation (ASPE), about your concerns, because he has been reviewing some of the documentation. You might talk about what would be useful to put in there in terms of long term care insurance, because it is obviously a topic that has to be covered. It has probably evolved to the point where some specialized instrumentation for that is appropriate.

QUESTION: You have got some users. Will NTIS be doing the support? I would also like to know if you have any comments on the difference in the prevalence estimates between the national health interview survey (NHIS) and the NLTCS.

KENNETH MANTON: In terms of further formal support, that has not been specifically addressed. If there were to be an 1988 survey, and currently that funding decision is being made. Obviously, there will be people working in the field and there would be support available in an informal sense.

HERBERT SILVERMAN: Making the public use tape available is just the beginning of the process, and it is a very difficult situation for agencies in the cutback mode to provide this kind of support. There is no in-house plan to provide an ongoing source of consultation formally. We are putting a great deal of store in the completeness and detail of the background documentation to make it as helpful as possible to understanding the data base.

QUESTION: We have just begun working on the 1982 survey, so I have some direct experience with the tape. I have some issues about the comprehensiveness of the documentation and some problems that we have found.

Actually, one problem that is still bothering us is just the very basic coming up with numbers that match the numbers that have been printed so far about the ADL's and IADL's, because my understanding of the documentation is that there were different sources for this information. On the data tape, there are a number of items where the source came from the control card information, from the initial screening. Then there is information from the detailed interview, with the sampled person themselves, and these numbers do not really match. It has been a problem for us to decide which is the appropriate identification of the ADL's and IADL's to go with, and I really do not know what resource you used to come up with your numbers for the number of people with ADL deficiencies.

KENNETH MANTON: On the screen there were 6,393 individuals identified. Of those 6,393, 6,088 actually had the detailed interview given. Of those 6,088, there were about 5,600 that completed question 13. Question 13 queries the person on what medical condition caused the disability or functional limitation.

I know that when we were starting to work with it, if you used the 6,393 in the weighted estimate, that comes out with 5.07 million weighted cases that have either a chronic ADL or IADL, and if you used the 5,600 number, it was about 4.65, so, to some degree, it depends on what questions you pick. The 5.07 million which comes from the screen or control card information is the most comprehensive. Regarding the difference between 6,393 and 6,088, we have done some analysis of that dropout group, and we have around 50 percent mortality; and it is a group that is very, very ill, and is probably responding for health reasons, to a large extent.

The difference between the 6,088 and the 5,600 is a more definitional question. For example, we have been looking at some data on the social health maintenance organization (HMO) evaluation and if you use nurses as interviewers, you get somewhat different numbers and different levels of screen.

Depending upon what criterion you use you can get somewhat different numbers, but to some degree that is a research question. We were doing some work on a GAO analysis, and they asked the question about unmet need for ADL types of problems, and IADL problems, and depending upon how you define that, you could get vastly different numbers.

QUESTION: I am not sure I understood when you spoke earlier about over-sampling of the age group 85 and older. Did you talk about it as it applies to the

1982 survey, to 1984 survey, or only to the future survey? Is that reflected in the weight that you assigned?

KENNETH MANTON: Both 1982 and 1984 had over-samples; in 1988 there is planned an oversample. The weights will reflect that.

QUESTION: For the community survey in the NLTCS, why are the estimates nearly twice as high as they are in the NHIS, and 1979 home care supplement?

KENNETH MANTON: What we are talking about is specifically home care supplement. If you look at those numbers, you find that they are very close when you look at the 85+, while the numbers are different at the younger ages.

As I recall, they might have used a different set of IADL's and ADL's. That could throw the distribution off.

We, for example, did not use incontinence as an ADL, but used walking around inside. Incontinence is a fairly severe ADL. One would expect a younger cohort to have less experience with that. On the other hand, walking around inside would be a problem that you would find more with the younger age group, relative to incontinence, and so by using walking around inside, we might create a larger prevalence because of that particular ADL.

Cathleen Yordi might comment on that because she was working on the social HMO data. If you go to a core group of more severely impaired, and you have got a nurse interviewer, you get higher agreement than if it is more of a judgment.

There is an article by Joan Huntley on a series of people in the mailbag that compared not only the 1979 Home Care Supplement but also talked about the NLTCS and also the three Established Populations for Epidemiological Studies of the Elderly (EPESE) at that time. The estimates for disability levels across the three sites in the EPESE studies vary quite broadly to include numbers that are above the NLTCS, and one of the sites at least has numbers that are very low.

KORBIN LIU: In another session, Jennifer Madans is probably talking a little about the next-of- kin versus the NNHS regarding the ADL's. In a briefing that I heard, you basically would find a lot of people with no need for assistance in bathing and dressing, when they were reported by the next-of-kin, but, 2 days later, you would find from the nursing home these same people were depending on bathing and dressing assistance. There are a lot of false-positives and false- negatives, and there are many artifacts with the function.

KENNETH MANTON: I would be more concerned about false-negatives losing people outside the sample than a certain small marginal false-positive rate, because there, you are obviously depending upon the definition you used. If you are thinking of an insurance product, you might be taking people and allowing them at a relatively low level of functional ability to still qualify. You might be using various types of cut-points and you want to look at the implications of different cut-points to see what population that is marketable with reasonable risk would be. The thing that would kill you is if you lost a lot of people who potentially could have qualified and did not have them in.

We are also talking about, for example, the case of the NNHS. Logically what we have here is two dimensions: one dealing with population coverage, or coverage for a certain sub-population; and the other dealing with time. The fact is we have three nationally representative longitudinal surveys: the NNHS 1985-1987 follow-up; the NLTCS 1982-1984, with potential 1988 follow-up; and the LSOA sample to the NHIS.

Obviously, there is a marginal difference in time, but the difference is probably more in population coverage than instrumentation. The population coverage in terms of the SOA, for example, is not stratified, even though they have a larger group, a little over 16,000 people, 55+; and about 11,000 people over the age of 65. They have 876, I think, in 1974 that are over age 85, whereas I think in 1982, the numbers are more like 2,400-2,500. Obviously, there is the age stratification fact, which gives you more precision on the 85+ group, which is going to have the long term care service needs.

Also, the full 6,393 that you have seen in the NLTCS has passed a telephone screen, using the criterion of a 90 day plus chronic ADL or IADL disability.

You are targeting in on the chronically disabled community-based population, and have greater precision. I do not know exactly what the numbers are for the full SOA for 1984, but if the proportions held up, you could expect about 1,500 total community-based chronically disabled people in the SOA or LSOA, so you have got roughly four times the sample size, plus the over- sample of the 85+.

There is quite a bit of a difference in sample coverage. You are going to get a large yield on the non-chronically disabled in the SOA.

They do overlap to some degree, but some overlap is comforting in the sense of coordinating results.

The NNHS is a different beast with roughly 11,000 people in the 1985 round. I think it is 5,000 in the current resident and 6,000 in the discharge sample. They have two sample components, one of people who are residents in an institution at the time of the survey, and another where they find out about discharges in the previous 12 months. This is not an admission cohort. It is the flip side when people come out rather than when they come in, and if there are very different cohort sizes, there are analytic models to try and take discharges and turn them into admissions by certain types of calculations. The sample sizes in the NNHS are focused on the nursing home population; it is much larger numbers and has specialized instrumentation, which is the other dimension of differences, the instruments and their focuses.

QUESTION: In the surveys of people who may be disabled but not institutionalized, do you capture data to indicate the percent of elderly who are dependent on high technology home health equipment and their payment source for it, such as ventilators and renal dialysis?

KORBIN LIU: I am not sure that it has got that level of detail.

QUESTION: Do you first have to have a ADL limitation before the subsequent questions are asked about what source of assistance you then have, either mechanical or in terms of personnel?

KORBIN LIU: They go through each of the ADL's, so in the questions, there is a fairly elaborate skip pattern. There is no sense in asking follow-up questions if that is not a problem in the first place.

QUESTION: You could be, if I understand it correctly, totally dependent on total parenteral nutrition (TPN), and not have an adl. I understand that there are people who are fully functional who are on TPN. TPN is a fairly high tech way of obtaining nutrition into the body. If you get that you are supposed to be fully functional.

KORBIN LIU: In the way that those ADL's were met, I do not recall a specific question on TPN. They were, for the most part, geared toward personal assistance, rather than high tech or mechanical.

QUESTION: I am really impressed by the creativity and forethought that went into putting this remarkably complex survey together. I have two questions: ONE, I wondered if we could just have a little brief descriptive history of how this got started; and TWO, could you tell us a little bit about what might be in the works right now in terms of research being done with this data set.

KENNETH MANTON: I guess in terms of past history, Herb and Korbin might want to say something. I can talk a little bit about more current usages.

HERBERT SILVERMAN: I am not the final repository of the history. There were a lot of discussions in the early 1980's about the long term care population and about how well were their needs being met. There were several interagency committees meeting at that time. I believe there might be members of some of those committees present here.

Several people got together from ASPE and HCFA back in 1980/1981, and developed the initial 1982 survey, and then HCFA took the initiative in picking up the 1984 rerun. One of the moving spirits in that was a fellow named Jack Sharp, who has since retired. I was involved in helping expand the scope of the 1984 survey. One of the shortcomings we realized from the 1982 survey was that we really did not get a full cross-section or look at the aged, impaired population. We did not include the institutionalized; we wanted to know more about that, so we deliberately went into the 1984 survey wanting to get both a longitudinal dimension on how changes took place across time, and a cross-sectional dimension, what was the prevalence of the impairments in the aged population.

We consulted extensively with Census, and the staff at HCFA, in terms of generating the sampling frame.

Basically, there was a combination of a broad policy perspective, and then the nitty-gritty technical work that went into its development.

KORBIN LIU: I really do not have too much to add. I was there too in HCFA's research office.

One of the major reasons was to write a backdrop for Channeling. This was about 1978-1981, when ASPE, HCFA, and the Administration on Aging (AOA) were going to invest in this enormous demonstration project on community-based care. Prior to that point we had funded a number of other community-based care programs like TRIAGE and ON LOK. At the same time HCFA, ASPE and AOA realized that the issue of generalizability would be raised, and it would be important at that point to start a nationally representative tivestudy or survey at the same time we were starting Channeling.

The incentive for the 1984 survey, I think, was in large part that we had this very rich cross-sectional data source. It would be such a waste not to use that information to estimate the risk of entering nursing homes. You would have a follow-up which dealt with this 1984 sample, which was clearly the cohort of people who were in the 1982 sample. We wanted to see what happened to them in that intervening period, based on the characteristics they had in 1982.

KENNETH MANTON: We looked at some of the impacts from 1982 to 1984 in terms of changes of service use, the Medicare service use, and the change in hospitalization versus home health use. There were some very dramatic changes from 1982 to 1984, which might be associated with reimbursement change impact. One of the strong motivations for 1988 is that a lot more of the changes will have worked themselves through the system.

We know from 1982 to 1984 there was a decrease in the rate of hospitalization and a shortening of length of stay. Where did those people go? Those types of questions could be approached.

We had requests for information from both the NLTCS and the 1977 NNHS to help in the design of some insurance products. We provided a series of tables for use of retirement communities and provided information for people from Travelers and Marriott.

KORBIN LIU: I might just add that there are a number of other groups that are starting to look at that data. The National Center for Health Services Research (NCHSR) has a research program that Robyn Stone and Peter Kemper are involved in. Based on a recent conversation with Peter, the issues they are looking at are risk of entering nursing homes, the patterns of informal care, what services are received in the community, and ultimately various packages of community care, both formal and informal that are received by disabled elderly persons in the community.

Sandy Newman at the Urban Institute is conducting a study on the risk of entering nursing homes. I think that Beth Soldo and Doug Wolfe at Georgetown are also using that data set to look at informal care and various service combinations.

QUESTION: I know that the conference is emphasizing accessing the data tapes, but prior to that it would be important to look at a psychometric package on each of those three instruments. I am wondering if such a package is available through NTIS. The package would consist of the instrument, the coding manuals, the training manual, and especially the validity and reliability studies on the instrument prior to fielding.

HERBERT SILVERMAN: It is intended that that will be part of the documentation accompanying the tape.

QUESTION: If that is the documentation, do we have to request the tapes to get the documentation, to decide whether we want to use the tape?

HERBERT SILVERMAN: There is a limited supply of questionnaires available.

QUESTION: It is not just questionnaires. The validity and reliability studies, the coding manuals, the training manual--all of that?

HERBERT SILVERMAN: The real hope is in packaging it all together as an accompaniment to the data tapes rather than as a piecemeal activity. Just write to me and make the request. We will try to comply with it.

QUESTION: I have done some work with the ICS, which is a subset of the 1982 NLTCS, and there are some discrepancies in both the number of caregivers and the number of impaired elders who are receiving care from those caregivers. It is beginning to become a problem in that some of these estimates are being used for policy purposes; and I have been asked a number of times which estimates are correct.

Basically these surveys were done by two different entities, the NLTCS was conducted by Census, and the ICS was conducted by the National Opinion Research Center (NORC). I just wanted to throw it out as an issue, because there are discrepancies in the national estimates. maybe you could speak to that in

terms of some of the possible reasons, some weighting problems, or some other methodological issues.

KENNETH MANTON: Beth Soldo asked me some specific questions or numbers about that. Census did the core community-based survey. NORC did the caregiver; they picked up individuals supposedly from the sample.

QUESTION: I think that the sample clearly came from the control card. The control cards were sent to NORC, so clearly in defining the ADL's and the IADL's. You should use the control card in at least trying to get comparability in estimates. Even after doing so, there are some discrepancies. I think, if nothing else, people ought to know that.

I have one other question, and that is more a data cleaning question. I have started using the 1984 data, and have begun constructing information on the caregivers, and there are discrepancies in using the different records.

For example, if you use the household record, and then you look at the helper record, and you match up the person numbers, sometimes you will get somebody on the Household record who is a spouse; they will turn up on the helper record as a child. That is just as an example.

You have got two different relationship types with the same person number. The question I have is if, in fact, you have set up a file which is hooked into the sample person, and from what I understand that you could merge all the files so one would not have to go to each one of these separate files, how did you handle the discrepancies? I am just curious because we do not know whether to call the person a spouse or a child. Have you handled them?

KENNETH MANTON: Obviously, you go as thoroughly as you can to perform the contingency checks. A complete set of contingency checks across all variables is never possible.

The first Census public use tape we got missed six million elderly people when you added up the sample weights. When we went through that, they went back through all their software and it turned out that they left truncated a nine-digit field to eight digits. They lost probably six million people when they weighted that up.

We had to convince them that we were not tabulating things wrong. That took 2-3 weeks, then we got them to go through their software. Then Herb and I had a number of discussions, concerning the variables used in calculating the weights.

The age variable that I would recommend using was the one that was finally used to generate the final sample weights. How that variable was arrived at was to look at the multiple age variable and do contingency checks to see what the greatest consistency was.

It is in no way the same thing going back to an independent data source and validating. There have been efforts to generate consistency on the basic variables, and that was gone fairly intensively.

We had another question in terms of an 1984. There is one person who showed up in prison, and we wondered if that was a valid code as an institutional code.

I cannot guarantee that every variable is absolutely squeaky clean, but if you did not have the demographic variables and the sample weights right, you were nowhere.

A lot of effort was spent on those, and then the basic demographics, the marital status and other things. There are a lot of contingency checks.

That does not catch the single case that is off, but it tells you if there are general inconsistencies or patterns. The bill file information, on which we have done a lot of cross-checking seems in aggregate to make sense.

We had straightened out the 1984 sample weights, and then we just happened to go back and check the 1982 cross-sectional final weights, and found that they did not add up to 5.07 million any more, but to 4.98 million.

Then Herb got a new tape in the mail, and the numbers did add up to 5.07 million.

There is no way of catching everyone, but there has been a fair amount of consistency checking.

KORBIN LIU: On your first point about the discrepancies between the NORC ICS and the NLTCS, it might be helpful for the group to give some sense of how big the discrepancy is.

KENNETH MANTON: Is the discrepancy thousands, tens of thousands, or hundreds of thousands?

KORBIN LIU: The bottom line, is it so big that people should not even try to use it?

QUESTION: I think they should try. I am just saying that there is a difference. The other problem is in trying to look at the number of caregivers in the NLTCS, and the number of caregivers who are estimated in the ICS. You have got some differences in that the ICS differentiates between primary and secondary caregivers, whereas in the NLTCS, there really is not that differentiation. They are very different instruments, but one is contingent on the other.

KENNETH MANTON: The ICS is contingent upon the NLTCS?

QUESTION: The ICS is much more detailed if you are interested in caregiver information, but, again, you are not getting the exact same population that you would looking at in the NLTCS. The ICS also is just cross-sectional. It was only for the 1982.

KENNETH MANTON: Yes, and you would get some numbers and differences. Remember, I was talking about the institutional component. If you talk about the freeze date of April 1, you are talking about 1,708 people. They also had 284 people approximately who were indicated to become institutionalized between the freeze date and the time in which they attempted to deliver the questionnaire. You have got a series, because you have got a longitudinal sample. You have got different survey dates. Unless the ICS was contemporaneous with the delivery of the household interview, you would expect some systematic measurement differences.

QUESTION: In the documentation there are several good write-ups on the ineligibility problems, the non-response rates, and things like that. There are these discrepancies, some of which, at least to date, I have not been able to reconcile completely.

KENNETH MANTON: If they have to do with survey date, you may not directly have the Information to deal with but you can only be aware of it.

To some degree, when you look at a survey, you have always got stochastic error. Then you have certain measurement problems that will be systematic in our measurement error. Some of those will be associated with sample design artifacts like date of survey delivery.

There is a certain amount of slippage that can go on because you have got different instruments delivered at different dates. The reason why the 1,982 versus 1,708, the 284 difference shows you what can go on in 3-4 months with respect to a phenomenon as volatile as institutionalization.

Institutionalized status is relevant as a non-response, a variable for 1982 only. In 1984, we had institutionalization.

Then you have got "moved outside the country," or "moved within country beyond the sampling limits" where they were going to pursue people in a particular area. The people are essentially ruled out of the sample due to either being deceased or institutionalized in 1982, or for geographic mobility.

Next is the standard types of non-response that one typically thinks of when one thinks about a survey non-response. This is both for 1982 and 1984. I believe it was roughly in 20 percent of the cases that in order to try to track down the screener information and be certain of that Census actually went and did a household screen.

They simply just did not do a telephone screen. If there were questions, they did a sizable number of personal visits to screen the individual.

There are essentially two, if you will, denominators in terms of the non-response rates in 1982 and 1984. One is going to be for the screener, which in 1982, for example, is going to be roughly the 36,000 individuals. Then you have the non-response at the level of when the subgroup or the chronically disabled group is identified when they tried to do the household interview.

At each of those levels the response rates are just about 96 percent. For example, 6,393 dropped down to 6,088. Our analyses of that subgroup, the difference between 6,393 and 6,088 was almost 50 percent mortality for the 1982 non-respondents.

They asked the reason there was the need for a proxy respondent. Once that was fixed, based on that screener interview, then the person received that diagnosis of senility or cognitive impairment, and then the proxy carried through the rest of the interview.

In addition to that, there is, in the instrument itself the SPMSQ, so that for those individuals who are not too impaired to respond, you can get some measure of cognitive performance.

QUESTION: Who was used as proxies in the institutional component?

KORBIN LIU: In the institutional questionnaire, the sampled person was asked the SPMSO questions and then somebody on the staff of a nursing home, a nurse, aide, whoever would be asked the questions on ADL, and ultimately the institution would be providing all other information including payment source information.

KENNETH MANTON: The extent of proxy responses especially for the extremely elderly population and highly functionally disabled is always a question in survey design. I think that is one of the reasons why in the SOA they decided not to over-sample. On average, we are getting a 96 percent response rate, overall, and that is with an over-sample of the 85+. I think the Census field operation staff did quite a good job on that.

QUESTION: Were there sample design effects for the 1984 survey?

KENNETH MANTON: The sample design effect for the 1984 survey is smaller, but Census did do analyses of sampling variances and produced various simple types of variance adjustment procedures with some look-up tables that you can use for, at least, first order analyses of precision of various types of estimates.

There are two different approaches when you are trying to deal with the sample design effect. One is more model-based; i.e., trying to explain the design effects within the analysis. The other is saying, it is going to be hard for me to get the true model of the phenomena. I have got ways of conservatively adjusting my variance estimates for what might be the perceived level of contamination or correlation and stay within a cluster.

One says I am going to search for the substantive model that underlies the design effects, and directly analyze it as part of my analysis. The other says, I do not ever know when I have the correct model, but I have ways of adjusting my variance upward, and will deal with that to give me an upper bound estimate.

One of the results that was interesting, referring back to an earlier question, in terms of analyses that have been done is that if you look at the population weighted number of people with ADL's 5 and 6, and compare that to the number of people who have that profound level of impairment in institutions, there apparently are more people in the community with that high level of impairment than are residing in institutions.

It is also very interesting that if you look at the relationship of economic characteristics and resources to ADL status for people in the community, it is curvilinear. What that means is that when you go one to two to three to four, there is a drop-off in status and resources. When you go to five to six, those individuals tend to have fairly good economic status; they tend to own their own home; they tend to have a spouse available.

In other words for a person to be retained within the community, at that profound level of disability, they have to have three or four factors going for them to keep them out of institutions.

Not only is it a larger group than you would find in an institution, but it is also a very specialized group.

QUESTION: What was the length of time that someone had to be disabled to be in the survey?

KENNETH MANTON: Remember it is 90 days, so you might think of somebody with hip fracture who could undergo rehabilitation. There are situations where you could conceive of rehabilitation, where there would be a medium-term disability, and obviously one of the challenges is to subdivide this table and see if that is associated with particular types of diagnoses.

If you adjust for the 37 percent who died, you are talking about 35-36 percent who got better among survivors; and what I think you are seeing is people of five and six ADL's are probably bimodal at least as a population. People who are that severely impaired because of some underlying acute type of condition, if you want to consider hip fracture, are different than others, such as an Alzheimer's type where there would be progressive, monotonic course.

You will find that there is a big difference between the 65-74 and the 85+ in terms of the probability of getting better or worse. There are about 3,200 deaths over this 2 year period, and over the 6 years total, you would expect a little over 10,000.

For any individual who is in the survey, you have the 5-6 years worth of Medicare service use, and you can aggregate that in the service use in different windows.

You would look at the full 5 years, or you might take a 12 month window that centers around the mean survey date, and ask for plus or minus 6 months from the survey date what was going on.

We took calendar year 1982 and calendar year 1984 and not using data from the survey but simply using data on the sample components, which include the identification of people, whether they were disabled or not, or in institutions or not, and looked at what was implied by those sample components in their use of hospitals.

Think of 100 percent of all people for all hospital episodes. We have abstracted out the total number, as in a life table calculation. That is like a rate X, and then we show how many people leave in the first day? How many leave in the second day? How many leave in the third day? We do this for all hospital episodes for 1982, as it is for the 1982 calendar year, and as it is for the 1984 calendar year.

What you can see are fairly major differences, in terms of hospital length of stay, in terms of the sample component.

The non-completed curve is that group that is the difference between 6,393 and 6,088 that I said had the high mortality rate. They also tend to use a lot of hospital services. They tend to be the longest stayers.

You can take that community disabled group, I mean the people who screened in and answered the questionnaire, the 6,393 people, and see how these service use measures varied as a function of disability level.

You could get similar types of life table calculations for hospitalization. You can not only do hospitalization with the Part A files, but you can also do home health services. You could take all home health service use for 1982 and 1984, and see what changes there were between 1982 and 1984 in terms of mean number of visits or mean number of days this person spent in a given home health episode.

You can do that for SNF's, as well. For the Medicare data, you can use life table methods to look at the episodes. I use the life table type procedures, because I want to be able to adjust for a certain type of censoring events. Once a person dies in the hospital then he is no longer eligible to accumulate length of stay. I want to make an adjustment for the fact that I now have missing data, because the person died.

The basic point here is that you not only have the survey data, but the associated continuous time use of the major types of Medicare service files, and there are ways of using the survey data in conjunction with those Medicare files to tell us a lot about chronic functional health status impact and acute service use. It allows us to examine questions like who is not becoming institutionalized or who is not using hospital services for 1982 or 1984.

From some of these results and from some things that we saw in the California MSSP, people with certain chronic disease diagnoses, like diabetes, seem to have a drop in hospitalization.

There seem to be certain types of chronic diseases where there were short hospitalizations for people without informal caregiver help. They were going to the hospital, rather than remaining in the community.

KORBIN LIU: One large component of the 1984 sample was the 1982 sample of noninstitutionalized disabled elderly people. Between 1982 and 1984, you do have an incidence of nursing home admission; and what we found was that approximately 15 percent of the 6,000 people in the 1982 sample had spent some time in a nursing home between 1982 and 1984.

The 1984 NLTCS also had an institutional component which described various characteristics of people who were in nursing homes in 1984. Some of the people who were in that 1984 institutional component were people in the original 1982 community sample, but not all of them. Not all of the people in the 1982 sample who went into nursing homes were found in the 1984 sample.

The reason is that some of the people returned to the community, or they were deceased, but you subsequently have the information to look at both long and short stay nursing home patients with the 1984 information and combined with the 1982 information.

QUESTION: On a deceased questionnaire, who were actually interviewed in regards to next-of- kin? Was it actually the next-of-kin or the person who assumed responsibility for the person?

KORBIN LIU: It was not necessarily next-of-kin. Essentially they were trying to find the most knowledgeable person about the sample person.

QUESTION: How did you determine that a particular person was senile?

KORBIN LIU: The question was asked to a proxy, and the proxy was responding. If the sample person were responding, that question was not asked.

KENNETH MANTON: When they identified the proxy respondent, they had a two-phased screen. They first tried to do a telephone screen, but in about 20 percent of the cases, they had to make a personal visit. At that time when they had to use the proxy respondent, they asked the reasons or determined the reasons we were using a proxy respondent.

If it was a profound cognitive impairment that prevented the person from responding, and that was on the list of reasons for proxy respondent, then that is where the diagnosis of "senility" came in. If they actually talked to the individual, then the short portable was given and for those individuals who were able to respond directly without full proxy responses you had the distribution, but it was a truncated distribution in the short portable.

QUESTION: You said that this was a backdrop to Channeling, were there any case management related questions in the NLTCS?

KORBIN LIU: It was primarily focused toward specific services that were being received for specific ADL's and IADL's.

QUESTION: Did you ask any questions about drug use? If so, did you ask for specifics, or ask them to get out the drugs that they were taking, either prescription or over-the-counter?

KORBIN LIU: There were questions in the instrument about medical services, including prescription drugs. The questions were oriented, not toward the quantity, but toward the expense. There was an attempt to find out how prescription drugs expenses were covered. There were other questions about whether, if there were no costs, then was it because of professional privileges, or was it covered because you were part of an HMO plan, or so forth.

QUESTION: What was your degree of confidence in the responses that they were not gaming their response to protect a home health care service, or to describe the client as more dependent than they might, in fact, really be to ensure that home care services might continue?

KORBIN LIU: Is your question that the sample member under this national survey would have been afraid of losing eligibility.

QUESTION: There might be a difference between getting 8 hours of attendance at home, or 2 hours, depending upon the degree of disability. I am just wondering how did you validate what was described was what, in fact, was going on?

KORBIN LIU: I am not as familiar with the confidentiality and clearance procedure. This is a survey that was conducted by Census, and so I think the lead-in would be the letters and the screeners, essentially just indicating this is a national survey to collect information for research purposes and so forth.

KENNETH MANTON: We think of the 1982 and 1984 surveys which have been conducted, and the proposed 1988 repeat, for each of the three dates there are a different survey components or instruments, delivered to a different survey population.

In 1982, we have primarily the community-based survey for the disabled elderly, people with a chronic impairment of 90 days or who anticipated that it would be for 90 days.

In the NORC ICS, they went back to a set of individuals for a sub-sample of the total community population. They talked to the caregivers about the burden of delivering care, both for a sample of individuals who were continuing to deliver care and for a group of individuals who had stopped delivering care.

The 1984 survey was more complex. There was a total of about 10,000 interviews conducted, in addition to the community-based interview, which is very similar between 1982 and 1984. You had the institutional survey and then you had the deceased questionnaire. In both dates, you also determined the status of this population.

That turned out to be useful for some aggregate level analyses. You have the detailed community-based survey for people who screen in who have chronic disability, but you can also then cut the pie apart and have the non-chronically disabled apart from the total institutional population. This allowed us to look at some basic aggregate level changes for the entire population and put these people in contact.

In addition to the survey instruments in 1988, it would involve a repeat of the community and the institutional surveys.

In addition to the survey instruments delivered at particular dates along this time line, you also have those survey records linked into Part A service file. This file includes the exact dates, reimbursement amounts, and number of visits for home health, for SNF's, and for hospitalization, for roughly the full survey plan, a 10 year period.

Currently, the data is available, and linked from 1980-1985 complete with some additional data in 1986.

There have been even some discussions of the possibility of Part B linkage, but currently the anticipated plan or projected plan is that both Part A bill files and the individual records with a survey respondent ID, i.e., a non-meaningful ID would be prepared and available as one file. Then a rectangularized version of the 25,000 individuals with the 1982 survey and the 1984 survey responses would be available in another file, with a common survey respondent identifier which allows you to link. You could have multiple bills associated with a particular survey record in a rectangularized format. Instead of doing what Census did with their public release tape, which has four or five distinct record types, and which had a separate component for the 4,916 people who were in the aging sample, we put them in one person-based file with all record types linked.

That basically takes the data processing away from one of writing some PL-1, Fortran code or whatever into various merged types of files. It is inefficient data storage wise, but it simplifies some of the programming tasks.

One thing to recognize in the design is that the 1984 sample is not a simple subset of the 1982 sample in that you have the 4,916 people over age 63-64 in 1982 who are aged in. A second feature is that there was only a 47.4 percent sample of the non-disabled people who screened out in 1982, because of budgetary constraints; also people who were disabled and received the detailed interview in 1982 were reinterviewed automatically in 1984. You get detailed characteristics on people who are chronically disabled at one date but who improved.

In addition to that, there were the various components, the aging sample in the non-disabled sub- sample were telephone screened and had the personal visit screens that determined who became newly disabled.

You get the full flow composition of that population. As you can see, there is an institutional group identified in 1982 of 1,992 individuals. In terms of screening, they found that the people that were institutionalized as of April 1, 1982, which was the freeze date of the sample, there were, I believe, 1,708, and there were about another 284 who became institutionalized between the freeze date and the date of survey.

The NLTCS is one, the SOA/LSOA conducted by the National Center for Health Statistics (NCHS) is a second, and the 1985 NNHS with the 1987 follow-up is the third survey. One can see that the one axis is time, and that they are roughly contemporaneous, or cover reasonably comparable experience, but they differ very much in terms of the portion of the population covered by the survey and in terms of an instrumentation.

The procedure was to draw 55,000 individuals and then to take reduction sets until they achieved a total sample size of 6,000 cases. They did not know exactly how many people were going to pass their criterion that they were using to quality for the detailed community survey. They took an upper bound of 55,000, and, as they went through the reduction sets, when they hit 36,000 they reached their targeted projected goal of 6,000 community surveys. The SOA/LSOA is more of a community-based sample with no such screening procedures.

If the yield rate that was achieved between the 36,000 and the 6,000 cases were to be applied to either the 16,000 individuals over 55 or to the 11,000 individuals more property over 65 you would expect about 1,500 people impaired in the SOA/LSOA, despite the large sample size.

In addition to that, in the SOA/LSOA, they did not do an age stratification, as I understand, so they only had 876 people over the age 85, despite the large base sample size, as opposed to on the order of 2,300 persons over age 85, in both 1982 and 1984.

The 1986 LSOA, the longitudinal follow-up, is about 5,500 persons, and had a complex sample selection procedure where they did pick up all people over age 80, and then did pick up certain groups between 70-79.

All minorities were picked up, and spouses of people over age 80 were picked up as well as the 50 percent sample of the residual, which ended up with a total of 5,500 individuals.

Again without the disability screen, and as a general population sample. The NLTCS has much more precision on the disabled community dwelling population and on the 85+, but you are missing a component in terms of the non-chronically disabled individuals who are back in the population.

There are also major differences in terms of instrumentation. Because of the target focus and the NLTCS on the disabled population, the instrumentation on ADL, IADL, personal services, and equipment used is much more detailed than in the SOA/LSOA.

The NNHS is an institutionalized population, about 11,000 individuals total, 6,000 in discharge, and 5,000 in current resident, although I tend to flip those numbers.

The instrumentation is very different focusing on an institutionalized population and looking at much more detailed aspects of the institutional experience than is available in the NLTCS.

The NNHS in the discharge sample will tell you something about an admission cohort, but you have to do some backward mathematics and analyses to make assumptions about the size of the entry cohorts to be able to know what the admission experience was that could have corresponded to the observed discharge experience.

The point is that there are complementarities among the three different surveys; there is also some common instrumentation that can allow you to relate the results of various surveys to one another. For all three surveys, there are plans to link to mortality data and to Medicare service use data, so you will have detailed endpoint to compare the experience of the various sub- populations and all the instruments that contain some degree of approximation of functional status and health status measures.

KORBIN LIU: One of the questions that came up is which data base is preferable for looking at specific questions like risk of entering nursing homes and length of stay. In line with what Ken has saying, the two data bases that start out with community population are the logical ones.

In both cases we are going to have fairly short nursing home use experience, so if one wants to look at length of stay, then the obvious source is the NNHS.

One of the problems with the 1977 NNHS was that it included multiple segments of nursing home stays for given individuals. If you try to compile those lengths of stay, they turned out to be a shortened pattern than one would expect. In 1985 they corrected that problem.

Effectively, if one wants to answer the question, what is the risk, duration and cost of nursing home care, you would have to use multiple data sources.

KENNETH MANTON: Type C is a survey eligibility type of screen, where you have people who drop out, because of death before April 1, or death between April 1 and the survey date. Institutionalization was a reason for screening out in the 1982 survey only.

Obviously, in 1984, there is an institutional sample, and they were brought directly into it. The numbers in 1982 were 1,992 people. In 1984, people dropped out because they were not in the geographic range of the survey operation.

Then the next type of non-response is the type A and again these are frequencies rather than rates just to show the various types. The response rates in the survey were remarkably high, about 96 percent so that the non-response problem was rather minimal.

The largest proportion are sample persons who answered. Things were reasonably stable between 1982 and 1984. Proxy responses go up proportionately as disability level goes up. The proportion of proxy failures in the previous table is fairly small.

Obviously, the field operation group at Census was able to do a fairly effective job here in the proxy identification methodology that they were using.

QUESTION: Were the people who were most disabled in 1982 most likely to be non-respondent in 1984?

KENNETH MANTON: The proxy response rate increases. You have got two types of responses, the person or the proxy. For the persons who are already disabled you can find an effect of proxy respondent? If one were to rely only on sample person responses, you would find, obviously, a huge gap.

QUESTION: There is a couple of hundred non-answers, right? If they were all from those with five or six ADL's, then that means a lot of the people that had five or six ADL's in 1982 did not answer.

KENNETH MANTON: It was a slight increase, but I do not have those exact numbers at my fingertips.

First of all, you are talking about 4 percent and 4.4 percent total non-response, and then you are subdividing the 4 percent non-response into certain other types of non-response, so you are talking in terms of maybe dealing with a total of 1-2 percent. Then there are people at the various levels, the one, two, three, and four. The numbers of the cases were certainly small, and it is not that all the nonresponses occurred at ADL five and six.

QUESTION: Can you talk a little bit about what the 1984 sample represents, in particular, since everyone who is impaired in 1982 was followed up in 1984, and you do not have screeners on everyone in 1984? How do you figure out what the 1984 population represents? How do you do the weighting for that?

KENNETH MANTON: You have individuals who are given the instrument in 1984, who show up non-impaired. Indeed, to compare service use between 1982 and 1984, there are certain additional adjustment factors needed to get to the comparable population. In that particular case, It is to look at the detailed responses and find individuals who came up non-impaired in terms of the detailed instrument.

One could not just take the sample component and deal with that. One has to go back and look at the ADL and IADL responses. There are certain check-questions between 1982 and 1984 that you can go to as control variables to help you subset that. You do have to be careful to decompose it that way.

Another instance that you have to be careful of is in terms of the institutional sample, because if you remember there are 1,992 in 1982 who were not interviewed because they were institutionalized. That could have been at two dates. To get our institutional comparable sample, we had to walk out those people who were institutionalized as of April 1, as opposed to additional people who were institutionalized when you attempted to interview.

The non-respondents in terms of the difference between people who screened in during 1982 was 6,393 versus 6,088, but that sub-sample was a high Medicare service use group, and had 50 percent mortality.

The comparable identified subgroup of non-responders in 1984, which is not defined exactly the same way, had about 25 percent mortality, was a little less health impaired, but still probably was not responding to a large degree because of the nature of the medical problem.

There are some fairly subtle differences that you do have to be careful about in terms of making sure that you are defining the same population in 1982 and 1984, because 1982 and 1984 are not precise enough.

QUESTION: Let me just ask two follow-up questions, if you use the 1984 survey tape in a cross-sectional sense, without worrying about the longitudinal part, what is it supposed to represent?

KENNETH MANTON: You have both final cross-sectional and final longitudinal weights.

The weights themselves are obviously affected by several factors, not just the aging group. You have got mortality over the interim, and non-response of certain types, but also you have got the fact that the people who were drawn from the 36,000 cases who were non-disabled in 1982, you only had a 47 percent sample.

There are several additional factors in terms of calculating the sample weights, but the longitudinal weights are adjusted appropriately to deal with those various factors, and the cross- sectional are derived to give you the appropriate cross-sectional distribution.

QUESTION: Where could one go for more information on some of the technical details, like the difference between these dates and the fact that some of these adjustments had to be made?

KENNETH MANTON: For the documentation, from the NTIS release. I have a short document which describes the system file structures, the reasons for putting them in that form, and some processing characteristics.

Then we redid the documentation, which is about 300 pages, describing all the different types and variables. We put that into an integral sample person-based format. In addition, we also included the 1982 and 1984 survey instructions for the interview manuals. You have to dig through the interviewer manuals in order to pick out the subtlety.

You have system file documentation, the documentation on the variables, the interviewer manuals, and then copies of all the instruments.

Then there was a question asked earlier in terms of any studies of validation. We have looked at some things in terms of proxy respondents in the response categories by the different subgroups, but that is validating against an independent experience.

There is always this measurement question. Can I have one definition of my long term care population? It seems to me that varies depending on the policy and research purpose. I do not think you can have one simple definition.

I think with respect here to the instrumentation, you have got a fairly broad screen with some small proportion of false-positives. That makes me feel comfortable. The false-negatives is what would kill you in terms of trying to represent the population, if you were losing individuals who should have been in who were dropped out.

To a certain point if the documentation is there, you are left with some hard work to go back and track down things, but you have to be careful not only with instrumentation but longitudinal aspects of the survey.

If the weights are calculated correctly, they will absorb a number of these adjustment factors, so the simple answer is the longitudinal weight should capture a lot of this. If you are not a trusting person, you have to look at a lot of details.

When we went back and forth with Census, we spent the last 4-5 months working on longitudinal weights. In the first set we lost six million people, because they had a nine-digit field that was truncated one from the left, so they lost one decimal point.

The next thing we went through was the variance calculations to adjust for sample design effects. Certainly the survey statisticians have one approach which involves some model of randomization which inflates the variance usually to adjust for cluster effects, or adjust the variance estimates for the fact of not having a simple sample design having a stratification and clustering structure built into it.

The NLTCS is relatively simple. There are strata, for example, on age and eligibility status, and a couple of other variables. The clustering effects are relatively minor and small. Census did calculate a first level of approximation at least for 1982, and they redid some of the material for 1984.

This is one way they have done it. For two sample components which have different f-factors which are based weight differences, one being black and those are Medicaid eligible, and then all others. You have a simple regression function where you plug in the population weighted value of people in that subgroup; (a) you simply put in the population value, and (b) you put in the square for that term.

If you are trying to do certain types of things like forecasting or if you are dealing with local area phenomena, like market phenomena, there is an alternative approach, which is based on what they call super-population models, where you attempt to view these sample effect as either, (a) irrelevant, in which case you ignore ft, or, (b) if relevant, to include it in your modeling effort and in your substantive analysis.

The notion of looking at the longitudinal 1982/1984 component, and at the information from the survey instrument in terms of functional status is shown on a table based on changes from 1982. The 1982 survey status is down the side, and the 1984 survey status is across the top, with the additional factor that sample members could have died over the 2 year period. Even for people with five and six ADL's, it looks like there is some improvement about 25 percent or a little less.

If you take out the non-survival group, the 36 percent who died, or the ADL five and six, which is roughly similar to the institutional group, you are talking about almost 35 percent survivors, who improved in terms of functional status. Some of the preliminary analyses suggest that for people at that impairment level, there may be two types of processes. One, they really have an acute problem like hip fracture which causes the 90 day impairment but they are rehabilitative versus something like an Alzheimer's condition, or a stroke, where you would figure the capacity of rehabilitation is less and the damage might be more permanent.

You are finding rehabilitation potential at the younger ages, at the higher disability levels, which is consistent with what one would expect.

We talked about the fact that these are linked to the Medicare service use files.

Those represent the continuous service use over a 5-6 year period; and the question is how do you relate those to the information on the survey data. One way to do this is to utilize various types of simple life table models as a way of adjusting for various types of sensory and competing risk effects.

One could think that if one were already in the SNF that certain types of hospitalization would not occur. In that sense the amount of time spent in the SNF would reduce the exposure time for hospitalization.

Likewise, death is also clearly a censoring event. If somebody is very ill, and then dies early in the year after measurement, then their exposure time for service use is greatly truncated. By recombining the exposure within a given interval, using life table methods, you can adjust for the exposure time differences.

Remember I talked about the non-completers for the high mortality rate. They also tend to be people staying in the hospital the longest time. In other words, the proportion staying in the hospital each length of stay tends to remain higher. They are a very high service use group.

People who are not chronically disabled are staying in the hospital shorter times than people with chronic disability.

My basic point is that one can think not only of analyzing changes in the survey characteristics but of linking those survey characteristics to the continuous services and conducting combined analyses to get some rather rich types of analyses on Medicare service use of a functional status for nationally representative population.

QUESTION: Did you keep track of ADL people that had the same or different impairments?

KENNETH MANTON: In the sample record, you will have all the survey responses, so you will have the ADL's on both dates, and you can see changes, not only in level but in type of ADL.

KORBIN LIU: We used a simple summated Katz ADL score. The reason we tried it this way was in part, because a lot of nursing home studies had looked at the Katz hierarchy and how it correlated with an ADL sum. For example, Pete Shaughnessy did that at the University of Colorado, with multiple samples of nursing home patients, and found a very high correlation between the two.

KENNETH MANTON: We wanted to look at certain types of intervention scenarios, in terms of health status changes. For that type of projection work, it was useful to have a summary score indicating disability level.

QUESTION: Could you give us any traps or problems with the data that you have come upon that might not be apparent to somebody just starting out?

KENNETH MANTON: We mentioned the date at which the survey is sample frozen or the interview date. You have got to be a bit careful about that because that can have a major impact in terms of interpreting certain types of changes.

There are probably lots of questions in terms of instrumentation. There are 29 medical conditions and they break down in 17 and 12, roughly, in terms of events that occurred within the last 12 months. There was a question 13 where they used a certain re-code list, where there were questions about what conditions caused disability. Some of the re-code lists would have made It difficult, for example, to get hip fractures out from other types of fractures.

The senile diagnosis that is based on proxy response is manifestly cognitive impairment. Other causes are the Alzheimer's related disorder question versus just general cognitive impairment, plus social factors and medication which can cause degradation of cognitive impairment. Trying to disentangle that complexity gets to be a knotty problem.

You have got behavioral problems in there. For certain types of measures that are softer you have to look at multiple indicators. The instrument is rich enough that you do have some consistency checks. For example, out-of-pocket payment at times was a questionable variable, but it seemed to make sense both within the survey, and also in terms of other ancillary data.

We tried to do some things that would determine measures of unmet need. Depending upon how that was defined, we could have broadly different numbers. The incontinence question could mean you increase your numbers by a factor of five or six. Was incontinence an unmet need, in the sense of what we could do to meet that problem? Clearly they had a problem, and there was discomfort in whatever involved. Maybe for urinary incontinence someone could do something but maybe not for bowel. There are questions of definition, if you are talking about new technology or surgical procedures that you could cure the bowel incontinence, so that might be relevant.

I think that, in general, for the purposes to which that was being put, it was decided not to work with the incontinence. First they gave very large numbers, that are a little implausible and the other numbers seemed more comfortable in terms of the unmet need.

KORBIN LIU: Just a couple of more examples. We are working on the out-of-pocket payment questions: did you pay; was this paid care; did you pay any of it? Answer yes: how much did you pay. Blank: did you pay any of it. Blank: then there was a number at the next line. It is the kind of problem that you frequently find in survey responses.

Similarly, with income some parts do not add up to the whole. There were questions on specific income sources and amounts, and there were summary questions. You are going to find variations, if you add up all the individual sources, and then the summary number.

Robyn Stone has been working on the ICS. The NLTCS was conducted by Census, and the ICS was conducted by NORC. Basically, they had samples from the NLTCS sample, and went to identify all caregivers of that particular sample.

When Robyn weighted up the number of caregivers and the number of sample persons from the ICS, she found a fairly large discrepancy between the number of disabled elderly people, with ADL limitations indicated by the weighted NORC survey and the numbers that we found with the NLTCS.

If you are going to be working with both files, and you had notions about merging them, it is definitely worth while to first talk to Robyn and others who have begun working in that file, and to look very carefully at the variations that currently exist from her analysis.

QUESTION: Have you looked at the usefulness of the information and diagnosis in the Medicare files versus the diagnostic information from the survey?

KENNETH MANTON: First of all, diagnosis is primarily on the hospital bills, though there are a certain number of SNF and home health bills where you get some diagnostic information. That information starts really to phase-in during October 1983 with respect to Prospective Payment System (PPS).

Before that, the information on diagnosis is generally spotty. Remembering the way the PPS came in, I believe it was the fiscal date of the hospital that caused it to trigger in during the 12 month period between October 1983 and October 1984. If you look at the distribution of completeness of diagnostic reporting in terms of even the hospital files, it got better during the year.

One can look at the diagnostic information from the bill files, but remember that is for an acute episode, and what you are tracking here are two types of diagnostic information. There are 29 medical condition variables, a certain set of events within the last 12 months, and another set are chronic conditions and then question 13, which is the medical condition which caused the disability with that particular coding.

QUESTION: Is the 1984 community survey similar to the 1982 survey?

KENNETH MANTON: There are just a very few small changes.

QUESTION: Individual caregivers could be identified and longitudinally followed in the same way as sample members?

KENNETH MANTON: My impression is that sample persons can be followed longitudinally and if they have a spouse in both times, then you could probably make an inference.

In terms of having like a common ID number where everything could be exactly matched up, I do not think that is the case. I have not looked at that specific question, but I do not think so.

QUESTION: Why was not there a 1986 survey?

KENNETH MANTON: It would have been desirable to have a 1986 survey and a 1988 survey. When 1982 was done questions were raised about the advisability of doing 1984. That was allowed to happen. In the context of the 1986 round, several other large data collection efforts like the National Medical Expenditure Survey (NMES) were underway. There was a question of budgetary constraints. The 1988 survey is actually being handled through a very different mechanism now under a regular grants program at the National Institute on Aging (NIA.)

You have got the 6 year window. What you lose is the short run changes in the functional dependency.

If you think of something like hip fracture and rehabilitation, I have a feeling that those things which can turn around probably will turn around in 2-4 months. The difference between a 2 and a 4 year loss, in terms of that information, might not be as great as what you would pick up if you did a 3 month reinterview to look at the short term changes.

You are going to miss some intermediate shifts. The recall information will give you part of that, but it will not be like having a continuous time line on service use.

QUESTION: How could state agencies use the national data base to estimate the prevalence of disability in a given state?

KENNETH MANTON: That is the reverse question of how to combine it with demonstration data for localized sites. If I have got Channeling and two experimental interventions, and if that affected service outcomes in certain ways, how do I know what the implications are at the national level, given those intervention effects?

What is needed is joint information and measurements between the demonstration data set and the national data set. If that information is good enough in terms of functional health outcome measures, then in effect you are taking the response that occurred for an individual with a given set of characteristics in the demonstration, and reweighting it to the national distribution from the survey data.

The question now is how can you back down to a state level. If you were willing to assume that the transitions or the service use characteristics for individuals of a certain type in the national survey were going to be similar to what was occurring within a given state, then you could take the responses for individuals with set characteristics in the national survey and reweight back to the state distribution.

There are various strategies whereby you might be able to identify a set of states with similar Medicaid programs. Then you might have more confidence to use combined information from five or six states that are the most similar.

QUESTION: I talked to Peter Kemper and he told me, in fact, that the Maine site really stood out, compared to the other nine channeling sites.

KORBIN LIU: It also gets back to the question that Tom Wan asked about area variations. Just anecdotally, there was a Senate Finance Committee Hearing on Medicare. Senator Long had asked Larry Bartlett, basically, "is there an access problem for Medicare SNF patients?" Larry Bartlett said, "Sir, I think there is because you do not have any Medicare SNF's in the state of Louisiana."

QUESTION: What if we just wanted to look at the 1984 NLTCS for the prevalence of disability and we wanted to somehow apply those estimates to a certain state, just cross-sectionally. Obviously, you would have to adjust somehow for the age and sex composition of a particular state. Beyond that, what would you suggest?

KENNETH MANTON: I would need additional factors to control for. Age, sex, and marital status would be the obvious ones.

Certainly, marital status would be a general one for remaining within the population of who remains within the community or who becomes institutionalized. There might be other factors that you might want to adjust for.

The adjustment could be done in a more or less sophisticated fashion. I mean, the first level of adjustment is like an indirect age, sex, and demographic characteristic standardization. They could go to a higher level of control with some simple regression model. You could get more sophisticated than that, depending upon how detailed you wanted to make things match up.

KORBIN LIU: You might also look at hospital discharge records and the kinds of cases you see. If there is a short term disability associated with stroke and hip fracture, by looking at the hospital records, that may also give you some additional information to estimate the disability levels in the types of disability.

QUESTION: Are the weights for the 1982 survey okay?

KENNETH MANTON: One of the problems is the 1982 survey cross-sectional weights on the new file did not match to the NTIS file. That was corrected, so now they correspond and match. The 1982 survey public use file from NTIS, as far as I know, has no problems. The weighting on that should be correct, so you should be able to use that and get your national population weighted numbers.

One can never guarantee every single variable in that file, but there should not be out-of-range values. When you look at the different age variables, there can be inconsistencies and you have got to come up with a single age variable that is the best compromise in order to produce your weights. The weights, I believe, are clean.

QUESTION: I am actually looking at issues and options in financing long term care. I would like to know some of the new applications that you are working on.

KORBIN LIU: In addition to the pre/post-PPS study which we talked about before, we were about to study the patterns of nursing home use and the effects on financial status of the disabled, and possibly the effects on spouses.

Between the 1982 and 1984 surveys about 900 people went into nursing homes. By the way, if you want to look at who goes in the nursing homes, there is a lot of information. You have got the sample person who goes into a nursing home and then there is a question at the end of the questionnaire that said, "For the sample people who were still in the community in 1984, did your spouse go to a nursing home?" You actually in one sense have doubled the size of the nursing home use population possibly.

Because of all the information that is available on income and assets, you can look at changes in income and assets over time.

QUESTION: What kind of asset information was collected?

KORBIN LIU: It is not as good as we like. The 1982 survey, basically, had a question about house ownership and given house ownership, what do you think the market value of the house is? There is no question at all on liquid assets in 1982. On car ownership, you do not know whether it is a Cadillac, Mercedes or my old Ford Stationwagon. I am not sure that helps you in terms of asset information.

There were questions on source of income, and one of them was, "Did you get income from savings and so forth?" You had to make that heroic assumption that every piece of asset is used as an income generator, and that may not be a safe assumption to make.

In the 1984 community survey, they enhanced the income information. There were questions on stocks, bonds, CD's and so forth, and that was an add-on for the 1984 survey, which I think is an improvement. Generally, I think there are better surveys for income and assets.

QUESTION: Beth Soldo did an analysis on the 1980 NHIS supplement, to look at the receipt of formal care. Have you done anything like that on either the 1982 or 1984 surveys?

KORBIN LIU: I think Beth is still doing that. She is working with Doug Wolf with the 1982 NLTCS on family living arrangements, formal care, informal care and so forth.

QUESTION: Have you looked at home health issues?

KENNETH MANTON: I worked with Tony Hausner in the Office of Demonstrations at HCFA on some issues with respect to home health service use and substitution. We did a 1982 study to look at case mix measures using the home health service users off the 1982 survey file. We were doing some replications looking to see how those case mix measures replicate for 1984.

QUESTION: Have you written up these analyses?

KENNETH MANTON: For the 1982 survey there is a paper that should be appearing in Health Care Financing Review. We have gone past the galley proof stage, I think, and it should be coming out shortly.

QUESTION: Long term care is not the same as long term care for the elderly, for children, or for handicapped people. Are you planning to expand your survey to other types of long term care?

KENNETH MANTON: Not the NLTCS. I have looked at some of the other long term care issues with other data bases.

For example, for the Supplemental Security Income (SSI) program, there was a file that took 12 monthly entry cohorts and looked at Medicaid Type D living arrangements, which are the nursing home use. It was in an administrative record file, so it did not have anything like a rich set of co-variates. They drew a sample out and then followed them for 36 months, but they took the entry cohort for each month during 1982. They got around 10,000 persons a month. They were followed up for 36 months to track people in and out of facilities. You could look at things in terms of reasons for qualifying, change in service use, and mortality. You obviously did not have anything like the rich set of variables that you do in this survey.

QUESTION: How appropriate do you feel these data bases may be for constructing claims costs and loss distribution estimates over a wide range of ages?

KORBIN LIU: It is very hard to do and obviously it is not a direct, insured environment we were talking about. What we were really talking about is some level of need and how that need, after being mediated through a number of other factors, translated into some kind of behavioral response to nursing homes.

I think you have got some of the best national data on the subject. I find it very hard, whether it is an insured or non-insured environment, for somebody who is heavily disabled with incontinence, with a caregiver that is been working constantly for 6 months, not be at high risk of going in nursing homes under any circumstances.

I think that there is some very basic information on risk and length of stay from the three or four data sets, but I was thinking about the NLTCS, the LSOA for predicting risk, and the NNHS for predicting length of stay. Between the two sets of information, risk and length of stay, you can develop a fairly good total liability or total utilization for a cohort, which I think is what you need for designing policies and costing amount.

There are other data bases around, too. There are specific ones for states. As you probably are aware, Connecticut is developing that nursing home inventory and their inventory's been translated into patient level files for length of stay.

If your policies are oriented toward home care as well as nursing home care, then the basic disability/morbidity relationships are going to be extremely important. If somebody is disabled because of epidemiology, then they are going to be requiring some kind of assistance.

There is a lot of information here on the basic biological underpinnings of long term care. That, in itself, should be extremely valuable. You will see variations because of the other factors.

KENNETH MANTON: Associated with that with people by their various risk factors, you will also be able to look at income and assets, although, we talked about assets being somewhat problematic.

If you are talking about a private insurance product, you have marketability, function of ability to pay, and how to cost the thing out. You do have economic ability to pay. You do have a basic need measures. You have the current service utilization for the acute services, at least, and other types of reports of long term care usage, home health service usage, etc. There is a lot of information there.

What you will not know are certain specific behavioral factors in terms of how willing people will be to purchase a given product, that is, what the actual experience under a given type of insured product would be.

I think any time you are starting a new market area, you are going to lack that experience. The best one can do is use the type of data that is represented here.

You can also look at things there in terms of various types of health insurance coverage, at least on a superficial level and coverage under various federal programs so you can see what coverage patterns are like that might also be relevant to filling gaps in service delivery.

KORBIN LIU: I would like to make an unsolicited point. On this question about predicting nursing home admission, it seems to me that we were assuming that a nursing home admission is a nursing home admission is a nursing home admission, and they are not.

People use nursing homes for different reasons. I think Ken has been pointing that out that you have people who go to a nursing home for post-acute convalescent care. You can have people who go to nursing homes for long term care. People who go to nursing homes for terminal care.

My guess is that if you want to try to predict nursing home use, it is important to decide which types of nursing home use you are predicting, because if you are just predicting nursing home use, it is all going to be scrambled. The variables that you are using to predict nursing home use could all wash out because the dependent variable is different.

One thing is to first identify what that nursing home use is and then begin to establish different functions for predicting different types of nursing home use.

QUESTION: How might you be able to differentiate different types of reasons for nursing home entry?

KORBIN LIU: Diagnosis is certainly very important, I think. Basically looking at the 1977 NNHS per se, a chronic brain syndrome had a mean length of stay of about 750 days. Cancer had a mean length of stay of about 39. Diagnosis could be critical to predict long versus short.

You can look at those lengths of stay. About 15 percent of the people in 1982 spent some time in nursing homes between 1982 and 1984. Only half of them were still in nursing homes in 1984. We clearly had some short stay people in there between those 2 years. We can take a look at them, see what kind of diagnoses they had, see what the discharge status was and so forth, and then you get into identifying what kind of a stay it was.

CHAPTER III. OVERVIEW OF THE NATIONAL LONG TERM CARE CHANNELING DEMONSTRATION

George Carcagno, Mathematica Policy Research

I am going to give you an overview of the National Long Term Care Channeling Demonstration so you will have a better appreciation of the factors that shape the data base.

The Channeling data base was constructed with a focus on supporting the evaluation, and so it is very different from the other data bases we will be talking about.

A recurring theme that you will be hearing is that there is a tradeoff; when you look at Channeling data, you find a very comprehensive detailed data base. In exchange for that detail and comprehensiveness, we do not have a statistically representative sample. That is a shortcoming that you will need to be aware of when you use it.

Channeling was designed to test comprehensive case management interventions that were designed to provide community services to frail elderly individuals, and where an appropriate substitute for nursing home placements.

Two models were tested, the basic case management model and the financial control model. They differed with respect to their capacity to purchase services.

The case managers did not have control over medical or nursing home expenditures, so that the Channeling case management was a particular variant of a case management approach. It is not the only way you could do case management, and that is something that you need to be sensitive to.

Case management is not a well-defined concept. Everybody has something else in mind when they talk about it, so Channeling tested a particular version of case management.

The two models shared a set of common core functions related to case management: outreach, screening activity to determine eligibility of people who were applying, in-person assessment, care planning, the arrangement of services, monitoring the receipt of services, and periodic reassessment.

The basic model relied primarily on existing services that were available in the community. They had limited gap-filling dollars to actually purchase services directly.

Essentially they relied on what already was out there in the existing community care system in the way of services.

In effect, what we were testing with the basic model was the notion that the problem with the long term care system was that it was difficult for people to find their way through it; that with better information and more coordination of the existing service providers, we could provide services that would substitute for nursing home placements.

The financial control model was much more ambitious with respect to our services. There were substantial expansion of funds that were available to purchase community services. These services could be provided without any regard to eligibility for particular programs other than Medicare, which was not really a constraint. One did not have to be eligible for Medicaid, for example to receive the services.

The case managers could authorize the amount, duration and scope of community services. There were some cost controls built into the model. For the caseloads as a whole, the total community care expenditures for the entire Channeling caseload in each site was limited to, and could not exceed, 60 percent of the nursing home rate in each community. In fact, they came in well below that, around 40 percent.

There was also a limit on the costs for any individual care plan. That was set at 85 percent of the nursing home rate. It could not be exceeded without special approval.

We tested two models of the case management approach; one essentially just case management, and the other was case management plus greatly expanded access to community services.

We sought participants in this demonstration who were frail, elderly, and at risk of institutionalization. We wanted to get people who had multiple deficits, in activities of daily living (ADL) and instrumental activities of daily living (IADL) measures.

The demonstration was tested in ten sites, five for each model.

The demonstration began in early 1982, and we continued to collect data through the middle of 1984. We were interested in testing the effects of the demonstration on formal service use; that is, hospital and ambulatory care services, long term care services, and community care services. The impacts on individuals with respect to physical functioning, mortality, and well-being. We also looked at expenditures incurred by both, individuals and public programs.

Finally, we looked at the impacts on informal caregivers, family and friends that provided care to the elderly sample members. Here we looked at the amount of care that was provided, caregivers stress, well-being, and the amount of financial contributions they made to the elderly sample members.

A randomized experimental design was used, which meant there was random assignment to the treatment or control group in each model so that in the data base there are, the treatment group that actually received the Channeling services and control group that was simply interviewed, and other data sources were used for that group as well. In fact, the control group represents everybody else in the community who did not participate, and Channeling then was used as the basis for the comparison as to the effects of Channeling's impacts.

Several data sources were used. There were interviews with elderly sample members and their caregivers; a baseline interview and multiple follow-ups for the elderly sample members as a baseline, follow-ups at 6 and 12 months for everybody, and an 18 month follow-up for half the sample; and for the informal caregivers we interviewed a subset of caregivers for only a portion of the sample.

For the caregiver group, there was a baseline interview and two follow-ups at 6 and 12 months.

The data base is quite complex. There are numerous data sources and also it is longitudinal, so you need to pay some attention. It is not a simple cross-sectional survey.

The sample consists of people who applied to Channeling, and met the eligibility criteria. This was a highly disabled group; average age was about 80.

The Channeling project agencies, the sites that were responsible for conducting the demonstration itself cast a wide net to get referrals to the program, and so there were referrals from a number of health service providers. From hospitals, home health agencies, social service agencies, and a number of referrals by family and friends.

There was not a concentration of referrals from particular type or source. For example, referrals only from nursing home discharges or only from hospital discharges.

We examined several dimensions to see how our sample compared to a more representative sample of the frail elderly. One of the things we did was, to use the National Long Term Care Survey (NLTCS) to simulate the eligibility process and identity a sample within that nationally representative sample, identity the sample of people who would be eligible for Channeling, and then use that to compare the characteristics of that simulated sample to the characteristics of people who actually participated in Channeling.

We estimate on the basis of this simulation, almost 5 percent of the noninstitutionalized population over 65 would have been eligible for Channeling in 1982. If you look at the simulated national sample and Channeling, there is similarity as you might expect, given that we selected the sample on the ADL/IADL measures, there is a great deal of comparability in these measures.

With respect to the use of informal care, there is also a great deal of similarity across the two samples. Looking at things like percent who live alone, percent married, and income, we see that the Channeling sample tended to live alone. Fewer of them were married, and they had lower incomes.

The biggest differences were in formal service use. Keep in mind, we are talking about characteristics at baseline. That is, four people who actually participated in Channeling received Channeling services. This was the actual interview before the start of services.

If you look at formal service use, you see that the Channeling sample was about twice as likely to be receiving formal in-home care. More than twice as likely to have had a hospital stay in the last 2 months; almost six times more likely to have had a nursing home admission within the last couple of months; and about four-five times more likely to be on a nursing home waiting list.

Probably some triggering event led people to apply for Channeling in the first place, e.g., an acute episode. That event differentiated the people who actually came forward to participate in Channeling from people who had similar ADL/IADL disabilities and impairments, who were not participating in Channeling.

We also looked more generally at the socioeconomic characteristics of the aged and the sites that actually were in the demonstration. There we found that taken as a whole, the demonstration sites were probably similar to the national data. The only difference worth noting was that we had so many more Hispanic persons in the sample, and that was because of the Miami site's participation in the demonstration.

On most measures of income, age, and sex, the aged population in the Channeling site was quite comparable to the national aged population.

When you get down to looking at individual sites, the sample sizes are small, and you get much more variability at that level than you do when you use the data base as a whole.

Clearly, another thing we had to look at with respect to the issue of how representative this sample looks, even though it was not statistically designed to be a representative sample, it was designed to look at the service environments of the ten sites.

We looked at nursing home bed supply data. Beds per 1,000 people over 65 for the nation and for the Channeling counties, and we saw the bed supply in the Channeling sites was somewhat lower than the national nursing home bed supply; about 50 beds per thousand in the basic model compared to 57 nationally, and about 43 in the financial control sites. If you take Miami out of the financial control numbers, the financial control model is much more like the basic model.

On the basis of these bed supply measures, bed supply seems somewhat lower in sites than in the nation as a whole, although bed supply is the best you can do, but you have this problem of whether you are looking at demand factors, supply factors or what.

We also obtained information from people in the sites about waiting times for nursing home admission; and on the basis of that found that wait times were relatively short, except for Medicaid recipients. We had concluded that at least as far as the outcome of the evaluation itself was concerned, that nursing home bed supply was probably not a factor that affected the outcomes of the demonstration, whether or not it affects your research is something you need to keep in mind in your analysis.

We also tried to look at the availability of community services in our sites compared to the rest of the country. We found that there were not data available that one could readily find to compare the richness or the poorness of our service environments in the sites with communities around the country.

We do know looking at control group data at baselines, that there was substantial use among the controls of formal community services; 10-20 percent of the control group used case management services; and 60-69 percent used at least one formal community service at baseline. These variations depend on the model you look at.

There was clearly some substantial service use among control groups. We also know that sites applied to participate in Channeling; there was a competitive selection process. One could assume that the Channeling sites might well be more highly developed in the community service systems than other areas in the country, although I suspect that in large urban areas there is not a lot of difference.

That is a word of caution when you use these data to keep in mind the differences in environment and what effects they may have on your results.

To sum up, I think the Channeling data base can be very useful. You need to be aware of its strengths and weaknesses, however. It requires caution and good judgment when you use it. I think the leaps of faith are the kind we are all used to making when you do research in this area, when you combine the Channeling data base, for example, with other data bases. You are following in a long tradition of the way people have used demonstration experimental data from past studies, to do some estimates of new programs, new benefits, and so forth.

One strong advantage of the Channeling data base is that it incorporates a behavioral response to an intervention, and to the extent you are interested in similar interventions it can give you some idea of the response that you might expect.

In using the data for that purpose you are probably well advised to try and find other demonstration data to see whether you get similar results, put some boundaries around the results and maybe do some sensitivity tests. I think you would be well served by using the data base which is exceedingly rich and comprehensive.

SUMMARY OF BREAKOUT SESSIONS

George Carcagno, Mathematica Policy Research
Judith Wooldridge, Mathematica Policy Research
Thomas Grannemann, Ph.D., Mathematica Policy Research
Peter Kemper, Ph.D., National Center for Health Services Research

GEORGE CARCAGNO: Judith Wooldridge will be chairing the meeting. Judith was responsible for analyses of nursing home and hospital use, and also was responsible for the design and maintenance of the data base. Tom Grannemann, was one of the researchers on the project, and had responsibility for much of the analysis of formal community care costs and utilization. Also on the panel is Peter Kemper, who was the co-principal investigator of the demonstration, and was, I think, our leading intellectual light here. We owe him a lot.

JUDITH WOOLDRIDGE: As you all have heard, the Channeling evaluation collected data on an elderly, very fragile population who had applied for community service care in place of nursing home care. They were a screened sample who had to pass certain eligibility criteria. As you are probably aware by now, this sample is not nationally representative as a result. There is a lot of things about the way the sample was selected for the evaluation and decisions that were made in the data base with respect to the evaluations that you will need to know to make use of these data to get the maximum out of them.

Let me just reiterate a few points about the data base. The sample came from ten sites. We had two models: the basic model which provided case management, and the financial control model which also provided services. It was a randomized design so that we have a treatment group and a control group. There were over 6,000 members of the sample, so that 6,341 people were randomized into the research sample, and that is the maximum sample size that you are going to encounter in any of the data files.

I would also like to mention at this point that follow-up from the point when people were randomized was a maximum of 18 months. This is not a very long term data set. It is long term care over a short time period.

In producing public use files, we wanted to allow replication of the analysis that we conducted. This meant that all the variables used in all of our analyses are present in the files. That means if you read any of our reports and you want to use a particular variable that appears in the particular report, you can find that variable on the public use files. When we produced these files we did have to maintain the confidentiality precautions that were taken to protect our respondents. We did not do a great deal to these files, however. What we did was to delete obvious identifiers, such as names, addresses, Medicare and Medicaid numbers. We also deleted information about whether there was a legal guardian.

Other than that, we modified a couple of variables, the age variable and the ethnicity variable because you got into some pretty small cells in some sites, and we wanted to make sure that you could not identify anybody in our sample. We also deleted information about providers in the community, hospital and nursing home that we collected in the follow-up interview. That information is not in the data base. That is the extent of modifications to the data from the files that we used in the analysis to the files that are available for public use.

Regarding the sources of data for Channeling, we interviewed the sample members themselves, and they were screened to check whether they were eligible to enter the program. They were assessed within a very short time period of their screening, and there were then follow-ups at 6 month intervals so long as we could trace them up to a maximum of 18 months. Part of the sample has follow-ups for 12 months, and part for 18 months; that is, those people who came into the sample sufficiently early, in the first half of the intake period, have follow-ups for 18 months.

We also interviewed caregivers of sample members. The primary caregivers at the baseline, at 6 months and 12 months. Other data sources included the client tracking file that each of the ten Channeling projects set up in conjunction with Mathematica Policy Research (MPR). With them, we designed forms that could be used to track the clients and all the information on all of the clients who came into the program throughout the intake period are available in that file.

There was another source of information--provider records, which we used to collect information on formal community services. In addition, we used provider records' extracting processes to pick up some hospital and nursing home data, although that was not the principal source of information for those types of data.

We have Medicare claims data and Medicaid claims data from each of the ten states that the sites were located in. Those claims cover all the services provided by Medicare and Medicaid in the appropriate jurisdictions.

The financial control model sites had information on service use by their clients that had to be supplied to Health Care Financing Administration (HCFA), and we used that information for the prime community service estimates of service use. In addition, we have one other source of data which was death records. The population was very fragile and had a very high mortality rate. Whereas, we did find out that some people had died when we tried to do follow-ups. We collected death records from each of the ten states to insure that we knew whether or not people were alive at the end of the 18 month period. Of course, we got death dates, which allowed us to know when they died in relation to their randomization date.

There are 14 data files which constitute the Channeling data base for the public use file data set. Those files are documented in 11 separate volumes.

In addition to the detailed documentation there is a short introductory volume which explains what data files are available and, in general, describes what is in each data set.

There are three types of data files in the data base. There is what we call source files, and by that, we really mean files that are based upon an interview or an instrument. There is a file based upon the screening instrument; there is one based on the sample in the baseline; and there is a file for each of the sample member follow-ups, the caregiver baseline, the caregiver follow-ups and the client tracking form. Those we call source files.

We also have four files that we used based upon the sample member follow-up for informal care analysis; there is a formal community service file; a file with hospital, nursing home and other medical service data; and a file on the quality of life. All of those are analysis files. Finally, there is a status file, which does not contain much substantive information as it is just a file to tell you what is in the other files.

The key features of the data base is that this is a system of files, and individuals showing up in one file will generally show up in another file, as well, subject to sample limitations of particular files. You can link any individual across all of these files by means of an ID number which is, in fact, the first variable in the file.

It is important to note that there are different samples in each file. I will talk a little bit about the samples in a moment just to give you a notion of why they are different. Within a given file there may be sub-samples, because we always included the maximum number we used and then if there were sub-samples used for the analysis, we have identified those with special sample flags.

All of these files contain some basic information, like the ID numbers, the site, the treatment, the status of the respondent and the model. All but two of the files, exceptions being the status file and the client tracking file, contain a set of variables that we used throughout the final analysis. We used the same set of control variables across all the substantive areas of the analysis and we included those in each of the files except the two I mentioned.

There are three caregiver-based files which contain an equivalent set of standard control variables based upon caregivers.

All of the files which are based upon instruments contain all of the variables in the instruments and some constructive variables, certain subjects, the fact that we have deleted certain operational variables arid, obviously, confidential variables.

The analysis files contain all the dependent variables we used on our analysis so that you can identify those and use them if you wish to. Let me just talk quickly about the types of samples.

As I mentioned, there were 6,341 people in the research sample. All the files contain subsets of that 6,341, with one exception which Is the client tracking file which does not include any of the control group. It only includes clients, and it includes clients who were not in the research sample. People who entered the program before we began randomization; there were a few of those, and quite a number of people who entered the program in the year during, which the program was running its steady state who were not included in the research sample. That is a special and different sample in that one file.

Other than that, we have a variety of samples used for different purposes. To the extent that we could, we maximized sample sizes. We also tried to make them equivalent to cross-analyses as much as possible without throwing away data points. There is some special aspects to some of them. The screen file contains 6,326 sample members, 15 less than were in the research sample.

The baseline file is a subset of that group. It is all of those people who were screened who had a baseline. The follow-up file is a subset of that. It is all those who were screened who had a baseline, a follow-up and so forth. The sample sizes do get smaller and for some special purposes the sample sizes can get very small, indeed, which I will talk about as we go through the individual files.

The purpose of the screening instrument was to assess people to determine if they were eligible to participate. For that reason it has information on functional status, ADL and IADL measures, fragility of the support system, unmet needs, and so forth. It is a fairly brief instrument but it is available for everybody who is in the research sample. The screen file includes all the variables that are on the screening instrument. Let me just indicate to you that the documentation includes the instruments where it is an instrument-based file.

The sample baseline file was administered as soon as possible after individuals had been screened, found eligible and randomized. There are two things to know about the baseline file. First of all, that there are two different versions of the baseline we developed; one for use in the community setting and one for use in the institutional setting. We have quite a few people who were getting ready to leave an institution and go back into the community, so we developed two instruments. You do not have to worry about that in using the file. We have taken care of that for you as much as possible by making a set of joint variables which are available from both sources. There are a few variables that were available from one or the other sources, and the documentation does indicate that.

The only thing you need to be aware of is that the baseline instrument was administered differently to the treatment group and the control group. The treatment group had their baselines administered by the case workers or the assessment group, whereas the control group had their baselines administered by MPR interviewers. All of these people who administered the interviews had some training. It was felt for clinical reasons that it is not good to have the client group baselined by their case manager in the project.

The baseline is an extremely rich source of information about functioning, health status in the period before enrollment, informal caregiving, financial resources, demographic factors, and unmet needs. The sample size for that file is 5,626. That is a large chunk of the group that was screened, though some people refused to be baselined after they became sample members who were randomized into the sample. That is the main reason for the discrepancy between the numbers in the screened sample and the baseline sample.

The client tracking status change file is a special file that was developed for administrative purposes. The sites used the client tracking forms to keep track of where the individual clients were in the process, and then they filled out status change forms every time the person moved between statuses. People were allowed to become inactive, although we later modified that and they only allowed to move between active and terminated. They could be reactivated. The file does not have a lot of information on anything except changes in status and elapsed time between screen, baseline and between baseline. MPR used those forms as they came in to monitor the state of the program. It is very much a process file.

There are three sample member follow-up files. There is one at 6 months, at 12 months and at 18 months. They contain the same information; that is, the questionnaires were identical so that you have the opportunity to look across three points in time and look at the same information for a given individual. The purpose was to find out what kind of outcomes were developing for the sample over those three time periods. There is a lot of information in there. We have information on insurance coverage, health status, housing conditions, expenditures, transfer payments, services, in-home service use, formal community service use, hospital use, nursing home use, well-being of the sample member, income, assets and functioning. The three files each contain 782 variables. Almost as many as the baseline file and covering very much the same kinds of information that was in the baseline.

This file contains all of the variables in the instruments subject, with of course, operational variables and confidential variables taken out. Variables that we constructed for the purposes of particular analyses from these follow-up files are to be found in the analysis files rather than in the follow-up files.

The next file is the status file. The information in here that you might need to use is all the sample flags. It tells you for a given individual which of all of the many samples we developed and the sample member falls into. It also includes information obtained from the death records and information that we collected on Medicare and Medicaid entitlement from HCFA and from the Medical Assistant Bureau in each state. In addition it has information on when instruments were fielded.

The next two sets of files related to the primary caregiver of sample members. We did not initially have a plan to interview caregivers, and so we did not actually start interviewing caregivers until some months after the intake period began. In March 1982 is when we first started taking sample members in and we took sample members into the research sample for the following 15 months. It was not until November 1982, some 8 months later, that we started the caregiver baseline survey. The follow-up started 6 months after the baseline. That means that we do not have the opportunity to have as large a sample for caregivers as we do for sample members. Information was collected on only l,919 caregivers who were baselined. There is another reason for that, which is that not all sample members indicated that they had a primary caregiver. We only went through an interview if they said they had one.

The caregiver instruments, the baseline includes information on the services they provide the elderly sample member, the financial contributions they make, economic and family behavior, and psychological and social well-being of the caregiver. You will recall that psychological and social well-being of the sample member is available from the sample member baseline and follow-up instruments. The caregiver follow-up occurred at 6 months and 12 months, and the purpose of these instruments was to assess the impact and collect information on the impact of the program on the caregivers themselves. The questions, therefore, focused on care provided 6 months and 12 months after randomization. Care provided by people other than the primary caregiver who was being interviewed, other people who provide care to the individual. The financial contributions, information about institutionalization and formal service use, and one important use of the caregiver follow-up was that in most cases where the sample member had died when we went out to do a follow-up, if there was a caregiver, we asked that caregiver information about service in the period prior to their death. In this way we were able to pick up a lot of extra information that we would otherwise not have had on formal community service use and nursing home use.

Of the remaining four files, that I just want to talk about fairly briefly, the first one is the formal community service file. This file includes within it a number of samples, and it is probably the most complex of the files in that respect. We have samples in there used for some purposes and larger than samples we have for other purposes. For example, based upon the sample of people with follow-up instruments, we have a follow-up sample with a lot of information on community services. We also have provided a records extract that we collected on formal community service use, but only for 20 percent of the sample, so that we have a very small sample of people, relatively, with fully detailed information on service use collected from providers. We have a much larger data set available on service use than the sample member was able to tell us about.

Anybody who has any questions on those samples in the formal community service file, you should raise those with us. I do not want to go into too much detail now.

I do not want to scare you off, but just to say that there is a set of, for the most part, nested samples. You are not going to get all the data on all the sample members that are in that file, although there are about 5,600 sample members in the file. They do not have all the data. It is a very detailed data set. It drew on the provider record extracts. We also did some surveys of individuals who were privately contracted by the household to provide services to the sample members. We have information in this file from the financial control model sites on service use provided by the projects. In addition, we have all of the information on community service use under Medicare and Medicaid that we drew from claims data. The file includes information on use of all major community services and expenditures for those services by funding source. I should mention that this file also contains information on case management, housing and transfers, which used slightly different samples than the other formal community service analysis, but the individual for whom there are full data are flagged in the file.

There are two things that I would like to mention about this file at this time. One is that the file is organized based upon the 6 month follow-up period. For example, we have data on community service use and expenditures over the period 6 months from randomization, that is from randomization to the first follow-up. Then we have information for the next 6 month period, from the beginning of the 7th month to the end of the 12th month. What the file provides is information on service use within that 6 month period. There are also some data on a snapshot period that occurred just before the follow-up instrument. That is the information that is available for the larger sample and the data for the whole 6 month period is available for a smaller sample.

The other thing I should mention is that expenditures data has been standardized and regardless of when the actual expenditure occurred, we standardized them to a February 1984 expenditures rate using price index information. From your perspective you do not need to know when the sample member received those services because across sites and everything, they have all been standardized.

I would like to just skip over the informal care analysis file and talk about the hospital, nursing home and other medical service analysis file. It is has some things in common with the community service file. For example, the data are organized in 6 month blocks the same way that the formal community services are arranged. It has many of the same data sources. It is based upon Medicare and Medicaid claims augmented by provider record extracts for those individuals where we felt that for one reason or another Medicare or Medicaid was not going to provide a complete source of information. Without going into it, I should explain that we reviewed everybody's Medicaid eligibility and how long they have been eligible to determine whether or not we felt that Medicaid was going to be a complete source of nursing home use, for example, that being a primary payer of the nursing home.

We assumed that if we had Medicare information on hospital use we had pretty complete data. We also drew on information in the sample member follow-ups and we also, when necessary, used the caregiver follow-ups for those sample members who were deceased in order to prompt provider record extracts or find out about service use in some other fashion. This file has information on hospital use, nursing home use and other medical services, such as physician services, and so forth, anything that was available to use from the Medicare and Medicaid files on other medical service use.

There are no stay data as such on this file. If you want to know when an individual went into a nursing home and when they came out, and when they went into a hospital and when they came out, and so forth, changes of that kind you can not tell from these files. What you do know from these files is how many times a person was admitted to a hospital or a nursing home, and how many days they spent in a hospital or a nursing home. Also, there are binary variables indicating whether or not a person did have any use, in addition to how many times they had an admission or a discharge.

Let me go on to the informal care analysis file. This file is based upon the sample member follow-up interviews that provides information on informal service provision by caregivers. Rather than coming from a caregiver follow-up, it comes from the sample member follow-up. There was quite an extensive data collection on informal services in the follow-ups, and all of the analysis variables that we used, rather than putting them in the follow-up file, they appear separately in this informal care file.

Anyone who wants to look up both formal and informal services would have to look across and merge files. As far as we were able to, we did try and make the variables very similar, compatible between formal and informal. We asked the same types of questions whenever we could, and we have coded up the variables in the same kinds of ways.

Finally, there is a file that was used to analyze the quality of life of the sample members. Again, this is based on the sample member follow-up interviews, and it includes information on satisfaction with care, social and psychological well-being, and functioning of the sample member at 6, 12 and 18 month intervals.

QUESTION: Are there any data on the use of home care devices?

JUDITH WOOLDRIDGE: Tom can correct me if I am wrong, but I believe the only information we have would be on durable medical equipment from the Medicare home health service claims and if there was anything equivalent, from Medicaid.

THOMAS GRANNEMANN: You should have an indicator of whether durable medical equipment was used and also the Medicaid and Medicare reimbursements for those. No indication of exactly what type of equipment or any detail on when precisely it was used except in these 6 month periods.

PETER KEMPER: There are also some interview questions. I doubt they are at the level of detail that you want, but surrounding the disability measures. For example, when they asked about incontinence, I believe there is a response about help with a device. There is also an interview question on equipment such as whether the person received any special equipment such as grab bars, that type of thing. Probably the best thing to do is once you have got that introduction, to actually go and look at the report that Tom worked on about home care, and look to see what variables were analyzed and then go look at the instruments to see what is there.

QUESTION: I am particularly interested in who used hospitals, who used nursing homes, and whether you have any measures of acuity, I know you have measures of chronicity and disability, but are there any measures of acuity from a medical point of view? What do you know about their diagnoses? Do you have anything on multiple hospitalizations, or if people used hospitals and nursing homes?

JUDITH WOOLDRIDGE: For each of the individuals in the hospital and nursing home use file there are measures of whether or not they used a hospital, how many times they were admitted in a 6 month period, and how many days they were in the hospital. There was also information available from the baseline on service use prior to enrollment and we do not have any diagnostic information on these individuals. What we do have is measures of functioning, both at baseline, and if you are interested in looking at functioning at the nearest 6 month time point, you could use the information from a follow-up interview to associate it with hospital use in a subsequent period or previous period, depending upon what the question was. You can tell, indeed, whether somebody was a multiple user from this file. It will tell you how many times a person was admitted over three 6 month periods.

QUESTION: Do you have any mental health measures?

JUDITH WOOLDRIDGE: This is an area where we do not have a great deal of information.

There is a measure in the baseline of people's mental status, what we call the portable mental status questionnaire. I do not know if that is a generally used term, but it had ten questions and the individuals were asked the questions, the question is how many they got right out of ten, you estimated them into the status on that basis. That, as far as I recall, is the only information we have, excepting that the Medicare and Medicaid claims files may in some cases have had information on personal counseling.

PETER KEMPER: There is a response on whether somebody received in-home mental health counseling and almost no one did. Also on the screen there are one or two questions on behavior problems and orientation of some clients. There is some measure on the caregiver interview of whether the person needs supervision or not. That is for a limited sub-sample who received that, for whom there was a caregiver interview.

One person you could talk to about the mental health measures is Korbin Liu from the Urban Institute who is doing some research in the area related to cognitive impairment and Alzheimer's, and is using the Channeling data.

QUESTION: I was wondering about the degree to which formal care substitutes for informal care over time. Are we loading up the system with the formal side on top of informal care?

Also, you have the 6,341 cases across ten sites in two different groups. Might the ten sites differ, like on a variable such as ethnicity, for example? Would it be useful to do any kind of comparisons across sites, saying that environments, indeed, are different. Might the population profiles be different except for a question of fragility?

GEORGE CARCAGNO: You can, indeed, look at issues of formal and informal care, and the possibility of substitution effects, that was one of the analyses that was carried out as part of our research. What I suggest you do is, start with our report on informal care and the substitution issues, and decide whether there are questions beyond that you want to address.

With respect to the comparisons across sites, there is a little supplementary report we did that has characteristics data by site. We did not do any impact analysis by sites. We did do some formal statistical tests to establish that, in fact, we could pool the data within models.

First of all, the story does not change a great deal across sites, so that we were not in a situation where when you aggregate up the results you have offsetting effects at different sites. We also tried to look at the sites and explain what differences did exist in the outcomes. That just proved to be a very difficult thing to do, because there was so much going on. There are so many differences. We had hypotheses, for example, about what you might expect to see in rural sites, and then you would find that would be true in Kentucky but not in Maine. In Maine, there was something else going on. It gets to be very difficult to go down and try to do any careful analysis or an analysis they have a lot of confidence in at the site.

QUESTION: I was actually interested in the ethnicity. That was the one I was most concerned about, not urban and rural.

JUDITH WOOLDRIDGE: You could look at ethnicity if you wanted to across sites. It does vary across sites, as you would expect. There is a big variation.

PETER KEMPER: I think those three questions illustrate an important point. This is a very rich but complex data set, and one that requires a commitment to use. If you write for the documentation, I do not know if it was absolutely clear or not, but you do not get one stack, you get twelve stacks. Finding your way into the data takes a commitment.

Each of these three areas, the site difference, the substitution of paid formal care for informal care provided by family and friends, and subgroup differences were the subject of a report that was part of the evaluation. There is not only this documentation, but there is a series of technical reports that we and others on the team did as part of the evaluation. We invested a fair amount of energy in documenting what we did and giving a full explanation. I think for people who have a particular area of interest, you should get that report and the executive summary of the evaluation.

QUESTION: One of the things that bothers me about channeling is that it was oriented toward a frail population. Is there another report or other studies that have been towards less frail populations? Has there been cross-analysis comparing the results at all?

PETER KEMPER: I guess, there are a couple of levels to respond. There have been other experiments like Channeling that served less frail populations. Quite a few of them, actually. There are reports available of those and some reviews. I have recently completed a review. If you will write to me, I will be glad to send you a copy of it.

The second level is what use is the Channeling data if given that we know it is made up of people who came to a program to get community services. They are not the same kind of people who would buy long term care insurance. It is probably the only data set that has such complete longitudinal data on service use at home, nursing homes, hospital use and expenditures.

THOMAS GRANNEMANN: I do not know if you or other people have talked about doing this crosswalk between this and the NLTCS data, where the NLTCS, at least in the screening, represents a broader population and this is a group of people who are users. They would have to see the Channeling data as representing a person, once he is in need of long term care, this is what the pattern would look like. The population is not going to be exactly representative of what would be under an insurance plan. It would provide a good indication of use patterns conditional on disability. You will have a lot of information on ADL and IADL that can tell you at a certain level of disability what are use patterns. We have got a separate analysis that breaks it down by ADL and IADL impairment. That can give you a good measure for any subgroups of data sample, what their use pattern is likely to be.

QUESTION: What can insurers learn about the case management results from channeling, both the positive and the negative?

JUDITH WOOLRIDGE: In our analysis we were interested to know whether case management would, indeed, save funds by keeping people out of expensive nursing homes and even out of hospitals to some extent. Our findings were not all that good on that point in the sense that the program cost money and did not save money, really. The actual nursing home use was extremely small, barely significant. We think that there was a slight effect, but it was one that we had to talk about to decide whether we thought there was an effect. The program did not keep people out of hospitals or cut hospital costs at all. I think if you start with our final report on the costs of the program and read it, that is a good place for you to start.

QUESTION: Do you have any suggestions as to what could have made it more effective?

GEORGE CARCAGNO: Let me just respond to your earlier question and then I will respond to that one. In the information on cost of case management for both of the two models, that information is available. There is also a qualitative report on the planning and operational experience of the demonstration that provides some descriptive information about the case management that was delivered and what kinds of people were involved as case managers and so on. That is another source of information about the case management that you might want to take a look at.

There are a lot of ways you can do case management, including having control over medical and nursing home expenditures, as well as just community care. This was a particular brand of case management and, of course, there is a demonstration that is going on now looking at social health maintenance organizations (HMO) which have much more control over the whole range of services. We still await the evidence on that.

As you look at the control group utilization of nursing homes, there was much less nursing home utilization than we had expected, despite the fact that we set out to identify people who we thought were at risk. I do not think we know much more today about how to identify those people than we did then. I think if we started out today to identify this population, we would probably do just about the same thing we did. The population made much less use of nursing homes than we had expected. It is very difficult to say that if we had done the case management differently we would have had different results.

I also find it difficult to know how to target better and come up with a different population. The problems in this kind of program are that it would be very difficult to identify people who if you didn't do anything would go into nursing homes and not get into your program, or people who, even though you did not give them services, would still stay in the community on their own. That is a problem, and I do not think we know how to do it presently.

PETER KEMPER: It seems to me that in the Channeling evaluation, the question it addressed is different from the question you would address as an insurance carrier. To me, your question is, if we had somebody entitled to a benefit, what is the role of the case manager in dealing with that client and in controlling costs? The results of Channeling may be somewhat relevant to that, but the real implications for you have to be drawn out from the experience, the whole set of information on operational experience that came from Channeling and the many other instances of case management that have been tried are very useful. If you wanted to think about what is involved in case management and what the functions are and what kinds of staffing is required to provide that case management, I think the implementation report that George and others did would be very useful to look at in order to understand that.

Certainly you would want to know what it costs to provide a case management service, at least one version or another. There is a report on the costs which actually compares Channeling to some other demonstrations and gives you some idea of what the costs and the caseloads are. Jerry Eggert has been heavily involved in case management. I would certainly talk to him about their experience with the costs of frequent screening of clients for eligibility because one issue is how often do you screen. I think there is some implications to be derived from the Channeling experience on that side of the demonstration.

Also, there were some findings in Tom's community service report that have to do with the effects of case management on the mix of services, with some suggestion that case management resulted in the substitution of lower cost services for higher cost services. In the Channeling context that was more than offset by the increase in services because of the expanded benefit. Given that somebody is entitled to a benefit, then you want to ask does a case manager substitute lower cost for higher cost services. There is some evidence on that you might want to look at. Also, the question of reimbursement rate. There was some experience in the demonstration in negotiating for rates which, once somebody is entitled, you control the rate that is paid. There is some evidence that Channeling was able to get a lower rate than people who were not in Channeling. That may have attributed to buying power or competitive bidding. There is some information there, again, in the implementation report that may be of interest.

THOMAS GRANNEMANN: One of the results of Channeling was to show the people to some extent greater satisfied with service delivery in a case managed system and even showed an impact on some of the quality of life measures. From an insurer's point of view that might mean that is a service people may be willing to pay something for, even if it is not something that saves costs. The other thing to keep in mind is, when we looked at impacts that compared Channeling to the existing case management system. In fact, many of the people in the control group got case management of some form, although not nearly as extensive as Channeling did, through arrangements with home health agencies who do some case management and many other social service agencies that are out there providing services. We do not purport to this is Channeling's impact or what case management does, but really it is an increment in what a couple of case management approaches does.

PETER KEMPER: We probably do not need Channeling to tell you who pays first is an important issue.

THOMAS GRANNEMANN: Indeed, also focusing on the nursing home costs a little bit from the targeting perspective, there was some evidence, although not strong evidence, that people who are already in a nursing home or are waitlisted for a nursing home would be the group most likely to show a reduction in nursing home use. There is also some evidence that to the extent that those nursing home costs were reduced, it is the private pay dollars more than the Medicare or Medicaid dollars that are reduced.

QUESTION: Are there any quality care measurements, such as would people get better nursing home care under case management than not?

PETER KEMPER: There is a self-report data on satisfaction with care arrangements. Uniformly, whether it is the respondent or the impaired elderly person or the informal caregiver satisfaction was increased for the Channeling group.

QUESTION: I am a nurse educator in gerontology at the College of New Rochelle. I am interested in how you selected the population group of frail elderly. Perhaps, in talking about cost-effectiveness, why you did not just select a group that possibly was just 65+ who were in need of comprehensive case management, because the elderly themselves, even when they are not frail, need to have a comprehensive kind of health care management.

GEORGE CARCAGNO: As Peter had mentioned earlier, Channeling was not the first demonstration to look at the issues that we addressed. Some of the demonstrations that had come before had a much broader approach to the population it served. Some attempted to target on people who were at risk of institutionalization. Others did not have as stringent a set of targeting criteria. It was largely on the basis of that prior work that we came to the conclusion that if you are interested in designing a demonstration that has some shot at reducing the costs of long term care that you had to target on a frail elderly population that was at risk of institutionalization. The view was that if you provided services to a much broader group of people, you are basically adding services to the system without getting a corresponding or greater reduction in nursing home use.

There is the social HMO demonstration that is going on now. From time to time people talked kind of wishfully about looking at the Medicare/Medicaid data for the people who were in Channeling to see if anything has changed over the longer term. I do not know if that is going to happen.

THOMAS GRANNEMANN: There is a congressionally mandated study on Alzheimer's, but that is still ahead of us.

QUESTION: The obvious thing is, in terms of preadmission to a nursing home list, take people who have actually signed up to enter nursing homes, or who are in for the first 90 days, and then try to see whether or not in the services that we provide along with case management would have an effect in reducing their use of nursing homes. We have not followed up with the second round of demonstrations that what we have learned from Channeling, and applied them to the next round to see what happens if you found people were actually about to enter. I know in Rochester it is a 6 month wait for people to get into a nursing home, You sign up and there is a waiting list, depending on what your payment status is. It could be anywhere from 6 months to a year and a half before you can get in. That to me is a real key group because they have already decided to go in and they may look the same as a lot in the community who have not decided to go in.

Maybe we are not looking at the right measures to predict who will go in. Maybe looking at the ADL and IADL is not enough, but we need some measures of acuity, which we really have not done.

GEORGE CARCAGNO: Regarding the measurement technology we have available to try and identify this at risk group, we do not have well tested measures. We took our best shot it may be that the measuring technology is flawed and that we need to do something more there. I do not know if there is any work going on in trying to move that along in a serious way. I am sure some people are working on it.

In South Carolina, [with preadmission screening] they got much higher incidence of nursing home use in the control group and with that they broke even. They did not save money. My personal view is that thinking about community care as a way to save money may not be the way to think about it. Figuring it in terms of taking care of people where they prefer to be taken care of; recognizing that it costs money and seeing that people seem to be better off and they prefer it-maybe it is worth doing. Hanging our hat on costs savings as a justification may be very tough to carry through.

QUESTION: I realize it is hard to sell community care as a cost saver, I am not interested particularly in what is going to happen today. I am interested in whether I have to build another 40-50 percent of my nursing home capacity in the next 10-15 years. The issue is whether it is worth the expenditure to expand the community care system, build these new nursing homes, or a combination of both. In New York we have taken a deliberate policy decision not to build nursing homes. At this point what we would like to do is design a system that provides community care at least at the same level of expenditure, hopefully less than that. The cost analysis debate is always nursing home versus home health today. The real issue is how are we going to expand the nursing home, in what proportion are we going to expand the capacity, because we know we have this increasing population. People fall to think about the future sufficiently.

THOMAS GRANNEMANN: On the issue of predicting who will 90 into a nursing home, we did a follow-up study to the Channeling evaluation that, among other things, looked at using the Channeling set to try to determine the predictors of nursing home use. We are able to identify a number of significant predictors of nursing home use. The problem is, however, that the percent of the variation explained is not very great. You can identify a lot of things that would predict nursing home use, but you can not be very good at predicting who will go in and who will not. There are a lot of unobserved things that determine who goes in. Maybe people rapidly deteriorated in conditions that we were not able to observe when we did our baseline, so it therefore was not a predictor for our point of view. There may be other factors that are not observed that the methodology for measuring ADL and other things; it is just not very precise. You can, with the data set, identify predictors of nursing home use, but those predictors are not sufficient to have a high predictive power to explain who goes in and who does not.

PETER KEMPER: This was billed as a data conference and we probably should make sure that those of you who have questions about the data, specifically, or perhaps are thinking about an analysis and would like to get a reaction about whether the Channeling data are appropriate for that, that you get a chance to ask those kinds of questions. Maybe just by showing you that stack of documentation we have discouraged you altogether. It is doable. One positive thing about that stack of paper is that it is documented and Judith deserves the credit for that. That is not true for all data sets.

JUDITH WOOLDRIDGE: I would just like to tell you a little bit about that documentation that I did not do earlier. If you are encouraged rather than discouraged, each of those files that I talked about earlier is documented quite thoroughly, I believe. There is an introduction to each of the reports which just gives you a little background. There is a narrative description of the file, the kind of variables you could expect to find in there, the sample, and so forth. The guts of each volume of documentation is a file layout that tells you what variables are present on the file. Then there is an annotated instrument for those files which are instrument-based, and the instrument is annotated with the variable name annotated in the file. That makes it easier to find the variable when you want to use it.

Every single variable that we constructed for use in the analysis is documented, and the algorithms we used and the kinds of sample flags are documented, how we selected the samples, and so forth. There are descriptive statistics in the documentation, and the first thing that you would want to do if you did get one of the files is to run a couple of those, make sure you come up with the same numbers shown In the descriptive statistics. Of course, there are the physical specifications for how to read the tapes. There is some conventions that are common across all the files. Every variable in the file has a name, and the name indicates the source of the variable. If it is from an instrument, the question number is part of the name. If it is a variable that is constructed from various sources or across questions, it has a kind of a little name that is supposed to mean something, constrained by the number of letters available.

There is a report on survey data collection design and procedures, it is one of our final reports prepared by Barbara Phillips and others, which, if you are thinking of using any of the instruments, is very useful. I would particularly recommend that if you are thinking of using the caregiver files, because the caregiver files have some curious things in them in the way the sample was developed which you will be able to understand better if you have read the fielding procedures manual.

PETER KEMPER: If you were particularly interested in the hospital and nursing home use data coming from Medicare and Medicaid claims, that is documented in the hospital and nursing home use report.

QUESTION: I have a data related question. I know that there is a difference between sites.

My question relates to variations between sites. I know in Florida they have about 23 nursing home beds per thousand over 65, wherein Rensselaer, one of your sites, where they have 60-70, among a 3 to 1 difference in the nursing home bed supply. My question is, does not it indicate that there is a different risk factor of entry in a nursing home if you have a big supply difference? It is the same thing on the hospital side, there is a big difference in the hospital beds per thousand. I am sure the AAPCC, I guess, in Miami is almost 200 percent of the national average, whereas in other places, like in Rochester, it is going to be 70 percent of the national average. The probability of getting into the hospital is much less in Rochester but more in the nursing home than it is in Florida, just vice versa. How could that be accounted for in the analysis or in the data?

THOMAS GRANNEMANN: In the analysis, we have controlled for site differences, although that was done simply with site dummies, so you can control for differences. In doing analysis with the files, you are able to control for differences across sites. If your question relates how well can you learn something about how variations in nursing home supply affects outcome, the short answer is, we only have ten sites, so you do not have very many observations on which to see what effect supply has. We did, however, look at that issue by replacing the set of site dummies we used with variables representing nursing home waitlists, patterned in the levels of use of community-based services in the sites, and did not find any significant difference where nursing home waits were high and low. Because there are only ten sites, we did not have very much power to detect such a difference.

JUDITH WOOLDRIDGE: Just as an aside, we were interested in the extent to which hospital and nursing home use might substitute for one another because of accessibility. We used that as a dependent variable and we did not have any difference between the treatment group and the control group when we looked at either the hospital or nursing home use variables.

QUESTION: In the sites that you studied, did you collect any information on supported housing that is available, such as board and care alternatives?

PETER KEMPER: As part of the interview, we collected self-report information on where the person lived. That included whether or not they were in supportive housing. That is available. There were also provider records collected from personal care homes. I do not know exactly what from that got on the public use file. Craig Thornton looked at those housing arrangements at MPR. In the report there are data on how many people were in supportive housing, how many people were in housing with congregate meals, and some information on costs. In general, the community data were of two sorts. One were data that we obtained from published sources that were available at the local level. In some cases we relied on state data. The second category was data that we collected in implementation interviews that research staff did on the sites. Those are documented in the process reports. I do not think there is anything particular on supportive housing in that.

There may be something in the interviewer training manuals, because they did do some inquiries in order to help the interviewers figure out whether someone was in a personal care home, I believe that the survey staff collected information on what personal care homes were in the community, at least what the main ones are. It's not like a data file or anything like that. It would be in memoranda.

JUDITH WOOLDRIDGE: The information on use is in the formal community services file on supportive housing and personal care homes.

QUESTION: Can you describe the selection procedure for the provider extracts? The 20 percent sample and the 10 percent sample, and cross validity checks between self-reported service use, the provider extracts and the Medicaid data that you have?

THOMAS GRANNEMANN: The 20 percent sample is simply a random sub-sample, for which we have the most information about community-based service use. In that sample you have got information from individual interviews, information from Medicare and Medicaid records, and extracts from the provider. Medicare and Medicaid records provide comprehensive information on the use of community-based services for those covered by those two payment sources, but obviously we omit a very important piece of it. The individual interview data was collected in a little bit different way, because the individual interview focused on a 2 week period that does not correspond directly to the period of observation for the Medicare and Medicaid records. We asked people what the caregiver did from the individual interviews where they said what this caregiver did, and they checked off a list of items that they did. We were able to identify from what the individual reported that the individual did and we were able to classify people, as whether they provided medical care, personal care or housekeeping type of services. That did not necessarily relate back to what we find in the provider records extracts where we have the provider's identification of what that caregiver was. For the provider extracts, obviously, if people did not identify a caregiver they will not get picked up in there, so there is a little bit of slosh back and forth there. In general, the impacts that you estimate across the data sources were consistent.

QUESTION: In extracting the records, was it only service use, or did you extract any kinds of clinical information?

GEORGE CARCAGNO: We did not get any clinical information. It was service use and basically, cost and billing records.

QUESTION: Is the bill in code?

GEORGE CARCAGNO: It is not a code. Those records were extracted according to our procedures, not a special system.

Keep in mind that most of the providers we went to, were filling in what was not available on Medicare and Medicaid, so a lot of them were community service providers rather than medical providers. Nursing homes were covered as well as community service providers of various kinds.

JUDITH WOOLDRIDGE: In case there is any confusion, let me add that there are two kinds of provider record extracts. There was a 20 percent sample of the full research sample for which we did provider record extracts for community services. We also used provider record extracting of hospitals and nursing homes for those instances where we felt, that the Medicare or Medicaid files were not going to provide us with the information we needed for eligibility reasons. For those, which we call provider record extracts by exception for hospital and nursing homes, that was not the particular sample. It was purely based upon the individual case. If the individual had a hospital or a nursing home use and we did not think we were going to get this information from the claims, then we went out and did a provider records extract.

GEORGE CARCAGNO: What that means is that for nursing home use, basically, for the whole sample you would have all payors for nursing home use and use under all payors, both public and private. For the community services, you would have Medicare and Medicaid payors, and for the financial control model of Channeling services that those payors covered, which are clearly not all home care. For this 20 percent sample, it drops to 10 percent from the 7-12 month period, and it was not continued after 12 months, you had the other payors and the other home care services. Provider records extracts differ between the home care services and the nursing home and hospital services.

QUESTION: Describe your procedures for missing data and whether those were constant across all your files and across the variables, and how that affects merging files.

As one example, if you had for members of your sample omitted data on particular items and functional status, you could estimate either by regression of everything else that you have what that would be, you could plug in a sample mean, you could just simply throw the person out for that particular variable, obviously with different implications as to how you can merge variables.

JUDITH WOOLDRIDGE: We did various things. For our standard control variables that we used in all of our analyses and all the substantive areas, we were concerned not to be throwing out cases because they were missing important standard control variables. For that reason we sometimes substituted screen data for baseline data and vice versa when we were trying to create those baseline variables. We did in a very few instances use procedures like means, I believe. That was a very infrequent procedure. Generally speaking, we only used data that was there. For particular analyses, people may have done one or two extra things. By and large, if an individual did not have the data that we needed they are coded missing and they are dropped from the analysis. As a result you will see that different analysis samples which are basically drawn from a kind of specific sample will vary in sample size a little bit because one of the dependent variables was missing. Obviously, we never substituted any information if the dependent variable was missing.

PETER KEMPER: I think it is important to distinguish between source variables and constructed variables. With respect to source variables, we adopted a principle that we wanted to provide the raw data. The source variables, I think with the exception of confidentiality procedures are as they were reported.

There were range checks done as part of the initial data cleaning procedures, and you can look at those to see if there is anything that you would not want to have had done. There is nothing you can do about those, and I do not think those were invasive procedures by and large.

Beyond that, the source data are there. If you do not like the constructed variables, those are documented. You can go back to the source variables and do what you want to do for the missing data.

For the Medicare and Medicaid claims data, the things that were derived from records data we did not include source data. Those come in hundreds of thousands of individual claims. Those have been organized as one record per person and laid out over the time period. That all hospital days have been aggregated and so on. All that work has been done for you.

JUDITH WOOLDRIDGE: We did not do imputations. By and large we made the assumption that I there were data it was complete and if there were no data there it meant zero rather than it was missing.

There were just a very few exceptions where in doing consistency checks in the secondary data we just felt that we had such a garbled claim that we simply could not use it, but that was rare.

QUESTION: Why was your sample so frail and so old when your screening criteria is so much younger?

JUDITH WOOLDRIDGE: This evaluation was intended to provide community services to a group at risk of nursing home entry to see whether case managed community services could be a cost-effective alternative to nursing home entry.

We jointly, the government and ourselves, had extensive discussions about who was likely to enter a nursing home. Since, clearly, a demonstration like this is very expensive, you want to target your group as much as possible to maximize the possibility of identifying any differences that the program provides. Statistically, you want to have as many people as possible who are likely to enter a nursing home.

I can add at this point that a very low proportion of our sample, in point of fact, went into a nursing home, more than the average for people over 65 and slightly more than average for the people of the age group, but by no means a very large proportion.

QUESTION: Was the 6 and 12 month interview for the caregivers 6 and 12 months after their initial interview, or the 6 and 12 months of the elderly persons?

JUDITH WOOLDRIDGE: Both, as a matter of fact. The caregiver baselines were administered as soon as possible after sample baselines. The 6 month and 12 month anniversary dates were the same for the sample members and their caregivers.

For sample members who joined the sample in the first 6 months, regardless of their caregivers, there was no caregiver baseline. We only did caregiver baseline for sample members who were baselined after November 1982.

QUESTION: In other words, the people who started out with a caregiver did not have their caregiver interviewed?

JUDITH WOOLDRIDGE: The early sample did not have caregiver interviews at all. The last half of the sample did and, in all cases, the caregiver and sample member follow-ups relates to the same time period.

The questions on the caregiver follow-up relate to the same general four areas I just summarized for the baseline.

There are some peculiarities about the caregiver samples used for analysis which I do not want to go into, except to say that it is possible for there to be more than one caregiver for a given sample member in the follow-up file. You could have more than one primary caregiver which is, by definition, wrong, but that was what we actually did.

Mostly, it was just one caregiver but, occasionally, there are two. Both of these caregivers can be related to the particular sample member by means of the sample member's ID which appears on both the records of the caregiver and of the sample member.

QUESTION: Why was Channeling undertaken? What do we learn from the results?

GEORGE CARCAGNO: The demonstration was motivated by the concerns that, I think, were spoken to by Steve Grossman and Bob Helms, namely, that long term care costs are a significant expenditure of public funds. The government pays about half of the national costs of nursing home care.

When you look at the data about where we were headed, it is quite clear from those demographic data that the elderly population is going to become an increasingly large proportion of the nation's population, and that the oldest old are increasing at an even faster rate, and they are the people who are at greatest risk of nursing home admission.

You look from where we are now where there is a lot of concern about the costs of nursing home care falls primarily on the Medicaid program. The state and federal governments have developed various stratagem to limit costs. Some of them, I think, are pretty obviously short term things. You can not hold down the nursing home bed supply forever. You have got to deal with the problem at some point.

What motivated the demonstration was that set of facts and projections looking ahead and wanting to test whether this particular approach to community care could prove to be a cost-effective way of delivering services to people in need of long term care in the community rather than in institutions.

When you look at the results, essentially, we found it cost more to deliver Channeling services, and it seemed to be primarily because there is relatively low use of nursing homes by the population that participated in the project than had been expected.

There was a substantial increase in the use of formal community services, particularly in the financial control model, reduction in unmet needs, some improvement in measures of well-being, but there was not any of the savings that had been hoped for in terms of reducing nursing home use because nursing homes were not used very much by anyone in the sample, and we know that by looking at what happened to the control group.

When you look at that, I think it is very important, in terms of trying to draw some conclusions from it, to keep in mind what we were testing. We were not testing something compared to nothing. We were testing a particular intervention called Channeling with its own variant of case management that had been developed.

There are other ways you can do case management. For example, case managers could have control over medical and nursing home expenditures, as well as community-based care. That is an approach that is being taken by the social HMO demonstration.

In Channeling, we just have case managers who dealt only with community services. You have a particular variant of case management that was being tested.

What is especially important is that what we were comparing Channeling to was not the absence of case management, but the case management and community care programs that were already out there in the communities that the control group had access to.

We were testing an addition or an increment to the existing system. What do you draw from that? I think one thing you do not conclude is that we should abandon all support of case management or community services because that was not what we found.

On the other hand, I think it would be very difficult, using the Channeling results, to argue for a substantial increase in the public funds available for community care except to keep pace with growth and population, or to argue that community care is a cost-effective intervention or way to save money. The results simply will not support either of those kinds of positions.

On the other hand, there are other ways of approaching case management that could be tested that could be more effective. We do not know. The socialization models are being evaluated. We may learn something from that.

If we had selected a less frail population, would the results have been different? I am sure they would have been different, but Channeling was not the first such demonstration that was attempted. It was, in fact, preceded by a number of community care demonstrations that had a wide variety of target populations that participated.

Largely on the basis of that previous work, the people who were involved in designing the demonstration came to the conclusion that if we were interested in trying to see if this intervention could be cost-effective, the only way you could do that was to try and identify people who, if you did not provide such services, would go into a nursing home, rather than taking a more preventive approach or trying to get people much earlier in the process of functional decline.

That was based on what had come before us, and what you find is that if you have a population that is much healthier and less frail than Channeling's, you can provide community services, and you provide them to a lot of people, you can probably improve well-being, but you would not see any of the offsetting cost reductions, certainly in the time periods that we were looking at in this demonstration.

If you could convince somebody to do a demonstration like Channeling or find some means of tracking people over a longer period of time so you could evaluate what happens over a 5-10 year period to these more preventably oriented programs. I can not speculate what the results would be but, certainly, it would be a different demonstration than the one we did.

QUESTION: I presume you were not looking at health outcomes, then. You were looking only at satisfaction levels? Were there any other health-related outcomes that you focused on?

GEORGE CARCAGNO: We looked at use of health-related services.

JUDITH WOOLDRIDGE: Just a self-reported status variable. The excellent, fair, poor type of question that you see in the National Health Interview Survey (NHIS).

THOMAS GRANNEMANN: We had the ADL measures.

QUESTION: You had ten different sites, and in each site you have a control group as well as the treatment group. Did you find that Channeling was cost-effective in any of the ten sites? Has anybody done site-specific analysis?

GEORGE CARCAGNO: We looked at site-specific results, and the story was essentially the same for all of the sites. There is always the possibility or concern that you have got something wonderful happening over here and something terrible happening over there, and you put them together and it appears that nothing is happening.

We looked at the impacts at individual sites and, as I said, the story that we were looking at there is essentially unchanged.

We also looked at subgroups of the population.

THOMAS GRANNEMANN: I think the subgroup analyses tend to, in general across the board, confirm the findings of the demonstration overall. We did not find any subgroups for which impacts were dramatically different for the program, say, of money or had bigger differences in impacts by a wide variety of subgroups we looked at.

In particular, to follow-up on the question on whether a less impaired group could have been identified earlier for which things might have come out differently, I think this subgroup analysis shows no evidence that a less impaired group would have a higher impact.

Of course, you can not say what happened outside the sample we looked at, but there was certainly nothing in trends along impairment levels of the groups we looked at that would suggest that. In fact, to the extent we do have some subgroup evidence of differences, the group that we show the biggest potential for reducing nursing home use, and again, that is not a large reduction, is the group of people who are already waitlisted or are in a nursing home at the time of randomization. That result tends to suggest that, rather than focusing on a broader, less impaired group, the important thing to do here is focus on a group, not necessarily more impaired, although that group probably is more impaired, but a group that has already made the decision to go into the nursing home. That operational thing that you do not get when you simply check off characteristics on a screen might be the thing that would help you better predict and target towards a group that was better. That kind of thing could have been done through a preadmission screening program, something where you get people at the point where they apply for a nursing home as opposed to Channeling which got its people, in general, from the community; anybody who was looking for help for services from within the community.

To the extent there are any results in the subgroup, I think it is just going toward a more impaired, more nursing home oriented group rather than toward a broader group.

QUESTION: I was surprised to see that you tried to evaluate your project after 18 months, and I had the idea, knowing the experience in the Netherlands where I am from, that you need the first 1-2 years to got the people together who are providing the care, so that they know each other. Then you can evaluate your project, is it for scientific reasons you wanted to evaluate after 18 months, or is it because lack of money?

GEORGE CARCAGNO: There is a very long report that talks about the planning and operational experience of the projects.

We used, by and large, established local agencies as the host agency to run the projects, so that we were not starting up with new agencies in the community. They were local agencies already well known to the local service providers.

There was a planning period of about 18 months that preceded the start up of the program, during which time local staff were hired, and they, in turn, were making contacts with the local service providers, explaining what the program would be, both with an eye to getting agencies who would refer people to their program, and also with an eye to identifying providers who would provide the community services to their clients.

People were enrolled over about a 15 month period for the research sample, and then we followed people for a 12-18 month period. The elapsed time on the calendar was just over 2 years.

By identifying a target population that seemed to be at imminent risk of institutionalization, the necessity to take a longer period of time seemed to be reduced.

I would have felt better to have had a longer period of follow-up, and that was a decision about what resources were available, and also how long we could continue doing data collection.

QUESTION: Do you have a sense of what might have happened if you had been able to continue data collection longer?

GEORGE CARCAGNO: Given the mortality rate, there would not be too many people left to analyze. One-third of the sample died within 12 months.

QUESTION: I have tracked nursing home data in Connecticut, and that is higher than the proportion of people who enter a nursing home.

JUDITH WOOLDRIDGE: That is right. We had a low proportion enter a nursing home. I think it is important to say that these were people with an acute precipitating event, by and large. They had a very high hospital use for the 2 months before they came into the program. Between 50 and 60 percent of them had been in a hospital.

Another thing I would like to mention is not only was the cumulative mortality rate going up very rapidly over time, but nursing home use was also increasing. We were not beginning to see any increase in effects over time. The difference between the treatment group and control group seemed to be pretty constant at 6, 12, and 18 months. That was something that we looked at to see whether, if we had gone, did we have any hint if we had gone on longer, there was likely to have been a bigger effect, and there really was not.

QUESTION: Why did you amalgamate the Asians and the Indians into one ethnic group?

JUDITH WOOLDRIDGE: For reasons of confidentiality.

QUESTION: We have several students who were quite anxious to look at the experience of the Asian elders.

JUDITH WOOLDRIDGE: There were not very many, so they would not really be able to do much of an analysis with them. It would be possible to identify some of those individuals, we felt, particularly at some of the smaller sites.

QUESTION: Do you have some advice about the print quality of the documentation. It is exceedingly poor, and I can not read the column numbers, for instance. I presume that you must have given a good quality print to National Technical Information Service (NTIS).

JUDITH WOOLDRIDGE: By and large, we did. One file documentation is really quite poor, though, and we have just redone some of the pages for that. That was the hospital and nursing home file. Some of the constructed variable pages were extremely pale. Everything else we gave was quite legible when we gave it to them.

QUESTION: Do you have some advice about merging longitudinally? If we wanted to merge the base 6, 12, and 18 months, we were going to have an absolutely gigantic file.

JUDITH WOOLDRIDGE: We have 14 public use files because we did not want to produce one gigantic file with all that on it. We knew that people would have particular interests. We produced individual analysis files in preparing our final report which were quite small, and sometimes we worked with more than one file in particular substantive areas just to keep things simple.

Extract only the variables that you think you are going to use from the files, keep the numbers of variables down.

QUESTION: Did I understand you to say that, in terms of the formal community services, the information is available for only the clients of Channeling, or they are available for both the control group and treatment group?

JUDITH WOOLDRIDGE: They are available for both the control and treatment groups. There is one data source that was only available for clients, and that is the financial control data from the financial control sites.

QUESTION: I am just wondering if I can get some idea of the magnitude of the relative costs between the control group and the treatment group. That is, you said it was not cost-effective.

THOMAS GRANNEMANN: The costs were not close in the sense we were quite confident of the result. The results of no cost savings are very robust. There are some differences. When we looked at cost by source of payment, as a government funded project, we focused primarily on Medicare and Medicaid costs as a primary objective, and it was quite clear that those costs went up.

In some of the subgroup analysis we found that nursing home expenditures from private sources, and in some cases, in community services went down. That was more than made up for by the Channeling expenditures on services.

We are quite confident to say the government is not going to save money by implementing a program like Channeling.

GEORGE CARCAGNO: You recall the model differences we talked about earlier, the basic case management model and financial control model, where the latter involved substantial expansion of community services.

Overall the basic model treatment group cost 6 percent more than the control group. In the financial control model it was about 18 percent.

If you look at government costs, they increased by about 14 percent under the basic model and 28 percent under the financial control model.

QUESTION: Do those costs include the costs of the overhead of running the project in any way?

GEORGE CARCAGNO: It is everything. This is for the entire treatment group and the entire control group. It is averaged over everybody, including the people who died at various stages or dropped out of the program.

We are talking about control group means of $1,300 in the basic and about $1,600 in the financial control compared to $1,400 in the basic treatment group and about $1,900 in the financial control group.

QUESTION: I want to pursue a little bit more the observation that, after a year, 30 percent of the clients entering the Channeling program had died and, depending on which program, lost 33-39 percent at 18 months.

We have in Connecticut an 8 year longitudinal set of all nursing home patients. We know what proportion of patients die at various given times, by year of admission and their length of stay.

Obviously, the chance of dying increases the longer you stay. The number 29 percent after a year sticks in my mind. You speak of the Channeling population as having a precipitating event that brings them into Channeling. What could be a more precipitating event than whatever brings you into a nursing home.

Is it possible that there is an underlying progression here of whatever is going to happen to elderly in this group that is going to happen to them whether they are in a nursing home or whether they are in Channeling?

With respect to something like mortality that maybe the type of service that is not going to make much difference. We have the Connecticut data for the most recent 3 years by ADL level and continence level, so it would be interesting to compare the functional level of the Channeling population with the Connecticut nursing home population. We do not have any of the social support data that you have. It would be interesting to note whether they are functionally similar populations.

GEORGE CARCAGNO: We did examine the characteristics of the Channeling sample against people in nursing homes from the National Nursing Home Survey (NNHS), and there are a lot of similarities.

One thing to keep in mind when you look at aggregate nursing home data is that you get a lot of short stayers in nursing homes, which will tend to have some effect on whatever aggregate means you are looking at for that population.

Your suggestions to look at that subset of nursing home population that bear similar characteristics to Channeling's population is a good one.

There are lots of people in the community who look like the people that are in the nursing homes, and sometimes it is a precipitating event that puts people into nursing homes.

In many cases it is a long, slow, worsening of condition and, finally, usually family members are unable to cope. It is not necessarily a particular thing, but an accumulation of many factors and a cumulated stress and burden on the caregiver.

THOMAS GRANNEMANN: There is a lot of information from the analysis that we have done that is available in the reports.

Information on the ADL's of Channeling clients at baseline or at follow-up is as hard to get as simply opening up the report and looking at it.

QUESTION: What is the cost of the tapes?

AUDIENCE: It is approximately $500.

JUDITH WOOLDRIDGE: Just as a matter of interest, did you request one file or did you just request one tape, the tape with all the files?

AUDIENCE: All the files.

QUESTION: Do your numbers parallel impairment assessments in terms of the NHIS?

THOMAS GRANNEMANN: The ADL scales that are used? If you are talking about impairment measures, those do parallel.

QUESTION: What happens now in the ten sites that participated? Has the project stopped and all the elderly people are at home now without community services?

Did you ever have problems saying, I allocate this older person to the control group and that older person to the treatment group, because sometimes you think it is better that this person goes to the treatment group because of human values.

GEORGE CARCAGNO: Actually, those are quite closely related questions.

There was a great deal of concern about those issues. The project had what is called an Institutional Review Board (IRB) that was concerned with the measures that we took in terms of protecting the people who were involved in the demonstration.

With respect to ending the project, one of the things the IRB did was make us think at the start of the project about how we were going to end the project, and that was very useful and important to us.

When people applied to the project, the whole randomization procedure was explained to them, and the fact that the project was of limited duration was also explained to them.

The sites were required to develop operational plans they submitted to the federal government about how they were going to conduct the operation in their sites.

With this, they also had to submit a termination plan, which the first one, we were now looking at something that was happening 3-4 years down the road.

As time passed, those termination plans were refined. At one point during the demonstration we stopped enrolling new people, and we allowed the caseload to get smaller.

In eight of the sites the program essentially continued under other auspices. The funding sources shifted from being federal demonstration money to some combination of regular Medicaid program or 2176 waiver services.

In the two sites that essentially closed down, the transition termination care plans were done, and the cases were transferred to other agencies.

With respect to the ethical issues involved in random assignment, I am not terribly troubled by that. We are basically looking at a situation here, the control group gets access to whatever is available in the community that, in the absence of this demonstration, they would be able to get. The treatment group is getting a treatment that, in this particular intervention, was relatively benign and not particularly risky.

We were not likely to have adverse consequences, but you could make up stories about trying to keep people in the community might involve greater risk than if they went into a nursing home, and these kinds of risks were part of the informed consent process. We brought those things in and explained to people what they were facing.

The people who are not getting the treatment are not being denied access to anything they would otherwise have available to them. The control basically has access to whatever was there if the project had not come along.

We had people from ten sites who were in the business of delivering services to people who felt these kinds of issues very keenly. They were convinced of the appropriateness of the research design and the randomization procedures, and felt comfortable with it. All of them were not at first, but they were in the end.

QUESTION: How was it determined that people who were let into the treatment group or control group were eligible for nursing home level of care by either Medicare or Medicaid? Were they screened?

GEORGE CARCAGNO: Not in any formal sense. in several sites they do that informally applying their state level of care procedures. They did in New York and Florida, and very high proportions of the caseload met that criteria.

QUESTION: Did not only 15 percent of your controls go to nursing homes? Is this evidence of bad targeting which is what goofed up the demonstration from a cost point of view?

THOMAS GRANNEMANN: We did a fairly extensive analysis, actually, an additional piece of analysis beyond the original design of the Channeling evaluation to look at the targeting issue to try to decide whether there was a subgroup within that we had somehow missed along the way. We developed several different ways of targeting and tried to test that to see if we would get any different results.

Part of that analysis involved looking at an analysis of what predicts nursing home use. We found that using the information that was available from the baseline instrument and the screen, we were able to identify a number of factors that predicted nursing home use and some that were fairly strong, in particular, in the group that was already in a nursing home or were waitlisted was a very big predictor.

We identified a number of predictors of nursing home use. Even using multiple regression analysis to take account of all the information that was available from the baseline screen, we were not able to explain a large part of the variance in nursing home use.

QUESTION: Not on an individual basis?

THOMAS GRANNEMANN: Not on an individual basis. I think you put your finger on an important issue. We were not able to do that with this type of a screen and, as I think I suggested earlier, what that may suggest is that you can not identify people very well from these kind of criteria by simply giving them an interview and checking off their characteristics.

It may need to be operational types of things, such as pre-admission screen processes that select people who are on their way in who are there because of all of these unobservable things that cause them to go into a nursing home. We are not at the point of being able to look at somebody out in the community and say, you are going to go in and you are not, and be able to target that way, even with all the information we have got.

QUESTION: How many got in through the criterion collapse of informal support versus those that got in simply because they had unmet needs?

THOMAS GRANNEMANN: I do not have any idea.

QUESTION: Does that suggest to you that maybe we ought to think more about caregiver crisis than unmet need in terms of risk of nursing home admission?

THOMAS GRANNEMAN: One of the things we did look at in our targeting study was the role of the caregiver in nursing home placements, and there was some evidence there that caregivers do make a difference in terms of who goes into a nursing home. Particularly whether there is a caregiver available, whether there is a close family relationship to the individual, has a close tie and is available to provide informal services.

That is saying caregivers are important in determining nursing home placement, but we were not, however, able to identify differences in the impact of Channeling, depending on the caregiver's role. Even though caregivers play an important role in nursing home placement, caregivers are not the deciding factor in whether Channeling is effective or not.

QUESTION: Did the results indicate the extent to which informal care was shifted to paid services by the presence of the project?

THOMAS GRANNEMANN: The basic analysis that we did was looking at informal care and formal care, and we find that formal care increased by a fair amount substantially in the financial control site where extra funding was available for that.

One worry was, of course, that while that was simply going to be a one-for-one substitution, those services were being provided on an informal basis.

We did not find any evidence that that was a significant worry. There was a modest 5 percent reduction in informal care, even in the financial control model where we had a 40 percent increase in the community-based services that were used.

GEORGE CARCAGNO: A lot of people had grave concerns that there would be substitution. The reductions in informal care that Tom referred to were really observed only in the financial control model and, essentially, in people who were visiting caregivers rather than those caregivers who were living with the elderly sample members.

You saw that people in situations where they were in the same household, there was no reduction in the amount of informal care that was given. There was a reduction in the care provided by visiting caregivers, and most of that reduction was from friends and neighbors rather than family members.

It was people on the periphery of the informal care network rather than the primary caregivers where we observed those reductions.

That is an important finding in terms of the kind of fears people have about substitution.

QUESTION: How can we get copies of your reports?

JUDITH WOOLDRIDGE: With respect to our reports, there is an Executive Summary of the Final Report. It does tell you what the full conclusions of the project were. In the back of that report is a list of all the technical reports available about the project. That includes technical reports on substantive areas and it also includes things like instruments. If you are interested in getting copies of the interview forms themselves, they are documented, you can get those in there. Of course all the data base documentation I think is listed in the back there as well. Most of these things are available either from MPR, NTIS, or the Department of Health and Human Services (DHHS).

There is also a document called the National Long Term Care Channeling Demonstration Abstracts of Reports [http://aspe.hhs.gov/daltcp/reports/chanrpts.htm], which gives a one paragraph description of each report. This is also available from DHHS.

There is a methodological report which describes the kind of special analyses we did to address issues. We were concerned about what to do with potential design problems, potential problems of attrition in the data and so forth.

GEORGE CARCAGNO: There is a very extensive data set here that covers the formal community services that people used and their costs. There are other formal services such as nursing homes, hospitals, physician services, those are also in the data base. Also units of service, amounts of service, their costs, and who paid. Were they paid by government programs, which ones, or by private individuals or private insurers.

There are data both in terms of the amounts of formal care and of informal care, that were provided. That includes personal care as well as financial support and we also in an interview with the informal caregivers themselves collected information about their satisfaction with the services that the elderly sample member was receiving, their stress and burden, and the amount of care that they provided.

There is also information on several quality of life measures and unmet needs, also data on physical functioning. Of course there is data on mortality.

I think I pretty much covered physical functioning. There is a great deal of data, all of which were used in the evaluation itself, so that you can look at the final research reports. There is the Executive Summary, there is a summary report of the research findings, and there are a number of technical reports on each of the specific areas. There is a separate report on the impacts of formal caregiving, a separate report on formal community service, use and costs, a separate report on the benefits and costs of Channeling, a separate methodological report, and so on.

There are a large number of reports, all of which are listed in the end of the Executive Summary.

QUESTION: What advice do you have for other researchers on conceptualizing and measuring quality of care?

GEORGE CARCAGNO: There were several questions that addressed the issue, but they were all based on the self-report of the elderly sample member and/or their primary caregiver. We did not set out to attempt some direct measurement of the quality of care.

If we were going to set out to do what we did, where quality of care is one component of it and given the resource constraints that we faced, would we do the same thing again? We would, and I do not think we would make any major changes to those questions. I certainly think that if you got hold of the instruments, both the follow-up instrument of the elderly sample members and the caregiver instruments, the questions in there on quality of care are ones that, I think, you could use.

THOMAS GRANNEMANN: One issue in measuring quality of care for this group is the use of proxies as respondents. We were forced to use proxies as respondents whenever the sample member could not respond. If you are doing this kind of work with this type of a very impaired population, how do you deal with situations where you are forced to use proxy response? I think that is a problem you probably have to solve for yourself, because I do not think we have the perfect answer to that because we did use proxies when necessary.

QUESTION: I have a question about the reliability of functional status data. How did you deal with that problem?

GEORGE CARCAGNO: We trained all the interviewers. At the baseline, the treatment group was interviewed by the staff of the Channeling project themselves and the control group was interviewed by MPR staff. Then all of the follow-up interviews were conducted by MPR interviewers, both treatments and controls.

From a research perspective, we would have preferred to do all the baseline assessments ourselves to remove any questions about comparability of data, but there were compelling clinical reasons why it made sense for the sites to do the baseline assessment.

We were convinced that they needed to do it themselves in order to gain the clinical insights that they needed to develop their plans and so on, and that it was not feasible to even think about having two baselines, one that we did and one that the sites did.

We did a small sample of validation interviews where we went out ourselves and reinterviewed a small sample of the people in the treatment group that had been assessed by the Channeling staff.

That turned out to be a better idea in theory than in practice, and one of the reasons was that it was very difficult to compare those two samples because there was passage of time, it was 1-2 weeks later, particularly if you were dealing with people who were coming out of the hospital.

QUESTION: You could not go together?

GEORGE CARCAGNO: There are potential logistic problems, but I think there were some clinical issues in terms of the burden and so on.

The validation sample did not turn out to be a terribly useful way to look at these issues. We did do some separate analyses of the comparability and there is a report on the comparability of the baseline data that you can take a look at.

What we found was that on a small number of variables there was not comparability at the baseline between data collected by the site staff and our own staff. What we did in those cases was to use the similar or same variables from the screening instrument, which was comparable for everybody, because that was administered to everybody at the point of application.

In terms of differences across sites, we trained all the interviewers, so they had the same training, as the site staff did on the baseline.

We conducted fairly rigorous quality control reviews and monitored the quality of the data that we were getting. To the best of my recollection, there were not large differences in the functioning measures across sites, although there was one site that had a relatively less disabled population than all the others. I think that involved measuring something that was going on there rather than a difference in methodology.

QUESTION: It seems to me there is an awful lot of interest among private insurance companies in doing something with alternate care, as well as among legislators on the Hill, in the general concept of case management. I have seen a number of volumes that have come out on Channeling. I do not recall seeing a particular document on case management. If there is not one, is one planned?

GEORGE CARCAGNO: There are several ways you can get at the issue of case management. With respect to the costs of case management, some of those data are in the final report, and more detailed information in the formal community service use and cost report. With respect to more qualitative descriptions of the kind of case management that took place in Channeling and what the case managers are like, what kind of training they got, and what their caseloads were and so on. There is a report which is actually a two volume report, called The Planning and Operational Experience of the Channeling Projects [http://aspe.hhs.gov/daltcp/reports/proceses.htm], which has a couple of chapters that talk directly about case management and the processes that were carried out, and there are also some chapters on the organizational structure of the Channeling agencies and how they were organized and conducted themselves.

QUESTION: What did you learn from case management and Channeling? What is the best way to do it that would be applicable to private insurance companies?

GEORGE CARCAGNO: In the planning and operational experience report, we did try to provide some consensus views about how to do case management.

The focus there was not necessarily looking at private insurance companies providing a case management benefit as part of a package of long term care, community and other kind of benefits, but was more from the perspective of case management, probably more nearly in a public program context. A lot of that is very useful and applicable to the kinds of case management that a private insurer might consider making available.

Case management is an ill defined concept, Channeling was a particular variant of case management that had a particular range of authority and limits on that and so on. There are other ways you could do it.

In Channeling, for example, the case management staff involved some combination of people with social work backgrounds and people with nursing backgrounds.

Some people say you should have only nurses, and other people say you should have only social workers. Just as with most, with those bitter debates, we concluded the truth was somewhere in between. The Channeling projects I think bore that out because those that started out that did not have nurses found that they needed nurses fairly quickly and arranged to have nurses on the staff.

I think by and large, the case managers as a group in Channeling were more social service oriented than having nurse backgrounds but there were always nurses available, either as consultants or supervisors, or as other case managers. In cases where having that kind of expertise was important, those resources were available.

We tried to define case management in a way that was comparable within the demonstration so that when we saw that there was substantial case management use among the control group. We set out to identify whether people were getting what we called the comprehensive case management that was available from Channeling or case management as, again, everybody does case management.

Visiting health agencies do case management--to some extent as intensively as Channeling--only on a small proportion of their total caseload, whereas Channeling attempted to do it for all of the caseload.

Depending on which model of Channeling you look at, 10-20 percent of the control group received case management similar to Channeling.

QUESTION: I have been having a discussion with my boss about costs and ways to compare costs between community-based care and institutional care. I wonder if you can narrow down what can and can not be done with Channeling to address that question.

THOMAS GRANNEMAN: The Channeling data set is probably the most comprehensive of the data sets that we have talked about at this Conference in terms of measuring costs.

We have records data on all the important costs. We have provider records extracts for all payers. We have got interview data that allows us to make amputations for costs of housing and expenses of maintaining people in the community. If you are thinking about doing an analysis that is broader in terms of cost of maintaining a person in the community versus the cost of maintaining people in an institution, it is got the pieces of information there.

Your question addresses how you go about comparing that, because what Channeling did was not to randomize people, put some people in a nursing home and put some people in the community, and see how much they cost.

The Channeling intervention was really an intervention that added community services and then let people voluntarily decide with these additional services can you make it in the community; does it make sense for you to stay there. Then we looked to see if there was an impact.

The question is, can you look at the data in a way that allows you to get around this problem? In part, the answer is no; there are inherent differences between the two groups. People who are in the community have self selected themselves into the community, and people in nursing homes have self selected themselves into the nursing home. Even though we can control statistically for some of the differences between those with baseline characteristics, we know there is a lot that is unexplained. The Channeling data and indeed other data sets do not have all the characteristics you need to have a good prediction. As a result of that, they do not give you a result similar to what you would get if you randomly assigned people to nursing homes.

One thing we did do in a follow-up study to Channeling was try to look at what were the costs for the groups of people, treatments and controls, in the community and in institutions. We did an analysis that compared for those who went in, what were the costs. In this case we looked at a 1 year period and found the costs were higher, of course, for those people who went in a nursing home and that those cost patterns, the differential between community and nursing homes, differed between the two groups.

What we are able to calculate from that is what diversion rate would be necessary to make a program cost-effective. Even though you do not know exactly what the costs would have been, it gives you some idea of the bounds on which you can put limits on those costs.

I think in that sense, Channeling can put some bounds on the question you are addressing but can not really answer the question precisely.

QUESTION: I am wondering if it is feasible to arrive at a consensus of whether the nursing status is home nursing, intermediate nursing, rehabilitative nursing, personal care, and whether there is a possibility of defining those categories and incorporating such categories into the various data bases so that one can analyze not merely whether a person moves from community into institutional, but the various levels of institutional care that a person moves through.

JUDITH WOOLDRIDGE: Theoretically, I think the answer to your question is yes. Right now I am working on another project to do with long term care assessment and management, a program the Commonwealth of Pennsylvania is running. They have in that state, in seven of their counties, introduced a screening process for anybody who is going to go into a nursing home. That is to say, anybody who is Medicaid and anybody else who wishes to apply to be screened for their nursing home eligibility.

In that process they go at least some of the way in the kind of distinction you are making. This program that they are running is intended to divert people from nursing homes wherever possible. What they do is, they have quite an extensive assessment instrument which asks a lot of questions about functioning and informal supports. On the basis of those issues, they classify individuals as needing skilled care on a long term basis or on a short term basis, intermediate care similarly.

They also classify people as needing community care. They actually have a program so that people can be classified as needing that specific program and they have other levels of care, for example, people who need personal care or domiciliary care programs. They actually have gone quite a long way in making that kind of an assessment.

My guess is that given the quite extensive detail in the Channeling data base on informal supports and functioning at different levels, different points in time, that you could do some such thing and make such an assessment even post hoc at this stage.

QUESTION: I was wondering if you could comment on the data on informal supports.

I heard from other sessions there apparently was a formal service substitution for that. Would it be a data problem or an effect of Channeling itself?

The reason I am asking is because we intend to work with insurance companies and they constantly ask: What is the cost of that going to be if they are going to start paying for home care?

GEORGE CARCAGNO: I think for the purpose of looking at substitution effects, one great advantage of the Channeling data is that you have imbedded in it data on a behavioral response to providing services that are paid for by somebody else to this population.

It is not simply a cross-section. We have a report and data on the impacts of Channeling on informal caregiving.

What those data show is that there were small reductions in the amount of informal care that was provided. Those reductions occurred primarily from reduced levels of care given by visiting caregivers rather than caregivers who lived in the same household and those reductions occurred primarily among friends and neighbors rather than family members.

In the financial control model we observed these reductions in the amount of informal care. They were relatively small and were concentrated among people who seemed to be at the fringes of the informal care network.

One of the jobs of the case managers was to provide support to that informal care network, and different sites did that in different ways.

Some sites had training sessions that they gave for caregivers and support groups, although not a lot of people actually came to those things.

There was an attempt to provide that kind of support, and it manifested itself in support group kinds of activity in one or two sites.

The case managers had as one of their responsibilities trying to keep the caregivers going. It is difficult for me to say to what extent that accounted for the outcomes that we observed. It certainly did not hurt.

QUESTION: I think that the last thing you said is important. Formal care may not be a substitution for informal care but complementary.

GEORGE CARCAGNO: That is right. Although, as I recall, you could think through several different models of how this could work. Maybe in the short term, there is some substitution but it turns out that because of that substitution, caregivers stay at the job longer than they otherwise would.

We did not really observe that kind of thing going on, although we thought it might happen if there was substitution in the short run. The results were pretty much the same over time.

QUESTION: Could you help me with some evaluative judgments about your screening tools?

There is a lot of interest on the Hill on screening, how you select people for long term care services. I am asking it in that context as well as in the context of a program like the 2176 waivers.

GEORGE CARCAGNO: When you talk about screening I think there may be two useful distinctions to keep in mind. One is the instrumentation itself and the other is who it is you administer it to.

The Channeling screening instrument was designed to determine who was eligible for Channeling and it was largely administered by telephone to over 11,000 people.

One of the things you have to face up to, with respect to the whole screening process, is you basically want some levels of screening to take place, because you have resource constraints. We certainly did. We started out with that telephone screen.

In effect, there really was another level of screening that took place at the point of assessment, although very, very few people were turned away from the program at that point based on the in-person assessment, but in principle there was a second level of screening that could take place. Anybody that was turned away because of the assessment results was still in the research sample because it was after randomization.

It is my opinion that, even though we designed the screening instrument many years ago, the technology of measuring and identifying people at risk has not advanced a great deal and that something like the screening instrument would be used today if we were to do it over.

We screened a fairly broad group of people who voluntarily came forward and applied to Channeling, were referred by either a hospital at the point of their being discharged, by a community service agency, a social service agency, or community care agency.

It has been suggested that one might have a much better success rate in terms of identifying people at risk if you administered this kind of screen to people who were in the pre-nursing home admissions process in terms of Medicaid. That is what they did in the South Carolina demonstration, and in fact, identified a much higher proportion of people who went into nursing homes as a result.

Programmatically, if the way you got community care in the future, say, was to go through a preadmission screening process for nursing homes and I that is the gateway to publicly financed community care, over time you might observe a shift in who, in fact, was coming forward to apply for nursing homes. It is the people who really want to get community care who go and apply to the nursing home to get community care. You may not end up with the same population that the people in South Carolina got, you may end up with a population that looks more like what we had in Channeling, overtime.

THOMAS GRANNEMANN: I did a follow-up study to the Channeling evaluation that produced what will be a report to Congress on identifying people at risk of institutionalization and really addressing the targeting issue. My understanding is that this report will be released shortly. It is in the Office of the Secretary getting a final approval right now.

It may be best to focus on the group of people who are already in a nursing home or on their way in. These preadmission screening places may be the place to do this.

We looked at a broad range of predictors based on ADL, IADL and individual characteristics. We were not able to develop a checklist or screening device that allows you to predict who will go in and who will not, and therefore for whom community-based care would be a cost-effective alternative to nursing home use. it is very difficult to make a community-based service program cost-effective simply by giving them a screen that picks them out.

The solution may be along the lines of these process things focusing on people going into nursing homes rather than a simple checklist. I do not think we have a perfect screen that identifies people from these programs that can be cost-effective.

On the other hand, the difficulty of predicting who goes in I think, from the insurance standpoint, may be something of a plus rather than a minus. Whereas the government would like to identify people that will go in to provide services to them, insurance companies may like to see that these things cannot easily be predicted and therefore are more insurable. The selection bias problem will be as great as it would have been if the thing had been predictable.

CHAPTER IV. OVERVIEW OF THE NATIONAL HEALTH INTERVIEW SURVEY/1984 SUPPLEMENT ON AGING

Gerry Hendershot, Ph.D., National Center for Health Statistics

For many years before his death, my father owned and operated a service station, and, as part of his work, he made auto repairs. He was very good at it, but he always denied being an expert. He said that "I just do the best I can on whatever comes down the road."

I am in somewhat the same position. I work on a general purpose health survey. I am not an expert on long term care like many of you. I am here to tell you about the 1984 Supplement on Aging (SCA) to the National Health Interview Survey (NHIS).

There are two other people from our staff in the audience. Susan Jack was very much involved in preparing the specifications for the SOA, and is very familiar with the structure of the file. She is also co-authoring a report on functional limitations.

The other person is Joe Fitti, who was very much involved in the planning and development of the questionnaire and has also worked closely on the Longitudinal Study on Aging (LSOA).

I do want to acknowledge the important contribution that Dr. Mary Grace Kovar has made and continues to make to the SOA. She was the prime mover in the initiation, planning and implementation of the survey, and she continues to serve as the coordinator of analytic activities underway at the National Center for Health Statistics (NCHS). More informally she acts as the center of a network of researchers who are using the SOA data tapes.

We are part of the Office of the Assistant Secretary for Health (OASH). In June of this year that is going to change: we are going to become part of the Centers for Disease Control. We are not going to move geographically; we will remain for the time being in Hyattsville, although a move somewhere else in the Washington area is probable in the next couple of years.

NCHS has a complex organization. We do a lot of different things, and the NHIS is only one of those things.

The NHIS is conducted by the Division of Health Interview Statistics in NCHS. We have four branches. I head the Illness and Disability Statistics Branch. Joe Fitti is in the Survey Planning and Development Branch and Susan Jack is in my branch. We have a programming staff, and we have a fourth unit which is called the Utilization and Expenditures Statistics Branch. That branch now performs the function of doing follow-up surveys on the NHIS, such as the LSOA.

The NHIS has these characteristics. It is a continuous survey; it has been in existence since 1957, and except for a couple of brief interruptions has been in the field every week over that whole period to date.

Each week's interview assignments constitute a nationally representative sample of the civilian noninstitutionalized population of the United States. It is a multi-staged area probability sample of data collected by personal interviews in sample households.

The field work is done for us under an interagency agreement by the field division of the Bureau of the Census. We get approximately a 95 percent response rate, year after year. We are quite proud of that, and proud of the Census field staff for achieving that high level of response.

Currently around 46,500 households are in the sample, about 122,000 people are in those households, and we get information about all the persons in these households.

There are two basic data collection instruments which we use. One is the basic health and demographics questionnaire, which remains the same year after year; it is revised about every 10 years. It was most recently revised in 1982, and we are currently planning another revision which will be implemented in 1989 as our current target.

In addition to that questionnaire we have special questionnaires each year on selected health topics.

In the basic health and demographics questionnaire, we get responses from adults in the household if they are there at the time of the interview; we get proxy responses for children and people who are not there at the time of the interview. We spend an average of 25 minutes on this part of the questionnaire in each household.

A list of the topics which are covered are: household composition; limitation of activities, which is a measure of chronic conditions; restricted activity days; acute conditions; visits to the doctor in the 2 weeks before the interview; and various health indicators, one of the most important and most useful of which turns out to be respondent-assessed health status, categorized as excellent, very good, good, fair, or poor.

We have six different lists of chronic conditions, and one-sixth of the sample is asked each of those lists.

A very large number of conditions are covered by those six lists, and each list is organized around a body system, so we get information on the prevalence of chronic conditions in that way.

We get additional information on any condition which is reported anywhere in the questionnaire, which is used largely for the purpose of medically coding the conditions that are reported.

Finally, we get some demographic information.

Our emphasis in the NHIS has changed in recent years from an emphasis on the basic health and demographic questionnaire to the questionnaires on special health topics. The way we see the survey now is that we do a survey each year on selected health topics, in addition to which we collect the basic health and demographic questionnaire. Emphasis is on these special health topics, and usually it is a separate questionnaire, maybe more than one questionnaire. The 1985 questionnaire was on health promotion and disease prevention.

These are typically annual or they may be less than a year. Last year, we did a vitamin and mineral supplement for the Food and Drug Administration (FDA), which was only 6 months. It could be more than 1 year. In 1979-1980, we did a special supplement on home care for both years. There is usually a random selection of one person in the household, although other sampling plans have been used, and it is usually self-reported data, although in some cases we have accepted proxy reporting in these special health topics. Again, it takes an average of about 25 minutes for these special health topic questionnaires.

The special health topic portion of the NHIS are collaborative arrangements between NCHS and other federal agencies. So far, it has been other public health services agencies, but it is possible for us to collaborate with others as well. Collaboration means that we join with them in planning the survey, and we ask that they contribute toward funding the survey. We now support about one-third of the cost of the survey through these collaborative arrangements with other agencies.

In 1979 and 1980 we did a special supplement on home care, and in 1984 we did the SOA. In the same year, we did a supplement on health insurance, which is one that we do periodically, so there may be some interest in getting both the SOA and the health insurance file.

The sample design for the NHIS is a nationally representative sample. There are primary sampling units in the U.S. representing the civilian, noninstitutionalized population. The 1970 design was used through 1984; therefore, it would apply to the SOA.

The sample was redesigned in 1985, so the sample that was in use in 1984 had 376 primary sampling units, of which 156 were self-representing, and 220 non-self-representing. Of 50,000 dwelling units, 40,000 had completed interviews, and there were about 110,000 individuals in those households.

I want to say a word about the analysis of these data. The data from the basic health and demographic questionnaire come in five separate files. They can be obtained from the National Technical Information Service (NTIS), which is our agent for distributing public use data tapes from the basic health and demographic questionnaire.

Each of these files has weights on it. This is a probability sample. To get accurate estimates for the population, the data have to be weighted up to national estimates, and the weights are there on the tape. They are a little bit difficult for some people to understand, but there is a basic weight, and the weight that you would typically be using is a so-called annual weight. The average size of the annual weight is about 2,000, which means that each person in the sample, on average, represents about 2,000 persons in the population.

Since it is a stratified, clustered sample, you do not get the same precision from a sample like this that you would get from a simple, random sample of the same size, and a measure of the effect of the complexity of the sample on the precision of the estimates is the so-called design effect. To give you some idea of what the design effects are for the NHIS, some design effects for selected measures for 1975 and 1976 are around two. On the SOA, they are considerably less than that for most of the measures you would be using.

If you are interested in making estimates for the population, you must use the weights. If you are estimating statistics for fairly large population groups and you can be fairly confident that the precision is good, you might not worry about the complexity of the sample design. If you do not understand how weights are used and variances are estimated, and what effect they have on the kinds of answers you get from the data, my recommendation is that you find yourself a good mathematical statistician, and put yourself in his or her hands.

We include in the reports that we publish from NCHS, in a technical appendix, a description of how we estimate the sampling errors for statistics from the NHIS, and give you some examples of how to calculate an estimated sampling error for statistics which you might generate from the data files.

We disseminate the data in NCHS publications such as Advance Data, and there are five Advance Data reports published from the SOA. We also published data from the NHIS in an NCHS publication called Vital and Health Statistics, Series 10. Our most important product each year is Current Estimates from the National Health Interview Survey, which provides basic statistics from the whole range of data collected in the basic health and demographic questionnaire.

It also includes the technical appendices that I referred to earlier, and reproductions of the questionnaires that were used in that data year.

One place to look for the SOA questionnaire is in the appendix to the 1984 Current Estimates.

We also do a number of unpublished tabulations, which are available for your use simply by calling or writing us. We call these the social, economic and demographic characteristics (SED lists). All of the major health measures are cross tabulated by a large number of social, economic, and demographic characteristics.

We make public use data tapes available for the basic health and demographic questionnaire, and you get a package of documentation, which includes: a tape format, an Interviewer's Manual, the Medical Coding Manual, a copy of that data year's Current Estimates, and a publication which describes the basic methodology of the NHIS. These are available from NTIS.

The supplements we distribute directly from NCHS, so if you want the SOA, you order it from us.

I will give you a little flavor for the kind of data that come out of the basic health and demographic questionnaire. By combining a couple of years, we can make some estimates for some very small population subgroups, such as Hispanic groups. There are some fascinating differences among the different Hispanic origin groups with different measures of health. They probably have a lot to do with age structure of these populations, more than any underlying differences in their health conditions.

The SOA was done in January 1984 through the first couple of weeks of January 1985. It represents the population 55 years of age and older. We took all persons in the NHIS sample households who were 65 years and older, and a systematic 50 percent sample of persons in those households who were 55-64 years of age; so we have a half sample for the younger persons, 5564, and a full sample for those 65 and older.

There was actually about 16,148 cases, I believe. It was a personal interview wherever we could get personal interviews, and that was in over 90 percent of the sample cases. Proxies and telephone interviews were allowed when the data could not be obtained in any other way. The information that is available on the data tape, which was released in December 1986, includes not all the core information. There are, however, five records, one of which we call the "person record." The person record has all the demographics, and summary measures of some of the health characteristics, from the basic health and demographic questionnaire. They are included on the SOA file, along with all the information from the SOA questionnaire itself.

I just want to discuss one item by broad age groups from each of those major topical areas covered in the SOA. In the topical area on family, for instance, we have some measures of whether or not they have children, and if they are in contact with children.

In the area on community, we have some information about contact with friends and neighbors, and other kinds of community services.

In the section on retirement, we ask a question about whether they retired for health reasons, and some other information about the circumstances of retirement.

In the section on impairments, we get information, for instance, on vision and hearing problems. In the section on functional limitations, we look at the instrumental activities of daily living (IADL's) and activities of daily living (ADL's).

We also ask some questions about nursing home stays.

In the section on health opinions, we asked a question about how much they worried about their health.

Five Advance Data reports have been published. They were all based on preliminary data for the first 6 months of the data collection period. Those analyses were repeated using the full year's data, and were presented at a meeting of the Gerontological Society of America last fall.

There was a report by Dr. Kovar on the basic and health demographic measures. It shows, for instance, living arrangements cross-classified by marital status in the population.

There was another report, an Advance Data, by Dr. Kovar on the characteristics and health of elderly persons living alone. This shows, for instance, where children are relative to those who are living alone and to those who are not living alone. A lot of those who live alone had children living near enough to provide some kind of support and care for them.

Dr. Robyn Stone did a paper on use of community services. One of the findings was that the elderly do not make a lot of use of community services. We do see that those living alone are much more likely to use those services than those who are living with others.

There is a report by Dr. Tamara Harris on incontinence, and this, for instance, shows that people who have more severe problems of incontinence are less likely to socialize.

There is a report by Dr. Richard Havlik on vision and hearing problems. This report shows the relationship between visual impairment and selected ADL problems.

In addition to the five Advance Data reports which have been published, we have already mentioned that there is a report on the methodology, which we expect to be published this summer, by Joe Fitti and Mary Grace Kovar. There is also a report in preparation on functional limitations which will be published by NCHS as a Series 10 report, co-authored by Susan Jack and John Fulton and Sidney Katz of Brown University.

I mentioned a longitudinal study. This is a follow-up to the 1984 SOA. This takes advantage of a new capability of the NHIS, which we now call targeted follow-up surveys. Basically, we now have the capability after the NHIS is done, to select persons from that sample who have already been interviewed, according to any kind of characteristics that we may be interested in, such as ADL's, for instance, or Hispanic origin, and go back to those same people to get additional information, either of the same kind or to expand the range of information obtained.

This can be done by personal interview, mail questionnaire, or telephone. Typically, it is done by telephone. It is also possible now to match NHIS interviews, or follow-up interviews with the National Death Index (NDI), which is a mechanism for determining if a death record has been filed for the person, and that is being done as part of the LSOA. For the LSOA, we are also matching to Medicare records.

The interviewing was done for the first follow-up in the LSOA in 1986. A public use data tape is expected to be available in July of this year, and I am told by Richard Suzman of the National Institute on Aging (NIA) that NIA is encouraging applications for research grants to do analyses of the SOA and the LSOA.

The LSOA was intended to identify a representative sample of those people who were living in the community in 1984, and to trace them into nursing homes, see if they died, see if they stayed in the community, and what happened to them over time. Those data for the first follow-up will be available on the LSOA tape, which will be released in July of this year.

The functional limitations questions, the ADL's and the IADL's, were also asked in 1986 in the NHIS. That public use data tape is expected to be available about December of this year.

SUMMARY OF BREAKOUT SESSIONS

Gerry E. Hendershot, Ph.D., National Center for Health Statistics
Susan S. Jack, National Center for Health Statistics
Joseph E. Fitti, National Center for Health Statistics

GERRY HENDERSHOT: Susan Jack was the lead person for writing the edit specifications for the SOA and is also co-authoring a report on functional limitations which will be published by NCHS. The other co-authors are John Fulton and Sidney Katz of Brown University. Joe Fitti is in our Survey Planning and Development Branch, and was the lead person in the development of the SOA including the questionnaire design, and also has had a major role in the LSOA, which is the follow-up to the 1984 SOA.

QUESTION: It would help if you had someone just briefly describe the long term care questions.

GERRY HENDERSHOT: The first section is on the family, whether they have any children, how far away the children live, that sort of thing. The next section is on community services, including formal community services and informal community contacts. The next section is on occupation and retirement. Conditions and impairments is the next section. There is a vision and hearing impairments and functional limitations section. There is the ADL and IADL checklist and one page on long term care. Not very much, actually, but it does include some questions about previous nursing home stays, knowledge of hospice services available, and a health opinion type question.

It is a complex sample design which is representative of the civilian noninstitutionalized population. Each case has a weight which represents the estimated number of people in the population represented by that sample person. To get accurate estimates for any statistic for the population, you have to multiply the characteristic of the sample person by that sample weight. If you've used any of the commonly used software analysis packages, you will know that is a very simple procedure to use.

How is that weight calculated? There are a number of factors that go into it. First of all we select a sample with the probability proportionate to the population size. The most important factor is the inverse of the probability of selection. We know the probability of each person in the sample having been selected. The first rule is to just weight them up by the inverse of that sampling fraction. There are some other ways you correct for non-response and at the end we do what we call post-stratification, where we compare estimates for 60 age, race and sex groups found in the Current Population Survey (CPS) with our estimates. If they differ, we inflate or deflate our estimates by a ratio to make them agree with the CPS.

SUSAN JACK: On the aging supplement itself, the "60 cells" are appropriate to the core questionnaire because, I believe, 65+ is the only age break for those over 65. They did a slightly more precise age weighting for the SOA itself.

If you have the core questionnaire and its weight for an individual who also had the SOA, they may not have exactly the same weight on the SOA as they do on the core because there was a non-response factor, which was less than 10 percent. They had to in effect, re-inflate them slightly. You will find in some groups, anyway, that there are different weights in the core and the SOA for the same individual. You have to use the weight that is actually on the SOA to come up with any estimates.

GERRY HENDERSHOT: The terms "core" and "supplement" refer to the basic health and demographic questionnaire and the special health topics questionnaires.

The SOA public use tape includes all of the information that was on the SOA questionnaire, plus the person record from the core questionnaire. You can also link that data set to the rest of the core data for that sample person. That is, you have an ID which allows you to link them. To do that you would also have to get the core public use data files, of which there are five.

Any of the information that is available from the core questionnaire can be linked to the information that is available from the SOA questionnaire.

SUSAN JACK: In terms of the financing of long term care and income, we actually have no information directly concerning finances. The only thing we have even vaguely related to that is their health insurance status at the time of the interview.

GERRY HENDERSHOT: We do have family income information.

JOSEPH FITTI: And sources of retirement income.

We have residential ownership or rental status. We do have dollar values in that question series which reflect the current mortgage and the estimated value of the property if they own it, or the amount of rent they are paying if they are paying rent.

QUESTION: What was your experience with proxy respondents?

GERRY HENDERSHOT: You may recall that the respondent rule for the supplement itself was primarily self-response. That was our aim in the original design. The sampling scheme that you have heard described was selecting among those persons who are in the NHIS households for that year of 1984 who were age 55 or over, one-half of those 55-64, and everyone who was 65 and older in those households.

The sampling plan was accompanied with the rule saying we would allow proxies in the event of mental or physical incapability for responding to the interview, or if the selected respondent was not going to be available at all during the period that the interviewer was going to be in the area. They work on a weekly sample basis with roughly a 3 week time-frame to gather all the interviews required. There was a temporal definition for gathering the interviews. That was the second condition by which we may not have actually spoken to the selected respondent.

The consequence of the respondent rule was that this impacted only on a small part of the questionnaire which we felt would not be reasonably responded to by somebody other than the individual. Particularly for the health opinion section which is asking for some information about attitudes and practices. About 8 percent of the data is responded to by proxies.

QUESTION: When you look at reliability comparisons when you do proxy interviews, what do you find in them?

JOSEPH FITTI: I do not have the figures, but there are some slight differences in the proxy data versus the household sample. If you look at the variables and then try to get them to line up, there are not large differences.

GERRY HENDERSHOT: If somebody wanted to exclude the proxy respondents there is a code on the tape which would allow you to identify them and exclude them.

QUESTION: Can you describe the coding of morbidity and the relationship to specific diagnostic attributes?

SUSAN JACK: Let me back up a little bit. On the basic demographic questionnaire, conditions arise in a variety of different ways. Any time they would arise, generally there was a special set of questions on the condition record. Those questions are used to code an ICD code. The coding is actually done by our staff in North Carolina, and they were to some extent trained medical coders, that is, trained using our version of ICD codes. We have something called impairment codes, that nobody else has, known as "X" codes. Very similar questions were asked for any condition that arose on the SOA. If you had a limitation of any kind and if you reported a condition in response to any of these condition lists that is another way to get the condition.

The ADL's and the condition list were, again, coded by the same coders that do our regular coding. Some of those ICD codes we created by computer, or re-code. There is a chronic condition re-code, an acute condition re-code and a re-code that covers all ICD codes. The current version is very similar to the one that is actually listed in the ICD book.

There are actually two different files for the SOA. There is the basic questionnaire, one for every person who was interviewed on the SOA. That could or could not generate a condition record. It is a little bit similar to our basic core questionnaire where you can or cannot have a condition record. There was a condition record generated from ADL, IADL and other condition you reported. The actual source is coded on the condition record, which is not true in our core questionnaire. There is a location that tells you if they recorded this from the specific activity, like dressing, eating or whatever. You have this separate file which has a fair amount of detail about onset.

For the ADL's and IADL's specifically, because we thought it was more useful to have everything on one file, we took a subset of the information on the separate condition record and it is placed at what basically is the bottom of the column asking if you have trouble dressing or whatever. There is a small set of information about the condition that the respondent said caused the limitation. Many people will never have to go out and access the other condition file as a part of the record.

GERRY HENDERSHOT: The SOA public use data is two separate files, both of which are included in a single price when you place your order. The price of $275 gets you both data tapes and all of the documentation. The first tape has the person information both from the core questionnaire and the SOA questionnaire. The second tape has the condition information, one record for each condition that was reported by an SOA sample person.

SUSAN JACK: You could have a person who could report ten conditions on his core questionnaire. If he never records anything to require generating a condition on the SOA, you will not have any condition records for him on the SOA file. You can match to those core condition records. In most cases, however, they will show up on the SOA. In the case where they reported a condition causing limitation of activity on core and they did not report it on the SOA, we went ahead and included it on the SOA.

A person can report something that is fairly general for a limitation of activity. If you ask him specifically about why he has trouble eating, they may well report a different condition which is much more specific. If we could not guarantee that they were the same condition, we just went ahead and called them two different conditions and that did leave us with some proportion of the conditions being reported for a cause of limitation on core and not on the SOA. We did move them and they are identified by a field that says they are only here because they indicated limitation of activity on the basic questionnaire.

JOSEPH FITTI: All these files are linkable. There are identification numbers that tie the SOA person's record, the SOA condition record, the survey basic records or the health insurance records for that year.

GERRY HENDERSHOT: If you have all the data sets you have not only the information about the SOA sample person but the other people in the NHIS household. You could relate SOA data to characteristics of other people in the SOA sample person's household.

The respondent on the core and supplement questionnaires may not have been the same person.

QUESTION: Is there anything on informal caregiving?

SUSAN JACK: If you have a problem with an ADL or an IADL, they did ask the category of people who are helping you and whether or not they were paid. You know whether it is a relative or non-relative who lives in or out of the household. You will have that for any ADL or IADL problem.

They also asked a question whether you needed somebody to help you out for a few days, and if you were disabled for a slightly longer period of time, was there somebody who could care for you. As I say you do not know who the individual is. You just know a category. It also could be five people and you would not know that either. You would just know the category of what kind of person they were.

JOSEPH FITTI: That coding on caregivers is generally, as she described, a relative or nonrelative, and whether that individual is living in or out of the household.

There is another category that does distinguish those who mentioned a spouse, child or parent who was the caregiver or helped with the ADL or IADL. So that distinction is made in the relative group.

QUESTION: Is there anything on psychosocial conditions like depression and loneliness?

JOSEPH FITTI: Psychosocial conditions are interesting. It was considered; an original document was designed for an earlier draft of the SOA but it was considerably longer and addressed areas that did not appear in the final version of the questionnaire. One of them was an attempt to get a measure on the mental health status of the sample person. We attempted to administer questions on the patient's mental health status. On the pretest, it was very unsuccessful, we discovered. The decision was not to include that and not to include other elements that were associated with an attempt to measure mental health. It became too problematic in the household setting.

In many of the households there were two people eligible; particularly in those households where the respondents were 65 and older, a husband and wife, we attempted to interview each individually and separately. It did not always happen. Either the wife was reluctant to leave her husband or the reverse. To complicate it even more, they would share the answers in some places. We did try to get only the individual who was addressed to provide the information. That did not always work. That was one of the major problems in trying to do the mental health scale. It was unable to be administered in a private setting.

SUSAN JACK: We do not have psychosocial conditions. There were questions about how good a job they think they are doing taking care of their health. There were psychological types of questions which certainly were not close to a depression scale. How is your current health compared to how it was a year ago? Has your overall health caused you a great deal of worry? Do you think you're as active as other people your same age compared to a year ago? How much control do you think you have over your future health? Apparently that is a question that shows you all kinds of things, at least for some people.

QUESTION: About 8 percent of your sample was black. Did you examine this black subset or were they related to the whole?

SUSAN JACK: We have run some tables looking at Black/White differences. The problem is the very small numbers, particularly for Black males. I have forgotten the total number of Black males in the sample population, but it is very small because they died off, to some extent.

QUESTION: Do you have information on retirement, especially male and female differences?

SUSAN JACK: On the retirement issue, we did ask if they were still working; among the 55-64 years olds, most of them are still working. If they were not working they were asked if there were some types of jobs they could do if jobs were available, and then if they thought there were, we asked them if they wanted to work. If they had ever worked, we did ask them some retirement questions. These included: had they retired more than once; was it because of a physical condition; whether they thought they would have a health problem if they continued to work. It goes into retirement income sources in specific form, but I don't know if anybody has looked at it in terms of sex differences.

GERRY HENDERSHOT: An Advance Data report will be available in about June. It has looked at the retirement data that is in the SOA, particularly the issues of interest and ability to work. It is not a complete analysis of the retirement and occupation section, but it does look at these items about whether or not they were able to work as measured by ten tasks and the ability to perform them, plus the items of opinion about whether they would like to work or not. The retirement section itself, is very extensive in some senses; it was designed to permit a classification of the sample as retired or not retired on a number of scales. One was self-defined status of retirement. A second was retirement as defined by income source. A third was a status of retirement that was more officially used in terms of Social Security Administration (SSA) standards. That data can be looked at in a number of ways on the question of retirement status among the population that we have in the sample. We have begun to look at it now, but I do not have any figures on how it breaks out among males and females. It does look as though most of the data on employment status, says that the males are employed more than the females.

QUESTION: What are the validity and reliability of the health status measures?

SUSAN JACK: We have other surveys in NCHS on some of our data, including hospitalizations and doctor visits; they measure them in different ways. In terms of the IADL's and ADL's, I have seen some other surveys that say we are in the same ball park. I think they can be measured in different ways. The first question that is asked is do you have trouble doing X, but they are allowed to answer that they do not do it for other reasons. Some people have not allowed for an answer like that so if you exclude those people from the population you end up with a very different base than if you included them. Some of the difference has been attributed to who you are actually including in your population. If you force them into a yes/no answer, where do you put the people who do not do this activity?.

JOSEPH FITTI: Some of the more general characteristics of the sample have been looked at in terms of other sources. The distributions by age and sex, they are basic and compare nicely with other data. Detailed information such as the percentage and characteristics of those who live alone, from our study, have been looked at with other data on those who live alone and there are some nice comparisons there also.

GERRY HENDERSHOT: The short answer is that there have not been thorough validation studies of these data. A lot of comparisons have been made with other data sources that give us confidence that we were measuring what we intend to be measuring.

There is a fairly large literature on the NHIS methodology and evaluation of the quality of the data which can be used, and, so far, not a lot specifically on the SOA.

JOSEPH FITTI: We did reinterviews as a reliability check on this study, which is standard procedure for the NHIS, and selected a number of households who were re-contacted after the initial interview was completed. We asked selected items of the SOA, and we re-asked the ADL's and IADL's and a selection among the occupation and retirement section of the sample person that was designated. That procedure was followed.

QUESTION: Regarding the information that you collected on the conditions, and also on the memory and cognitive difficulty, have any analyses been done on that?

JOSEPH FITTI: Not yet. I have not seen anything on the conditions themselves that were collected in the SOA. There are some conditions in the SOA which were designed to produce published estimates among this population. They are probably a better source of the information than the NHIS itself. A couple of them have been looked at. They are in an Advance Data report. Vision and hearing impairments have been looked at, and there is some preliminary information available on that. Urinary problems and incontinence have also been looked at and an Advance Data report has been produced for that.

QUESTION: Within the list of conditions, is Alzheimer's listed on this?

GERRY HENDERSHOT: Alzheimer's, osteoporosis, and broken hip are specifically designated.

SUSAN JACK: If you were interested in looking at Alzheimer's, we do have marginals on all those things, so we can tell you how many cases are showing up. I have run some tables for the ADL and IADL functional limitation report that I am co-authoring, and they were actually run, crossed by their functional limitation status as re-coded by John Fulton and Sidney Katz. In some cases we have regrouped them because the purpose of asking the broken hip was to catch people who did not know they had osteoporosis on the assumption that the broken hip was caused by osteoporosis.

QUESTION: Did you ask if people had representative payee, guardianship, power of attorney or anything of that nature?

SUSAN JACK: The answer to the last part is no. The answer to the first part is, if you want to do it, we would be delighted to have somebody do it, but no, as far as I know. We have, for our basic information, an SED list. We run our basic data outline for many different demographic variables. We have not done that with the aging supplement. I personally would like to run some of those tables, so we can answer some of these questions.

GERRY HENDERSHOT: Maybe I should mention that our analytic staff is relatively small, seven or eight full-time equivalents (FTE's), and we do a survey every year. In 1984 we did the SOA; in 1985 we did health promotion and disease prevention; in 1986 we did vitamin and mineral, insurance and functional limitations; in 1987 we are doing cancer risk factors and cancer control; in 1988 there is another long list. We do not have the staff to do a complete analysis of any of the surveys we do. We try to get out some preliminary reports and assist other people in analyzing the data, but we expect that the main part of the analysis will be done by people who purchase public use data tapes.

The data tapes became available from the SOA in December 1986. Through yesterday we have sold 35 of them, so they are moving very briskly. I expect that within 6 months or so we will begin to see analyses coming out in publications from people who have purchased those public use data tapes.

QUESTION: Do you include in your questionnaire questions about depression? In my country one out of four who's 65+ is continuously depressed.

JOSEPH FITTI: That is what I was alluding to when I mentioned that we tested that and hoped to include depression scales as a set of items. Our experience in actually trying to gather and pretest was such that we were not going to have good data if we had included it. It was excluded, and we do not have it.

GERRY HENDERSHOT: Let me interject one more thing. We have got a small contract in process now, it will be out shortly, to create a microcomputer public use data set from the SOA. It will not contain all cases. It will not contain all items on the questionnaire, and it is not really intended for a rigorous scientific analysis. You will be getting a rough idea of how things lie, for people who then want to go on to analyze the full public use data tapes. That will be available probably toward the end of the year.

QUESTION: You mentioned earlier two other data sets, I think, if my notes are not wrong, the National Household Longitudinal Surveys (NHLS) and LSOA. Would you define those for us and tell us what the status is again?

GERRY HENDERSHOT: The NHLS is a generic term. We also use another term, targeted follow-up surveys, to refer to the same thing. That refers to the capability that the NHIS now has to do follow-up surveys of people interviewed in any particular NHIS. An example of that is the LSOA, which is a follow-up to a person's first interview in the SOA in 1984. They were reinterviewed in 1986. Plans are to reinterview them again in 1988. Part of the LSOA is also to match information obtained in the original SOA and the LSOA with death records through the NDI and Medicare records.

JOSEPH FITTI: Just to clarify, the LSOA is a three-pronged effort.

We are matching with the NDI for all persons who were in the original SOA file, everyone 55 and older, and will be matched against that every year between the years 1984 and 1990 for a 6 year period. We are also going to be looking at Medicare Part A files for persons who were in the 1984 age 65 and older sample for the same years, 1984-1990. The third aspect of the longitudinal follow-up is the reinterview, occurring in 1986 and 1988. For that set we are selecting a sample of the total SOA respondents--only those persons who were 70 and older in 1984, and that in itself has been sub-sampled. Half of those 70-74 have been sub-sampled, and everybody 75 and older. There are 5,151 individuals in the reinterview set.

We have completed the first reinterview, which is essentially a reading of their current functional status repeating the ADL's and the IADL's, and whether they have died. Also, there is a reading on changes, if they have occurred, in living arrangements: whether they are still living where they were; are still living independently; have moved in with someone else; if so, who that person is; or whether they have become institutionalized.

We find, by the way, in our re-contacts, about 12 percent in a 2 years lapse, among the 70 and older group, that we were being told have died in that period. We were checking change in living arrangements and changes in functional status, primarily. We were getting nursing home experience in the interim time and hospitalizations also. That is the content of the reinterview.

This file, which will include NDI match data from the years 1984 and 1985 plus the first reinterview data, will be available in July of this year.

QUESTION: We have the National Long Term Care Survey (NLTCS), so we have information on the disabled. The SOA can give us information on the non-disabled population. Those are two separate reports. Is there a way to put together the data so we can get the whole set of information?

GERRY HENDERSHOT: The two surveys are complementary. I do not think it would be possible to actually pool the data from the two sources, but certainly analyses of the two data sets ought to be set side by side to get a complete picture of long term care for both the institutionalized and noninstitutionalized population.

JOSEPH FITTI: An interesting comparison or combination of data will be the National Nursing Home Survey (NNHS). The 1984 SOA was designed consciously aware of that study and we matched as many variables as we could that appear in both of the studies, the ADL's and IADL's, for instance.

The 1984 SOA did access questionnaires that were either used or planned to be used on other studies of the aging population in the design of its items. There are comparable items in the NLTCS as well as the SOA that could be looked at for comparable data.

QUESTION: Were veterans identified in the survey?

GERRY HENDERSHOT: We did in the SOA address the population aged 55 and older, and we do have in that set a number of veterans that are available. I think I have the raw sample count here. I do not have what it projects to the total population, but among the total of 16,148 people in the SOA, there are 2,812 veterans of World War II. They are certainly a set that would probably be possible to look at independently, if it was desired.

SUSAN JACK: We have that information on core, and which period of military service they had.

QUESTION: Is there anything about the veteran's income, for example, pensions that you might have gotten out of the income question?

JOSEPH FITTI: We have not specified Veterans Administration (VA) or veterans income as a separate category.

GERRY HENDERSHOT: The health insurance supplement which was asked the same year, has information on coverage for health care by veterans' programs.

QUESTION: I am interested in more information about the sample design, which you mentioned was a targeted sample.

JOSEPH FITTI: The LSOA is a follow-up, essentially, of the SOA sample over time. It has already begun, and the long range plan will carry forward through the year 1990, 6 years. There are three major lines of follow-up that will be incorporated in the full LSOA. One will be a follow-up of all persons in the 1984 SOA aged 55+ through links with the NDI which the NCHS maintains. The objective here is to establish some information on mortality, through the registration of certificates. We will also extract from those files information about cause of death to expand the whole set of illness and disability on the sample.

That was one area of follow-up. The second area of follow-up will be done with those persons who were 65+ in 1984 among the SOA sample who will be followed through matching the Part A records for the period 1984-1990. There is a great deal of information there. We are not at the present time planning to extract all of it. Our primary concern and interest in that file is information on hospital utilization and some information on medical expenditures that will be available in the Part A file. That, too, will be done on an annual basis through the year 1990.

The third line of follow-up that is part of the LSOA is re-contact. This will be done among selected samples out of the 1984 SOA group, the first of which has already been designated and the first re-contact was with persons 70+ in 1984. We have reinterviewed them one time already by telephone in 1986 with an interview that essentially was designed to update their functional status, obtain any information on changes through readings of the ADL's and IADL's at that point. Changes in living arrangements is a second area of interest that is in the reinterview conducted in 1986, and also information about nursing home stays that occurred between 1984 and the re-contact, and hospitalizations that occurred between 1984 and the re-contact.

We have 5,151 persons that fall in this category for the re-contact interview in 1986, of which, by the way, we got 93 percent identified in terms of a status, including approximately 12 percent who were reported as dead during the re-contacts. Those will be validated through our NDI matches, obviously.

SUSAN JACK: Let me tell you the general sections that are covered in the SOA. First of all, separate from the SOA there was another supplemental questionnaire that year on health insurance, so there is health insurance data for these people. It is physically on a different data tape. There is information on family structure relations, support and living arrangements. There is also information on community and social support services. There is some information on occupation and retirement. Conditions and impairments, ADL's, IADL's and nursing home stays.

There is help with care. There are really only two questions about whether or not someone can help you: if there is somebody to help you for a few days, or somebody to help you for more than a few days. There is a question about whether or not they know about hospices. There are some health opinion questions. If there is a need for help with ADL's, IADL's or if they mention a condition on the condition list, a condition record is generated.

There are two different files in the SOA. There is a file that has a person record on the front which is all the core information, including income, education, or anything that is on the core personal tape. There is a condition file which is all the conditions generated as a result of going through the SOA.

GERRY HENDERSHOT: Susan referred to the core and the supplement. The core questionnaire is the questionnaire that is used every year, and contains information on everybody in the NHIS sample household. The supplement, the SOA questionnaire, was for a sample of older people in the households. The information from both sources on an SOA sample person is available. We have the core public use data tapes which are available from NTIS, and the SOA public use data tapes which are available from NCHS. If you get both sets of data you can link any of the data from either of the two questionnaires.

SUSAN JACK: We have problems with Medicaid eligibility even on the core data tapes. It varies from month to month who is actually eligible for Medicaid. We do have

Medicare information. We do have some Medicaid information because it is on the health insurance tape. They were asked whether or not they have used Medicaid. A person who does not use Medicaid usually does not know if they are eligible for it.

We do list possible sources of income to remind them of things that are income. It is down to the thousand dollar increments, at least for the lower income groups, which is a lot better than we used to do. A lot of people do not know. Close to two-thirds of them are over $20,000. The poverty index is on core, and that deals partly with whether or not there is a person 65+, the number of children in the household, and their income status.

JOSEPH FITTI: We ask the respondents if they had retirement income and whether it was from SSA, railroad retirement, private employer or union pension, government employee pension, military retirement or some other source. That pertains only to retirement income among the SOA sample. The additional income data is from the NHIS.

QUESTION: How do you match the LSOA to Medicare?

JOSEPH FITTI: We actually asked in the reinterview for their health insurance claim number which will be used against the Medicare file. We can also do matches against Medicare using the Social Security number, which we also have from the 1984 interview.

QUESTION: What do you have on the rural/urban dimension?

SUSAN JACK: There is the non-SMSA, and SMSA information and there is a breakdown of SMSA between central city/non-central city. There is also a farm/non-farm non-SIVISA kind of breakdown which is essentially urban/rural,

QUESTION: I noticed that you did a special project on home care utilization a few years ago. I was wondering whether you have given any thought to perhaps making it a routine collection item.

GERRY HENDERSHOT: I guess you are referring to the 1979-1980 home care supplement?

That has about the same information that is contained in the 1984 SOA on ADL and who provides care, if a person has a limitation in ADL's or IADL's.

SUSAN JACK: The categories are not the same and it was not addressed the same way. We asked if you needed help with something. There are only two different possibilities, if you needed help with an ADL or IADL in general. In 1984, the activities were specific and there are categories of persons who helped you, either a relative or a non-relative who lives *in* the household, or a relative or non-relative <u>outside</u> the household. You know a category but not a person.

There are also two questions on disability. For a short period of time or if it were a somewhat longer period of time, was there somebody who could help you, and the same four categories of helpers.

In the functional limitation supplement in 1986, those same questions are on, but again, it is for a specific activity which is not the same exactly as it was on the home care supplement. You could make similar inferences from it.

GERRY HENDERSHOT: We have collected data in 1979, 1980, 1984, and 1986, and it is being collected in the LSOA. We do not have any plans at the moment to collect that kind of data on a regular basis.

SUSAN JACK: Technically, there is core information that does relate to it. I do not know how large the numbers are. In the doctor visit file there are questions about whether or not you have seen a medical person in the last 2 weeks. For somebody who is getting routine care from, possibly, a visiting nurse, in theory it should show up in there as a home visit, because we know the place of that visit. You could combine several years and look at the home doctor visits in the last 2 weeks to see what kind of person is providing them. That is not going to pick up somebody who comes in and cleans up your house because you can not do it, but it should get medical personnel, like a visiting nurse or somebody.

QUESTION: What would be involved in weighting the NNHS to reflect the total actual nursing home population and then literally creating some kind of merged file.

JOSEPH FITTI: That would be ideal, but I do not think that is really possible. What is possible will be parallel sets of data for the institutionalized and noninstitutionalized population.

QUESTION: Can you weight them so that both sets of data are appropriately reflective of national estimates?

JOSEPH FITTI: Whether you could combine them to get, say, total persons 65+, including those institutionalized and noninstitutionalized, I do not think that is going to be possible.

QUESTION: We were talking about repeats of the aging supplement, a repeat already done and a repeat projected. There were 5,000-6,000 health persons. Will the same people be interviewed again?

JOSEPH FITTI: Correct. This is part of the LSOA, the reinterview aspect. We have 5,000 from the 1984 SOA who were aged 70+ who are being followed in that set.

QUESTION: What were the questions on social and family support about?

JOSEPH FITTI: These questions on community support, as such, appeared only in the 1984 SOA. They are not being repeated in the re-contacts. The areas of community support specifically asked in the original SOA were whether or not they used a senior center, special transportation for the elderly, whether they had meals delivered to their homes, such as Meals-on-Wheels programs, whether they go to senior centers specifically to eat meals, whether they use a homemaker service, whether they use a service that routinely checks by telephone, visiting nurse service, home health aide, or an adult day care center utilization. These areas are the ones that were specifically asked about in the 1984 SOA. The reinterview in 1986 and 1988, as it is planned, will not repeat these questions. We will ask whether or not they are still living in the same place, whether they have moved to an institution or not, whether they have moved into another location to live with another person or whether someone else has come in to live with them as a living arrangement change.

QUESTION: What other kinds of questions are being repeated?

JOSEPH FITTI: The ADL's and IADL's are asked specifically. The change in living arrangement will be obtained. Whether or not they have had nursing home stays since the 1984 or previous interview, what hospital stays they have had and what physician contacts they have had in that interim period. That essentially is the follow-up reinterview data.

QUESTION: On the LSOA, are people who are 55-64 years old but are SSDI disabled beneficiaries lost, or can they be merged with Part A data files? Second, what are the procedures for getting the Part A data from the NDI match?

JOSEPH FITTI: I do not think anybody but the NCHS would be able to do that, because we have proprietary information which must be protected that we gathered in the 1984 interview that only we can handle. What you would need to make the links, we could not give to you. It is an interesting concept. We have not thought of that, actually. We plan to match only the 65+ set. The identifiers would be needed to make those links and we can not provide those to the public.

QUESTION: You would not want us to get the follow-up data on mortality. How are we going to do that?

JOSEPH FITTI: You would have to make a request to NCHS and see if we will do it.

GERRY HENDERSHOT: We will be providing mortality information from our NDI matches on an annual basis for that sample.

JOSEPH FITTI: The LSOA plans for data releases, by the way, are annual during this 6 year period. The first set of data will be out in July of this year, the public use file. Mortality data will be primarily from the NDI match. That is, we will identify those persons in our original sample who have come up in the NDI files and provide probably a date of death and a cause of death bit of information. We also have another source of mortality data among the set who are being reinterviewed.

GERRY HENDERSHOT: The NDI is a system operated by NCHS which allows researchers who have identifying information on persons to discover whether or not a death certificate has been filed for that person. Then researchers have the information they need to go back to the states where the death certificate was filed to get additional information that is recorded on the death certificate. It is that NDI mechanism that is being used to identify persons in the LSOA who have died.

Another general issue that comes out of this discussion that is just gone on is that there are many things that could be done in the way of follow-up surveys or new surveys. To do follow-up surveys, because of confidentiality limitations, it has to be NCHS that actually does the field work and data collection work. We do have an interest and a real wish to cooperate with people in the research community to mount such special follow-up surveys. We have the mechanisms and the staff to do that. We would be glad to talk to anybody who has an interest in doing special follow-up surveys.

There is also a possibility of repeating the SOA as a cross-sectional survey in future years.

QUESTION: How often do you revise the core items on the survey, and to what degree are insurance related issues covered in the core? I do not see any reference to insurance topics and I am wondering if that might not deserve to be on the permanent core survey.

GERRY HENDERSHOT: The general rule of thumb is that we revise the questionnaire about every decade. It was last revised in 1982. We are currently in the process of designing a new core questionnaire with a target of 1989. We did ask insurance questions every other year, in even numbered years.

SUSAN JACK: In spite of the fact it is not listed in 1984, it was done in 1984. You have to understand we have this timing problem on the questionnaire. There is the argument that if things do not change every year why ask them every year. The health insurance has been asked when there is a specific reason for asking it. For instance, in 1983, the reason that it was asked was that was a year of very high unemployment, and we added this supplement for half a year to check whether there was a problem with less of insurance coverage.

GERRY HENDERSHOT: In a general way, the answer to your question about why we do not collect health insurance information is that we have a limited amount of time that we can spend in the household collecting information. There are lots of competing interests for data. In view of that, you might be distressed to learn that the major purpose of our current revision of the core questionnaire is to reduce its length from about 30 minutes to about 15-20 minutes. The reason for doing that is that because of budget pressures the NCHS can no longer support the full survey from its own budget. The way we are making up the difference between what NCHS can include in its budget and the cost of the survey is to offer our services as a data collection mechanism for health statistics to the research community, primarily, the public health service research community. We are increasing the amount of time that is available for these special health topics questionnaires from the current 25-30 minutes to more like 40-45 minutes, or longer, and making that time available to other agencies who have an interest in collecting data on a particular health topic, such as health insurance.

QUESTION: Have you collected information on insurance for long term care, or do you plan to in the future?

SUSAN JACK: There is no good reason why we could not. We have from time to time added questions on health insurance, the 1983 supplement on unemployment. In 1986 we added a question about dental health care coverage, which we had never asked before. Certainly if we did an aging supplement again, obviously, it is a very good question to ask.

GERRY HENDERSHOT: The SOA was a special supplement to the NHIS in l984. The NHIS is an on-going survey in the field, literally all the time. Each week interview assignments go out and each week's assignments are a nationally representative sample of the civilian noninstitutionalized population in the U.S. It is a personal interview in each sample household. We get information on everybody in the household for certain basic health and demographic items which are the same year after year.

In addition, in any given year we do one or more special surveys on selected public health topics. Usually that is for a single randomly selected sample person in the household.

In 1984 the special health topic on which we focused was health of the aging. We selected all persons in NHIS households who were 65 years of age and older for that questionnaire. A random 50 percent sub-sample of persons 55-64 got the same questionnaire. We have everybody 65+, and half of those 55-64. That is about 16,000 cases total, and 11,000 65+.

The major topics include measures of functional limitation, ADL's and non-ADL's, which have gotten a lot of attention at this Conference. Some other physical conditions such as vision impairment, hearing impairments, and so on, as well as use of community services, and a little bit of information on history of use of nursing homes. Any of that data can be combined with data that are collected on the basic health and demographic questionnaire, which includes a lot of information on health conditions, as well.

You have got two sources of data, two questionnaires for the same sample of people.

On the question of periodicity of our collection of data of this kind, there was a similar survey in both 1979 and 1980, which we have called the home care supplement. That did include questions also on functional limitations, the ADL's and IADL's. Unfortunately, the questions in the two surveys were asked a little differently. In the 1979-1980 survey, the ADL and IADL questions were asked something like, because of a health problem or physical condition, do you need or receive help? In 1984, we asked, because of the health or physical problem, do you have difficulty, first of all, in each activity. If they did report any difficulty, we asked how much difficulty, how difficult it was. Then we asked if they received help. It is difficulty and receipt rather than need for and receipt, in 1984. We thought that was an improvement in asking questions, but it does make it different from the 1979-1980 data.

In 1986, for persons 65+, the questions used in the 1984 survey on ADL's and IADL's were repeated. We now have exactly comparable data on ADL's and IADL's for cross-sectional samples in 1984 and 1986, and similar but not exactly comparable data for 1979 and 1980.

There are no plans to repeat this on a periodic basis as things now stand. Essentially, we do the basic health and demographic questionnaire each year, and then the supplements we do in any particular year are determined by a process of inviting proposals from other federal agencies for data collection, reviewing those proposals, and deciding on the basis of technical merit, public health importance, and the availability of funding which of those topics we will do. Whether or not we do another cross-sectional survey like the SOA in the future depends on a number of things which are not well known at this point.

This is a place where I should mention, too, that there is a LSOA which is a follow-up to the 1984 SOA, which is funded by the NIA. That takes the 1984 SOA sample and they will be followed in the NDI, all of them, for at least 6 years. The NDI is an operation of the NCHS which allows a researcher, if he has certain information about an individual, to determine whether or not a death certificate has been filed for that person. It also tells you what state you go to get the death certificate information.

The 1984 sample will be followed for at least 6 years in the NDI so that we will know if they died, when they died, and can relate that to the information collected in 1984.

Those who are 65+ in 1984 will also be followed in the Medicare records, matching to the Medicare records with the cooperation of the Health Care Financing Administration (HCFA). In addition to those two continuing data collections on the 1984 sample, periodically sub-samples of them will be reinterviewed. The first reinterview has already been completed. That was done about August 1986. A sample of those 70 years of age and older in 1984 was reinterviewed, mostly by telephone. They were followed into nursing homes, or wherever they happened to be. We did not just go back to the household they lived in 1984. Part of the purpose of that reinterview was to find out what happens to people over time; do they go into nursing homes, die or what? Each year there will be a new public use data tape released containing the information for the reinterview group on the original SOA, the reinterview data, the NDI information and the Medicare information. That will be updated each year. The first of those data tapes will be available in July of this year. I have been told by Richard Suzman of NIA that his agency is very interested in receiving applications for grants to do research on both the SOA and the LSOA.

We plan to reinterview that same sample again in 1988. Beyond that, it is difficult to say. I mean, it is getting too far in the future, but the hope is that we can follow them for a long period of time. There were about 5,000 in the first reinterview.

Comparability to the NLTCS? I do not really know enough about the NLTCS to say much about that. I guess an important difference is that the SOA and the LSOA are representative samples of the whole community living elderly population, whereas the NLTCS sample was screened for disability. The NLTCS, obviously, has more kinds of data input and has more frequent follow-up.

On insurance, periodically we do a special supplement to the NHIS on insurance. We do not get very much information, but the insurance data were collected in 1984. We had both the insurance supplement and the SOA, os it is possible to get the insurance information and link it to the information from the SOA.

Incidentally, there is an annual publication from the NHIS which is entitled Current Estimates from the National Health Interview Survey. In health insurance, we ask whether they are covered by Medicare; does the plan pay any part of hospital expenses; does it pay doctor or surgeon bills; was it obtained through an employer or union. It also tells whether they are on AFDC, Supplemental Security Income, Medicaid (SSI), any other public health system's program that pays for health care; also, military types of health care coverage such as CHAMPUS. Those have been asked roughly every 2 years for a long time. They were asked again in 1986 so they could be linked to the functional limitation data which were collected in 1986.

We have hospice care. We asked if they are aware of what a hospice is, and we also asked them if there is hospice care available to them in their area. That would be a perception of the availability of that particular kind of service in the area. We have, in some supplements, asked questions about distance from medical doctors and usual source of care.

We decide each year what special health topics are going to be covered. We are planning right now for 1989. We just received proposals a couple of months ago for topics for 1989. That is a wide open process. We receive proposals from anybody who cares to submit them. This is a relatively new procedure for the NHIS and it arose, frankly, because of budget restrictions. NCHS is not able from its own budget to fund the complete costs of the survey. It can fund only about two-thirds of the cost. The other third we generate by, in effect, selling time on the survey to anybody who needs to have health data collected, provided it is in our judgment within the mission of our agency and serves an important public health need.

We have received some proposals from the private sector organizations and expect to receive more in the future. We got one from the American Speech and Hearing Association (ASHA) this year. I think it was the first one we have gotten from a private sector organization.

In 1984 there were approximately 16,000 people interviewed, 65 years of age and older. In 1986 a sample of those who were 70 years or older in 1984 was reinterviewed. There were about 5,000 of them. The plan is to reinterview those 5,000 or their survivors, again in 1988. The capability exists, of course, to reinterview any of the others, as well, the younger ones. Depending on interest and the availability of funds, probably some of the others will also be reinterviewed.

The SOA refers to the cross-sectional 1984 survey. All of the follow-up activities which are being conducted come under the rubric of the LSOA.

I guess the strength of the SOA is that it is a large nationally representative sample of all persons living in the community over the age of 55 and the data were collected in a standard way. They were collected in sufficient detail to allow you to define a limitation for your particular purposes, because we get whether or not they have difficulty, how much difficulty, and whether they receive the help of another person.

You can use difficulty as your cut-off, a lot of difficulty as your cut-off, or receiving the help of another person as your cut-off. It gives you some options on how you would want to measure it. Of course, the option you choose will have a big effect on your estimate of prevalence. A lot more people find things difficult than receive help.

As I said earlier, I am not an expert in long term care, but sitting through 2 days of hearing experts talk about it I think that standardization in the measure of disability and functional limitation is something that is very much in need. If we could agree on how we want to measure it, then I think we could get some standardization in the way it is actually measured.

CHAPTER V. OVERVIEW OF THE 1985 NATIONAL NURSING HOME SURVEY

Evelyn Mathis, National Center for Health Statistics

The National Nursing Home Survey (NNHS) system was developed in 1972 to learn more about the residents of nursing and personal care homes and the services they received. The survey produces data from two perspectives. These are that of the recipient of services and that of the provider of services.

The purpose of the NNHS is to collect comprehensive information about nursing facilities, their services, their residents, their discharges and their staff. Estimates from the survey are from all nursing and related care facilities, without regard to licensure or Medicare/Medicaid certification status. All information are collected under a guarantee of confidentiality and the survey is voluntary.

The 1985 NNHS was the third in a series in nursing home surveys. The first survey was done in 1973, and the second in 1977. These three surveys were preceded by a series of surveys between 1963-1969, conducted by the National Center for Health Statistics (NCHS), which were called the Resident Places Surveys.

While each of these past surveys emphasized different topics, they all provided some common basic information about nursing homes as well as about their residents and staff.

The 1985 survey was jointly funded by NCHS and several other Federal agencies. The sample selected for the 1985 survey consisted of 1,220 nursing and related care homes. The data were collected through a combination of personal interviews, and self-enumeration, through the use of six components or questionnaires.

Information about the facility itself was collected through a personal interview with the administrator or a designee. These were the number of beds, type of ownership, certification status, number and kinds of staff, and per them rates.

With the administrator's permission, a questionnaire was sent to the facility's accountant to obtain basic expense and revenue information. The administrators and their accountants are also given the option of submitting a recent financial statement in lieu of completing the expense questionnaire. The sample includes a maximum of four registered nurses per facility to obtain demographic characteristics of registered nurses (RN's) working in nursing homes. Information is obtained about their level of education and information related to job retention, salaries, and duties.

In 1985, the staff sample was limited to RN's.

Information was collected on a sample of no more than five current residents and six discharges.

In addition to the basic demographic characteristics about the residents and discharges, data were collected about their medical condition, impairment, hospitalization during the nursing home stay, functional limitation, the services they received, a history of nursing home utilization, and sources of payment for their care.

A family member or other acquaintance of the current residents and discharges was contacted by telephone to obtain data on the resident's health and functioning status during the period preceding the admission and prior episodes of health care, information which generally is not available in the facilities' records.

Ninety-three percent of the facilities who were eligible to participate in the NNHS actually participated. The results of the 1985 NNHS will be released in Advance Data reports, Series 13 reports, and public use computer tapes.

No information will be on the public use tapes which could lead to their identification of individual residents or facilities.

Two Advance Data reports have been published. One is on the characteristics of nursing homes, and the other on the utilization of nursing homes. Other reports from this survey are in various stages of preparation.

Before we send the tapes or the documentation to National Technical Information Service (NTIS), we do distribute the public use tapes right from NCHS, and you can give us your name, telephone number and address, and we will send you information on how to order the tapes.

We hope to have the tapes ready for distribution from NCHS by early August. The tapes are ready, but the documentation to be able to interpret the tapes is in preparation now.

SUMMARY OF BREAKOUT SESSIONS

Evelyn S. Mathis, National Center for Health Statistics
Genevieve Strahan, National Center for Health Statistics
Esther Hing, National Center for Health Statistics
Edward S. Sekscenski, National Center for Health Statistics
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EVELYN MATHIS: The NNHS is conducted by the NCHS as part of its responsibility for the collection and dissemination of information on the health of the whole United States. The survey provides information on the size and composition of the population in nursing homes, the services they receive and the sources of funding for care. The development of the data set for the 1985 survey was initiated during 1982. The data set was developed from a review of the data items that were used in the 1977 NNHS, the recommended long term care minimum data set, and recommendations made by people working within the federal government in the field of long term care.

First we start off by sending letters to people in both public and private sectors of long term care to inform them of plans to conduct the NNHS and to solicit their recommendations as to the type of information that we should collect. Questionnaires were drafted and distributed to a wide variety of individuals representing organizations in the areas of policy making, research, evaluation and analysis, for review and comments. After several reviews and discussions, a data set to be tested was agreed upon. Five federal agencies entered into interagency agreements with NCHS.

These agencies either added new questionnaires or items to the existing questionnaires, or both. Office of Management and Budget (OMB) clearance was obtained. The pretest consisted of eight different components of questionnaires and was conducted among 150 nursing and related care facilities, in four metropolitan areas, each representing one of the four census regions, namely, the south, west, midwest and northeast.

All of the data collection instruments are color coordinated. Whether you are talking about a sample list or a questionnaire, they were all the same color.

The sponsoring agencies, in addition to the NCHS, were the National Institute of Mental Health (NIMH), the Bureau of Health Professions, the Health Care Financing Administration (HCFA), the Veterans Administration (VA) and the National Institute on Aging (NIA).

Training sessions were held for all aspects of the survey. After the training of the field supervisors and interviewers, the survey was initiated. Visits to the nursing homes took place from August 1985 to January 27, 1986 and the contacts of next-of-kin followed the field work and continued until October 1986.

The NNHS is a stratified two-stage probability sample of nursing and related care homes in the U.S. The first-stage consisted of the selection of facilities by NCHS, and providing them to the contractor. The second-stage consisted of the selection of samples of RN's, current residents and discharges, and was carried out by the field interviewers.

The universe from which the sample was selected was the National Master Facility Inventory (NMFI). The inventory is a comprehensive file of in-patient health facilities. The facilities in the inventory are categorized into three broad types; they are hospitals, nursing and related care homes, and then we have a catch-all category called other. Obviously, the category for the NNHS was the nursing and related care homes.

Two mechanisms are used to keep the NMFI as current as possible. One mechanism is through periodic surveys and the other is through our agency reporting system where state agencies and national organizations send NCHS their most recent directories and lists.

Another activity associated with the NMFI is the complement survey. The compliment survey is conducted periodically to assess the completeness of the NMFI.

The frame for the 1985 NNHS consisted of the results of the 1982 survey of the NMFI, homes that were identified in the 1982 complement survey, homes that opened for business after the 1982 survey, and hospital-based nursing homes identified in the records of HCFA. The resulting frame contained over 20,000 facilities.

These facilities were sorted into two strata, those certified by either Medicare or Medicaid, and those not certified by either Medicare or Medicaid. Facilities in each of these two strata were divided into two groups. One was the 1982 complement survey and then all of the other files. The facilities in the non-complement survey strata were further sorted into bed size groups, producing 20 primary strata.

The nursing homes in the universe were then ordered by ownership, geographic region, metropolitan status, state, county and Zip Code. The sample was then selected systematically after a random start within each primary strata.

The second-stage was done at the nursing home. The universes for the RN's, the residents and the discharges were developed as a part of the data gathering process. If the nursing home had a list that was already prepared, we allowed the interviewers to use the prepared list.

GENEVIEVE STRAHAN: The homes that participated in the 1985 NNHS were selected from a universe of over 20,000 nursing and related care homes. Of the 1,220 facilities selected, six were identified as having been included in the pretest phase of the survey. It was decided by the NCHS not to re-contact the same facilities, but instead to transcribe data from the pretest instrument to the national survey instruments. Of the remaining 1,214 facilities, 57 were identified as either out of scope or out of business. Of the remaining in-scope facilities, 1,079 participated in the survey for a response of 93 percent.

First contact with the facility was made in May 1985 prior to the beginning of the survey. A telephone pre-screening procedure was performed to verify contact information for the facility selected in the sample. This pre-screening was designed to update facility data concerning facility name, address, telephone number and the administrator's name. The next contact made with the sample facility was in the form of an introductory information package to the administrator. The packet contained a letter from the Director of NCHS explaining the importance of the survey and informing the administrator that an interviewer would be calling for an appointment. The packet also included letters of endorsement from professional health organizations.

After the packet should have been received, the interviewer contacted the administrator to set up an appointment and to conduct the survey. Depending on the size of the facility, one interviewer or a team of two or three interviewers visited the facility. A part of the facility visit included the administration of three questionnaires: (1) facility questionnaire, (2) expense questionnaire, and (3) nursing staff questionnaire.

The facility questionnaire, printed in canary yellow, was completed by the interviewer in a face to face interview with the administrator or his designee. Collected on the facility questionnaire was basic information about the facility: ownership, certification status, bed size, number of admissions and discharges, in-patient days of care, services provided to residents and nonresidents, and number of nonresidents served.

Staffing in several occupational categories was collected for full-time and part-time employees. Full-time equivalent employees for each category were tabulated utilizing the number of hours worked by part-time employees. Thirty-five hours of part-time work are taken to equal one full-time.

The 1985 survey collected for the first time per them rates for routine care set by nursing homes. These rates were collected separately for Medicare, Medicaid and private pay patients. Per them rates will be one of the key units of analysis from the facility file. By matching the unique facility ID number from all documents completed in the sample home, information collected in other components of the survey can be described by characteristics of the facility. For example, estimates of current residents can be tabulated by ownership of the facility.

The administrator did not always have all the data required for the facility questionnaire at hand, and needed to consult records and staff in other off ices. Questions that required specific numerical data were printed on a separate sheet, referred to as the facility questionnaire worksheet; it is also yellow in color, a single page printed on both sides. The questions were exact duplicates from the facility questionnaire.

The interviewer gave the work sheet to the administrator at the end of the interview to be completed later. She picked it up at the end of the day, or at some later date if that was required.

In 1985 the typical nursing home was independently and privately owned. It had about 85 beds, most of which had some form of certification. The estimated 19,100 nursing home sets average rates of $61 for skilled private pay daily care and $62 per day for Medicare skilled care. These data and more are included in Advance Data report number 131, nursing home characteristics, and preliminary data from the 1985

NNHS. Data from the facility file, along with data from four other components of the NNHS will be included in a special report to be published by the end of this year.

Upon completion of the facility questionnaire, the expense questionnaire and its accompanying definition booklet printed in green, like money, were presented to the administrator for completion. In many facilities the administrator completed the expense questionnaire. In others, he referred the interviewer to an accountant, a bookkeeper or a central off ice. This instrument was completed by a respondent at his or her convenience, and postage paid return envelopes were provided for the return of the expense questionnaire. The expense questionnaire collected data on two major topics; expenses and revenues. Expense data include payroll, health care services, insurance, taxes, food, utilities, maintenance and drug expenses. Revenue data included sources of income from patients and non-patient sources, such as contributions. In lieu of the completed expenses questionnaire, each facility was offered the option of providing the interviewer with a financial statement, and many homes did that.

After obtaining the financial statement or the name and address of the anticipated respondent for any necessary follow-up, the interviewer introduced the nursing staff component of the NNHS. These two documents, the nursing staff sampling list and the nursing staff questionnaire were used to collect data on RN's working in nursing homes.

The nursing staff sample list, printed in blue, was completed by the interviewer in collaboration with a staff member designated to help her. For the preparation of this list it was necessary to divide employment status of all facility RN's into three categories: those who are employed on the staff of the facility; those scheduled to work who were retained through a special contractual relationship; and those scheduled to work who were attained through a temporary service.

Three columns were provided in which to list separately persons in each of these categories. The sample list provided the universe of RN's separated into three groupings. With the introduction of the nursing staff sampling list came the first need to use sampling tables.

Each interviewer received a packet of sampling tables. The packet consisted of ten independent sets of three different kinds of tables which were numbered and color coded according to the component to which they were applied. Table 1 was blue and was used to select the nursing staff sample. In order to insure random in-facility samples, Table 1 had ten versions numbered 0 through 9. The fourth digit of the facility ID number determined which version of Table 1 was to be used to select the RN sample at that facility. For example, if the facility ID number was 123400-7, the interviewer would consult version 4 of Table 1-4. This method of assignment assured a fairly even distribution of facilities among all versions of the sampling tables.

After finding the total number of RN's recorded on the nursing staff sampling list, the interviewer referred to the version of Table 1 mandated by the fourth digit of the facility ID number and looked at column 1 which is total number listed, and went across. That interviewer could now decide which line numbers to choose for those nurses that would be in the sample. For instance, if there had been ten RN's in a facility that had a fourth digit of 7, then the line numbers would be 1, 4, 6, and 9. The RN's listed on those lines would be included in the survey for that facility.

The selection of up to four RN's from each sample nursing home yielded a sample of 3,439 RN's. The nursing staff questionnaire, also printed in blue, was personally distributed by the interviewer to those RN's selected in the sample. The nursing staff questionnaire was self-administered. When personal delivery was not possible, the questionnaire was either mailed to a home address or left at the facility. A postage paid business reply envelope was provided for return of the completed questionnaire. If a questionnaire was not received within 28 days of the facility visit, a reminder letter and a duplicate instrument were sent. The nursing staff questionnaire gave information on the work experience, hours, activities, education, training, salary, and opinion about recruitment and retention issues of RN's working in nursing homes. Basic demographics about each RN were also collected.

Data were collected for 2,763 of the sample RN's for an 80 percent response rate. The typical RN working in a nursing home was prepared to work as an RN in a diploma program and has been employed as an RN for more than 10 years. She, and I say she because 98 percent are female, worked full-time on a non-rotating day shift. She is white, married with either no children living at home or children of school age, that is, 6-18 years. She is scheduled to work an average of 32.5 hours per week and earns about $334 a week. An Advance Data report will be published this year reporting characteristics of RN's in nursing homes. Future reports will provide detailed information about RN's working in nursing homes, and will be published in both Series 13 and 14 reports.

Data on RN's will also appear in a special report that will also include data from four of the other components.

ESTHER HING: Data from the current resident component of the NNHS are cross-sectional and are representative of the nursing home population in the U.S. as of the night of the survey. To draw a sample of residents, lists of residents in the facility were constructed at the time of the survey. Nearly half of the homes that we surveyed, the lists were provided by the facility and were computer generated lists. In the remaining homes, lists had to be constructed by the interviewers, and in 3 percent of the remaining homes the lists had to be constructed by copying the names of residents from ledgers or other patient lists. A sample of five or fewer residents were selected per sample home, resulting in an overall sample of 5,395 current residents.

The current resident questionnaire, which was Orange, was used to collect data on the sample of current residents. This questionnaire was administered by personal interview with a knowledgeable staff member who referred to the resident's medical record when necessary. The most frequent respondent was a nurse, that was 55 percent of the time, followed by the administrator or owner of the nursing homes. In about 3 percent of the cases, no staff was available and the interviewer had to extract the data from the medical records herself.

Participation for this questionnaire was very high. The response rate was 97 percent. Item response rates for this questionnaire were also generally high as a result of our pretest during which we eliminated most of the items which had low responses. In addition to the data collected from the nursing home staff on this sample of current residents, we also had a telephone follow-up of these current residents in a component called the next-of-kin component. In this component, the resident's next-of-kin, guardians or friends might have been contacted. Only residents who had a next-of-kin or other known contacts were eligible for this telephone follow-up. In general, the types of data items collected in this telephone follow-up were data items that were not available to the nursing home staff.

The current resident questionnaire collected information on the demographic, medical and utilization characteristics of the nursing home population. Demographic variables include age, sex, race, Hispanic origin, and martial status. Medical data include diagnoses at admission and currently. Up to eight diagnoses were listed for each time period. The data were coded according to the Clinical Modification of the Ninth Revision of the International Classification of Diseases. Other medical data collected include vision and hearing status, and prevalence of mental disorders. Utilization data collected include the length of stay since admission and the total monthly charge last month.

Items collected for the first time in the NNHS include marital status at the time of admission, presence of living children, diagnosis related group (DRG) data for hospital transfers, hospital stays while a resident, history of other nursing home stays, instrumental activities of daily living (IADL), disorientation or memory impairment, and sources of payment at the time of admission.

The tape for the current resident questionnaire will include the facility number and the resident weight. The facility number uniquely identifies each facility in the survey. By matching the facility number on the current resident questionnaire with the facility number on the facility tape, information about the facility, such as bed size or ownership, can be analyzed with the current resident data.

The resident weight is used to inflate the sample data to national estimates.

One of the principal strengths of the current resident data is that it provides national estimates of the population in nursing homes. This is useful to help planners and policy-makers who need descriptive data on the utilization of nursing homes. In addition, the 1985 NNHS also includes some items of particular interest to policy-makers. The item on sources of payment at admission and last month, for example, will provide estimates of nursing home residents who had to spend-down, in other words, exhaust their own income sources before they could become eligible for medical assistance from Medicaid.

A question was also added to the current resident questionnaire on the DRG for all persons transferred to the nursing home from short stay hospitals. This data, along with other variables from the survey, may be used to assess the impact of the Medicare Prospective Payment System (PPS) on nursing home care since its implementation in 1983.

Because the residents selected are patients currently in the facility as of last night, the length of stay for the residents is incomplete and underestimates the true length of stay that would be achieved at some point in the future. Residents with long lengths of stay, however, are overrepresented in the current resident sample because of the fact that only persons who are in the facility as of last night were included in the sample. Thus, a person admitted to a nursing home for one day has fewer chances to be included in the sample than a person who had been in the nursing home 1 year. An example of the skewness of the data from the current residents is the average length of stay of about 3 years, whereas the median length of stay from the current resident data is only 1.7 years. Because of these limitations, the current resident data is inappropriate to examine the flow of patients in and out of nursing homes. The best data for investigating this issue would be the longitudinal study of persons admitted to nursing homes. Longitudinal surveys, however, are expensive to conduct. We plan to construct a cohort of nursing home admissions using data from both the current resident and discharged resident questionnaire as well as the next-of-kin follow-up.

To date, one report on the use of nursing homes by the elderly has been published using the current resident data. This report showed that about 5 percent of the elderly resided in nursing homes on any given day during the survey period of the 1985 survey. Use of nursing homes increases with age for both sexes, but was greater for females than males. Use of nursing homes was lower for elderly persons who are Black or of other races than for White. For the most part, these trends have not changed since 1973 when the first NNHS was conducted. However, there are some exceptions. There has been an increase in the use of nursing homes by elderly Black persons and a decrease in the use by those 85+ since 1973.

The next report that will present current resident data will be the summary report that Genevieve has already mentioned. This report will probably be released at the end of the year. The next report after that using current resident data will be the study of impact of the Medicare PPS on nursing home care.

QUESTION: Who administered the interviews to the residents in the facility?

ESTHER HING: No resident was ever directly interviewed. We interviewed the staff of the nursing home.

QUESTION: Could you give me some examples of behavior problems and disturbance in general?

ESTHER HING: The disturbance of mood question is basically a question with a checklist that asks whether the resident displayed depression, anxiety, fearfulness or worry to such a degree that they were distressed in functioning nearly every day. A general question asked whether the resident had displayed any behaviors that were considered dependent or disruptive. The disruptive behaviors included disrobing, exposing oneself, screaming, being physically abusive to self or others, stealing, getting lost, wandering into unacceptable places and the inability to avoid simple dangers.

EDWARD SEKSCENSKI: Although continuities do exist with many of the data items in the 1973-1974 and 1977 discharged resident segments of the NNHS, some of the items have not been repeated and a number of other items have been added to the 1985 survey. I will briefly outline some of the similarities and differences between the 1973-1974, 1977 and 1985 surveys, and hope to cover all the items in the 1985 survey of the discharged resident component.

Data in the discharged resident file of the 1985 survey were obtained from personal interviews conducted in the sample nursing homes with employees deemed most knowledgeable of the discharged resident's health status and condition during their stay at the sample home. In most cases the interviewee was either a nurse or medical records person who consulted with the available medical records of the discharged resident during the course of the interview. As was true in both previous NNHS's and in the current resident segment of the 1985 survey, no resident was consulted personally in the discharge component of the 1985 survey. Unlike the 1973-1974 and 1977 surveys, the 12 month reference period from which the discharged resident sample was drawn for the 1985 survey ended on the date immediately preceding the survey date. The survey was conducted between August 1985 and January 1986. Therefore, the 12 month reference periods could range from August 1984 through January 1986.

Previous survey reference periods for the discharges were calendar years 1972 and 1976. The survey's reference period was changed for the 1985 survey in an attempt to obtain both more current and readily available data and to provide information on the utilization of nursing homes by both residents and discharges over a more closely related period of time. However, data from the 1985 NNHS for discharged resident population and the current resident population continue to differ in several major areas.

Briefly, while the discharged resident estimates represent all discharges over a 12 month period, the current resident population is estimated for a single night, that immediately prior to the survey dates. The discharge sample, therefore, may underestimate those nursing home residents who tend to stay for very lengthy durations and the current resident population may underestimate those persons with very short durations of stay. While the current resident file provides for what may be considered a snapshot of nursing home residents on any given day, the discharged resident file provides for some indication of the over the year changes in the nursing home population, at least, that is, in terms of who is being discharged from the nation's approximately 20,000 nursing and related care homes.

A randomized sample of six or fewer discharged residents was selected per sample home. This resulted in an overall sample of 6,023 discharged residents. The discharged resident questionnaire collected data on the discharged residents' demographic characteristics, including age, sex, race, Hispanic origin, marital status, their discharge diagnoses, the discharge destinations of live discharges, whether or not the resident had difficulty controlling his bowel or urine in the last 7 days before discharge, and whether or not he or she was bedfast or chairfast during those last 7 days.

Also obtained was information on all sources of payment for the month of discharge from the nursing home. Unlike the current resident questionnaire, however, no charge data were obtained on the discharged residents in this discharge questionnaire. All of these above data items provided continuity with similar data items in the 1977 NNHS.

New to the 1985 discharged resident component of the survey are data items on primary diagnoses of discharged residents at admission, categorical information on prior living arrangements immediately preceding the admission, and the sources of payment for the month of admission. All of these data items focus on the characteristics of discharged residents prior to or at the time of their admissions to the nursing home. The admission that is relevant to the discharge which fell in the purview of the survey.

Also new were questions on the discharged residents' history of other stays in the sample home, in other nursing homes and the total number of homes which the discharged resident had ever been a resident in. The data from these latter questions will begin to provide some evidence of patterns of nursing home utilization over a longer period of time than a single stay in a single nursing home.

We received information on the marital status of the discharged resident both at the time of admission and the time of discharge. We received for the first time information on the discharged residents' living arrangement immediately prior to the admission to the nursing home.

We also asked information on the living arrangements of live discharges subsequent to their discharge from the nursing home. We asked a question as to whether they went to another health facility and whether they died in that other health facility.

Other questions dealt with whether the resident had been a resident of any other nursing home besides the nursing home that was in the sample, and we obtained information on the next-of-kin, a friend, or a person who would know about the condition of the discharged resident after leaving the nursing home and immediately preceding admission to the nursing home. This respondent was utilized in the next-of-kin survey.

We also received admission and discharge diagnoses data, the primary diagnosis and all listed diagnoses on the medical records, and they were subsequently coded into ICD9/CM classifications.

In the 1985 survey, we did not receive detailed activities of daily living (ADL) information on discharges. The functional status information on discharges was limited to these categories: whether they were chair fast, bedfast, and whether they had difficulties in controlling bowel or bladder during the last 7 days of their stay in the nursing home.

QUESTION: Why did not you do all ADL?

EDWARD SEKSCENSKI: In the pretest that information was not deemed as being as reliable for discharges as for the current residents.

The final questions that we asked were on sources of payment. The new question here compared to the 1977 survey was sources of payment, both all sources and primary sources of payment, in the month of admission. This was repeated for the month of discharge.

An Advance Data report on discharges will be coming out in about 2-3 months in the publications of NCHS and a Series report on discharges will be coming out next year.

QUESTION: I have a concern about sources of payment. I am concerned that if someone uses that for public policy decisions that it might be misleading. I am not aware that sources of payment is a part of a medical record that the nursing staff and the medical records technician would know. How did you test the reliability of sources of payment?

EVELYN MATHIS: The sources of payment did not come from the medical record. For the current resident and for the discharges, when we got into certain kinds of information, we had to go to the financial people who kept the bills, paid the bills or did the billing. It did not come from the medical record.

JENNIFER MADANS: The next-of-kin component is unique in that it has not been a part of the NNHS previously. The fact that it has been included in 1985 survey reflects the more complicated questions that are being asked of long term care data bases.

First, some historic background. In the pretest, there was interest in looking at an admission cohort, not only in sampling current residents and discharged residents. In the pretest we actually took a sample of admissions. It proved to be very expensive and very time-consuming. As an alternative, we decided to change the sampling list for the discharges. The sampling frame was discharges in the past 12 months. An admission component could then be recreated from the other two resident components.

In the pretest, a nursing home history questionnaire was part of that admission cohort design. A family questionnaire was used in conjunction with the current resident component. Those two were combined into the next-of-kin component.

The next-of-kin component was designed to collect information that would not be available on the record. There are two reasons for doing this. One, to increase the analytic capability of the current resident and discharged resident components if you are dealing with them by themselves. The other, when you put together an admission cohort, was to look at a longer time-frame and to look at transition probabilities. We were interested in the subject's health and functioning status prior to the admission; for example, why were they admitted, what were they like before they were admitted to the nursing home, and did they have any history of previous nursing home utilization. These are things that might be absent from the record, especially in some smaller homes where they do not do a very extensive preadmission screening. We looked at ADL's at the time of the admission, so you could look at change over time in this factor and also in change in living arrangements that might have taken place since the facility-based component.

The next-of-kin component has three general objectives. We wanted to look at patterns of nursing home utilization and also patterns of hospital care that often accompanied the use of nursing homes. We did some analysis of the admission data from the pretest to show just how important it is to look at the combination of these two. We also wanted to look at predictors of nursing home care and predictors of different patterns of care. For example, what would predict a long term user, a short term user or someone who had multiple hospital stays in between nursing home stays. Finally, to the extent possible, we were interested in describing the natural history of functional dependence over time.

The original admission cohort included four re-contacts. When we went to the national design there was only one re-contact which took place relatively soon after the facility contact. However, we are now trying to follow-up on those people and we have about 2 years time lapse between the follow-up and the original data collection.

The people who are eligible for the next-of-kin are those 5,243 current residents and 6,023 discharged residents who had the resident questionnaires filled out. All of those people were eligible for the next-of-kin component. If you add those up you do not get 11,196. That is because the discharge component is an event-based sample. Someone could have multiple discharges. We were only interested in following people so you have to subtract out all of the overlap cases.

We got the name of the next-of-kin; in some cases it was the name of the resident if that person had been discharged from the questionnaires themselves from the nursing home. Only 90 percent of the eligible residents were included in the data collection. There were many reasons for this. Primarily it was because the facility refused to release the name of the resident or the name of the next-of-kin. In some cases there just was no next-of-kin and either the resident was still in the home or had been discharged dead. Of the 10,123 where we attempted to get an interview, there was a 90 percent completion rate. The interviewing of the next-of-kin component was done through a computer assisted telephone interview. We felt that we had to go with something like that because there are so many possibilities, so many different scenarios of utilization patterns depending on the administrative definition of the stay or where the person was at the time of the facility contact. Any hard copy version would just be too complicated for an interviewer to administer. We developed this computer assisted telephone interview which worked quite well. It also allowed us to do a lot of data editing and consistency checks while collecting the data, so when we got the file out we had less cleaning to do.

In the proposed follow-up, we hope to re-contact someone for each of the residents who were included in the next-of-kin component who was alive at the time that the next-of-kin interview was done. One alternative that is being considered is just to go back to the person who gave us the information at the time of the next-of-kin. Recall that when we did the next-of-kin, we got someone who knew the person prior to the admission because we wanted some information about their history. However, in the case where someone was still in a home, either in the sample facility or some other facility, it is likely that the facility itself could give us more information about their current status and also their use of hospitals. There is a proposal to go back to the home that the person was in if they were still a nursing home resident.

We are also going to try to pull in people who got dropped at various stages, either because there was no name or because they could not contact the person at the time we were in the field. Six months after we do the first phase of this follow-up, we hope to re-contact using the same design and the same questionnaire to update the information. Here we are basically going to collect utilization information, such as where the person is currently living, their vital status, and if they have had any nursing home or hospital stays in the intervening follow-up time.

We hope to go into the field with this follow-up sometime this summer. We have sufficient funding for a core interview and we are soliciting additional funding to expand the scope. If there are any funders; out there, contact me.

NIA is interested in funding some work on analyzing these data tapes, particularly when the follow-up data tape comes out. They are a major funder of the follow-up. You should contact Richard Suzman on that.

ESTHER HING: The design of the 1985 NNHS is a complex multi-stage probability sample. For the data to reflect national estimates, the data needs to be inflated by a weighting factor. The weights for the 1985 NNHS estimators included three basic components: (1) inflation by the reciprocal of the probability of selection, (2) adjustment for non-response, and (3) a first-stage ratio adjustment to total beds in the sampling frame. For facility level estimates, such as the number of homes, beds or total costs, the probability of selection is a product of the facility's probability of being included in the sampling frame times the probability of its being selected from the frame. Only homes from the complement survey had a probability of being included in the sampling frame of less than one. For second-stage estimates of current residents, discharged residents, and RN's, the probability of selection is the product of the probability of the facility's selection times the second-stage probability of selection for these sampling units.

The non-response adjustment factor brings estimates based on the responding cases up to the level that would have been achieved if all eligible cases had responded. The effect of the first-stage bed ratio adjustment is to bring the sample in closer agreement with the known universe of beds.

All three components were used to estimate the facility characteristics correlated with bed size and estimates of current residents, discharged residents and RN's. The first-stage bed size radio adjustment, however, was not included in the estimates of nursing homes and facility characteristics unrelated to bed size.

Weighting factors used to estimate the number of residents and discharges with next-of-kin are similar to the weights for the current resident and discharged residents with the exception of an additional non-response adjustment factor for whether they responded to the question requesting the names of next-of-kin and an adjustment factor for the existence of next-of-kin. As a result, estimates of the residents and discharges with next-of-kin will be less than the overall estimates of residents and discharges.

QUESTION: What are some findings from the survey?

ESTHER HING: There are two Advance Data reports with data from the 1985 NNHS. One of them on the use of nursing homes by the elderly shows that the use rate of nursing homes, or residents per 1,000 population, has not really changed since 1977, or even from 1973. It is still about 5 percent on any given day. Basically, females are still using nursing homes at a higher rate than males. Whites are using nursing homes at a higher rate than Blacks and others.

These trends have not changed also since the first NNHS was conducted, but there was an increase in the percent of Black elderly in nursing homes. It is increased from 2 percent to almost 4 percent in 1985, and there has been a decline in the use rate by elderly 85 years and over since 1973.

QUESTION: There seems to be a new found interest in board and care facilities. To what extent can you use this data to take a look at these facilities?

EVELYN MATHIS: Board and care and almost all of your in-patient facilities are defined by different states or by different counties, and so the definition is going to vary.

What we have defined for the NNHS, is defined by our NMFI. If a facility meets the requirements or the criteria to be in the NMFI, then it is in the NNHS. For a facility to be in the NMFI, it must have at least three beds, it must provide care on an overnight basis, and it must provide something other than just room and board. If a facility is called room and board in a given area, but they provide medical, nursing, or personal care services, then it would be in.

QUESTION: Based on those criteria, what numbers are we talking about?

EVELYN MATHIS: You can look at our 1982 NMFI report. In 1986, the NMFI was surveyed again. That particular survey was called the Institutional Population of the Inventory of Long Term Care Places (ILTCP). It included not only what we call nursing and related care homes, but also some residential places.

If you look in one of the reports on current residents, it will tell you how the universe was compiled for this particular survey. Again, if something is called room and board but it provided the services to make it meet the qualification for the NNHS then it is in there.

QUESTION: On nursing home characteristics, you do have level of care of nursing homes, but, is it possible to differentiate?

EVELYN MATHIS: You can only use these data if the respondent answered questions about certification status and whether or not they had beds that were just residential care.

QUESTION: Are you seeing an average level of impairment higher than in 1977?

ESTHER HING: One Advance Data report shows that, in general, there are more elderly who have higher levels of ADL impairment in 1985 than in 1977.

QUESTION: The number of blacks per 1,000 nursing home residents has risen rather dramatically since 1973. Do you have any information to explain this? The two possible explanations that come to my mind are, one, the effect of anti-discrimination laws making it possible for people to go into nursing homes, and the second would be some family support.

ESTHER HING: In this report I could not explain it. Basically, a variable like antidiscrimination laws is something that is beyond the scope of our survey. We have no information on that. Insofar as what is happening out in the community, we do know that the Black elderly do tend to stay out of nursing homes as long as possible, and rely on their relatives and friends. That is about the only thing we could say about this trend.

QUESTION: Is there anything different about the factors that lead to utilization among black residents as opposed to others?

ESTHER HING: We have limited information in the NNHS. We have few demographic variables and basically what we do have on the demographics is in this report. There are other variables that we just do not have information on, and we could not say any more than that because it would be just speculation.

JENNIFER MADANS: One of the objectives of the next-of-kin component and the planned nursing home follow-up is to look at patterns of utilization and also factors that are associated with admission. We could look at differences in the distribution of the White/Black population at admission and also look at differences in the utilization pattern, the family characteristics and the living arrangements prior to admission. I do not know if there are enough Blacks in the sample to really do a very detailed analysis, but we could definitely start looking at the problem.

QUESTION: In your Advance Data report on use of nursing homes by the elderly, there is a category age 85+ which represents 25 percent of residents of national nursing homes. Merely by numbers in that category, is it not time to stop giving that as an open-ended category?

ESTHER HING: The next report that we publish will have information from all the questionnaires and we will be presenting more detailed age breaks in that report.

QUESTION: I recall in the survey you were going to be doing some tracking to try to establish some longitudinal categories and some longitudinal information.

EVELYN MATHIS: One aim of the entire NNHS is to look at utilization patterns and also to look at the interrelationships of hospital and nursing home utilization. The original design of the pretest had built into it a longitudinal component where we would go back and interview the next-of-kin or the resident if they had been discharged, for a sample of people who had been admitted in the prior 12 months. That component was dropped.

It will be possible to construct an admission cohort from the current resident and discharged resident samples. We have gone back and contacted the next-of-kin for anyone who had a completed current resident or discharged resident questionnaire. Next-of-kin was contacted possibly 3 months after the facility contact and information was collected on that person's history of use. We have information from the next-of-kin and from the facility.

We hope to go back into the field sometime this summer and update that information. We have approximately 2 years more of follow-up through which to track their utilization patterns. We would like to match this data to the HCFA files to get a more complete reporting of all hospitalizations.

From the analysis of the pretest I can tell you that there is a huge interrelationship. If you look at the difference in facilities, how they determine whether someone who is being readmitted if it is a new admission or an old admission, a fair amount of hospital utilization that is surrounding many of these stays would have been internal to them.

QUESTION: Are you linking the different data on the survey?

JENNIFER MADANS: We collect the Social Security number. That is not perfect, because it is not the claim number. On the follow-up we will get Medicare numbers and just do a computer match. We also hope to use the Social Security number to match to the National Death Index (NDI). A fair number of these discharged residents are deceased already, but we could follow the current residents. This becomes, I think, increasingly important if you want to look at an admission cohort since most of those people were alive at the time of the facility contact.

QUESTION: You just might be interested in the experience in tracking by Medicaid number in New York State, to take one state. We were amazed by the turnover of Medicaid numbers there was.

JENNIFER MADANS: We originally were going to match to Medicaid records. That proved to be infeasible. We will only match to Medicare records to get the hospital utilization. We hope to be able to get the nursing home utilization from a respondent whether it is the facility itself or from the next-of-kin. Where there is not next-of-kin it will be impossible, of course, to get the information.

It will be necessary to take the raw data as it appears on the file from the resident samples and from the next-of-kin sample and massage it, because you are going to get conflicting reports about when the stays started and stopped. You are using multiple sources of information with problem of the administrative versus "real" stays. What does that stay really look like? Since our interest was in not that administrative definition, we let the respondent on the next-of-kin questionnaire define the admission date. We got their characteristics prior to that admission, but it is going to be inconsistent with what the home told us. It becomes extremely complicated to use this kind of data. You have to make an attempt or start by trying to reconstruct these histories. As I said the data is not crystal clear; it is not very clean.

QUESTION: Given at the beginning of the year a person is at a certain age, a certain sex, obviously, and a certain nursing status, what is the probability within the following year that he is going to die, be transferred to a higher level of nursing care or be discharged? You were saying it is even difficult to establish the date of admissions. What reliability do you place on the data on the level of nursing care the person is receiving?

WILLIAM SCANLON: The level of care is not necessarily a variable which would be reliable, because level of care definitions are so different across states. What I think you are talking about is trying to create a cohort for a particular point in time and then try to look at that from another point in time. Some of that is feasible.

JENNIFER MADANS: You may also be aware that they have been discharged, if it was to another facility or hospital. If we can add the ADL's on to the next wave of contacts, you will have some change in functional status, but that is one of the variables that is now unfunded.

QUESTION: Have you thought about linking data with NDI?

EVELYN MATHIS: We plan to link to the NDI.

QUESTION: Is there source of payment information?

EDWARD SEKSCENSKI: It will be available in the discharged resident Advance Data report. It also will be available in the Series report on the current residents. There is information on all sources and primary source of payment for the admission month and discharge month, with no charge data for the discharge population. You have some charge data for the current resident population, from the current resident questionnaire.

ESTHER HING: In the next report, the summary report from the 1985 NNHS, one table will show the payment source at admission crossed by the payment source last month.

EDWARD SEKSCENSKI: That is for the current resident component. For the discharge component, hold your calls for awhile.

QUESTION: In what respect does the 1985 survey differ from the 1977 survey?

ESTHER HING: The 1985 survey was designed to be comparable with the 1977, but there are differences. In 1977 we had a number of questionnaires. There was a facility questionnaire which got information about the nursing home and its utilization characteristics, such as bed size, the number of resident days, and other certification. There was a questionnaire on expense which collected information on the costs of providing care. We also had a questionnaire on staff, in which we collected information on the demographic characteristics of all staff who provided direct services to the patients. We also had two patient samples. One of them was on current residents, which included all persons who were in the home as of the night before the survey, and there was a sample of persons discharged during calendar year 1976. The reason why we selected that time period is this sample was for people who had left nursing homes. They had completed length of stay, we could also find out their outcome, or if they went to another health facility. We actually wanted calendar year data for the previous year to be comparable with the NNHS previous to that.

If you can remember all of those components, basically the same components were fielded in 1985, but there were differences. In the 1985 NNHS the staff questionnaire, rather than collecting information on all staff who provided direct patient care, only was administered to RN's. There was a particular interest in finding out the factors that affect the recruitment and retention of RN's in nursing homes because, apparently, there is a shortage of RN's in nursing homes.

Another big difference is that in 1985, rather than having a sample of discharges for the previous calendar year, the discharges were for a calendar year as of one year preceding the day of the survey. It is basically the last 12 months of data. That was done in conjunction with the new component that we added to the NNHS which we called the next-of-kin. We are planning to try to have an admissions cohort using both data from the current resident sample and the discharge sample.

We also conducted a follow-up of those samples with the next-of-kin or any other contacts that we could identify in our nursing home visit. That next-of-kin component was conducted by telephone. There are a lot of changes, but there were still a lot that is comparable to the last survey.

QUESTION: Can an admissions cohort be constructed?

JENNIFER MADANS: We were interested in getting an admissions cohort. One way to do it is to get a list of all the people who were admitted that year, but it would be expensive.

Using both resident files to construct the cohort is just a more cost-efficient way of collecting that data. The questionnaire was modified so that some analysis of utilization numbers could be reflected. This is in conjunction with the interests of getting the admissions cohort.

The other reason to modify the questionnaire relates to the problem of hospital stays that occur on either end of the nursing home stay or within a stay. Different facilities use different definitions of admissions. What we want to do is redefine these stays so that you have a consistent definition across facilities.

EVELYN MATHIS: If you deal with the admission event, as it is defined by the home, the admission took place in the last 365 days. If you go in on June 1, the last 365 days, would be June 1 to May 31. Somebody who was admitted in January, has either been discharged between January and June, so they could fall in the discharge sample, or they were still in the home, so they could fall in the current resident sample. If you sample current residents and discharged residents you get all the people who were admitted in the last 365 days, plus a whole bunch of other people. Those other people you throw out in the analysis when you look at the admission cohort. You keep them in the analysis if you look at current residents and discharged residents.

EDWARD SEKSCENSKI: One of the things we already have looked at was the completed length of stay of discharged persons. There was an observed increase in the median length of stay, but this increase was not statistically significant.

JENNIFER MADANS: If the nature of homes are changing or reimbursement rules are changing, that may be affecting how a home defines a readmission or a new admission. In other words, do they or do they not hold the bed. That seems to be the difference. If they hold the bed, it is not a readmission. If they do not hold the bed it is a new admission. That tends to be related to funding or payment. If there has been a change in the kinds of facilities that do one thing or the other, you may see something that looks like an increased length of stay, but it is purely an administrative artifact. When we did the pretest for the 1985 survey, and we had the admission cohort, we redefined the stay. We said, all right, if we want to look at an admission date, where were these people before they were admitted. They were in a hospital. Where were they before that? They were in that home. That is not a real admission. We backed up the date until we came to what we called the real admission date.

We recalculated the length of stay and we compared that to what Manton and Liu calculated, where they made that kind of synthetic cohort for 1977, and you get an increase in length of stay. What you do not know is that is it a real change or is it just a change in how you define the stay. When you look at the difference between length of stay calculated on the administrative definition and length of stay calculated on this "analytic" definition, you get much longer lengths of stay.

EDWARD SEKSCENSKI: The median length of stay that I was talking about was calculated from the difference between the admission and discharge dates that were given in the answers to the question in the discharge questionnaire. That median changed from 75 to 82 days. That difference was not significant. The length of stay distributions for less than 1 month, 1-2 months, 3-6 months, 6 months-1 year, 1-3 years, 3-5 years, and 5+ years also showed observed increases. Again, none of these was significant either.

JENNIFER MADANS: There was some idea with DRG's there would be more short stayers and a lot of little stays, but most of the long stayers are in for cognitive impairment and they have very long stays. To the extent that their use increases, the proportion of the long stayers is going to increase. I do not think we will ever be able to really figure out a real difference.

QUESTION: Can you tell if people were readmitted?

ESTHER HING: We added a question this time to capture those people that were readmitted to the same nursing home.

EDWARD SEKSCENSKI: We have any other nursing home stays, including the nursing home that is in the sample.

QUESTION: Does the discharge sample follow people or events?

ESTHER HING: The discharge is an event sample. You come in as many times as you have been discharged. The next-of-kin follows people.

QUESTION: Is Medicaid spend-down information available?

JENNIFER MADANS: You can get spend-down information from the record and from the next-of-kin. We ask questions to the next-of-kin about a primary payment source for each stay and when it changed. We would like to ask much more direct questions in the follow-up: when was the person first admitted; were they Medicaid eligible; if not, when did they become eligible. You can get at it the way it is now, it is just a little bit harder.

QUESTION: Can you get payment source?

JENNIFER MADANS: As part of the current resident and discharged resident questionnaires you get payment source. Therefore, you have it for the admission component. I think you get It from both of them in admission and for the current residents, currently; and for the discharged residents, at discharge. You really have to combine the sources of data and then you have all the problems that we had that people talked about earlier. All the identifiers will match. Sometimes all the data does not.

QUESTION: What reports will be issued on the survey?

ESTHER HING: There will be a summary volume similar to what we had in 1977. The next individual report of current resident data will be the impact of the hospital payments system on the nursing home care. There are a number of other reports. There is going to be another utilization report that I am trying to work on. I think there is going to an Advance Data report on the RN's.

QUESTION: Can you compare full-time with part-time employees?

EVELYN MATHIS: In the facility questionnaire itself, there is a list of various kinds of employees. The instruction is to list the number of part-time and full-time employees. We did not ask them to give us the ratios, but one would be able to determine that.

CHAPTER VI. OVERVIEW OF OTHER DATA BASES

A. NHANES I EPIDEMIOLOGICAL FOLLOW-UP STUDY

Jennifer Madans, Ph.D., National Center for Health Statistics

I am going to present the NHANES I Epidemiological Follow-up Study, which is a jointly funded and truly collaborative study between the National Center for Health Statistics (NCHS) and various agencies in the National Institutes of Health (NIH) and the Alcohol, Drug Abuse and Mental Health Administration.

As the name implies, this is a longitudinal study that uses as its baseline cohort those persons who are examined as part of the first National Health and Nutrition Examination Survey (NHANES).

We had three major objectives in designing this survey, with the major aim being trying to make the most of a longitudinal nature of this data base.

The first was to relate morbidity, mortality and institutionalization to risk factors measured at baseline.

Second, we wanted to look at changes in individual characteristics between baseline and the follow-up. Here we are basically talking about risk factors. In some cases, we have measurements at time one and a measurement at time two. In other cases, there was some retrospective history collected at the time of the follow-up.

Third, to the extent possible, we wanted to look at the natural history of chronic disease and also functional impairments.

First, let me say something about the NHANES program.

You heard earlier about two of the other data systems in NCHS, the National Health Interview Survey (NHIS) and the National Nursing Home Survey (NNHS). One of the other major data collection systems is the National Health Examination Survey (NHES).

These started in the 1960's. The first three were called Cycles I, II and III.

NHANES I is really the fourth in the cycle, but in the early 1970's the survey was expanded to take into account an interest at that time in poverty, the effects of poverty on nutritional status and then the effects of nutrition on health. There was a major nutritional component added to the NHES, and, hence, the name NHANES.

The second NHANES was done in the late 1970's. An Hispanic NHANES was done in the early 1980's. We are currently planning the third in the series and that should be fielded in about 2 years.

These surveys are unique in that they contain objective measures of health as opposed to the interview surveys which are based on self-reports or the surveys that are based on records.

We do a multi-stage probability sample down to the household level, an interviewer visits the household and takes some history information, does a series of interviews there and then the sample person is asked to come to a trailer where a standardized exam is administered. There is a lot of data collected at this point.

The first NHANES was done between 1971 and 1975. It has a very complicated sample design. There was a nutrition component and then a detailed component and sub-sampling within that. It is somewhat difficult to do longitudinal analysis on this kind of data base.

We have decided to follow the 14,407 people who were 25+ and over at the time of that survey.

The initial follow, which is what I will be talking to you about today, was conducted between 1982 and 1984. Based on earlier presentations, these sound like some very good years for data collection.

There were multiple parts of this design, which I will go through in some detail. This is an ongoing survey. In 1986, we did a telephone re-contact of survivors who were 55+, and over at the time of the baseline. That data collection is completed and is now being processed and cleaned, and hopefully we will have data tapes for that in 1988-1989.

We are currently in the field with the third wave of follow-up, which is another phone re-contact of the entire surviving cohort.

We will be following this cohort through the National Death Index (NDI) until they are all deceased. We may have a series of other interview contacts over the next 10 years, depending on need and funding.

Let me say that the tapes for the initial follow-up will be released through National Technical Information Service (NTIS) in July. If you have any questions prior to that, we do have some materials in the office and would be happy to send those to you.

The kind of data collected at the time of NHANES I includes medical histories, a health care needs and the nutrition component, the standardized examination, and a series of laboratory tests and X-rays.

To give you some idea of the magnitude of this data collection, there are 14 data tapes from NHANES I, all of which are public use and can be ordered from NTIS.

The design for the follow-up did not include an examination, but did have four other kinds of data collection mechanisms. The first activity, of course, was to trace the people in the cohort. This was somewhat problematic because NHANES I was not designed as a longitudinal survey, and there was no tracing information collected. We had no information about these people over the 10 year period of the follow-up.

We used various methods of tracing to determine vital status, which was the first data point, and also to get an address of the subject or of a proxy who could act as a respondent if the subject was deceased.

Once that address was obtained, we conducted personal interviews with surviving subjects and did some physical measurements at the time of the interview. We also did telephone interviews with proxies for decedents.

The other major data collection activity was getting the hospital and nursing home records for the 10 year period of follow-up. We got the names of all the hospitals and nursing homes they had been in, contacted those facilities and got copies of the records.

Finally, we obtained death certificates through state Vital Statistics Offices for all decedents.

We started out with 14,407 in the cohort and managed to trace 93 percent of them over the 10 year period. By "traced," I mean we could determine their vital status, either because we contacted subjects who were surviving and could respond to our validation questions, if we could get a proxy to do the proxy interview, or if we got a death certificate.

In terms of the results of the interview component, we have broken that out to show the difference between the surviving subjects and the decedents.

The response rate for surviving subjects is 93 percent.

However, for deceased subjects, we could only get proxy interviews for about 84 percent. A lot of the tracing was done through mortality records. We would get a death certificate, but there was no way to contact a proxy. There were no leads that we could pick up on to find someone who would do the interview.

We have death certificates for about 96 percent of all known decedents.

Blood pressure, weight and pulse measurements are the three physical measurements that we conducted; that also was quite successful with 96 percent response rate there.

The longitudinal data is wonderful. That seems to be the wave of the future. You have to have good follow-up, otherwise you can not really generalize about your findings. The first thing we tried to do is evaluate how good the tracing was, particularly because there was no built-in tracing mechanism in the baseline.

Here you have the results of tracing by sex and age, and there is clearly some differences. The older people were much easier to trace and there is a race/sex interaction. White males tend to be the easiest to find and Black females the hardest to find.

We do have problems in the younger age groups, especially among females because of name changes.

When this survey was designed there was a lot of interest in poverty and the sample was designed to over-sample areas where they thought they would find high levels of malnutrition or health effects of malnutrition. There was over-sampling among women of child-bearing age, the elderly, and of people living in poverty areas.

The sample was designed to maximize the rates that were to be calculated by subgroups. It was not really even designed as an epidemiologic study. You get this very funny age distribution, which is bad for some things, but happens to be very good for studying nursing home utilization.

We did look at how health effects measured at baseline were related to whether or not a person was traced.

If we were having a hard time finding people who were sicker at baseline, that would indicate that probably our mortality follow-up was not as good as it should be. We have looked at a multiple regression with age, sex, race and health characteristics to see if they were significantly related to successful tracking.

The only variable that seems to be related to not being traced is smoking. There is some indication here that either we are missing some deaths, possibly among the younger age group, or smoking is acting as some kind of surrogate for some other characteristic that makes people hard to find, people who move often, for example.

In the course of doing these continued follow-ups, we keep trying to find those lost to follow-up. Eventually, we will find them, if through nothing else, through the mortality records.

As the NDI is expanded backwards in time, I think it starts in 1977 now, we will be able to fill in that gap where we have not been able to do adequate death tracing. We are finding people at each stage. You lose some; you find some. I think that especially in the elderly our response rate is up close, I think, to 96-97 percent. We are always looking for new and interesting tracing mechanisms.

Finally, we compared the mortality experience of our cohorts with what would be expected given the national mortality rates occurring at that time. What you find are proportions surviving for White males and White females 65-69. We do have a representative population and that we are not missing any significant portion of that population or a particular kind of person.

You would expect in the early years for our cohort to have lower mortality (because they had to be healthy enough to make it to the van) and, therefore, would have a lower death rate.

On the other hand, we over-sampled in poverty areas and in other groups where we thought we would have higher mortality. The poverty areas do have higher mortality. The non-poverty areas have lower mortality.

When you put those two together, they just kind of converge on the center. In the final analysis, the data is behaving as one would expect it should.

The next aspect of the data collection was the interview procedure and this consisted of a very lengthy questionnaire--it took about 2 hours--and also the physical measurements.

I said this was a collaborative study. It is truly a collaborative study. There are about 12 institutes that participated all with their own agendas. If you look at the questionnaire topics, you can identify who participated in this study.

It was an extremely complicated interview. I would say that the majority of it was taken up by determining whether someone had some chronic condition or acute condition in the 10 year follow-up. If they did have it, when was the onset and were they hospitalized.

If they were hospitalized, the name of the hospital was obtained. All that information was taken down and used for the next kind of data collection.

There was also some more risk factor information collected, some psychosocial variables, some mental health variables, smoking history and that kind of thing.

Most of the subject interviews were done in-person, the proxies were done by telephone.

Again, the physical measurements were pulse, blood pressure and weight. The interviewers actually carried around a little scale and blood pressure equipment, and took three blood pressure measurements.

The non-response goes up with age. These were people who, for some reason, we felt should not take part in the physical measurement section because of a health condition. In some cases, we had an interview with someone using a proxy respondent because the subject was incapacitated; for example, they were in a nursing home where they were too ill to participate. In those cases, of course, we could not get physical measurements.

Finally, the health care facility data collection included the names of all of the institutions that someone had been in; all the hospitals, nursing homes, any other kind of overnight stay the person had. We asked people to sign a release form, sent those to the hospitals, got all the records back and so have, in essence, a 10 year history of utilization for 14,000 people.

The continued waves of follow-up also get this information and we are continuing to go back to hospitals to get these records.

We asked them to fill out an abstract form, but also to send us a Xerox of the face sheet and the discharge summary.

It is a little difficult to give you response rates on this kind of data collection, because we were not quite sure what we should have. We were asking people to recall dates and reasons for hospitalization over a 10 year period. People are not very good at remembering dates.

We do have information from about 2,500 facilities and 400 nursing homes. Some did refuse to participate, and, in some cases, the respondent refused to sign the release form.

We are dealing with about 17,000 hospital records and about 400 nursing home records.

We feel this is a very important data base and can be used for a lot of different activities, including health services utilization, but also used to verify certain diagnoses.

We have objective measures of health at baseline. We do not have objective measures at follow-up, but if someone reports that they had cancer, an MI or something like that, we can look at the hospital record and try to get a verification of that.

We do have some hospitals that refused plus some people that refused. We have an additional contract to do an evaluation of these records to try to merge what the person told us and on a case-by-case basis match that with what the hospital sent. We try to make up dummy records where we are pretty sure we should have a record, but the hospital refused to participate. The entire file will also be matched to the Medicare file to evaluate completeness. We also will do some methodological work on how far back people can remember and do they remember certain kinds of conditions better than others, etc.

That is currently underway. The hospital records will be released with the entire file, but we will then do another release of this evaluation tape in about a year and a half.

Finally, the collection of death certificates. There are a few cases where we do not have the death certificate and keep going back to the states trying to obtain them.

That pretty well describes the data collection. I guess the next question is what can it do for issues of long term care. I think the first thing you should be aware of is this funny age distribution and that we do have a lot of people in the older age groups.

The epidemiologic follow-up is a representative sample it is a large sample, and it is multipurpose. It was not specifically designed to look at nursing home care, and was not designed to look at institutionalization; it was not designed to look at any one particular thing.

Because of that, it has a lot of different kinds of information and you can start to look at things like the interrelationship between health and sociodemographic or socioeconomic factors and the use of nursing homes.

We have a couple of little scenarios about how people can get into a nursing home. In this case you have a health effect that leads to an income change. Then there is some outside factor, some home support not being available and the person goes into a nursing home.

Alternatively, you have some problem with income, then you have the health effect and that leads to a nursing home. You have various payment strategies once you are in the home.

You can have a scenario where a person had much better higher level of income and through some outside factors like the death of a spouse, also ends up in a nursing home at some later date with a different kinds of payment.

The epidemiologic follow-up clearly cannot differentiate between these patterns of health and utilization. It can start to look at some of the components in trying to understand these very complicated interrelationships between health and social factors and utilization.

What we are trying to do now is look at something fairly simple.

We are looking at some of the socioeconomic variables measured at baseline in relation to outcome. This is the kind of table that we are planning on running, using survival techniques. We can look at the percent institutionalized at any point in the follow-up period, the percent not institutionalized, but functionally dependent, and then the percent not functionally dependent. Family income is measured in the dollars in 1970-1975. About 15 percent of this sample had been in a nursing home at some time during the follow-up. About 9 percent were in a home at the time of the interview or had been in a home prior to their death, and then about 3 percent who had been in and out again.

The data base includes these hospital and nursing home records. You can look at how the hospital experience relates to the nursing home stay, over a 10 year period, which is a fairly long period of observation. That is just for the initial follow-up, and now we are adding about another 3 years to that.

B. INVENTORY OF LONG TERM CARE PLACES

Curt D. Mueller, National Center for Health Services Research

The Inventory of Long Term Care Places (ILTCP), is a comprehensive listing of nursing and personal care homes and facilities for the mentally retarded or developmentally disabled.

It was created primarily to serve as a sampling frame for the institutionalized population component portion of the 1987 National Medical Expenditure Survey (NMES).

The institutionalized population component is currently in the field and data is being collected which describes medical care use and expenditures by persons in nursing homes and facilities for the mentally retarded.

The sample of facilities of the NMES were selected from the universe of places as depicted by the inventory.

The inventory data that was collected were used to stratify the sampling frame prior to the sample drawn.

The inventory is of interest from a research standpoint because it is an up-to-date census of these kinds of facilities.

Inventory development and fieldwork were cosponsored by NCHS, the Health Care Financing Administration (HCFA), and the National Center for Health Services Research (NCHSR).

Inventory data were collected by the Bureau of the Census using a mail questionnaire. Three rounds of mail questionnaires were distributed, the first in February 1986.

After the first mail out, up to two additional questionnaires were sent to non-responding facilities. Those facilities which did not respond or which responded in a way which did not give us certain key data items were subject to certain kinds of follow-ups, primarily telephone, but some personal follow-ups were attempted as well.

Census attempted to contact some 56,700 places identified by NCHS. Those 56,700 places were on mailing lists that personnel at NCHS compiled.

The nursing home list was obtained by updating the list of places appearing in the 1982 National Master Facility Inventory (NMFI).

That process involved contacting states and relevant associations for their most current listings and these were then compared to the NMFI listings. What appeared to be new places were added to the list.

The list of places appearing in the 1982 National Census of Residential Facilities (NCRF) was updated to serve as the mailing list for facilities for the mentally retarded and developmentally disabled.

This list was compiled by the Center for Residential and Community Services at the University of Minnesota in 1982.

The updating procedures used to compile this list were similar to those used to update the list of nursing homes. States and relevant associations were contacted for their listings and facilities not appearing on the earlier list were added to the mailing list.

This updating process, of course, is not exact and consequently was a source of some error. One problem is that the mailing lists did contain some facilities which were represented more than once.

This often happens because of minor differences in facility names and addresses and it is difficult to say, "Well, yes, this is the same facility," or, "No, it is a completely different facility."

Some of these duplicates were identified in the field by Census. On the public use tape, which is soon to be released, these places are identified as such.

Another problem with the updating process is that it is only as good as the sources of lists that you have. At the time the lists were compiled, a complete unduplicated listing of skilled nursing facilities (SNF), that are hospital-based was not available. It is probably true that the ILTCP undercounts these places.

The inventory data of some 56,000 places will be released in two parts. The first part contains some 45,000 facility level records representing these homes or facilities, which had complete or partial responses to the mail questionnaire and follow-ups.

The remaining 11,500 or so are on a separate file. This file, again, is facility level records, but they are records of facilities for which data was not available for a variety of reasons, the facility may have gone out of business, some just could not be located, a small number of refusals and so on. There is a list of the different kinds of field status codes which comes as part of the public use tape.

I would like to briefly concentrate on the data items which are available for either the complete or the partial respondents, that is the 45,000 some places.

Each facility was asked to characterize itself from a list of different facility types. There were approximately seven different kinds of places you might regard as a nursing home or a personal care home in the list.

The list includes such types of facilities as the SNF's, approximately 20 percent of the 45,000 indicated that they were skilled nursing facilities SNF's.

Intermediate care facilities (ICF's), and as I said earlier, long term care units of hospitals, licensed personal care homes, but homes which were not certified and so on.

There were also five or six different kinds of facilities for the mentally retarded identified on the questionnaire. These include ICF's for the mentally retarded, foster homes for the mentally retarded or developmentally disabled, state institutions, semi-independent living quarters and so on.

This characterization can be used, and in the public use data, is a crucial part of identifying which places should be defined as nursing homes and which places would be facilities for the mentally retarded.

I might add at this point that the definition that the institutionalized population component of NMES us

Most of the remainder appear to be facilities for the mentally retarded on the public use tape. Although, there are some other facilities which managed to slip on the mailing lists, such as homes for unwed mothers.

The ILTCP provides various measures of facility size. I guess the most important one is the total number of beds set up and staffed for use.

In addition to the total number of beds, you can identify the number of beds certified under the various public programs, Medicare SNF beds, Medicaid SNF beds, Medicaid ICF beds and ICF/MR beds as well.

Other measures of size available include the number of residents in the facility the previous night and the number of admissions occurring during the calendar year of 1985.

As part of the inventory there are questions which refer to the type of ownership of the facility, whether it is for profit, nonprofit, or some sort of government owned facility, federal, state, or local.

For a large number of the facilities, the county can be identified and for most facilities, you certainly know the state of the facility.

Finally, there is a set of variables which I like to call administrative variables. These mainly describe the facilities response to the various mail questionnaires. When, for example, the first mail questionnaire was received, if the first mail questionnaire was returned and so on. There are variables which can be used for certain kinds of methodological studies.

A couple of final notes. The public use file is soon to be released. For the most part, the data appear as reported. There has been very little editing done in attempts to get the data in public use form as quickly as possible.

C. SURVEY OF INCOME AND PROGRAM PARTICIPATION

Daniel Kasprzyk, Bureau of the Census
Robert Friedland, Ph.D., Employee Benefit Research Institute

MARY HARAHAN: Our next two speakers will be discussing the data base that is a little bit different. It is certainly not strictly a health care or long term care data base. But we think it has tremendous possibilities for those of you who are interested in looking at the income and asset characteristics of the population.

DANIEL KASPRZYK: This survey actually began about 10-15 years ago in the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services (DHHS). It was a combined effort of Census at that time, ASPE, and the Social Security Administration (SSA).

ASPE was extremely instrumental in the design and content of the survey. In fact, I am quite certain that left to our own designs the survey would look quite different now without the kind of broad governmental information we have received from various agencies.

I would like to just make it clear that this survey is not a long term care data base. It is a household survey principally designed to provide information about income and program participation. It does, however, have some questions designed by working groups of employees from government agencies which had an interest in long term care.

The Survey of Income and Program Participation (SIPP) is a nationally-representative household survey program. It was intended primarily to provide information on cash and noncash income, eligibility and participation in various government transfer programs, disability, labor force status, assets and liabilities and many more items.

SIPP arose in recognition that the best source of information on the distribution of household and personal income in the United States, the March Income Supplement to the Current Population Survey (CPS), had limitations that could only be rectified by a total redesign or a change in the instrument and procedures.

These deficiencies in the March income supplement in the CPS became especially apparent in the early 1970's when many public assistance programs were expanded and reorganized.

It was in response to these deficiencies that a development program arose. This development program was called the Income Survey Development Program. It was funded, principally, by ASPE and DHHS.

The purpose of this survey was to develop methods to overcome some of the shortcomings of the CPS, namely the under-reporting of property income and other irregular sources of income, the under-reporting and misclassif ication of various participation in federal programs and to provide information to assist at the analysis of program participation and eligibility.

During the period 1977-1981, this development program was in operation. Various tests, including a feasibility test that was essentially a survey of 8,000 households, was conducted in 1979. All these tests led to the design of the SIPP.

The kinds of data that SIPP provides are personal, household, and family income data for each month of the calendar year.

The monthly income data are based on a wide variety of cash and noncash sources, monthly data on most government income transfer programs and detailed data on assets, liabilities, and a number of special topics which I will describe later.

SIPP began in October 1983. It is an ongoing survey program for Census. That sample, which began in October 1983, consisted of approximately 21,000 households in 174 areas around the country. It is designed to represent the noninstitutional population of the U.S.

Each household is interviewed once every 4 months for 2 1/2 years to produce sufficient data for short term longitudinal analyses, while attempting to provide a relatively short recall period for reporting monthly income.

The reference period for the principal survey items, namely the income and program participation data, is the 4 months preceding the interview.

We have started a panel in October 1983. We began a new sample in February 1985, the same characteristics, namely a national household sample in about the same number of areas in the country, extending for 2 1/2 years, with interviews every 4 months. Similarly, in 1986 and 1987.

Several panels run concurrently. By looking at the timing of these data collections, you can combine samples to produce estimates from a larger sample.

Each sample is divided into four approximately equal sub-samples. We call these the "rotation groups." One rotation group is interviewed in each month. When I say the interviews were conducted between October 1983 and January 1984, one-fourth of the sample was interviewed in October 1983. The next fourth was interviewed in November, the next fourth December and then finally in January. Then we repeat again.

The purpose is that this design creates manageable interviewing workloads, hand processing workloads each month, instead of one large workload every 4 months. The real problem with that design is that it results in each rotation group or each sub-sample getting a slightly difference period, by one month.

If you are interviewing in January, you ask questions about labor force participation, hours, earnings that you have received over the 4 month period for that 4 month period. It would be September, October, November and December.

Then the next rotation group comes in in February and they have their reference period for the principal survey items is the 4 months preceding the interview month. The reference period is October, November, December and January and so on. In order to get monthly data for the full sample, you have to understand that each rotation group has a slightly different reference period.

For this survey, the important feature of panels, these are basically new samples, and they are initiated each year. There are waves of interviews and each wave of an interview is every 4 months. A wave is an interview.

Each panel consisted of eight interviews, except for the first one, which consists of nine. It got started a little earlier than we anticipated. Then within each wave of interviewing are rotation groups. That is just the sub-samples.

The data collection for the survey is handled through the Census Regional Office. The interviewers that are assigned to these offices conduct personal interviews with each sample household every 4 months.

At the time of the interviewer's visit, each person who is 15 years of age and older, who is present is asked to provide information about himself or herself. We do take proxies. We have not done much telephone interviewing at this point. Telephone interviewing is only used as a stopgap measure to get information if it was otherwise not able to be obtained in a personal interview.

For the interview, the median interview time was about 43 minutes overall. For a one person household, it was about 29 minutes.

We had planned on 30, so I guess we did all right there. It is a rather burdensome interview, or so most people think.

We do try to get mostly self-interview. We do try give instructions for self-interviews. However, the rate is not all that terrific, in my opinion.

One feature of SIPP is that at the time the sample is drawn, we have an address. We go to the address at the time of the first interview and we enumerate everyone who lives at that address.

From that point on, the sample is no longer an address sample, but rather a person-based sample. We follow those individuals whom we identify at the first interview for the next 2 1/2 years. It actually becomes the cohort of people identified at the time of the first interview.

For cost and operational reasons, these personal visit interviews are only conducted at the new addresses when people move, if that new address is within 100 miles of one of our sampling areas.

I am told that the interviewers have taken it upon themselves to ignore our advice and follow-up when they move beyond the hash marks. They follow-up through telephone interviews.

When you are designing the survey you try to think about how you get the best data and how not to burden our interviewers. I must have spent I do not know how many meetings talking about how far we should follow people. We really did not know whether we ought to have the interview or just make these phone calls and track them down. When we finally make the momentous decision, say yes, the interviewers should do this, we found out that, in fact, they had been doing it. Our interviewers are quite flexible.

It is a person-based sample after the time of the first interview, so you can get some rates on how the respondents change over time. That may or may not effect the quality of the data.

There are four components to the SIPP data collection, first is a control card, then the core set of questions that are repeated in every interview. Then there are modules which we call fixed modules that are assigned to specific ways of interviewing. Then, finally, variable modules that are added from time to time.

The control card, the first method of collecting data, is used to obtain and maintain information on the basic characteristics associated with households and persons, and to record some information for operational control purposes.

The characteristics on this control card are recorded by the interviewer and includes the basic demographics: age, race, sex, ethnic origin, marital status, educational level for each member of the household, some information on the housing unit, and relationships to the householder.

A household respondent, typically, provides this information. The control card is also used as a way of keeping track of the employment and income information that are reported in each interview.

Although the data are recorded on a questionnaire, the methodology is such that the interviewer refers to previously reported income types in each succeeding wave. This control card is a vehicle for writing down after the interview what exactly was reported and then the interviewer at the next interview refers to that.

Finally, the last reason for the control card is that it provides us as a way of keeping track of information for following people, the basic method that we use is just to ask at the time of the first interview whether there is one or more people within the household or outside the household who will always know where you will be at. That turns out to be fairly good in terms of being able to use that data for tracking people.

The other way we track people, of course, is through the ingenuity of the field staff. They can find more ways of nosing around the neighborhood to find out where our sample respondents move.

In the core section of the questionnaire is the principal reason for the survey. I mean, the content of SIPP was developed around these core data. It was designed to measure the economic situation of persons in the U.S.

These questions, as I said, are repeated at each interview. The core data built, basically, an income profile for everyone who is 15 years of age and older in the sample household.

The profile is developed by asking a series of questions about labor force participation over the 4 month period. Essentially, a calendar is developed, so you have weekly labor force participation.

Then asking specific questions about the types and amounts of various sources of income, and, particularly a number of detailed questions on program participation and asset ownership. There are a few questions that deal with health insurance, also.

There are several different questions on income types that are asked about during the interview. It pretty much runs the range of all the major federal income security programs. Then there is the asset listing; the usual listing of assets, savings, CD's, NOW accounts, IRA's, mortgages, royalties. There are a lot of questions and a lot of details.

In addition to these questions that we repeat each interview, we also ask a series of questions depending on the interview that we call "fixed topical modules."

The data from these modules should allow an analysis of well-being, which go beyond strictly the income and demographic area.

The idea behind SIPP was to provide a broader context for analyzing by adding questions on topics not covered at the core section.

The administration of these modules is made possible by the fact that when we go back in the second and subsequent interviews less time is required to update the income data and some time in the interview is freed up. Topics covered in these modules take up about 10 minutes, actually, for each module, each interview.

Typically, the data collected in a module does not have the same reference period that we have in the core data. It can be the last two jobs held. It could be over the last year. The reference period varies depending on the topic.

We have an information handout which you can request. It shows the breadth of data collected in this survey. It is called "Topical Modules for the 1984 Panel," and then goes on to 1985, 1986 and 1987 panels.

The kinds of questions that we ask deal with topics of health and disability, and our third interview of the 1984 panel, education and work history. A detailed series of questions on assets and liabilities, assets held and liabilities owned, and the values of those assets. Pension plan coverage, retirement plan shelter costs are in another interview. Child care arrangements and expenses in yet another interview.

Support for non-household members, marital history, fertility history, and migration history--all of these topics get asked in one module or another.

In the 1986 panel, and toward the end of the 1985 panel, there were a series of questions on health status and utilization of health care services, and another series of questions on long term care.

These tend to be questions about health conditions that last 3 months or longer. Then they ask if they need any help in looking after personal needs and who helped them, if they need help doing certain activities and, again, who helped.

These questions, and all questions that have to do with the topical content of SIPP, are not developed independently by Census.

When Census acquired funding for the survey in 1981, after the yearly budget cuts of the Reagan Administration, and DHHS had to bow out of the enterprise, a SIPP Advisory Committee was formed by the Office of Management and Budget (OMB). This Advisory Committee advises and recommends to Census changes in the SIPP content, particularly changes that relate to data required for policy analysis. The OMB Advisory Committee has representatives from over 20 federal agencies and it is through this Committee that we sort out the difficult task of deciding what goes on a survey of this nature.

It is a multipurpose survey and so you have got the problems of rule by committee. Everybody that comes to these meetings has their own agenda for action and for analysis, and it is through a process of working through committees and working groups that the content of SIPP is finally determined with regard to these topical modules.

The survey itself, because of the way we approach the modules, is viewed as government data resource and every effort is made by Census to maintain open lines of communication with this Advisory Committee with regard to the content.

In fact, we are now going through an exercise to develop the content for the 1988 panel of the survey. We have solicited information from various agencies on the Advisory Committee, asked whether there is any changes they require, demonstrated by data with regard to the core section of the questionnaire and sometime this summer we probably will start the process with regard to the topical module.

There is at this point one topical module open sometime in the 1988 panel, late part of the 1987 panel. I am sure that it is a varying policy. The government will have lively debates as to what ought to be considered in that module.

A little bit about non-response. SIPP, at the first interview, it was a household address sample and then it becomes a person-based survey. So the kinds of non-response rates you can devise vary.

Household rates, of a fashion, are a little complicated algorithm to create that because we do follow people and splits in household take place. It is not a one time concept, it is not a cross-sectional concept.

You can see that in the 1984 panel our non-response rate for the first interview was 4.9 percent, about 60-75 percent of that were refusals. That rate is pretty comparable to the rates that they see in the CPS in the March supplement.

As you go down there from wave one through wave nine, you will see that obviously the non-response accumulates. You will also notice that from wave to wave we lose fewer households over time, so that it averages probably about 2 percent a wave. We lose most of the people in the first three interviews. It is similar with the 1985 panel.

Another way of looking at non-response in this survey is to look at it from a person-based point of view. That is probably a better way. Looking at it from a person point of view, you are interested, usually, in the cohort of people that were there at the time of the first interview.

We have got about 79 percent who were there for five interviews straight. The dominant pattern of missing this is the attrition pattern. Once they drop out, they are gone. It is very difficult to convert them.

The way we treat our follow-up for non-response goes something like this. If you are out for two interviews in a row, just drop them from the sample, and we never go back. Otherwise, our interviewers try their best to convert the respondents, and they try hard.

Another form of non-response is the item non-response. Obviously, the interest in the survey is on income and program participation, whether we are getting better measurements of it.

We are getting lower item non-response rates for many income types that we are concerned with, compared to the March CPS.

Because it is a multi-interview design, you want to be able to link the people across time. An identifier is used to match data across time.

By and large, it works. The matching using the ID is very effective. We can match over time. Problems arise and you should try to understand why something does not match, it becomes very complicated, because people drop out of the survey for a variety of reasons, only one of which is non-response. Another could be they have moved, another they could have been institutionalized, or they could have died. There is a variety of reasons why you might not make a match, but, by and large, this identifier does work and people have been successful in matching over time.

The final thing I would like to mention are data products. The SIPP has several data products. One report series is the Series P-70, Household Economic Studies, which was originally providing average monthly data for calendar quarter; now looking more like a Series that provides information on special topics. The last three reports have dealt with assets and liabilities or wealth in the country, functional limitations and disability, and child care arrangements. Like any Census report, it is available through the Government Printing Office (GPO).

There are also working papers. These are papers developed by staff, and they are principally evaluation papers to deal with survey methodology and in some cases may even provide some substantive analyses, but only preliminary. That is, you have done a study and you do not quite feel that it is final, but you want to get it out to a broader community, the working papers vehicle is the way we do it.

The most important data product coming out of SIPP is the micro-data files. By nature, as I have mentioned, the content of SIPP is so diverse it is virtually impossible for Census or anyone to analyze all that data.

At this time, there are several kinds of micro-data files. We release data for the core portion, that is, the income and program participation data. We release it in two structures. One a complex structure that has a series of record types, household, family, person, and income. All these record types are related to each other through a series of pointers.

Another product is the same data just in a different format. That is a rectangular format. For every person in the sample there is one record and so it is a rectangular file. We have got what we call a complex file and a rectangular file--same data, just a different structure.

Then we release the topical module data. The topical module data is always in a rectangular format and it has all the core data collected at the time the module data were collected.

These are the files that are currently available. We have released the waves one-nine core data for the 1984 panel; all nine interviews are now available. We have released the wave three, four and five of the topical module data for the 1984 panel. The release of wave seven, which is another asset/liability module, is imminent within the next month or so. The release of some core data from the 1985 panel will take place within the next several months.

Finally, we have a multi-wave data collection, but all the files I have just mentioned to you are cross-sectional. They are just for the interviews that we have conducted. One of the problems we have had difficulty dealing with is how to create the multi-wave file in such a way, that it links data, edits and imputes it over time so that it all makes sense. The project is difficult. An initial stab has been made of it, and that is what we call the "multi-wave research file." It is not, strictly speaking, a Census public use file. It is a research file that is not available through the normal means of going to our Data Users Services Division. It is available by writing to me or David McMillan at Census.

It is a file that puts together three interviews of income and program data, edits and imputes for missing data in a way that attempts to be more logically consistent than what you would find by linking the individual wave files.

The wave files, as we release them, are processed independently so that if you match them together there may be cases of change in status which are solely a function of the processing system, not a function of any reporting by the respondent.

Those are the basic data products. The public use cross-sectional files are available through our Data Users Services Division.

Another way of accessing SIPP, by not going through Census is through a data base at the University of Wisconsin. The National Science Foundation has funded what is called SIPP Access. It is a data base system that is up at the University of Wisconsin. The contact there is Martin David, who is a Professor of Economics.

We have coming out shortly a users guide for SIPP that attempts to help people merge their way through these files; and a quality profile for SIPP, which talks a little bit about the non-sampling error aspects of the survey, and the other things you might run into.

MARY HARAHAN: We have a second speaker who will be talking about SIPP. By now you all know how very complicated it is.

ROBERT FRIEDLAND: The Employee Benefit Research Institute (EBRI) is a nonprofit, nonpartisan public policy research institute located in Washington, whose primary objective is to facilitate responsible public and private health and welfare retirement policies.

We are at the moment conducting two studies that explicitly examine the ability of retirees to finance health care for themselves and their dependents.

Both of these studies are using a number of public data bases, many of the data bases that we are discussing in these two days. One of the data bases that the two studies share in common is SIPP. SIPP is just one of the many data bases we are using for these two studies.

The first study, which should be out by this fall, is directed by my colleague Deborah Challet, and it examines the elderly's ability to finance their health care in general. I am conducting a companion study which examines financing of long term care, and I expect that to be complete a year hence.

The starting point for both studies is the economic status of the elderly, and, in particular, the degree to which the elderly are vulnerable to change, change from the loss of a spouse, illness, or inflation.

Long term care, in large part, is an issue related to retirement income adequacy. In a sense, this is why we turn to a data base like SIPP.

I was invited to talk about our views of SIPP. In particular, I would like to tell you why we chose this particular data base and how we ended up modifying SIPP to meet our purposes. In doing so, I would like to convey both the strengths and the weaknesses of this data base.

The primary reason we chose SIPP is that we felt this data could provide us with the most comprehensive picture of economic status of the elderly.

As we have just heard, it is quite a rich data base. Most of the first panel is now available. We can examine employment, earnings, sources and amount of retirement income, assets, liabilities, housing conditions, sources of health insurance including post-retirement employer provided health insurance, characteristics about current or past employers and occupations, the health and disability for any age, sex or marital group, or living arrangement that you want to put together.

SIPP will enable us to get a sense of the extent of limitations in activities of daily living (ADL), and instrumental activities of daily living (IADL).

We are able to get a sense of the degree of assistance needed, who provides that assistance, and whether or not this assistance is paid for.

In addition, some of the conditions address what health conditions were considered the primary reason for that limitation. This is for the entire population.

We can get a sense of how many days an individual spent in bed in a year. There are a few questions that ask about health care use. However, it really is limited to hospital use and ambulatory care. Unfortunately, nursing home care, in the data that is now available, is not asked. Also unfortunate is when there is exit from the survey, then there is reentry, and it is because of institutionalization, we do not know what kind of institution has been entered.

The scope in this area is wide, but it is certainly not as deep as the 1982 National Long Term Care Survey (NLTCS). The assessment for disability is somewhat limited. It is limited to hearing, vision, speaking, mobility, transferring, some light housework, meal preparation, and a broad category called "personal needs."

Cognitive disfunction and continence are not assessed, nor is there any attention paid to technological aids, such that you find in the 1982 NLTCS.

A secondary reason why we chose to use SIPP is that the data base offers potential for addressing so many different social, economic and public policy questions. Its richness is enhanced because the longitudinal nature of the core questions that we have just heard about that are asked every 4 months.

There is also a list of topical modules. There is a wide range of topical modules over the next 6 years.

The designers of SIPP I have to commend. They were ingenious in their way of minimizing the cost of collecting the data and getting the data out quickly without sacrificing, it appears, the integrity of the data.

As soon as each of the four rotation groups is interviewed, the data is prepared for release as a wave.

Each of the 4 months of data is labeled as month one through four. Corresponding month one, for example, of each of the four rotation groups of the weight is not the same as calendar month for each person in the rotation group.

Because each rotation group is interviewed one after the other, there is partial overlap.

To illustrate, when you get a wave of data, you are getting information about January in July on one quarter of the panel, and information on April is available for everybody.

It is not bad to use this approach for just one wave. But I think there are some limitations in just using one wave of data. The cost of using two waves of data increases tremendously when you try to put them together.

This is the biggest disadvantage of using SIPP. The cost of producing SIPP has been shifted to us who use the data base and minimized by Census. On one hand, as a taxpayer, I applaud this and as a researcher I get a little older trying to sort this through.

You practically need a commercial pilot's license to navigate through the relationship between rotation groups and waves. The data base is very complicated and can be very expensive to run.

We were not particularly happy with the wave format and we decided early on that we, for our purposes, needed to combine waves. We combined waves two through five to create a 12 month longitudinal file corresponding to 1984.

We started this process before Census announced that they would create a longitudinal file. I understand the longitudinal file that is available from Census is a 12 month file, but not necessarily a calendar year file.

We felt, for purposes of public policy discussion and in particular, those who deal with public policy, the ability to compare numbers from different data bases. In particular we had to worry about, after using the CPS for all these years, numbers that come out in one data base versus the numbers in the CPS.

We put together, for that reason, among other reasons, a calendar year file. That was not an easy trick.

We have just completed this process and we are now attaching to our calendar year file of core data, data from two topical modules. Topical modules from waves three and four provide us information at a point in time on assets. I am glad to hear that the second asset module is coming. We will have two point of time of assets, liabilities, health, and disability.

We have really just begun to look at the data and I am glad that we put the many waves together because one finding, not terribly surprising, was the propensity for inconsistency on the part of the respondents. The data seems to be relatively very clean on the part of the coding and the Census edits are beautiful, but they can not control for inconsistency on the part of the respondents. The inconsistency, if you are looking at the elderly, appears to increase dramatically with age, particularly when you hit around age 75.

If we had not put the waves together, we would not have seen this, and we would not have been able to come up with an algorithm to try and adjust for that.

I would like to close with a thank you to ASPE and the Office of the Assistant Secretary for Health (OASH) and all those who participated in the development of this Conference.

In some ways, finding out about data, especially forthcoming data, can be at times as frustrating as trying to find out about available community-based services for our loved ones.

In taking the analogy one step further, very often the answer depends on where you begin the process.

Having some personal experience in both of these matters, I know that the consequences cannot be compared. This forum will help a great deal as research is conducted, as markets develop, and as public policy is formulated using information, availability of these data bases will be critical in that process. If you have questions about how we put together our SIPP data base, I would be happy to answer those questions.

D. OTHER LONG TERM CARE DATA SOURCES

Aurora Zappolo, Health Care Financing Administration

MARY HARAHAN: We thought it would be useful to have some discussion about other data bases which may not be so large or so complicated in-scope, but which do have relevance for long term care policy.

AURORA ZAPPOLO: The data bases that are being discussed or at least the three primary national ones, are specifically designed to address long term care issues from a national perspective.

They are of special interest because they provide current information on functionally impaired elderly people living in nursing homes and in the community.

A number of important questions can be answered by these data bases, especially relating to the magnitude of the populations that we are looking at.

However, with recent policy debates on various aspects of long term care, I am increasingly hearing that these surveys do not answer all of the questions. In particular, the kinds of topics that people say they can not find answers to are duration of nursing home stays, outcomes of such stays, the likelihood that people living in the community will need nursing home care at some point in the future, and the point in a nursing home stay at which a person depletes his or her assets and becomes a Medicaid recipient.

I have two basic points to make in answer to these concerns. The first is that some questions are better addressed at state and local levels, and can never be answered adequately by a national survey. The second is that there are studies that are already done that we just need to become more aware of. The gap is often in our knowledge about data bases, rather than in the data bases themselves.

Some of what I am going to refer to are data bases that are in progress right now and are not available for that reason.

There are a wide range of what I am calling "sub-national studies" that have been conducted at various levels, whether state or local. There are also studies in other countries that we should be looking at.

I do not in any way intend to give anything more than examples of some of these data bases that you should be aware of. I do not know where to look for a complete inventory.

Let me start with national studies. My talk originally was going to be only about sub-national studies, but it became clear as we developed the agenda that there were just some studies that should be mentioned. Those that you have heard this morning are important examples of other national studies to be aware of.

In particular, there are questions of duration, outcome, likelihood of institutionalization, Medicaid spend-down, and utilization of health resources.

We have talked at various times about the need to model long term care insurance options, for example, and measuring the magnitude of federal responsibility for nursing home coverage.

The common characteristic of many of the questions is that we need repeated measures of the same individual over time. Jennifer Madans made reference to the increasing attention being given to longitudinal surveys.

One of the major efforts going on right now that you should be aware of is NMES. NMES is collecting a full year's data on the functional status, health services utilization and expenditures not only for persons living in households, but for those living in nursing homes and in facilities for the mentally retarded.

Repeated observations of the same individuals over time will give us measures of change in functional status, admission to nursing homes and hospitals, discharge from those places and the length of time in a nursing home before someone spends down to Medicaid. Another unique aspect of NMES is in its collection of data simultaneously from persons in households and in institutions, which allows comparisons based on the same time period and using identical or similar questions.

NMES is going to be a rich data base, and although it will not be available for a few years, I think that most or all of the current questions will still be with us at that time.

The ILTCP, which Curt Mueller referred to, is the sampling frame for the institutional part of NMES, and it is important as a data base in itself. It broadens the universe of long term care facilities that we are looking at one point in that it includes facilities for the mentally retarded, as well as nursing and personal care homes.

It does not include all long term care facilities, however. Facilities for the mentally ill and the chronically physically impaired are not included. Nevertheless, it provides valuable information on the supply of services that are available according to standardized characteristics. An important point to keep in mind with the inventory is that it is a census, and because it is a census we can look at state and local level data without the limitations that come from sample surveys.

The importance of data bases on facilities used for long term care is in the analysis of supply issues. Studies which examine utilization of health resources, for example, without regard to the availability of those resources, the kind of picture you get on a national scale, can be misleading. This is especially true for those studies that are conducted in areas in which the population in that area has few alternatives for the services that they need.

Another national survey that is being developed which you might want to know about is the National Mortality Follow-Back Survey (NMFBS).

This survey, which is being done by the NCHS, includes information on utilization of nursing homes during the last year of life.

We also should become more aware of those studies that are done by the Veterans Administration (VA), because they have done a great deal of work, especially in terms of projections of the elderly.

In addition to surveys there are two special categories of national data that I just want to mention. They are relevant to long term care, even through they are not designed to be long term care data bases.

The first of these is the Decennial Census. Although the census is not designed as a long term care data base, every census has data on people living in institutions. Just as NMES on a sample survey basis will allow us to compare those in institutions with those in households, every census lets us do that.

In addition, Census is considering or has decided, I am not sure where we are at the moment in this, that in the 1990 census there will be a pair of questions that will collect the functional status of the population.

The two questions being considered are global. The first is like ADL, asking whether a person needs help in bathing, dressing or getting around inside the house. The other is an approximation of IADL, asking whether he need help in shopping, housework or getting around outside the house.

Although these items are general and they do not differentiate the kind of impairment, they are going to be the first data available on such a large scale on functional dependencies. They will provide bench-mark data from which we can access changes in the proportion of functionally impaired in different settings.

The final category of national data that I want to mention are the various administrative data systems at HCFA.

These are not available in the form of data tapes. But they are disseminated in statistical reports for the agency.

The Medicare statistical system is composed of three administrative record systems: the Health Insurance Master File (HIMF), the Provider of Service File (PSF) and the Utilization File (UF).

The HIMF contains a record on each person enrolled in Medicare, showing age and other basic information. The NLTCS was designed based on that file, or it was sampled from that file. The PSF describes hospitals, nursing homes, home health agencies and other providers who are approved to give care to Medicare beneficiaries. The UF is based on the billing records, which includes dates of service and amount billed. Since the advent of the Prospective Payment System (PPS), we also have diagnostic detail on 100 percent of the hospital bills. The combination of these three files allows both population-based and provider-based analyses. Like the Decennial Census, these data are important as overall measures of the population.

In the case of the Medicare files, they represent most of the elderly in the country and their use of covered health services.

I would like to move into the area of state data sets. Although we have national data on the Medicare population from administrative records, there is no similar data set on the Medicaid population. Consequently, the project known as Tape-to-Tape was developed at HCFA.

This project is a major effort to produce person level data on the Medicaid population; and it is in five states, California, Georgia, Michigan, New York and Tennessee. The data will eventually cover 8 years of enrollment claims and provider information which can be compared from one state to another.

One of the projects that is currently underway is directed specifically at the spend-down question, the point at which someone becomes a Medicaid recipient. SysteMetrics is developing tapes which will be used for a series of papers comparing the date of admission and the date of coverage on Medicaid. Data from the spend-down study will be available this year. The data tapes will not be available generally, in this case, because the agreements with the States require prior approval. Another part of the Tape-to-Tape analysis, in fact, that came out this week in the American Journal of Public Health, focuses on the oldest old and you might want to take a look at that article.

The development of the Tape-to-Tape project is important in health services research not only for the data it produces but for its methods, which brings me to the next part of the talk.

One of the difficulties in using most national surveys for studies of the Medicaid population is that the sample designs do not permit making specific estimates for specific states.

The cost of data collection on a national basis simply precludes the inclusion of the number of cases which would be necessary. Often, the fact that state differences are smoothed over is overlooked in analyses. In studies which focus on Medicaid recipients, the use of national estimates is actually less meaningful than the use of state estimates. Since Medicaid is a state-administered program and, in fact, varies by state in the services that are provided, it is important to recognize these differences.

Such studies should be based on the smallest geographic unit on which the data are available. Of course, even state level data can smooth over differences between urban and rural areas.

In recognition of the need for state level data another agency is emphasizing this --NCHSR.

Currently, they are assisting selected states in the development of data bases to examine spend-down. It is part of an overall project to encourage a public/private partnership in the development of financing option for long term care.

Many states have already collected and analyzed data on their long term care populations either through administrative mechanisms or occasionally through survey mechanisms.

Connecticut is one that I became aware of that has a very interesting data set. The Department of Health Services has a comprehensive longitudinal data base showing the characteristics of nursing home residents. Data are available at admission and on a fixed report date, which is the discharge date, when that is appropriate.

Additional data on prior nursing home stays and whether discharged to another health facility for each individual allows more accurate analyses of length of stay, outcomes and episodes of institutionalization than is possible with any national data base that is currently available.

Furthermore, the identification of source of payment at admission and discharge data allows analysis of Medicaid spend-down in the context of Connecticut's Medicaid program.

There is a directory of agency heads and contact persons for designated state statistical agencies. The directory was put together by NCHS as pan of its ongoing efforts to exchange information with state governments. You might want to contact the state government that you are working with, or that you are interested in collecting data on, to explore the availability of data bases.

Another source of state level data is, of course, university research. A study I would like to mention that is going on right now and has been going on for a while is at the University of Maryland. The study represents all licensed nursing homes in the state and it is a project that is funded by the National Institute on Aging (NIA). The data base is stratified to represent nursing homes at all levels of care. Data are collected from patient records within the sample nursing home similar to how the NNHS does it.

Let us look at local areas. A variety of federally-sponsored studies are available on local areas. One that is of particular prominence are the studies at NIA, especially the Established Populations for Epidemiological Studies of the Elderly (EPESE).

Richard Suzman from NIA has a handout describing all their various studies.

Let me just mention what the EPESE study is about. It was begun in 1980. These epidemiological studies were developed in three communities originally, East Boston, Massachusetts, Washington County, Iowa and New Haven, Connecticut. In 1984, a fourth community was added in Durham, North Carolina.

The project is designed to produce estimates of chronic conditions and impairments among the institutionalized elderly and eventually, over a period of time, to develop predictors of mortality, hospitalization and admission to nursing homes.

The project, I think, is going to be an important one in years to come. At this point, the only data that are available are the original cross-sectional data. If you do want to find out what is in that data collection activity, you can get a copy of the baseline data book from NIA.

This is another case in which data tapes are not available, but there is a mass of cross-sectional data that is published already.

At HCFA, the Office of Research and Demonstration is another federal agency that collects or conducts studies in smaller geographic areas.

Currently, there are over 300 studies going on that are research evaluation or demonstration projects related to the federal programs. Many of them relate to long term care, not necessarily under that name.

There are studies of nursing home case mix, home health, hospice services, the impact of prospective payment on nursing home utilization, and beneficiary awareness studies regarding their health insurance options.

The Health Care Financing Status Report, a large red volume, describes all of the extra-mural projects and many of the intramural projects that are currently under way. If you want a copy of that report, you can purchase a copy through the NTIS.

You might also want to look at the Health Care Financing Review. One of the issues, in particular, includes an article by Candace Macken describing the 1982 NLTCS.

The NCHSR is another federal agency that sponsors studies in smaller geographic areas.

They have both extra-mural and intramural research. Some of their intramural research activities have focused on such topics as the cost and economic implications of informal support, the size and sources of long term care expenditures, and the feasibility of alternative financing mechanisms, such as long term care insurance.

Other federal agencies produce data related to long term care. The important thing that I want you to know is that the place to find out about all of them is NTIS. NTIS is an archive of federal statistical information and it includes both data tapes and reports.

I wanted to also mention data bases from other countries.

Data from other countries can fall into one of two categories, and, in a sense, it is how you choose to use it. It can be cross-national, that is, comparative, or it can focus on a particular country.

The concern for the increasing size of the elderly population is not limited to the U.S. It is a worldwide concern and consequently there is a lot of research activity going on in many of the western nations.

Two examples of countries that have produced extensive relevant analyses of these populations are Canada and Sweden.

The Canadian study that I want to mention is a longitudinal study of nursing home admissions in the Province of Manitoba. It was initiated in 1974. There are four levels of nursing home care that are available there. Three of them represent levels that seem to be like our skilled and intermediate care. The lowest level of care, though, provides service that, as I interpret it, is more of a personal care service.

I think that fact alone could make it an interesting comparison for us to look at, suggesting the implications of an additional care level.

Some comparisons that have been noted by the Canadian researchers are that Manitobans enter nursing homes later than their American counterparts and they stay longer after that.

Turning our attention to Sweden, there are a number of important epidemiological studies that have been going on for some time. Most of the research that I am aware of is more in the area of epidemiology rather than health services research. However, they are moving in this direction. As you know, Sweden has a very generous national policy regarding services for the elderly and chronically impaired.

A recent law requires local jurisdictions to reduce the population in long term care institutions and prevent further institutionalizations, all under a very tight timetable. This has resulted in dramatic changes in their delivery system.

Many of these changes are still going on, and a number of studies are focused on looking at those changes. In Sweden, it is interesting to note that there is much less emphasis on national estimates than we have here.

A study which some of you may have heard of is the Longitudinal Study of the Elderly in Gothenberg, which was begun in 1971. The study collected information on personal and health characteristics of a cohort of elderly using personal interviews and physical examinations. A somewhat similar study is being developed in Lund this year.

I was fortunate last year to have the opportunity to visit long term care providers in Sweden and I think that one of the most important and interesting lessons I learned is that international research can tell us a lot about our own system.

I was asked frequently to explain some aspect of the U.S. long term care system, and usually it was something that was either difficult to explain or that gave me an insight into our own system once I thought about it.

We can learn both from other nations' views of our system and from a fresh perspective based on distancing ourselves from old habits and patterns of thinking.

I might add the same kind of fresh perspective can be gained from looking at other aspects of long term care, other than nursing homes and the elderly in the development of the part of NMES that is on the facilities for the mentally retarded.

Again, there were insights into our long term care system for the elderly as we learned about what is going on in the service system for the mentally retarded here in the U.S.

I told you at the outset that the examples I am giving are only examples for illustration. The key point to remember is to look beyond the large national data bases for other sources of information.

I have noted some of the directories. I want to repeat the key ones that you should know about. NTIS, as I said, houses most studies sponsored by the federal government.

There is the Health Care Financing Status Report which describes current research projects. There is no particular vehicle for showing all of the completed ones. That is why I draw your attention to the current one, because then you can track them, You can see when they should be completed and then find out what is available on them.

There are two others. The HHS Data Inventory, which identifies data bases throughout the Department, including a brief description and a contact person.

Again, you might want to look at those that do not particularly focus on long term care or the elderly to see where there is information that we can use in regard to long term care research.

The other collection of studies is the National Archive of Computerized Data on Aging. This is conducted by something called the Inter-University Consortium for Political and Social Research. They are located at the University of Michigan, and they have funding from the NIA to have an ongoing archive of data bases.

Universities that participate in the Consortium get data tapes free from the Consortium. However, anyone can contact them and I do not know what the charges are, but I gather that they are nominal to get information on these studies.

This particular archive includes not only national data bases but sub-national data bases. It also includes not just federally-funded projects but from any funding source.

There is no single entity, as far as I know, that identifies all long term care projects without regard to sponsorship. Clearly, we need a complete inventory of existing data bases, including published research reports and identification of those for which data tapes are available. Until such an inventory is available, it will be up to each of us to discover the less recognized data bases.

I think another important need is to synthesize and integrate the information that we can get from these various data bases.

I would like to close by repeating my theme that the answers to many of our questions are available if we increase our awareness of existing data bases and recognize that national studies are not necessary for all purposes.

With the abundance of long term care studies that have been done, we have a wonderful opportunity for researchers to discover new relationships by integrating the findings from different studies.

CHRISTINE PATTEE: I am the long term care person from Connecticut and I realized after Aurora gave this nice little summary of our data system that we are not listed in the Connecticut Data Center Contact. So if anyone would like to hear about the Connecticut data system, and we would be happy to share information with you.

CHAPTER VII. OVERVIEW OF LONG TERM CARE DATA BASE APPLICATIONS

William Scanlon, Ph.D., Georgetown University
Joan F. Van Nostrand, National Center for Health Statistics
Korbin Liu, Sc.D., Urban Institute
Kenneth Manton, Ph.D., Duke University
Judith Wooldridge, Mathematica Policy Research
Thomas Grannemann, Ph.D., Mathematica Policy Research
Evelyn S. Mathis, National Center for Health Statistics
Gerry E. Hendershot, Ph.D., National Center for Health Statistics

WILLIAM SCANLON: This is labeled the producer panel, and its primary objective is to give you the opportunity to ask the questions that you have been developing to this point, particularly since the amount of material that has been presented in these data bases that are being discussed is incredibly vast and complex.

I think calling this a producer panel in some ways is a misnomer because the people on this panel are not just producers of the data but they have been extensive users of the data over the years and concerned with long term care issues. You are really going to get a very broad perspective on the use of these data sets.

The more information that you can draw out of these people about how their data sets might be used is going to be of value to both yourselves and to others in the audience.

We also had hoped to learn more about the relative strengths and weaknesses of the various data sets. We would be very interested when you have questions that can draw out these kinds of comparisons.

As moderator and as a potential user, I am going to take the prerogative and use the power of the microphone to ask some questions to begin with, to get the discussion going.

Basically, the first question is whether a data base provides adequate coverage of an issue and, in terms of its content, what kinds of significant omissions are there with respect to an issue. Also I am concerned about what ability there is to examine the validity of the data that I may have from a particular data set. Are there other sources which I can use to test validity or do I have to rely only on the information from that data set?

Another concern is how the administration of surveys, or the collection of the data, and the content of the particular wording of questions may affect the result that I am going to see from those data sets and when it generates conflict with other statistics that are published elsewhere what did I make of those conflicts?

Finally, I think a point that was brought home very well with respect to Survey of Income and Program Participation (SIPP) is how hard is it going to be for me to get information out of any of these data sets. It is very easy to send our checks to the National Technical Information Service (NTIS) and to get back a public use file. Then what is it going to cost us in terms of hiring programmers and others to extract information from the data sets?

In terms of starting off this discussion, I think there are two major application areas that we would like to discuss.

The first involves service use, both institutional service use and community service use. As Aurora indicated, ideally what we would know about service use and long term care is that we would have a continuous measure on individuals and basically be able to observe every time a service was used, what type of person that was, and under what circumstances did they use the service.

That is not the kind of data that we have, but what we have is data that to a greater or lesser extent tries to approximate that through histories and through recall questions. What we would like to get a sense of is what are the limits of this picture of service use that we have and in terms of new methodologies that are being used in these data sets. The notion of collecting a history is something that has not been done previously in long term care surveys to this extent.

To what extent do we need to be concerned about what means for validating the information are available?

Along with knowing the quantities of service use that we observe, it is very key to understand the circumstances under which people use services. Particularly for those of you who are considering analysis of these data with respect to changing the financing arrangements for services, we would I like to know to what extent we can relate service use to financing or to the price that consumers might face.

We need to know whether we should start a quest through these data sets for that kind of information or whether that is just missing altogether.

The other area which I think is important to address is the area of measuring the prevalence of various dependencies. We clearly want to know the type of population that we are dealing with and the numbers of that population. It is critical to both the public and private sector in their development of long term care policies.

As we look through the data sets, what we see is that there are rich detail about activities of daily living (ADL) and instrumental activities of daily living (IADL) dependencies. At the same time what we see is that there is often subtle wording changes from survey to survey and sometimes even within a survey.

One of the things I think that you are going to face if you buy one of these public use samples and go to use it is what are we to make of these differences? How significant are they? Does this group know from prior research that something is very significant or it can be insignificant and not be of great concern?

Without any more ado, what I would like to do is turn it over to the panel to maybe start with the service use question and start in the area of institutional use.

JOAN VAN NOSTRAND: I think from a policy point of view one of the most crucial questions, particularly when you are looking at service use and financing, is the lifetime of nursing home care.

A few years ago when I used to answer that question I would say, "We have not the faintest idea." But now, I am getting better because I am able to say there are various data sources that you can look at that will add some information so that we can answer that question.

Clearly, what one would like is a longitudinal survey of various cohorts that follow people starting around age 50 or so all the way until their death, but it is too expensive. We are just now starting to focus on these issues of longitudinal data. So we do not have that.

So the next question is, "What do we have and how can we try to work at piecing what we now have together and improving it in our future data collections?"

We have asked some questions from people in nursing homes about what their lifetime use of nursing home care is. We have asked information as to when they were admitted, when they were discharged, and where it was, so that we can try to build this kind of a history, and, in relation to the history, the changes in sources of payment at each admission and at each discharge.

Also, in the Supplement on Aging (SOA) that Gerry Hendershot might be mentioning, that same kind of a question has come out.

I do not want to speak on the National Long Term Care Survey (NLTCS) because there are other people here who are much more knowledgeable about it than I am, except to say that the difference over that 2 year period and who was institutionalized, given that they are all at fairly high risk, is also going to add to the information we have on what the lifetime use of nursing home care is.

I think we are moving closer and closer to being able to answer that question. I hope by the time I retire, when someone calls me and says, "What is the lifetime use of probability of nursing home care?" I will have an answer, and I will be able to say it is really a good one. We are moving there.

WILLIAM SCANLON: We talked a little bit in the National Nursing Home Survey (NNHS) Breakout Session about the plans for validation of the histories, the fact that in the next-of-kin survey and the current resident and discharge survey that you basically collect independent histories, one from the nursing home and one from the next-of-kin. Plans are, I think, underway that there will be a comparison of these data to see how well history can be collected.

Maybe Ken or Korbin with the NLTCS and Medicare claims; were you able to look at any of these issues of how good recall is versus actual information from a third-party source?

KORBIN LIU: In 1982 there were questions in the survey about nursing home history. Basically, the questions were phrased, "Had you spent any time in a nursing home? How many times did you enter a nursing home? How long were you in those nursing homes when you went in?"

That was essentially the part of the questionnaire that provided information on the history of nursing home use in 1982. The 1982 sample was subsequently followed in 1984 and several things could have happened to them. They could have died, they could have been in the community, or they could have been in a nursing home.

In 1984, for those people who were in the community, similar types of questions were asked that were asked in 1982. It was that kind of a history that they were trying to record; which was how many times and how long.

Specific dates were given. Clearly for the 1984, because they did not have to go back any further, the question was phrased "in the last 2 years, how many times were you in a nursing home and for how long?"

If those people were found in a nursing home in 1984, a different set of questions were asked. They were asked when they were admitted, and whether there was a prior nursing home stay before the one that found them in the nursing home in 1984.

For the people who were deceased or were not able to respond, the question was asked of the next-of-kin or somebody knowledgeable about that person. In that particular questionnaire, they were tracking nursing home use between 1982 and 1984, similarly, number of times and duration.

Basically, for the 1982 sample, you have both information on prior use before the survey in 1982.

By virtue of their being in the community in 1982, one would assume that those prior stays were fairly short. That is not necessarily the case, but they could have been fairly short stays. By 1984, they went back, you had another 2 years of history on the people who were in the 1982 sample.

The NLTCS does not have a built-in validation mechanism for those histories. I mean, there was not another next-of-kin survey, for example, to compare with the recall information from the surveys themselves.

The one thing that is available is that we have those files merged with Medicare records. At least on some nursing home use, if they happen to be Medicare use, then there should be some correspondence between what was reported by the individual and what was recorded by the Medicare bills. That is at least one way to begin to try to validate the recall information.

KENNETH MANTON: Some general comments on that, because this is a general thing that comes into the prevalence question that you alluded to. You have a different additional sampling factor when you are talking about episodes or trying to get events out of an event history than when you have the survey date and you are asking people about certain events; there are various factors operational like length bias sampling.

If you ask people within a certain window the probability of a person being included it is going to be a function of how long that episode was. In any given interval of time, if a person has been in a long time, the probability of pulling him in is greater.

These questions come up with respect to the NNHS when you either have the discharge sample or you have a current residence sample and you have got a question of length via sampling. In current residents, the fact that they are still within an episode means that is a truncated episode. You have got to worry about ways of backing that out.

One question came up in looking at certain analyses with NNHS data. Would you really want to longitudinally follow a cohort rather than trying to take some cross-sectional data, say for a current year and doing some analysis to reconstruct the histories? If you spend a lot of time with a long term longitudinal follow-up, the experience in terms of institutionalization 10 years ago for people at a certain age within a cohort may no longer be applicable.

They have got two or three things going on aside from the accuracy of the recall data in terms of actually reconstructing the use of institutions; both the question that you are sampling (episodes), the length of the episode and the nature of the sampling can affect the information about the resident within the survey data itself.

On the question of institutionalization, if you go from 1969 or 1973 up through 1977, you see one set of rates. After 1980 you see different things in terms of the growth of the nursing home population. A cohort study might not have been a very cost-effective way to pick up those types of temporal trends in institutionalization. That is an additional factor of the measurement issue.

There are decay functions or windows, if you will, where you think that recall is going to be reasonably reliable and a 6 month window will give you certain types of things that you can get out in greater detail rather than trying to go back a full year.

There are a number of detailed studies on what is an appropriate recall period, and where the accuracy starts to break down.

JUDITH WOOLDRIDGE: I think it is worth mentioning a few things about the purposes of the National Long Term Care Channeling Demonstration data base before commenting on the service use data.

The Channeling data base is not a nationally representative sample, but it is a sample drawn from the population of individuals whom we hoped would be a high risk of institutionalization. The purpose of the evaluation was to see whether a demonstration program could divert people who are heading into nursing homes into a community service program in a cost-effective way. This is a very special population from ten sites.

The thing about this population is that it was not a greater user of nursing homes and so the data we have on nursing homes is for a relatively few number of people. We wanted to get a very complete data set with respect to hospital, nursing home and community service use over the period during which we followed the individuals.

For the most part, the maximum period we followed anyone was 18 months. For some of the sample, we only followed them for 12 months. For some of the sample, we only followed then for 6 months, part of the community service sample was quite short.

However, it is a very complete data sample with respect to hospital use and costs, and costs by source of payment for nursing home and community service as well.

We established samples for the hospital analysis and the nursing home analysis that were designed to exclude people who we thought would have incomplete data.

We were able to get complete hospital data on the very large part of our research sample. Our assumption was that if somebody was covered under Medicare, and virtually everybody in our sample was covered under Medicare Part A, that we would get good utilization and reimbursement data from Medicare from the claims that we used as a major source of data.

In addition, people who were not Medicare-covered but who where Medicaid-covered throughout the period that we were analyzing, we assumed that Medicaid would be a complete source of coverage for that individual if they were covered throughout.

Otherwise, for a sample of individuals who did not fall into either of those categories, if they had a follow-up interview or if their caregiver was able to provide information to us which told us about service use in the previous 6 months and which providers were used, we went to the providers and extracted data at the provider.

With this combination of data sets and with this kind of approach to identifying who would have a complete sample, we have excellent hospital use data for 18 months.

The nursing home sample was a little bit more limited and the reason for that is largely to do with the issue of coverage.

We assumed, again, the only people who could be considered to have complete data would be those who were Medicaid-covered throughout the period, because Medicaid is a payer of nursing home use and anybody who is Medicaid entitled will be covered for their nursing home use, if they have any.

We did not make any assumptions about Medicare coverage being complete, because Medicare is a very limited payer of nursing home services.

For a large part of the sample, again, those who had a follow-up interview or a caregiver follow-up interview, we were able to go to nursing homes and actually extract information about the nursing home use that occurred in the 6 prior months, both the use, the reimbursement, and who was paying, so that as a result we have three types of reimbursement data. That was from Medicare and Medicaid claims. We also have information on private payment that came from the provider records extract whenever that was used.

We merged all of these data sources and created hospital stays and nursing home stays, which meant that we had to match up all the stay information from these diverse sources. I think it is important, with respect to the validity questions at this point, to mention that for those people who we started out with the interview data and then went to the providers to try and find what their precise service use was, we were able to find most of them.

In a few instances, we could not find a record at all at that provider. For the most part we could and the dates of service matched quite reasonably well.

We then took the stay data and the data that is available from public use is not from the formal stays, and I think for some of you this is a weakness.

What we did was to create utilization of reimbursement estimates for 6 month periods, for the first 6 months, for the second 6 months and the third 6 months after randomization, so that the kinds of data that are available on hospital and nursing homes for that 6 month block include the total number of days and total payments. It also included whether or not an individual had any stays, and whether they were admitted, which is a slightly different issue from the number of stays, because you could have had a stay in a period but have been admitted in a prior period.

We had reimbursement by sources for the 6 month period. We had total days, number of admissions, number of stays and reimbursements. But no information in the sense of a continuous history. You can not see when a person went in and out of the hospital and nursing home. You can not look there to see what kind of service use occurred immediately before a hospital stay in the community, or immediately after a hospital stay in the community. Also from the public use files, within the 6 month period, you can not tell whether or not an individual moved from a hospital to a nursing home or vice versa.

What you can do with these data, though, is because there are three 6 month blocks, you can look over time to see whether an individual had an increasing probability of being in a nursing home at month 6, 12, and 18. That was one of the things we did in our final report.

I should mention that there is data on other medical services paid for by Medicare and Medicaid, such as physician use. We grouped all the other types of Medicare and Medicaid services such as podiatry and everything else, basically, outside of hospital and nursing home use. We have whether or not such services were used, and the reimbursements available.

This excludes a large portion of private payments. For example, if physicians did not accept assignment of benefits, we did not know that and we don't have information on that payment from the individual.

I mentioned that we did not explicitly compare self-report data on the interviews with claims data or provider records, but implicitly we did make a comparison of the interviewer and the provider information, and found most of the data that we were looking for in the provider records.

It is probably worth mentioning, too, that we were matching Medicare and Medicaid claims for ten different states Medicaid files, and we found very good match of Medicaid crossover claims with Medicare claims for hospital stays, and also the nursing home stays.

Another source that we drew on was death records to confirm whether or not we were not finding utilization because an individual was now dead.

All in all I think the data appears to be very consistent across sources, and, therefore, I think probably reasonably valid.

THOMAS GRANNEMANN: I will just talk briefly about the community services data available from the Channeling evaluation.

As Judith mentioned, it is a very select sample. We do have one advantage to this Channeling sample, we have got two groups, a treatment group and a control group. The control group simply represents what the people in the existing system got. If we were interested in what is happening out there now, what are the patterns of service use that are currently in place, we have got a control group.

We also have a treatment group which, particularly for the community services, allows you to make some estimates of what the impact is of providing additional coverage for those services and providing case management.

We were able to look at both those things. In terms of the data sources, we have several sources for the community services. We have Medicare and Medicaid records, but that only covers the things for which Medicare and Medicaid cover.

We do have from that source both quantity of services and dollar amounts of services. It is a data set that provides a lot of information on financial aspects.

For the individual interviews on those services, we asked individuals to report for each of their caregivers what they provided. Those records in terms of being able to validate across data sources reflect something a little different than what the Medicare records do. They would not be classified as nursing and homemaker services as providers do, but will be classified as the individual who actually reported those services. It is a little bit difficult in using the individual interview data for which a large part of the sample has those records to go back and validate across data sources there.

For a 20 percent sample, we have provider records extracts for community-based services. These cover not only the services that the Medicare and Medicaid records do, the traditional home health services that are covered, but also personal care, homemaker, transportation, and meal services.

Because of the way those providers were identified, the sample will not match up. Starting with a 20 percent sample, we are only able to go to providers when the individual reported having received the service and was able to identify the provider, and then only when the provider was able to supply that information. We got very good cooperation from providers, but, again, that gives you a little bit different sample than you get from the other sources.

The other thing that you are able to do with this data set is because we have a lot of information on individual characteristics, you are able to look at some subgroups by ADL categories, by economic resources. We have information on assets and income, the information on Medicaid coverage in the ten sites. This does provide a basis for sorting out what some of the determinates, of community-based service use are.

Both in an environment looking at the control group for what is happening now and under a situation of expanded coverage for community services. If you are trying to make estimates of what would be the effect to expanding some coverage in a case managed type of system, this can provide that kind of information.

KENNETH MANTON: We have seen a number of surveys, that have a complex structure where you are talking about SIPP, and to think about the cross data base analyses become even more daunting.

What I think that says is that there are some issues with respect to structure. The way the information systems are set up, that could be set up in a more parallel fashion that would facilitate both cross study and, for that matter, we also see a lot of complexity within studies with different record types.

I think what has happened is there is a tendency to try and be efficient in data storage, to go to the different record types and put the effort in terms of linking of cross records rather than saying, "Well, I will be less efficient in data storage but maximize the ability to do analysis."

I think there is probably a lot of mileage that could be gained in terms of both cross study and with hidden study validation analyses and substantive analyses that there could be a lot of facilitation by looking at the question of data structures and the information system. Right now, you get the feeling that, "Well, we are putting this into NTIS," but they are coming in in different data structures. Some are turned into person-based records. Others are left with different types of episode structures. You can encode the service you state in a number of different ways. One is an aggregated interval type of record. The other is a full-time line type of data. A third is a bill or episode type of record. All different types of records seem to be being used and that is additional complexity. The data is complex enough without having the complexity of different people doing very different things.

I think that is one area that it would require somebody to do some coordinating work in terms of what is the most efficient data and information structures, especially for the cross study validation and analytic studies.

WILLIAM SCANLON: I think that point is very well taken. I think that one of the things that we face in this is always the loss of information that comes with simplification and abbreviation. At the same time, sometimes the accessibility that comes with both of those things, but sometimes that loss of information can not be tolerated.

KENNETH MANTON: Sometimes it is not even loss of information in the data structure. I mean, if you think of a rectangularized person-based file versus multiple record types encoding the episodes, both have same information. One, he wastes some space on a tape, but in some cases I would much rather waste 30-40 percent of a tape than have four or five different record types. In one case I am dealing with a one-dimensional structure, sorting through on a variable format for a person. In the other case, I have got four or five different formats and record types, and I have got to do special purpose programming to link and merge variables together.

It is not necessarily a data loss question so much as a tradeoff. We have technologies for mass data storage; does it matter a tape costs $10? Do you care if you waste 30-40 percent of it?

There are some implications for various computer systems. I think we are going historically rather than analyzing what the current possibilities are.

WILLIAM SCANLON: I think there are instances, though, where what we do is we aggregate and there is the potential for losing the information.

Let us turn briefly to this issue of measuring dependency and given the diversity that we see in the questions. Does anyone want to comment on what experiences you may have had with looking at these different measures? What kinds of conflicts we might expect and how we might reconcile some of these things or how we might be comfortable with some of these conflicts, as opposed to being disturbed by them?

KENNETH MANTON: I guess I would say that first of all this is an area where there are no simple answers. They have got to look at the questions and the wording of the questions. Some of the prevalence estimates between the 1979 supplement and some of the NLTCS things. I was looking at an article in Milbank by Joan Comone (phonetic) Huntley and other people where they were looking at two or three or four data bases where there are different prevalence estimates and you have to be a little bit of a lawyer to see what some are talking about with the prevalent estimates. At least as best I can tell from the write-up, and also talking to Bill Lyzak, since he produced some estimates like this; you have to see that they are talking about limitations where the help of another person is needed.

Later he said, when he could not start with some of the prevalence estimates, he was focusing on people who require personal services. There is a class of people who may get by with special equipment, you have got to be very careful about a prevalence of what, and sometimes that really means going down to the specific wording of the question, especially some something like functional disability, which can be multi-dimensional in the softer concept.

For functional disability, some people are getting better, some are getting worse. If you freeze the sample or component group at a particular time, over time some of that is going to change on different time schedules.

For example, I am thinking of the NLTCS and, again, the notion of a sampling frame that captures certain types of duration-weighted phenomena. What are you getting a measure of at a given point in time and what can you tell, say, with a 2 year interval versus a 4 year interval versus a 6 month interval?

There are various types of functional or dependency changes that each and of themselves could be substantively very interesting. The hip fracture patient becomes rehabilitated, the Alzheimer's patient who has a fairly long, regular, slow decline, the stroke patient who might have a more prolonged period of disability, but maybe there is some long term rehabilitation. All those are different types of disease entities, the relationships, the disabilities and different phenomena that are of interest for one purpose or the other.

Certain sample designs are going to pick up aspects of those and will not pick up aspects of others.

KORBIN LIU: I think in comparing national estimates, in terms of the population that is disabled, there is the other question of which variables are used in estimating disability. I think even when we were looking initially at care survey, we had selected a set of ADL's and IADL's and Candy Macken who we were working with had selected a different set.

Immediately we came up with different estimates right there. I think some of these comparisons, for example, would be 1979 home care supplement, whether we were using the same ADL's. If you see differences in the rates, they may be a function of the ADL's and IADL's which were used by the two groups.

JOAN VAN NOSTRAND: I just wanted to make the point and kind of expand on a bit of what Korbin was saying. Not only are we looking at the different ADL's and particularly IADL's, because this whole issue of what you need to be able to do to live independently in the community is a crucial one. There are other kinds of screening variables that tend to have some important implications.

One of them is the fact that many of these questions start off with saying, "Because of a mental or physical problem do you have difficulty with ..." and then they list the particular ADL or IADL. These problems they are looking at are chronic. Believe it or not, there are two major definitions of "chronic" and they differ. That leads to very different estimates from what you see in the NLTCS, which is a much higher rate than what you would see from the 1984 SOA, and it has to do with the question in the 1984 SOA, I believe, is this condition chronic and has it lasted for 3 months or more, and there is a certain list of chronic conditions. In the NLTCS, I believe it is that it has lasted 3 months or is going to last for 3 months. That judgmental factor by the person who is responding as to whether or not that is going to last for more than 3 months makes a big difference in what our estimates are.

EVELYN MATHIS: I would add that you need to pay attention to the way the questions are worded and you look for things like "need" or "help." Then you also need for those people who are in institutions, to be aware of policies of institutions. Some of the policy of the institutions will cause the people to become more dependent or even if they are not, they are still going to get the help just because of the policies and the rules of the institutions.

The other thing that you need to be aware of, too, if you can get at the medical diagnoses a lot of that will help you with some things that could cause dependencies.

WILLIAM SCANLON: We are now going to turn to questions from the audience and, hopefully, we have already dealt with some of the things that were of concern to you. Now let us hear about other issues.

QUESTION: I think the first comment I would like to make is I wish you would all applaud for the generosity of the producers who produce all the data for public use.

As a key consumer of the public use data tapes, I am a little bit puzzled by the degree that all the data being gathered were considered to identify the market attributes. By that I mean the individuals living in the community are not living alone. They are not living in the vacuum system, but they are living in the area that faces the competitive market situation and living in that situation they do not know what kind of providers are giving the proper services.

My question is to what degree the NLTCS's have some identifier to identify the Zip Code, county code or city code, and so on? This is the great distinct possibility to link the individual file with area resources file that many of you probably have utilized. Therefore, you can identify to what degree the market forces impact upon the use of service and to what degree they impact upon the access to care.

That is my first question. My second question is analytically whether we could analyze the data either at an individual level or at an everyday level, that is individual behavior in use of long term care services.

At the individual level we all know, including all the variables you can analyze, probably you may account for relative 20-30 percent of variance in chance to be institutionalized. The question is where are those unknowns? What are those black boxes?

One possibility may be to identity what are the contextual variables that are beyond the individual behavioral. The individual attribute might impact upon the use of services or impact upon outcomes of care.

At an everyday level, I think that is a very serious one that we keep gathering data at an institutional level, but pay very little attention on quality of care issue, that is the process of care issues.

I think certain elements should be incorporated in the institutional base survey, not just who the patient is, but also what kind of providers are giving service to him, and to what degree the quality of the care within the institution can be rated consistently.

My third question maybe is much more global. What degree can we identify so-called determinants of the institutionalization or determinants of adverse outcomes of care? Is it possible that we can compose a summary index to identity so-called frailty level?

Susan Hughes mentioned to me that she is trying to formulate a one page instrument that allows you to summarize the risk. If that is the case, to what degree can concurrent validity be addressed? That is, why do we need a 45 page instrument instead of one if one can provide a better result?

I think that it is about time to think about if we can simplify all the data gathering in terms of a much more easy way to identify either frailty level, risk of the institutionalization, risk for hospitalization or risk for dying?

WILLIAM SCANLON: I think there were both some questions there and some real challenges, so I am glad I am a moderator and not a member of the panel.

KORBIN LIU: I guess the one response to the first one is that, obviously, there is no perfect data base for everything. The NLTCS was a nationally representative survey. The sample size was 6,000 people.

I do not think one could ask that type of survey to have geographic specificity and also have cases by geographic areas, like counties, to have any significance.

One of the reasons I think we are here is to look at the multi-data bases and see that they are available. To see how we could derive information from each one to help concatenate or whatever to get the best possible estimates.

On the institutional quality, that is a very geographic, very person, very facilities specific type of survey you are talking about. Incidentally, I think that is very hard to do on a national basis.

There are a number of other options. One is that there are administrative records systems like the Medicare/Medicaid automated certification system that surveys every facility, in theory, every year.

You have facility specificity there. There is some case mix information that was collected, particular data sources. We are seeing an emergence of case mix reimbursement for nursing homes. The data systems that are being derived to establish payment rates have a tremendous amount of patient specific information, because they have got the case mix based system, there are at least four or five of these states now that have case mix data.

That data is also collected longitudinally. I think there are some plans afoot, sponsored by the Health Care Financing Administration (HCFA), to use that longitudinal for the case mix payment to track patients and to look at outliers in terms of, perhaps, his ulcers or whatever, and use that as a tickler system for quality assurance monitoring.

KENNETH MANTON: I think what is relevant in almost any of the national surveys is the local area estimation or looking at the characteristics for identifiable local areas as opposed to using controls for market characteristics in a given set of local areas.

One is can you produce stable rate estimates for a given set of counties. The other is to say that in the areas that you sampled, can you get an initial set of factors as market characteristics that could be put into an explanatory model?

I think the issue there, in terms of national surveys, is these things are generally structured geographically and the question is what is the primary sampling unit structure that is used in a given survey?

A lot of times that is based on a county level thing. If you have provision tied to a county level marker, you could in theory link that. The Zip Code is obviously a lot more specific and obviously when you are going out and surveying the people you have their addresses available. Then there get to be some very tricky confidentiality issues in terms of how far can you decompose the geographic identifiers.

In counties it might be possible for a PSU level type of decomposition. The PSU's are tied either to counties or groups of counties. There would be a basis of linking them there. The Zip Codes are obviously available to the Bureau of the Census, but that probably would not be possible to do in terms of a public use tape.

Then to go to the second question, which is an analytic one in terms of you have a lot of unexplained variance. You do not believe all the rest is simple stochastic random factors. They are systematic unobservables. What important variables are we missing? You can think about that, too, in terms of aggregation effects.

There are various models dealing with the question of aggregation bias as you build up from individuals into county groups or groups of individuals and ask what are unobserved heterogeneic components in the analytic modeling effort.

There are models which adjust for heterogeneity bias in the economics for unemployment durations, etc. There are similar types of models for health event data, which says that there are systematic components, but we can not identify the variables. We can adjust our model estimates for some of those effects if we conceptualize it in certain ways.

One of the ways to get a handle on those unobserved effects is by looking at the packaging of that variance across different size aggregates or units. There are some analytic strategies for that.

THOMAS GRANNEMANN: I want to make just a few comments on the third question which was the ability to predict institutionalization.

We found in the Channeling data that it was fairly difficult to have a good predictor of institutionalization, and it was not really entirely clear what the cause of that is.

I think there is certainly some reason to think there is some imperfect measures in terms of the way we measure ADL and IADL that does not really capture the critical factors.

There are also potentially unobserved things that perhaps might be observable or might not be observable factors that may cause people to go into a nursing home.

The other factor, which I think there may be some evidence for, is the precipitating event thing when we look at people at a point in time. We can not predict very well who will go in because we do not know what is going to happen to them at a later point, maybe things that you can not observe at a given point in time that later happened to them that caused them to go in.

I think there is some evidence of this when you compare studies that have looked at predicting in advance who will go in, those are able to explain less of the differences than the cross-sectional studies which look and say who is there already.

There is some evidence from those kinds of studies that say you can identify some of those characteristics after they are in, but by then it is too late to use it as a predictor.

A comment on the question about whether there is a single number of index that could be constructed. One of the things we did was a HCFA funded follow-up study for the Channeling evaluation, to look at ways of predicting institutionalization. One of the things we did was to develop a summary index based on multiple regression analysis that took account of all the various variables we had on the file and tried to construct an index which was a predictor of nursing home use.

We were, in fact, successful in identifying a high risk group, a group that had several times the probability of going in as the whole Channeling sample, which to begin with started with a fairly impaired group.

I think there was some success there. The purpose was to try to identify people who could be targeted to be diverted from institutionalization, and I think on that count we were less successful in being able to identify people who could be diverted by Channeling. I think we have gone a fair way toward identifying risk factors that can allow you to identify high risk and low risk groups for institutionalization, and I think Channeling data is one source that provides a good basis for making those kind of estimates, although, again, with the qualifications we talked about earlier. That was not a general population we look at.

JOAN VAN NOSTRAND: I want to address the second issue which deals with the question about quality of care, and the need for data, particularly on the quality of institutional care.

As you know, HCFA has been recently reviewing their quality of care process and is in the progress of instituting an entirely new process which focuses not so much on the paper and pencil review, but on actual information about the clients. I think that is a big step forward.

The Institute of Medicine has put out a very large volume on looking at quality of care and measuring quality of care.

In particular for the NNHS, as we were going through the process of developing a pretest and including in it some questions on quality of care, we had a whole variety of questions. It was clear as we went to the Office of Management and Budget (OMB) for our final clearance that there were more questions than we could pay for, because resources, as always, are limited.

We turned to some of our sister agencies, particularly HCFA and basically made a plea for funding. They have limited resources also. We were not able to get the funding, and the guidance we received from OMB was that the focus was to be more on issues of financing and a deemphasis on issues of quality.

We used that guide to help us decide what we could possibly include in the survey, given the amount of money that was available.

GERRY HENDERSHOT: I wanted to return briefly to the question about the small area data.

It is possible to link data for counties to the National Health Interview Survey (NHIS) data files including the SOA. If you have a good county level data file, it is possible to merge that with the SOA, and there are only two obstacles to that. One is it is not part of our usual work and we do not budget for it, and so somebody has to come up with the money to do it.

It is not that expensive to do. It is not that difficult a task, if you have got the good area data file.

The second problem is confidentiality. We do not release small area identifiers on public use data tapes for reasons of confidentiality, so the actual match would have to be done by some kind of special arrangement between us and the user. Usually we do the match ourselves for the user. We are willing and able to do that kind of matching and have, in fact, done it frequently in the past.

QUESTION: I do appreciate the opportunity to hear from the people closest to the data. The question I have is much easier than the last one you had, but it is in three parts. I will be very quick.

In the No. 131 Advance Data, 1985 NNHS the indications were that the number of beds was up over 1977, the number of homes was up, the occupancy rate was up, discharges were up, but not as much. Admissions were actually down in absolute number, and the admission rate was down about 18 percent, if you look at the rate per bed.

My question is, is this a function perhaps of a change in definition between 1977 and 1985 of what constituted a discharge or an admission, or is there an implication with respect to length of stay?

Finally, was there a cross-check done between the Inventory of Long Term Care Places (ILTCP) number of 1985 admissions to test to see if this was a consistent number, that admissions were actually down?

EVELYN MATHIS: The ILTCP was mainly an updating of the National Master Facility Inventory (NMFI).

In the NMFI, the definition of places in the inventory did not change a great deal. How we got the data changed over the years, but the definition of places in the inventory did not change.

The inventory is made up of three different categories of places. One category is hospitals. Of course, we did not use that in the NNHS other than where we got a list of those nursing homes that were based in hospitals.

The second category of places in the inventory, that category we call "nursing and related care homes."

The third category of places in the inventory is facilities for the mentally retarded.

In that other category in the NMFI, not only do we have places for the mentally retarded, there are also facilities for the physical handicapped and the emotionally disturbed, and a lot of other kinds of places.

For the inventory that you heard earlier it included two categories, the one that was the facilities for the mentally retarded and the nursing and related care home.

In the past, and I think it was up until about 1976, we had all of the facilities in the inventory, we sent out a questionnaire and we classified them based on some common criteria that we applied across all facilities.

Beginning in 1976, up through I think it was 1982, we got some of the data from the states and the states that did not supply us with the data, we surveyed those places ourselves. We did not attempt to apply that common set of criteria across the board to all facilities.

If a state reported something as being a nursing facility, then we accepted it as a nursing facility. If it was reported as being a residential place or personal care home, we accepted it as such.

We have not had a chance yet though to look at the data to see how much of an impact the way the data got reported and collected had on the findings of the NNHS.

One thing to bear in mind, regardless of how we got the data, all of the facilities had to meet some very basic criteria.

Number one, they all had to provide care on an in-patient basis. They all had to have at least three beds or more and they all had to provide some level of care in addition to just room and board. If room and board were the only type level of care provided, they were out of scope for the purposes of not just the NNHS, but the NMFI also.

When the interviewer went to the facility in the NNHS, one of the first questions the interviewers asked as a part of our questionnaire so they would not forget, was to establish whether something else was provided in addition to just room and board.

I do not think that you are going to find a great variation in the kinds of places that you are going to find in the universe.

With the second report, No. 135, there was a very detailed outline of the kinds of places that were placed into the universe for sampling.

We also noticed those differences. We think there are several different reasons why you are observing the things that were pointed out in that report.

QUESTION: I am a little concerned. Evelyn said a minute ago "Bear in mind the medical diagnosis." I have a little trouble with that, especially those of us in mental health and psychosocial illness. I think because of the Institution for Mental Disease's (IMD) the medical diagnosis does not mean a great deal in the nursing home, and I would like to get some explanation or her reflections on that.

By and large if an institution has more than 50 percent of their nursing home patients with a primary psychiatric diagnosis, it is considered an IMD. Then there is a question about the reimbursement from Medicare/Medicaid if it is an IMD. There seems to be a tendency in many areas in nursing homes to give the patient a reimbursable diagnosis rather than the true medical operating diagnosis,

especially I favor talking about functional capabilities instead of diagnosis anyway.

EVELYN MATHIS: The only way that I can respond to your question is that in developing what we call the current resident questionnaire, and that was the questionnaire that was completed for the sample of residents, we have an open-ended question there where we ask the interviewers to list all of the diagnoses that were listed in the record, and they did it two different times. One was at the time of admission and one was the current or the latest.

We also have some questions on the questionnaire that we got from the National Institute of Mental Health (NIMH) and they gave us the questions to try to capture whether or not the nursing home residents had a mental health diagnosis. They gave us the categories to ask.

NIMH will be getting the data tape. Get in touch with me and I will let you know the office to reach.

The other help that we got from NIMH in this, after we had keyed all of the data, was a check list. In addition to the check list, they had written in "and other specified."

We sent all of the "other specified" to the NIMH. They went through the check lists along with what was written, because some things were duplicated, and they went through that to make sure that what was written in was the same as what they had checked.

We depended entirely on NIMH to help us with the mental health diagnosis. I hope what we collected would be responsive to NIMH, at least we tried to be.

JOAN VAN NOSTRAND: There has been a lot of discussion, particularly with diagnosis related groups (DRG's), that there is often an effort to gain them and select a diagnoses in which the payment would be the largest, although most of the comments I hear from HCFA are that they feel that there is no gaming on the DRG's.

For the NNHS, the sample was something like five current residents and six discharge residents. There was really no way to tell what was happening with 50 percent of them.

Most of the time the responses were given by several nurses. Generally, we asked to talk to the nurse that was most familiar with the care. It is my judgment that they are not as concerned about answering this in terms of that IMD rule.

The other issue I think, though, that it raises is one that Evelyn brought up. What we are asking them to report are things that are recorded in the record. How that IMD rule affects what was recorded in the record is something else again. I would think one might want to do studies on that.

I think based on what was recorded I do not feel that there was that much of a problem with what was reported by those varying nurses on those very few residents or discharges in the nursing home. It is a good question and a great issue to deal with.

QUESTION: Are there any plans or recommendations that you can make to help us with looking at the DRG effect on the institutionalized elderly? We are finding, at least in New York, that we are bouncing them back and forth to the hospital. They are admitted [to the nursing home] from the hospital, and they are going back to the hospital because they are coming in too unstable.

I need to link that question, though, with the nursing shortage which is crippling us, particularly in the nursing home sector. Are there any places to do studies or to develop data to look at the nursing shortage in terms of patient dependency, morbidity, and mortality.

JUDITH WOOLDRIDGE: I just would like to mention that HCFA is working on a study of aftercare right now with Mathematica Policy Research (MPR). Aftercare is defined as the care that people receive when they leave the hospital. I do not think that this is related to the nursing shortage issue.

QUESTION: The linkage I am trying to make is that we seem to be getting the patients sicker and quicker. That sounds cute, but it is a reality. We do not have registered nurses (RN's) in nursing homes to the degree we had them 3 years ago. If we are getting a more technologically dependent patient in the nursing home, we do not have the staff to give them that care. We are bouncing them back to the hospital, which I was wondering also if that affected your admission data. In other words, the number of admissions in X period of time. Are you carrying that as an admission or as a transfer in and out?

JUDITH WOOLDRIDGE: With respect to the Channeling data, I can mention that the majority of the data were collected before DRG's became effective, so that is not an issue.

To the extent that the bouncing back and forth did begin for people in the Channeling sample, as a result of DRG's, that is simply not something that you can identify in our data set.

EVELYN MATHIS: In the NNHS, the Bureau of Health Professions, sponsored one component to look at nurses in nursing homes. The Bureau is in the process of analyzing the data and reviewing it.

In the facility questionnaire, we asked the administrator, or whoever was designated to respond, to give account of the numbers of full-time and part-time employees in various categories working in the nursing homes. I know that from the NNHS, the Bureau and ourselves will be doing some review of that data, but we are attempting to look at the number and sample is limited to just RN's, where we had them to fill out a questionnaire,

A part of that questionnaire was to ask them questions about retention; what was important to them in looking for a job, working in nursing homes, why they would, why they would not, how important certain things were to them to stay there, and why they would not.

I think you will see in about a year or so, some information about what things are important to RN's to accept positions and to work in nursing homes. I know that they are looking at the data and they are in the process of analyzing it. I know they are also planning some very detailed reports on that issue.

KORBIN LIU: We are doing a study with the 1982 and 1984 NLTCS's with the merged Medicare records. I think that the nature of that study highlights, in many ways, the power of that data base, particularly with the Medicare services involved. The study is directed toward looking at pre/post-PPS changes in hospital readmission and post-acute care use.

The 1982 NLTCS constitutes a pre-Prospective Payment System (PPS) situation. The 1984 is almost a post-PPS. We have got to keep in mind that PPS did come in place October 1983.

On the other hand, the beauty of this merged file is that Medicare records are continuous and so we have got Medicare records looking from 1980 to the present time; and that gets into 1985, because we would expect most of the PPS effects to occur not in 1984 but in 1985. I bring this up in part, to highlight the utility of that particular data base which will be public use very soon.

At the same time, Medicare records, the enrollment records, have information on mortality and status of the patients. With these types of administrative records merged with survey data, you have the ability to look at changes over time. With the survey data, the NLTCS are loaded with ADL information which one would not find in the routinely collected information in the administrative records for Medicare.

We have a combination of case mix information that you can get from the survey at two points in time and this continuous utilization information.

KENNETH MANTON: Korbin summarized that fairly well, but you just emphasized that with the different types of episodes, what we were able to do for certain windows, one could look at the tradeoffs in terms of both length of stay and rate of admission between the different types of services. With the changes in the hospitalization rates and lengths of stay, you could see corresponding shifts or to pre and post in terms of the home health. You have the detailed survey data on this highly vulnerable, high-service use group, where you can get very extensive information on their functional dependency and examine the tradeoffs there for that particular group, but you also have all the other sample components.

You can look at these service substitution or tradeoffs pre and post both for a highly chronically disabled community-based population. Then for the sub-samples of a non-chronically disabled population, you can sort them out as well as the institutional group in 1982. You do not have the change data for 1984, but you do have a bit more information on the institutionalized and you have people on the 1984 survey.

That gives you an additional dimension, a look at the change effects within a particular interval pre and post in terms of if people are not going into hospitals where might they be going, what other types of services are they using and what is the pattern of that service use, and gives you a systematic effect, if you will, of the impact rather than just saying, "Well, what was the impact on hospital episodes?"

QUESTION: Betty Cornelius at HCFA has some data in terms of staff being a relationship to quality care and she is tracking it in five different states, looking at the area of dehydration, decubiti, incontinence and several other areas. In fact, she had some preliminary findings that there is an inverse relationship between decubiti, incontinence, dehydration and relationship to staffing ratios.

WILLIAM SCANLON: I would add that HCFA is interested enough in this problem, that in addition to all the other stuff that you just heard, they are funding a study of ours, which is looking at area variations in post-hospital use, pre/post-PPS, and we are looking at the issue of readmissions as well as the use of Medicare staffs on an area basis.

QUESTION: I have the impression that the more research is done the less policy is made.

In Europe and in the country where I live, the research is not on the level as I heard earlier, and that is also why I am here. On the other hand, in my country, and I know also of my neighbor countries, a lot of policy for the elderly is made at the state and federal level on providing good insurance for the elderly people, building nursing homes and so on. I am surprised that there is so much emphasis on collecting data, but the final question is what to do with those data and what is the impact on policy.

KORBIN LIU: I think that the problem is you can not anticipate the policy questions. They are catalyzed by events.

You do not have enough data and you do not have it fast enough to directly address the question, you need to average the data bases. These surveys were conducted in the effort to see what they can each do. The nature of this particular session is to give you a sense for what kind of resources you have when the policy question comes up, and then be able to answer it.

Sometimes it happens that way and sometimes it does not. I mean, clearly we all know situations where policies are made without any empirical support for them.

Let me just talk about a little research that Ken and I did some years ago. We were very interested in the question of length of stay in nursing homes. I think that was 7 years ago when we started that. It was fairly arcane research, and I guess he and I were interested in terms of an intellectual issue.

I think we are fairly gratified now, as private long term care insurance has turned into more than just a notion, that some of the research became probably more relevant now than it was. The length of stay information is probably more relevant now than it was 7 years ago.

It takes maybe 7 years for the data or that type of analysis to become useful for policy. I think maybe that is the nature of the process.

KENNETH MANTON: We had some questions and I think there has been a lot of discussion in terms of change in reimbursement policy and the effect of quality of care. That is an attempt to monitor and fine tune policy in terms of outcomes that are producers, and I think that is probably a very important type of monitoring that one would want to conduct.

Though it can be expensive, research tends to be a lot less expensive than certain types of policy mistakes.

It is important to be efficient. One of the better examples of that is the recent evidence on the changeability of functional status of elderly and the oldest old. The potential for that suggests that there are different types of options for providing services to those individuals. Some of them may be more in a preventative mode of maintaining functional status, and that maybe keeps them from a dependent relationship.

A lot of research at the National Institute on Aging (NIA) is more basic research. Clearly when you look at the projections, the demographic structure of the population, you go out 10, 15, 20 years and you start getting some of these larger birth cohorts coming through. If we keep the traditional patterns at roughly the same rates, We are just going to be overwhelmed with the oldest old population in 20-30 years and the long term care demands.

It almost demands an alternative solution or just an incredible drain on general economic resources within the country.

There may be much more potential for improving the functional status of older people. How do we translate that into action? That seems to me a societal or a humanitarian goal.

The other is if you look at the demographic imperative or population aging, you almost have to develop some alternative responses.

WILLIAM SCANLON: I guess I would add to that, I am usually pessimistic about a lot of things, but one of the things that I feel more optimistic about is the progress that health services research has made, because in some sense health services research is still in its infancy. We are really now getting data bases in long term care that are much better than we have ever had before.

Legitimately, lack of knowledge was a barrier to adopting policies. The federal government has a problem in that once it takes a step, it really does not have a reverse gear to back out of a mistake.

That hesitancy on the part of the federal government is very understandable. All kinds of things have gone on within the states that are much more innovative, much more experimental, and sometimes are abandoned because it is politically easier to do that at a state level or at a local level, so that I think we are leering a lot. It should not be an excuse for too long that we are ignorant and therefore we can not do anything, but to some extent in the past that approach has had some legitimacy.

CHAPTER VIII. IN THE PIPELINE

Joan F. Van Nostrand, National Center for Health Statistics

I will try to describe to you why this talk is called "in the Pipeline" and what it means. This presentation could have been called "A Preview of Coming Attractions."

It is a focus on data bases relevant to long term care that are being planned, collected or computerized, but not yet released.

It is an attempt to whet your data appetite and to alert you to the schedule for release, so that you can build the data into your long range analysis plans.

I have a broad definition of data bases. I am including data tapes, reports, and conferences. I have organized this preview according to schedule. I will begin with what is coming out first.

The first data base has just been released. It is a data tape for the Study of Secular Change and Aging. It is a concatenation of data tapes from the National Health Interview Survey (NHIS) covering the years 1969-1981. The tape includes the core data items from NHIS for any person who was age 30+ for each of those years, in a standard format. One of the strong points of it is that it can be used to examine changes over time. It is currently available from the National Center for Health Statistics (NCHS) or from the National Archive of Computerized Data on Aging in Michigan.

The second data base in the pipeline is a report that provides detailed data on the health of older persons. This report focuses on all the surveys of NCHS. It provides data in great age detail, often up to the category age 85+. It is an excellent reference report. If you have a question on activities of daily living (ADL's), intermediate activities of daily living (IADL's) or cognitive impairments, you can flip to the correct page and get basic data on a nationally representative population. It also has a special appendix that describes in detail the content of many NCHS data sets. This is useful because an analyst can pinpoint some of the data sets and data items that might be useful in an analysis. The report will be released in the middle of July. It is called Health Statistics on Older Persons, 1986. If you want a copy, you can come to the next item on my list, the Public Health Conference on Records and Statistics.

This year the topic of the conference is data on aging. It will address issues in health, in research and in public policy for now and into the 21st century. There are some sessions in this conference that focus on long term care.

It is a 3 day conference, from July 13-15 in Washington, D.C., and is open free to the public. The report Health Statistics on Older Persons will be in the registration package. One of the plenary sessions has Josh Wiener from Brookings talking about public policy and long term care. There are concurrent sessions that look at long term care in relation to issues of community-based care, mental health, and forecasting health and service use. In another plenary session, Ann Sommers will speak on Politics and Personal Preferences, A Consumer's View. I think she will be rather provocative and raise some interesting issues about long term care.

The third data base in the pipeline is a data tape from the 1986 National Mortality Follow-Back Survey (NMFBS). This is information about the last year of life for a sample of about 10,000 older persons who died in 1986. Data were collected by NCHS from the next-of-kin and from hospitals, nursing homes and hospices that were identified as having provided care to the sample in the last year of life. It should provide data on high users of health care services and their risk factors. It also has information on socioeconomic status and on net worth. This provides the opportunity to relate socioeconomic status to the use of institutional care in hospitals, nursing homes, and hospices.

The fourth data base is entering the pipeline, so to speak. It is the National Health and Nutrition Examination Survey (NHANES) III scheduled for fall 1988. It includes physical examinations, medical tests, and food intake. Cycles I and II had a limitation, a cut-off at age 74. For the 1988 cycle, NCHS is planning to eliminate the age cut-off, so that all elderly would be included. NCHS is developing an in-home examination to address the problems of limited mobility that often lead to a lower participation rate for the elderly, since it was difficult for them to get to the trailed examination centers. This in-home exam is structured to include basics like heights, weight, blood pressure, and measures of physical functioning. This survey will provide data for an in-depth analysis of the health of the aging.

The next data base is also one that is entering the pipeline. It will provide data on the use of community-based long term care.

There are some rich data sets, like the National Long Term Care Survey (NLTCS) and the Supplement on Aging (SOA), which look at the use of community-based long-term care from a population point of view. One problem with them is that when the analyst wishes to study subgroups of users, say women who are 85+ or persons who are part of the minority population, the number of cases is so small that the analysis is impossible to conduct.

NCHS plans to launch a National Health Care Survey in 1992 by collecting data from the providers of care. The long term care component will cover nursing homes, home health agencies, and hospices. Such data will be important for making comparisons among different providers in terms of clients, costs, and payment sources.

The last data base I want to bring to your attention is a report by the National Academy of Sciences due to be released in 1988. It is on the needs for data for health policy analysis for an aging society. It is a set of recommendations on how to fill data gaps to analyze health policy in relation to the geriatric revolution that is occurring. It has a chapter on long term care and another on the financing of care. It is going to focus more attention on the federal data system in relation to data for health policy analysis.

I think it will also serve to intensify debate on what the priority data gaps are and on how to fill them. It is important that you as a group of users with critical data needs, are aware of this report so that you will have a chance to provide input into this discussion of gaps, how to fill them, and what priorities to follow.

CHAPTER IX. SUMMARY/CONCLUSION

William Scanlon, Ph.D., Georgetown University
Mary Harahan, Department of Health and Human Services

WILLIAM SCANLON: I am going to turn the podium back over to Mary Harahan, but before I do that I want to thank the panel for dealing so effectively with those questions as well as for their roles in producing these data sets we are all going to be using for many years to come.

MARY HARAHAN: I have been asked to make a few announcements. One is to repeat that we will be distributing the proceedings of the Conference and we will be mailing it out to everyone who has attended here. It will also be available upon request if you write us or other people write us.

An evaluation form will be sent to you also. It is not part of any of the reams of material that you have and hopefully that will give us some guidance about next steps, should there be next steps.

Finally, there will be a grants announcement that my office will be publishing in the Federal Register. It will focus on utilizing some, all, or even data bases that we have not talked about, with respect to long term care policies issues that we have identified. I hope you look for it.

I would again like to thank the speakers who have participated with us. I think they have been excellent. I think the Conference has done everything we could have ever wanted it to do.

Again, I am extremely grateful to the staff in the Office of the Assistant Secretary for Planning and Evaluation (ASPE) who have worked very hard to organize the logistics of this Conference. I thank the Office of the Assistant Secretary for Health (OASH) and I thank all of you for coming.

APPENDIX A. AGENDA

DEPARTMENT OF HEALTH AND HUMAN SERVICES
CONFERENCE ON LONG TERM CARE DATA BASES

The Ritz-Carlton Hotel
Washington, D.C. 20008
May 21-22, 1987

Thursday, May 21

8:00 am – 9:00 am (BALLROOM LOBBY)	**Conference Registration and Coffee**
9:00 am – 9:30 am (BALLROOM)	
Introductions	**Mary F. Harahan** Director, Division of Disability, Aging and Long Term Care Policy, DHHS/Office of the Assistant Secretary for Planning and Evaluation
Welcome	**Robert B. Helms, Ph.D.** Assistant Secretary for Planning and Evaluation
	Arnold R. Tompkins Deputy Assistant Secretary for Social Service Policy, DHHS/Office of the Assistant Secretary for Planning and Evaluation
	Steven A. Grossman Deputy Assistant Secretary for Health (Planning and Evaluation), DHHS/Office of the Assistant Secretary for Health

9:30 am – 11:30 am Overview of LTC Data Bases: General Session (BALLROOM)	
Introduction	**Mary F. Harahan** Office of the Assistant Secretary for Planning and Evaluation
1982-1984 National Long Term Care Survey	**Kenneth Manton, Ph.D.** Duke University
National Long Term Care Channeling Demonstration	**George Carcagno** Mathematica Policy Research
National Health Interview Survey 1984 Supplement on Aging	**Gerry Hendershot, Ph.D.** National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health
1985 National Nursing Home Survey	**Evelyn Mathis** National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health
11:30 am – 1:00 pm Lunch Break (Reconvene at 1:00 pm)	
1:00 pm – 3:00 pm Examination of Long Term Care Data Bases (BREAKOUT SESSION NO. 1)	
(1) 1982-84 National Long Term Care Survey (BALLROOM)	**Kenneth Manton, Ph.D.** Duke University **Korbin Liu, Sc.D.** Urban Institute
(2) National Long Term Care Channeling Demonstration (CARLTON)	**George Carcagno** Mathematica Policy Research **Peter Kemper, Ph.D.** National Center for Health Services Research, DHHS/Office of the Assistant Secretary for Health **Judith Wooldridge** Mathematica Policy Research **Thomas Grannemann, Ph.D.** Mathematica Policy Research

(3) Combined Session
(BALCONY)

(A) National Health Interview Survey: 1984 Supplement on Aging

Gerry Hendershot, Ph.D.
National Center for Health Statistics

Susan Jack
National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

Joseph Fitti
National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

(B) 1985 National Nursing Home Survey

Evelyn Mathis
National Center for Health Statistics

Esther Hing
National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

Genevieve Strahan
National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

Edward Sekscenski
National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

Jennifer Madans, Ph.D.
National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

William Scanlon, Ph.D.
Center for Health Policy, Georgetown University

3:00 pm – 3:15 pm
Break

3:15 pm – 5:15 pm
Examination of Long Term Care Data Bases (BREAKOUT SESSION NO. 2)

(1) 1982-84 National Long Term Care Survey
(BALLROOM)

Kenneth Manton, Ph.D.
Duke University

Korbin Liu, Sc.D.
Urban Institute

(2) National Long Term Care Channeling Demonstration
(CARLTON)

George Carcagno
Mathematica Policy Research

Peter Kemper, Ph.D.
National Center for Health Services Research, DHHS/Office of the Assistant Secretary for Health

Judith Wooldridge
Mathematica Policy Research

Thomas Grannemann, Ph.D.
Mathematica Policy Research

(3) Combined Session
(BALCONY)

(A) National Health Interview Survey: 1984 Supplement on Aging

Gerry Hendershot, Ph.D.
National Center for Health Statistics

Susan Jack
National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

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National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

(B) 1985 National Nursing Home Survey

Evelyn Mathis
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National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

Edward Sekscenski
National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

Jennifer Madans, Ph.D.
National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

William Scanlon, Ph.D.
Center for Health Policy, Georgetown University

5:30 pm – 7:30 pm
RECEPTION at Ritz Carlton
(BALLROOM LOBBY)

(Co-sponsored by the American Association of Retired Persons, the American Health Care Association, the Blue Cross and Blue Shield Association, and the Health Insurance Association of America)

Friday, May 22

7:45 am – 8:00 am (BALLROOM)	Coffee
8:00 am – 8:30 am NHANES I Epidemiological Followup Study (General Session) (BALLROOM)	**Jennifer Madans, Ph.D.** National Center for Health Statistics
8:30 am – 8:50 am Inventory of Long Term Care Places (General Session) (BALLROOM)	**Curt Mueller** National Center for Health Services Research, DHHS/Office of the Assistant Secretary for Health
8:50 am – 9:40 am Overview of Survey of Income and Program Participation (General Session) (BALLROOM)	**Daniel Kasprzyk** Population Division, U.S. Bureau of the Census **Robert Friedland, Ph.D.** Employee Benefit Research Institute
9:40 am – 10:15 am Other Long Term Care Data Sources (General Session) (BALLROOM)	**Aurora Zappolo** DHHS/Health Care Financing Administration
10:15 am – 10:30 am Break	

10:30 am – 12:15 pm Long Term Care Data Bases Producer Panel Applications (General Session) (BALLROOM)	**Kenneth Manton, Ph.D.** Duke University **Korbin Liu, Sc.D.** Urban Institute **Judith Wooldridge** Mathematica Policy Research **Thomas Grannemann, Ph.D.** Mathematica Policy Research **Joan Van Nostrand** National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health **Evelyn Mathis** National Center for Health Statistics **Gerry Hendershot, Ph.D.** National Center for Health Statistics *Moderator* **William Scanlon, Ph.D.** Center for Health Policy *Participants* Entire Audience
12:15 pm – 12:30 pm “In the Pipeline” (General Session) (BALLROOM)	**Joan Van Nostrand** National Center for Health Statistics
12:30 pm – 12:45 pm Summary and Conclusion (General Session) (BALLROOM)	**Mary F. Harahan** Office of the Assistant Secretary for Planning and Evaluation
12:45 pm – 2:00 pm Lunch Break (Reconvene at 2:00 pm)	
2:00 pm – 3:30 pm Examination of Long Term Care Data Bases (BREAKOUT SESSION NO. 3 -- INFORMAL)	
(1) 1982-84 National Long Term Care Survey (BALLROOM)	**Kenneth Manton, Ph.D.** Duke University **Korbin Liu, Sc.D.** Urban Institute

(2) National Long Term Care Channeling Demonstration
(CARLTON)

George Carcagno
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Judith Wooldridge
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(3) Combined Session
(BALCONY)

(A) National Health Interview Survey: 1984 Supplement on Aging

Gerry Hendershot, Ph.D.
National Center for Health Statistics

Susan Jack
National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

Joseph Fitti
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(B) 1985 National Nursing Home Survey

Evelyn Mathis
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Esther Hing
National Center for Health Statistics, DHHS/Office of the Assistant Secretary for Health

Genevieve Strahan
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APPENDIX B. LONG TERM CARE DATA BASE SUMMARIES

National Long Term Care Channeling Demonstration

Referral Person:	Judith Wooldridge
Phone Number:	(609) 275-2370
Target Population:	Individuals 65 years or older. Noninstitutionalized. Functionally limited.
Sample Size:	6,326 screens.
Type of Survey:	Longitudinal (baseline, 6, 12, 18 months); multiple data sources.
Universe:	Aged noninstitutional functionally limited persons.
Sample Frame:	Persons randomized (treatment/controls) into Channeling demonstration.
Clustering:	10 sites.
Stratification:	Age, eligibility criteria.
Collection Agency:	Mathematica Policy Research, Inc.
Smallest Geographical Unit Results:	Demonstration site.
Year of Data:	1982-1985.
Final Data Tapes:	January 1987.
Cost of Survey:	ASPE/HCFA/AOA - $13 million (for full Channeling evaluation).

1982 National Long Term Care Survey

Referral Person:	Ken Manton
Phone Number:	(919) 684-6126
Target Population:	Individuals 65 years and older, noninstitutionalized. Functionally limited.
Sample Size:	36,000 screened. 6,400 detailed.
Type of Survey:	Cross-sectional.
Universe:	Aged noninstitutional functionally limited persons in nation.
Sample Frame:	Medicare Health Insurance Master File.
Clustering:	173 sampled areas.
Stratification:	Age and original reason for entitlement.
Collection Agency:	Census Bureau.
Smallest Geographical Unit Results:	Census Bureau.
Year of Data:	1982.
Final Data Tapes:	February 1984.
Cost of Survey:	ASPE - \$1.1 million. HCFA - \$1.0 million.

1984 National Long Term Care Survey

Referral Person:	Ken Manton
Phone Number:	(919) 684-6126
Target Population:	Individuals 65 years and older, total. Functionally limited.
Sample Size:	20,000 screened. 11,000 detailed.
Type of Survey:	Panel with 1982 National Long Term Care Survey, cross-sectional for 1984.
Universe:	Aged functionally limited persons in nation.
Sample Frame:	Medicare Health Insurance Master File.
Clustering:	173 sampled areas.
Stratification:	Age and original reason for entitlement.
Collection Agency:	Census Bureau.
Smallest Geographical Unit Results:	Census Bureau.
Year of Data:	1984
Final Data Tapes:	August 1985.
Cost of Survey:	NCHSR - $78 thousand. HCFA - $2 million.

1985 National Nursing Home Survey

Referral Person:	Evelyn Mathis
Phone Number:	(301) 436-8830
Target Population:	Persons in nursing homes. Supplemented by admissions in 1983. All ages.
Sample Size:	2,000 facilities. 12,000 residents.
Type of Survey:	Facilities, residential cross-sectional; admissions-longitudinal.
Universe:	Facilities - nursing and related care homes. Residents - institutionalized persons. Admissions during 1983.
Sample Frame:	Master Facilities Inventory.
Clustering:	
Stratification:	Type of ownership size, type of care.
Collection Agency:	Contract to be awarded to minority contractor.
Smallest Geographical Unit Results:	Administrative region.
Year of Data:	1985 cross-sectional. 1984/1985 admission.
Final Data Tapes:	Early 1987.
Cost of Survey:	NCHS - not yet determined. HCFA - $1.4 million.

1984 National Health Insurance Survey/Supplement on Aging

Referral Person: Gerry Hendershot

Phone Number: (301) 436-7084

Target Population: Civilian noninstutionalized 55 years plus.

Sample Size: 16,000 surveyed.

Type of Survey: Cross-sectional personal.

Universe: All households.

Sample Frame: Area probability sample.

Clustering: 376 primary sampling unit. 12,000 neighborhood segments.

Stratification: Post-stratified to independent estimate of age, sex, race population subgroup.

Collection Agency: Census Bureau.

Smallest Geographical Unit Results: 4 major geographical regions and selected SSMA's.

Year of Data: 1984.

Final Data Tapes: December 1986.

Cost of Survey: NCHS - $1.5 million.

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