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The 2004 PACE Health Survey for the Minnesota and Wisconsin Demonstration Programs: Methodology and Results

Final Report (without Plan IDs)

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*RTI International is a trade name of Research Triangle Institute.

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EXECUTIVE SUMMARY

The Centers for Medicare & Medicaid Services (CMS) contracted with RTI International to conduct the PACE Health Survey (PHS) for the 8 Minnesota and Wisconsin demonstration programs enrolling dually eligible Medicare beneficiaries. The PHS, a modified version of the Health Outcomes Survey (HOS), is a source of health status measures that have been linked to Medicare costs and is being used as part of the risk adjustment methodology for PACE and the dual demonstrations. The PHS is a brief survey instrument comprised of the SF-12, a set of functional status measures derived from the Medicare Current Beneficiary Survey (MCBS) and questions about proxy respondents and the types of help provided by proxies in responding to the survey. In 2003, RTI International and the New England Research Institutes (NERI) administered the PHS nationally to 26 PACE organizations and 8 Minnesota and Wisconsin demonstration programs, and analyzed the resulting data. In 2004, they repeated this process with 27 PACE organizations and the 8 Minnesota and Wisconsin dual demonstration programs. This report describes the experience of the implementation of the 2004 PACE Health Survey for demonstration programs in Minnesota and Wisconsin and presents the survey methods and survey findings. Findings from the nonresponse analyses will be reported separately after completion of both the 2003 and 2004 survey and non-response analyses. Under this contract, RTI also created and submitted to CMS the following deliverables:

- ADL distribution for each organization and by program;
- Individual reports to demonstration programs tabulating response rates and key survey findings; and
- Charts summarizing survey findings.

E.1 Background

The BBA mandated that Medicare capitated payments to PACE organizations be based on Medicare Advantage payment rates, adjusted to account for the comparative frailty of PACE enrollees. While not mandated by BBA, CMS chose to use the same methodology for demonstration programs such as MSHO/MnDHO and the Wisconsin Partnership Programs that also focus on enrolling frail populations. CMS developed a risk adjustment approach that appropriately accounts for frailty. The “frailty adjuster” is being applied in conjunction with the CMS Hierarchical Condition Category (HCC) risk adjustment model for the dual eligible demonstrations, the Social/HMOs and PACE. Thus, PACE organizations and demonstration programs are required to submit diagnosis data to support this payment approach. In addition, CMS collects functional impairment information from enrollees in these programs to calculate the frailty adjuster to their Medicare payments: the PHS supplies data for PACE and dual eligible demonstrations and the Health Outcomes Survey (HOS) for Social/HMOs. A ‘frailty factor” is assigned to the number of ADL difficulties for each enrollee for whom data are collected. The average factor across all community-based respondents age 55 and over in an organization is calculated, and this organization-level frailty score is applied to the payment for each community based enrollee aged 55 and over for that organization. CMS anticipates using the same methodology for the Massachusetts Senior Care Organizations in 2005.

E.2 Methods

Using Medicare Enrollment Data Base (EDB) information, RTI created a survey sample frame of community-residing dual demonstration participants alive and enrolled in their respective programs for at least one month by April 1, 2004. Dual demonstration programs provided RTI with a data file with extensive contact information for each enrollee and also supplied RTI with a flag to identify program participants with a Nursing Home Certifiable (NHC) status. The contact information included updated and verified mailing addresses and phone numbers for the beneficiaries themselves and for up to 4 personal contacts that can be used for proxy responses. RTI repeatedly updated death and disenrollment information for beneficiaries included in the sample frame using the EDB and updates faxed from individual dual demonstration programs to remove individuals no longer eligible for the survey.

We conducted several analyses with the primary goal of evaluating the PHS response rates and assessing the health status of dual demonstration enrollees. The descriptive analyses covered following domains:

- Sample distribution and various inclusion and exclusion criteria
- Mode of survey administration
- Response rates
- Demographic characteristics
- Limitations in the Activities of Daily Living and other frailty measures such as rates of memory impairment and incontinence
- SF-12 Scores, and
- Proxy response issues.

E.3 Key Findings

E.3.1 Response rates and demographic characteristics of the sample

Of the 2,968 beneficiaries remaining eligible for the survey after RTI removed deceased and disenrolled, 2,288 dual demonstration participants responded to the survey and 2,227 completed it, yielding an overall response rate of 75.0% (number of completed surveys divided by the total number of survey eligibles). The response rate for all Minnesota programs was 73.2% and for all Wisconsin programs was 78.5%. These response rates are slightly lower than they were in the 2003 survey. PHS survey response rates varied in both years by program. In 2004, they ranged from 67.9% to 90.3%. Overall, about 84% responded by mail and 16% responded by telephone interviews. These rates are identical to the ones found in the 2003 survey.

PHS respondents in Minnesota and Wisconsin were about 76 years old on average (which is older than the 2003 average of 74), with the mean age of 74 for males and 76 for females. About 64% of PHS respondents were white, 14% were African- Americans, 16% were Asians and 2% Hispanic. About 28% of the respondent sample were male and 72% female.

E.3.2 Health and functional status characteristics

When examining functional impairment levels for dual demonstration programs, it is important to note that the Minnesota plans enroll a mixture of community-well and NHC beneficiaries while Wisconsin Programs only enroll NHC beneficiaries. Of the 1,404 beneficiaries enrolled in the Minnesota program, 660 are certified as nursing home eligible and 744 as community-well. Furthermore, this report presents findings for dual eligible demonstration participants of all ages, including beneficiaries under the age of 55, so these results are not directly relevant for payment.

As expected, the Minnesota NHC group has a much higher level of impairment when compared to community-well with an average of 3 and 1 ADL impairment respectively. Among NHCs, only 18.2% report no ADL limitations compared to 51.9% of the community-well. Twenty-one percent of NHCs report between 3 and 4 ADL limitations compared to about 10% among community-well. Almost one third of NHCs belong to the most impaired group with 5 to 6 ADL impairments compared to only 9.5% of the community-well. These results are very consistent with the 2003 survey data.

Within the Minnesota NHC group, enrollees in MnDHO UCare present substantially more impairment with about 4.1 ADLs on average and almost 60% with 5-6 ADLs, higher than in any other Minnesota or Wisconsin program. These results are similar to the ones found in 2003, though the 2004 sample appears slightly less impaired. With the exception of Plan A, NHCs in other Minnesota and Wisconsin plans present a relatively uniform group without much difference by state. This is interesting to note as Minnesota, compared to Wisconsin, has more inclusive NHC eligibility guidelines that include individuals with only IADL impairments.

When all beneficiaries in these dual demonstration programs are examined regardless of their NHC status, over 28% report no ADL limitations, 29% report 1-2 ADL limitations, 18% report 3-4 ADL limitations and almost 24% report 5-6 ADL limitations. Dual demonstration program enrollees have 2.4 ADLs on average, with a mean of 2 ADLs in Minnesota and 3 ADLs in Wisconsin. Again, these results are very consistent with the data found from the 2003 survey.

In addition to limitations in activities of daily living, we examined additional measures of health and functional status such as SF-12 scores and rates of self-reported memory loss and incontinence. We calculated raw unadjusted SF-12 Physical and Mental Component Scores (PCS and MCS). The SF-12 scores presented in this report are not adjusted for program case mix and thus cannot be compared to other published SF scores such as MCO program scores derived from the Health Outcomes Survey. However, these scores are useful as they illustrate the general health status of program participants. In the PHS, incontinence is defined as self-reported difficulty controlling urination daily or having a urinary catheter.

The mean PCS score for the sample is 32.5 (34.0 for Minnesota and 29.8 for Wisconsin) and the mean MCS score is 47.4 (47.8 for Minnesota and 46.6 for Wisconsin). These scores are similar to the ones in the 2003 survey, although the mean scores in 2004 are slightly lower. There is some variation between the PCS scores across the Minnesota programs, particularly relative to the 2003 results. In 2004, the scores ranged from 29.8 to 34.6 compared to 30.7 to 34.9 in 2003. Similarly, the range in the scores for Wisconsin are more pronounced in 2004,

ranging from 24.9 to 31.5 (compared to 27.4 to 32.4 in 2003). The MCS scores in 2003 were more uniform across states and across programs (ranging from 44.9 to 48.4), but in 2004 this range expanded to be from 43.1 to 49.0.

Overall, about 36% of all PHS respondents across the programs reported having memory loss, the same percentage as in 2003. Of this population, 10% of self-respondents report memory loss compared to 21% of respondents assisted by family proxies and just 2.8% of respondents helped by professionals. However, in 2003, much larger percentages reported memory loss: 23% of self-respondents reported memory loss compared to 53.2% of respondents assisted by family proxies and 36% of respondents helped by professionals. About 43% of PHS respondents reported incontinence problems, almost double the rate in 2003. Rates of incontinence vary by program from 18.4% to 43.1%.

E.3.3 Proxy characteristics

Due to the high levels of frailty, cognitive impairment and other factors that might preclude program participants from responding to the PHS themselves, family members and health or social service professionals were allowed to respond on behalf of the PHS eligibles. About 45% of PHS respondents (45.3% in Minnesota and 45.8% in Wisconsin) were capable of responding to the survey without assistance. The rest (54%) responded by proxy, of whom about 40% were family members and friends and 8% were health professionals. These rates are very consistent with the findings from 2003. Most often, a combination of language barriers, physical health, and cognitive problems required PHS respondents to seek help in filling out the survey instrument. For all proxy survey participants, inability of respondents to speak or read English presented as a major reason for requiring proxy help (40.3%), mostly driven by a high proportion of foreign language speakers in Minnesota (56%). In Wisconsin, only 14.1% of proxy responders were in need of an interpreter. Physical health problems necessitated the use of help for about 28% of proxy respondents and memory loss or cognitive and mental health problems also account for about one fifth of all cases. Similar results were found in the 2003 survey.

The proxy respondents were also asked to describe the type of help they had provided. Over 43% of proxies read the questions to a sample member and one third wrote down answers for survey participants. Over 46% of proxies had answered the survey based on their own experience in taking care of the respondent and 9 percent used medical records. Overall, about 21 percent of proxies provided language translation help with survey questions.

E.4 Conclusions

RTI International and the New England Research Institutes (NERI) administered the PHS to 8 dual demonstration programs in Minnesota and Wisconsin for the first time in 2003. Based on the survey response rates and data analysis findings, we can conclude that this survey effort was successful as functional data information was collected for over 78% of survey participants. Several major factors contributed to its success:

- RTI received support and cooperation from the states and health plans' staff, who publicized and promoted the survey, collected contact information for program enrollees, updated RTI on deaths and disenrollments, assisted beneficiaries in filling

out the questionnaires (by serving as proxies), and helped to mail surveys back to NERI;

- RTI collected extensive contact information for health plans' enrollees, increasing the chance of family members' participation as proxies. Increased proxy rates lead to the increases in overall survey response rates;
- RTI collected death and disenrollment information from the programs and via Medicare Enrollment Database repeatedly through the survey process, further boosting the response rates by correctly identifying Medicare beneficiaries no longer eligible for the survey.

The major purpose of this contract was to collect self-reported functional status data from beneficiaries and their proxies participating in the dual demonstrations that are necessary for calculating frailty adjustors. As expected, we found a discrepancy in functional impairment levels due to the fact that dual demonstration programs enroll a mixture of community-well and nursing home certifiable (NHC) beneficiaries in Minnesota and only nursing home certifiable beneficiaries in Wisconsin. The NHC population in both states reports high levels of functional and cognitive impairment that are about three times higher that that of the general Medicare population. However, we also observe some case mix differences within the NHC group by individual program in each state. These differences are reflected in both the mean number of ADL limitations and in the proportion of beneficiaries with ADL categories.

RTI has also completed the analysis on potential PHS nonresponse bias for the Dual Eligible Demonstrations. The findings from both the 2003 and 2004 nonresponse analyses are presented elsewhere.

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SECTION 1
INTRODUCTION

1.1 Overview

The Centers for Medicare & Medicaid Services (CMS) contracted with RTI International to conduct the PACE Health Survey (PHS) for Minnesota and Wisconsin demonstration programs enrolling dually eligible Medicare beneficiaries. The PHS, a modified version of the Health Outcomes Survey, is a source of health status measures that have been linked to Medicare costs and is being used as part of the risk adjustment methodology for PACE and the dual demonstrations. The PHS is a brief survey instrument comprised of the SF-12, a set of functional status measures derived from the Medicare Current Beneficiary Survey (MCBS) and questions about proxy respondents and the types of help provided by proxies in responding to the survey. In 2004, RTI International and the New England Research Institutes (NERI) administered the PHS nationally to 27 PACE organizations and 8 Minnesota and Wisconsin demonstration programs, and analyzed the resulting data. This report describes the experience of the implementation of the PACE Health Survey for demonstration programs in Minnesota and Wisconsin and presents the survey methods and survey findings. Findings from the non-response analyses will be reported separately after completion of both the 2003 and 2004 survey and non-response analyses. Under this contract, RTI also created and submitted to CMS the following deliverables:

- ADL distribution for each organization and by program;
- Individual reports to demonstration programs tabulating response rates and key survey findings; and
- Charts summarizing survey findings.

1.2 The Minnesota and Wisconsin Dual Demonstrations

The following descriptions of the Minnesota and Wisconsin Dual Demonstration programs are taken from the CMS fact sheets (Minnesota Senior Health Options/Minnesota Disability Health Options Medicare Payment/Medicaid Waiver Demonstration Fact Sheet, 2004, CMS and Wisconsin Partnership Program Fact Sheet, 2004, CMS).

Minnesota Programs: In April 1995, the State of Minnesota was awarded Medicare and Medicaid waivers for a 5-year demonstration, the Minnesota Senior Health Options (MSHO) program, designed to test delivery systems that integrate long-term care and acute-care services for elderly dual eligibles. Under this demonstration, the State is being treated as a health plan that contracts with CMS to provide services, and provides those services through subcontracts with three health care plans. CMS approved the State's request in year 2001 to extend MSHO and expand eligibility criteria to include persons under the age of 65 with disabilities. The expansion program titled, "Minnesota Disability Health Options Program"(MnDHO) includes both disabled dual eligible beneficiaries and Medicaid eligible only beneficiaries. Administration of this program is similar to MSHO. The MSHO extension and MnDHO expansion was approved through the period of October 1, 2001 through December 31, 2004. Medicare services for MSHO

and MnDHO are provided using a demonstration waiver under §402 of the Social Security Amendments of 1967. Medicaid services are provided under §1915(a) and §1915(c) of the Social Security Act. The State of Minnesota formally requested to extend the demonstration for an additional three years as well as expand the MnDHO eligibility to beneficiaries diagnosed with Mental Retardation and Developmental Disabilities (MR/DD). Further, the State has requested to expand MSHO statewide and add more health plans to the project. These three requests are currently being reviewed by CMS.

MSHO and MnDHO are managed care products that integrate Medicare and Medicaid financing; acute and long-term care service delivery, including home and community based waiver services for dually eligible and Medicaid eligible physically disabled adults and elderly in a ten county area in Minnesota, including the Twin Cities. MnDHO was implemented initially in Hennepin, Ramsey, Dakota and Anoka counties and will expand to three more of the 10 MSHO counties. Enrollment in MSHO and MnDHO is voluntary and available to dually eligible beneficiaries living in institutions, community enrollees who meet institutional placement criteria and other community enrollees whose needs do not meet institutional levels of care.

In Minnesota, all MSHO and MnDHO plans participated in the PHS:

- H2407 UCare Complete MnDHO program,
- H2456 UCare MSHO program,
- H2457 Metropolitan Health Plan (MHP) MSHO program, and
- H2458 Medica MSHO program.

Wisconsin Programs: The State of Wisconsin submitted an application to the Centers for Medicare and Medicaid Services (then HCFA) in February 1996 for Medicare 402/222 and Medicaid 1115 demonstration waivers to establish a “Partnership” model of care for dually-entitled nursing home-certifiable beneficiaries who are either elderly or under age 65 with physical disabilities. Waivers were approved for this demonstration on October 16, 1998 and all four sites called for in the demonstration – Elder Care and Community Living Alliance (CLA) in Madison, Community Care for the Elderly (CCE) in Milwaukee, and Community Health Partnership (CHP) in Eau Claire – became operational between 1/1/99 and 5/1/99. A total of 1616 beneficiaries were enrolled as of 1/31/04. In Milwaukee, the Partnership site is co-located with a pre-existing PACE site and serves an elderly population. ElderCare, also serves only elderly participants. CLA serves only people under 65 with disabilities, and CHP serves both populations. The CLA and CHP were the first plans in the nation to provide fully capitated Medicare and Medicaid services for people with physical disabilities. Roughly a quarter of Partnership enrollees are persons with disabilities and about 85% of the total enrollment is dually eligible. The proportion of dual eligibles varies from 60% among persons with disabilities to 95% among the elderly.

The Partnership model is similar to the PACE model in the use of multidisciplinary care teams, combined Medicare and Medicaid capitation payments, and sponsorship by community-based service providers. The programs differ in two important ways. The Partnership treatment team consists of a community-based primary care physician (PCP) plus a nurse practitioner,

nurse, and social worker who are employed by the health plan. The plan-based team members provide in-home services and facilitate continuity and coordination of care with the PCP and other health providers. The Partnership team is smaller than the PACE team since it does not include occupational, physical, or speech therapists. Partnership plans also do not require direct participation of primary care physicians in team meetings as does PACE. In the Partnership model, the nurse practitioner has primary responsibility for coordinating the activities of the plan-based team with those of the community-based physician. A second important difference between the two programs is that PACE sites have traditionally established day treatment programs where participants receive their primary care along with a variety of therapies and supportive services.

While most participants in the Partnership program are able to choose their PCP, there is not complete freedom of choice because plans must place some limits on the number of participating physicians in order to maintain efficient communication and coordination between the plan-based team members and the community-based physicians. Plans have also found that physicians are more likely to "buy into" the Partnership model when more of their patients are program participants.

The four demonstrations programs in Wisconsin participated in the PHS:

- H5204 Community Living Alliance,
- H5206 Community Health Partnership,
- H5207 Community Care for the Elderly (Milwaukee), and
- H5209 ElderCare.

1.3 Risk Adjustment Implementation for M+C Organizations

The Balanced Budget Act of 1997 (BBA) mandated the implementation of risk adjustment for M+C (now Medicare Advantage) organizations no later than January 1, 2000. As an initial step under BBA authority, CMS began collecting inpatient hospital diagnosis data from M+C (MA) organizations in July 1997. CMS implemented a risk adjustment payment methodology based on the inpatient hospital encounter data in January 2000. The Principal Inpatient Diagnostic Cost Group model was selected as the initial inpatient model. Thereafter, the Benefits Improvement Protection Act of 2000 (BIPA) mandated the incorporation of ambulatory risk adjustment data by 2004. BIPA also provided a transition schedule for implementing risk adjustment in order to protect against substantial financial impacts for M+C (MA) organizations.

In an effort to meet the BIPA mandate to incorporate ambulatory data into the risk adjustment payment methodology, CMS chose to use a selected significant disease model. The specific model selected was the CMS modification of the Hierarchical Condition Category (HCC) model originally developed by Health Economics Research, Inc. (called the CMS-HCC model). This model relies on diagnostic data from inpatient hospital, outpatient hospital and physician settings. CMS first implemented the CMS-HCC model for M+C (MA) organizations in 2004.

1.4 Payment for Demonstration Programs

The BBA mandated that Medicare capitated payments to PACE organizations be based on M+C (MA) payment rates, adjusted to account for the comparative frailty of PACE enrollees. While not mandated by the BBA, a similar methodology was to be applied to demonstration programs such as MSHO/MnDHO and the Wisconsin Partnership Programs that enroll frail populations. Preliminary research suggested that diagnosis-based risk adjustment models did not necessarily account for the Medicare costs of frail populations. CMS therefore exempted PACE and dual demonstrations from M+C (MA) risk adjustment while it developed a payment approach that was appropriate for these organization.

Although the CMS-HCC model performed well for M+C (MA) organizations, it did not adequately explain the Medicare costs of community frail populations. Therefore, in conjunction with the CMS-HCC model, CMS has recently developed a risk adjustment approach that appropriately accounts for frailty. The "frailty adjuster" is to be applied in conjunction with the CMS-HCC model for the dual demonstrations, the Social/HMOs and PACE. Thus, PACE organizations and certain demonstration programs are required to submit diagnosis data to support the risk adjusted aspects of this payment approach.

1.5 Frailty Adjustment

Risk adjustment predicts (or explains) the future expenditures of an individual based on diagnoses and demographics. But risk adjustment may not explain all of the variation in expenditures for frail populations. The frailty adjuster uses measures of functional impairment to predict these unexplained expenditures. The frailty adjuster modifies each organization's risk adjusted payment amount depending upon the organizations enrollees' level of functional impairment. In order to implement frailty adjustment, CMS collects functional impairment information about enrollees in the dual eligible demonstrations, PACE organizations and the Social HMOs.

1.6 Collection of Functional Impairment Data

Initially, CMS considered using the annual required HOS to collect information for frailty adjustment. To assess the feasibility of this approach, the HOS was administered to PACE in 1999. The response rate to the HOS across all PACE organizations (44 percent) was considered too low to be useful for payment adjustment. (The PACE HOS response rates in 2000 and 2001 were 50 percent and 37 percent, respectively). So CMS decided to develop a survey approach that was more appropriate for frail populations. As the HOS response rate for the Social HMOs was higher, about 70%, CMS decided to continue to use the HOS for these organizations.

In 2000, CMS developed the Medicare Health Survey for PACE and Evercare (MHSPE). The survey instrument was much shorter than the HOS. It included questions worded identically to the MCBS that were candidates for frailty adjustment, as well as some measures from the HOS (i.e., the SF-12) to enable the comparison of health outcomes between PACE or Evercare and M+C (MA) organizations. The instrument was pre-tested on 9 frail beneficiaries enrolled in either PACE or Evercare.

CMS refined the survey instrument questions based on the pre-test. Whether the shorter, more appropriate instrument would result in higher response rates than HOS was unknown. Findings from the pre-test suggested that increased involvement of organization staff in survey administration could result in improved response rates. Therefore, in 2001 CMS developed three approaches for administering the survey that called for various levels of staff involvement in the distribution of the surveys. In addition, under each approach, CMS would allow staff (in addition to family members who are allowed under HOS) to respond as proxies on behalf of the beneficiaries.

CMS contracted with RTI to conduct a pilot test of the new, shortened instrument in 2002 using three different protocols. This pilot was designed to evaluate several factors, including the effect on response rates of both the shortened instrument and of various levels of PACE staff involvement reflected in three approaches to distributing the survey. In addition, CMS wanted to compare functional status ratings derived from the survey responses to those found in beneficiaries' medical records and to evaluate burden on the individual PACE organizations, the role of PACE staff serving as proxies, and potential nonresponse bias across the various approaches. Based on the results of the pilot study (Walsh, Nason, Moore and Khatutsky, 2003) CMS made further refinements to the instruments and selected and refined a survey distribution approach. The final instrument was renamed the PACE Health Survey (PHS). The PHS supplies data for PACE and dual demonstrations such as MSHO, MnDHO and Wisconsin Partnership programs. The Health Outcomes Survey (HOS) supplies data for Social/HMOs.

In 2003, the PACE Health Survey was administered to the eight demonstration programs for dual eligibles in Minnesota and Wisconsin for the first time. Survey implementation, methodology and findings are presented in the final report to CMS (Khatutsky, Walsh, Moore and Kramer, 2004). This report describes the experience of the second national implementation of the PACE Health Survey. The report presents the survey methods with a particular emphasis in describing our extensive efforts to foster high response rates, survey findings, and results of a response bias analysis. The individual plan frailty scores were reported by CMS directly to each health plan. Nonresponse bias analyses to be conducted in both the 2003 and 2004 rounds of the PHS will be reported separately.

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SECTION 2
METHODS

This section of the report presents RTI's methodology for creating a sampling frame and respondent contact files for the PHS in the Minnesota and Wisconsin dual demonstrations and explains several survey definitions used throughout the report. We also describe RTI's extensive work with the demonstration programs in preparing and administering the survey as well as data collection procedures. Our approach to incorporating write-in responses is also explained.

2.1 Sampling

RTI used a sampling methodology similar to that used for the first national implementation for the PHS. However, since 2003, CMS has implemented a new data system that precluded a quick sampling from the EDB. To speed up the process, CMS supplied RTI with a finder file of beneficiary Medicare Health Insurance Claim Numbers (HICNUMs) based on the list of participating PACE organization PLAN IDs. This finder file was used by RTI to access Medicare's Enrollment Data Base (EDB) through the EDB WORKBENCH utility to identify beneficiaries eligible for the survey and collect their demographic, enrollment and eligibility information.

To be eligible for inclusion in the sampling frame, beneficiaries had to meet the following criteria:

- Be alive and enrolled in Minnesota or Wisconsin demonstration programs for at least one month by Apri1 1, 2004
- Be enrolled in Medicare (part A, B or both)
- Reside in the community[1], and
- Be aged 55 and over.

From the EDB, CMS obtained for RTI each beneficiary's name and HICNUM, as well as enrollment and demographic information such as race, age, sex, and language. This file was appended by adding supplemental information received from the individual demonstration programs. The supplemental information included current address and telephone number for both enrollees and, to the extent available, informal caregivers who might serve as proxy respondents.

From the moment the sampling frame was drawn from the EDB and throughout the survey process, participant information was continually updated. Demonstration programs were asked and reminded to notify RTI staff (who in turn notified NERI) of any deaths, disenrollments or changes in participant or proxy contact information. Any death or disenrollment information received prior to sending the file to NERI led to removal from the sample list by RTI, and any updates received after the file was sent to NERI were recorded and forwarded to NERI contacts. Additionally, during the calling phase of the survey, RTI used the EDB to identify additional

[1] In Minnesota, the state identified and removed permanent nursing facility residents which represent a substantial number of their enrollees. At the end of the survey implementation for both Minnesota and Wisconsin, we deleted sample members as ineligible due to facility residence(those for whom CMS had a 90-day Minimum Data Set Assessment).

individuals who may have died or disenrolled but were not yet reported by the programs. Using this methodology, a total of 3,581 deceased and disenrolled program participants were identified and removed from the file during the survey process. These measures helped to focus our survey efforts, minimize burden on grieving families, and improve the survey response rate.

2.2 Working with Dual Demonstration Programs

All demonstration plans from Minnesota and Wisconsin supplied RTI with files listing their full enrollment of community-residing Medicare enrollees and their contact information. When the files were created, Minnesota program staff removed participants that were long-term facility residents and only included community-residing beneficiaries. Each plan was asked to submit updated/verified mailing addresses and phone numbers for the beneficiaries, and names, mailing address and telephone numbers of up to four personal contacts that could be used for proxy responses.

Some dual demonstration programs also provided a list of Care Coordinators and their phone numbers. Then, if a person could not be contacted and a proxy listed was not available, NERI called the Care Coordinator to get additional contact information for the participant. NERI then used this new contact information to find a person who could complete this survey on the participant's behalf.

Additionally, plans provided information on the language spoken by contacts and participants, and indicated whether the survey should be mailed to the participant or the contact. When the contact data files were received from the plans, they were checked for inconsistencies and missing data before merging with the data from the EDB. Minnesota plans also identified whether each participant was NHC or community-well for use in analysis.

In addition to the communication that occurred throughout the survey process between RTI and the individual Minnesota and Wisconsin programs, RTI and CMS conducted an initial telephone conference with all of the programs to explain the project and the necessary data collection tasks. At this meeting, each program received an orientation packet detailing the specifications for the data needed and the project variables (see ***Appendix A and B***), and was given the opportunity to ask questions and express concerns.

2.3 Survey Definitions

Several survey samples were created for this project: the COMPLETE survey sample, the PAYMENT survey sample, and the SF-12 sample.

- Most of the analyses for this study, as well as survey response rate calculations, were conducted for the sample of beneficiaries with COMPLETE survey responses. RTI defined COMPLETE survey responses as responses from eligible survey participants where all six ADL questions were completed. The COMPLETE survey sample includes community-residing and a few institutionalized beneficiaries not removed originally by the programs, and regardless of their receipt of the ESRD Medicare benefits. In other words, the response rate for the COMPLETE sample measured the responsiveness of the participants and the effectiveness of the survey protocol.

- Functional status analysis was also carried out separately for the PAYMENT sample that restricts survey eligibles to community residing, non-ESRD demonstration program enrollees aged 55 and over. The PAYMENT sample is used for calculating the frailty adjusters which are only applicable to this group.
- Finally, the SF-12 sample was used only to calculate SF-12 -derived Physical and Mental Component Scores (PCS and MCS). These scores were calculated for all PHS respondents who answered all 12 questions needed for creating PCS and MCS scores regardless of whether these survey participants answered all 6 ADLs questions, lived in community or institution, and have ESRD or not.

2.4 Data Collection Procedures

As the survey subcontractor, NERI determined a standard procedure for survey implementation. Initially, NERI sent a pre-notification post card to participants, followed by the first mailing of the survey. If the survey was not returned, a reminder postcard was sent. Depending on whether or not the survey was returned, this was followed by a second mailing and a second reminder postcard, followed by up to six phone calls until a response was received, or it was determined that a contact could not be made, or until time ran out. NERI fielded the survey in batches (one batch for each program) beginning in June and ending in August. Please see ***Appendix C*** for a detailed description of the survey protocol and for general survey procedures used by NERI for this study. The PHS survey instrument is included in ***Appendix D***.

2.5 Recoding of Write-in Responses

The PHS survey contains several open-ended questions that require write-in responses. Specifically, participants had the opportunity to specify responses when they selected the "other" category. These questions relate to the reasons for proxy responses and the type of help provided in completing the survey.

15. WHAT WAS THE REASON YOU FILLED OUT THIS SURVEY FOR SOMEONE ELSE? (PLEASE ANSWER ALL THAT APPLY.)

PHYSICAL PROBLEMS 1
MEMORY LOSS OR MENTAL PROBLEMS 2
UNABLE TO SPEAK OR READ ENGLISH 3
PERSON NOT AVAILABLE.....4
OTHER (PLEASE SPECIFY BELOW).....5

16. HOW DID YOU HELP COMPLETE THIS SURVEY? (PLEASE ANSWER ALL THAT APPLY.)

READ THE QUESTIONS TO THE PERSON.....1
WROTE DOWN THE PERSON'S ANSWERS 2
ANSWERED THE QUESTIONS BASED ON MY EXPERIENCE WITH THE PERSON 3

USED MEDICAL RECORDS TO FILL OUT THE SURVEY 4
TRANSLATED THE SURVEY QUESTIONS 5
OTHER (PLEASE SPECIFY BELOW).....6

In addition, NERI incorporated responses that were written in the margins of the PHS questionnaire. Before beginning the data analyses, RTI examined each write-in response to determine whether the response fit into one of the pre-established categories. The following rules were followed in determining how to appropriately code write-in responses that elaborated on the "other" category:

- If an "other" response fit into one of the pre-existing categories, the "other" response was removed and the appropriate category was coded.
- If an "other" response simply qualified an existing response, it was removed.
- If an "other" response did not fit into a pre-existing category, or it was unclear as to which category it should go into, and was relevant to the question, it was kept as "other".
- Write in answers for question 15 ("*What was the reason you filled out this survey for someone else?*"), of dementia, Alzheimer's, or depression were re-coded to memory loss or mental health problems. However, responses such as lack of comprehension, anxiety, nervousness were kept as "other" if memory loss or mental problems were not already identified.
- Illiteracy was recoded to the "Unable to speak or read English" category.

SECTION 3
SURVEY FINDINGS

In this section we report the 2004 survey findings from the PACE Health Survey (PHS) for the dual demonstration programs in Minnesota and Wisconsin. We focus on the following domains:

- Sample distribution and various inclusion and exclusion criteria
- Mode of survey administration (completion by mail versus telephone interview)
- Response rates
- Demographic characteristics
- Limitations in the Activities of Daily Living and other measures such as rates of memory impairment and incontinence
- SF-12 Scores, and
- Proxy response issues.

Most of our analyses were performed for the sample of PACE Health Survey for Minnesota and Wisconsin respondents who completed all 6 ADL questions (Question 4 in the PHS). This definition is used to identify COMPLETE PHS survey records. One exception from this rule is the analysis of the SF-12 scores, which is carried out for all PHS respondents who answered 12 questions needed for calculating PCS and MCS scores regardless of whether these participants answered all 6 ADLs questions. The SF-12 scores presented in this report are not adjusted for case mix (age, race, health and other differences between individual programs) and should only be used as additional health status measures. These SF-12 scores should not be used for comparison of the PHS plan level scores with MCO plan level scores reported by other sources such as the Health Outcomes Survey (HOS).

3.1 Sample Distribution

The initial PHS sample frame, created by a combination of EDB records and data supplied by the demonstration programs or the states, was delivered to the New England Research Institute by RTI prior to survey administration. ***Table 1*** presents the sample distribution numbers for the overall PHS-Minnesota/ Wisconsin sample and separately by state. ***Table 2*** presents sample distributions for each individual dual demonstration program participating in the PHS. The initial sample frame included 6,549 Medicare beneficiaries eligible for survey participation. The sample size more than doubled since the 2003 survey (2,798 beneficiaries in the 2003 sample size). While plans removed most of the institutionalized Medicare beneficiaries from the records they supplied to RTI, an additional 2,226 people were identified by CMS as residing in nursing home facilities. Forty beneficiaries were identified by RTI as eligible for Medicare due to the End Stage Renal Disease (ESRD). Removal of deceased and disenrolled individuals from the initial sample frame (N=3,581) resulted in a total sample of 2,968 survey eligibles. Of these eligible beneficiaries, 2,288 responded to the survey and 2,227 completed all 6 required ADL items, yielding an overall response rate of about 75% (number of completed

Table 1
Sample distribution for the 2004 PACE Health Survey for Minnesota and Wisconsin

	All	MN	WI
Initial sample frame	6,549	5,159	1,390
Total survey eligibles[1]	2,968	1,919	1,049
Survey respondents[2]	2,288	1,441	847
Completed all 6 ADL survey questions [3]	2,227	1,404	823
Payment sample (community-residing, non-ESRD, all 6 ADLs completed)	2,178	1,387	791
Completed all questions needed for calculating SF-12 PCS and MCS scores	1,942	1,242	700
Institutionalized[4]	2,226	2,162	64
ESRD[4]	40	28	12

NOTES: Categories are not mutually exclusive.

[1] Deaths, disenrollments and other ineligibles removed.

[2] Beneficiaries who returned complete or incomplete surveys.

[3] PACE Health Survey definition of a complete survey.

[4] Some institutionalized beneficiaries were initially removed by the plans. Any institutional beneficiaries not removed by the plans were removed based on MDS records. ESRD beneficiaries were removed based on the EDB.

SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004.

Computer Output: MNWIPHS2004_02c.

Table 2
Sample distribution for the 2004 PACE Health Survey for Minnesota and Wisconsin, by plan

	Minnesota				Wisconsin			
	Plan A	Plan B	Plan C	Plan D	Plan E	Plan F	Plan G	Plan H
Initial sample frame	157	2,312	406	2,284	179	441	339	431
Total survey eligibles[1]	31	997	237	654	56	368	264	361
Survey respondents[2]	28	769	191	453	38	333	189	287
Completed all 6 ADL survey questions (community and institutional)[3]	28	744	185	447	38	322	183	280
Payment sample (community-residing, non-ESRD, all 6 ADLs completed)[4]	27	739	183	438	38	305	171	277
Completed all questions needed for calculating SF-12 PCS and MCS scores	28	659	161	394	32	247	154	240
Institutionalized[4]	7	890	69	1,196	2	22	20	20
ESRD[4]	2	10	4	12	2	3	5	2

NOTES: Categories are not mutually exclusive.

[1] Deaths, disenrollments and other ineligibles removed.

[2] Beneficiaries who returned complete or incomplete surveys.

[3] PACE Health Survey definition of a complete survey.

[4] Some institutionalized beneficiaries were initially removed by the plans. Any institutional beneficiaries not removed by the plans were removed based on MDS records. ESRD beneficiaries were removed based on the EDB.

SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004.

Computer Output: MNWIPHS2004_02c.

surveys divided by the total number of survey eligibles). This response rate is slightly lower than the response rate of 78.4% in 2003.

Survey response rates were calculated as a ratio of survey respondents to survey eligibles using the following algorithm:

- Denominator- the number of survey eligibles defined as community or institutional dual demonstration program participants with Medicare as their primary health insurance, alive and enrolled at the time of survey administration and enrolled in their respective programs for at least one month on April 1, 2004. Thus, the denominator includes all individuals included in the initial sample frame minus those who were discovered to be deceased or disenrolled during the survey administration phase.
- Numerator- the number of eligible survey respondents who completed all six ADL survey questions.

It is important to note that this sample definition is different from the definition of the community frailty payment sample. The payment sample used for calculating frailty adjusters is restricted to the community residing, non-ESRD dual demonstration program enrollees aged 55 and over and included 2,178 beneficiaries in Minnesota and Wisconsin. This definition is also different from that for the SF-12 Physical and Mental Component scores (SF-12), defined as all those who responded to the entire SF-12 battery of questions. We collected enough data to calculate SF-12 scores for 1,942 PHS participants in Minnesota and Wisconsin.

3.2 Survey Dispositions

Table 3 examines the distribution of respondents by survey mode in total, by state and by individual program. Overall about 84% responded by mail and 16% responded by telephone interviews. These rates are identical to the 2003 mail and telephone mode rates. In Minnesota, 87% responded by mail and 14% by phone, compared to 80% and 20% respectively in Wisconsin. However, survey mode varies substantially by program: the proportion of telephone interviews in Minnesota was as low as 12.1% and as high as 28.6%. In Wisconsin, though, the proportion of telephone interviews was as low as 17.5% and reached 35.0%.

3.3 Survey Response Rates

Table 4 presents response rates overall, by state, and for each individual demonstration program. As stated above, the overall response rate for the 2004 PHS in Minnesota and Wisconsin was 75.0%, a remarkably high rate for a sample of highly frail elderly Medicare beneficiaries enrolled in demonstration programs. Special efforts undertaken by RTI and NERI to achieve these response rates are described in ***Appendix C***. The response rate for all Minnesota programs was 73.2% and for all Wisconsin programs was 78.5%. PHS survey rates by program, however, show a large range. The lowest response rate was 67.9% and the highest response rate was 90.3%.

Table 3
2004 PACE Health Survey for Minnesota and Wisconsin: Respondent[1] survey mode

Plan	Telephone interview	Mail
	%	%
All programs	15.8	84.2
Minnesota	13.5	86.5
A	28.6	71.4
B	12.8	87.2
C	17.3	82.7
D	12.1	87.9
Wisconsin	19.8	80.2
E	18.4	81.6
F	13.4	86.7
G	35.0	65.0
H	17.5	82.5

NOTES:
[1] Respondents are defined as eligibles who completed all 6 ADL questions.
SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004.
Computer Output: MNWIPHS2004_02e.

Table 4
2004 PACE Health Survey for Minnesota and Wisconsin: Response rates

Plan	Number of eligibles	Number of respondents[1]	Response rate
			%
All programs	2,968	2,227	75.0
Minnesota	1,919	1,404	73.2
A	31	28	90.3
B	997	744	74.6
C	237	185	78.1
D	654	447	68.3
Wisconsin	1,049	823	78.5
E	56	38	67.9
F	368	322	87.5
G	264	183	69.3
H	361	280	77.6

NOTES:
[1] Respondents are defined as eligibles who completed all 6 ADL questions.
SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004.
Computer Output: MNWIPHS2004_02d.

Table 5 compares PHS response rates across the two years that the survey was administered in Minnesota and Wisconsin. In 2004, the response rate decreased 3.4% from 78.4% to 75.0%. Similarly, the individual response rates by state decreased slightly as well. Minnesota's response rate decreased from 75.8% in 2003, and Wisconsin's response rate decreased from 82.9%. When examined at the program level, the variation in response rates was less pronounced in 2003. The response rates by program range from 74.8% to 86.6%.

3.4 Demographic Characteristics

Table 6 presents demographic characteristics for the sample of PHS respondents in Minnesota and Wisconsin. Demographic information was not collected during the survey to preserve the instrument's brevity and to lessen respondent burden. RTI obtained this information via CMS from the Medicare Enrollment Data Base (EDB). The EDB provided data on age, gender and race.

PHS respondents in Minnesota and Wisconsin were about 76 years old on average, with the mean age of 74 for males and 76 for females. About 63% of PHS respondents were White, 13% were African- Americans, 17% were Asians and 2% Hispanic. North American Natives represent only 0.5% of the PHS respondents. About 4% were classified as "other race". About 26% of the respondent sample were male and 74% female. These results are very similar to those found in the 2003 survey analysis. The 2004 respondents are, on average, slightly older (76 years old versus 74 in 2003). While the mean age for males decreased slightly in 2004 (from 75 in 2003), the mean age for females increased (from 71 in 2003). The distribution of racial categories is consistent across both years of the survey, as well as the percentage of males to females in the sample.

While there was no major variability on the age distribution or gender distribution by state, the racial composition varied substantially between Minnesota and Wisconsin. While only 53.4% of the Minnesota respondents were White, as much as 80% of the Wisconsin population identified as White. Conversely, Minnesota has a much larger population of Asians, including Hmong (25.7%) compared to Wisconsin (1.6%). When the results are examined at the program level, there is even more noticeable variation. The average age by program in both states ranges from as low as 60 to a high of 77. The racial distributions of the different programs vary as well. The White population in Minnesota ranges from 46.8% of the enrollment to 89.3%. Similarly, the White population in Wisconsin ranges from 47.5% to 97.5%. The African American population in Minnesota is fairly small, while the African American population over all is larger in Wisconsin. For the other racial categories, the distributions by program are consistent with the average rates.

3.5 Limitations with Activities of Daily Living

This report presents findings for dual eligible demonstration participants of all ages, including beneficiaries under the age of 55, so these results are not directly relevant for payment.

Tables 7 to 9 describe the functional status of the PHS respondents in Minnesota and Wisconsin by presenting the mean number of ADL limitations, ADL categories (no limitations, 1-2, 3-4, and 5-6 ADL impairments) as well as impairment levels on each individual activity:

Table 5
Comparison of response rates for 2004 and 2003 PACE Health Survey for Minnesota and Wisconsin: Response rates

Plan	2004 PHS # of eligibles	2004 PHS # of respondents[1]	2004 PHS Response rate	2003 PHS # of eligibles	2003 PHS # of respondents[1]	2003 PHS Response rate
			%			%
All programs	2,968	2,227	75.0	2,564	2,011	78.4
Minnesota	1,919	1,404	73.2	1,618	1,227	75.8
A	31	28	90.3	77	58	75.3
B	997	744	74.6	877	656	74.8
C	237	185	78.1	239	181	75.7
D	654	447	68.3	425	332	78.1
Wisconsin	1,049	823	78.5	946	784	82.9
E	56	38	67.9	126	97	77.0
F	368	322	87.5	268	225	84.0
G	264	183	69.3	223	177	79.4
H	361	280	77.6	329	285	86.6

NOTES:

[1] Respondents are defined as eligibles who completed all 6 ADL questions (community and institutional).

SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004 and 2003.

Computer Output: MNWIPHS2004_02, MN_WI PACE 01TabA.

Table 6
2004 PACE Health Survey for Minnesota and Wisconsin: Respondent[1] demographic characteristics

	All programs	Minnesota					Wisconsin				
		All	Plan A	Plan B	Plan C	Plan D	All	Plan E	Plan F	Plan G	Plan H
Age (mean)											
Total	75.6	75.4	59.6	75.6	73.5	76.8	75.9	60.3	76.8	76.3	76.6
Males	73.9	74.0	59.9	74.9	72.5	73.9	73.9	59.1	75.0	74.2	74.3
Females	76.2	75.9	59.6	75.9	74.0	77.5	76.6	60.8	77.6	77.1	77.4
Race (%)											
White	63.3	53.4	89.3	46.8	40.0	67.8	80.2	68.4	97.5	47.5	83.2
Black	13.1	11.5	7.1	7.4	37.8	7.8	15.7	26.3	0.0	49.2	10.4
Other	4.0	5.8	0.0	7.3	4.3	4.3	1.0	2.6	0.3	0.0	2.1
Asian	16.8	25.7	0.0	36.3	10.8	15.9	1.6	0.0	1.6	0.0	2.9
Hispanic	1.8	2.2	0.0	1.5	3.8	2.9	1.0	2.6	0.0	2.7	0.7
North American Native	0.5	0.6	0.0	0.5	2.7	0.0	0.2	0.0	0.3	0.6	0.0
Unknown	0.6	0.7	3.6	0.3	0.5	1.3	0.4	0.0	0.3	0.0	0.7
Gender (%)											
Male	26.4	25.8	25.0	27.3	33.0	20.6	27.3	26.3	29.5	27.3	25.0
Female	73.6	74.2	75.0	72.7	67.0	79.4	72.7	73.7	70.5	72.7	75.0

NOTES:

[1] Respondents are defined as eligibles who completed all 6 ADL questions.

SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004.

Computer Output: MNWIPHS2004_02f.

dressing, eating, bathing, transferring, walking, and toileting. The comparison between 2004 and 2003 survey findings on functional status are also presented. To estimate levels of functional impairment, RTI examined the survey question where respondents were asked whether they have any difficulty due to a health or physical problem doing the ADL activities without special equipment or help from another person. When respondents marked "*have difficulty"* or *"unable to do,*" they were categorized as being impaired in that activity.

Table 7 presents the mean number of ADL limitations and the mean impairments by ADL categories (no limitations, 1-2, 3-4 and 5-6 ADLs). On average, respondents reported 2.4 ADL limitations (2.0 for Minnesota and 3.0 for Wisconsin). However, the mean number of ADLs ranges from low of 1.6 to a high of 4.1, signifying that there is a substantial variation in functional impairment across the demonstration programs. In Wisconsin, the plan with the highest level of ADL impairment had a mean of 3.5 ADLs. This variation can also be seen in the distribution of ADL categories. For example, overall, 28.5 % of the respondent sample have no ADL limitations (36.0% in Minnesota and only 15.6% in Wisconsin), but this ranged from 5.3 to 39%.

With an average of 29.2% with 1-2 ADL limitations among PHS respondents (29.1% for Minnesota and 29.5% for Wisconsin), this proportion varies from about 7.1% to 36.8 %. Over 18% of respondents report 3-4 ADL impairments (over 15% in Minnesota and almost 24% in Wisconsin). This ranges from 10.8% in Minnesota to 34.2 % in Wisconsin. The highest proportion of the most impaired respondents with 5-6 ADLs was 57.1%.

Table 8 compares the distribution of ADL limitations from the 2004 survey with results from the 2003 survey. Overall, the frailty levels are very stable. Indeed, the average limitation is 2.4 for both years. Similarly, the average in Minnesota is 2.0 and in Wisconsin is 3.0 for both survey years. The percent reporting no ADLs is slightly higher in 2004 than in 2003. The overall average is 28.5% in 2004 compared to 27.4% in 2003 (36% versus 35.9% in Minnesota and 15.6% versus 14.2% in Wisconsin). The most dramatic increase happened at the Plan A, where the percent reporting no ADLs increased from 6.9% in 2003 to 17.9% in 2004. The distribution of the remaining ADL categories remained fairly consistent across the two survey years. In both years, about 29% of respondents have 1 to 2 ADL impairments, and about 18% have 3 to 4 impairments. Almost 24% of respondents reported between 5 and 6 ADL limitations in 2004 compared to almost 25% in 2003. In Minnesota, the average rate dropped slightly from 19.8% to 19.5% in 2004, and in Wisconsin, the rate dropped from 32.8% to 31.0%. Certain demonstration programs seem to consistently enroll a more frail population and report higher levels of functional impairment, while others tend to enroll a healthier group of beneficiaries.

Table 9 presents 2004 data on individual ADLs and ***Table 11*** provides data on ADL counts. As expected, walking and bathing present the most challenges: over 65% have limitations in walking across a room and about 48% of all respondents have difficulty bathing themselves. Only about 17% have any difficulty eating. Almost 36% of respondents report difficulty with dressing, 44% with transferring, and about 28% have difficulty with toileting. These rates are identical to the ones found in the 2003 survey.

Consistent with the difference in program eligibility by state, higher levels of impairment with each individual ADL are observed for Wisconsin programs when compared to Minnesota.

Table 7
2004 PACE Health Survey in Minnesota and Wisconsin: ADL counts

Plan	Number of respondents	# ADL impairments: Mean # of ADLs	No ADLs	1-2 ADLs	3-4 ADLs	5-6 ADLs
			%	%	%	%
All programs	2,227	2.4	28.5	29.2	18.5	23.8
Minnesota	1,404	2.0	36.0	29.1	15.4	19.5
A	28	4.1	17.9	7.1	17.9	57.1
B	744	2.0	37.4	28.0	15.3	19.4
C	185	1.6	38.9	36.8	10.8	13.5
D	447	2.1	33.8	29.1	17.2	19.9
Wisconsin	823	3.0	15.6	29.5	23.9	31.0
E	38	3.5	5.3	26.3	34.2	34.2
F	322	3.0	14.6	30.1	21.7	33.5
G	183	3.2	13.7	26.2	28.4	31.7
H	280	2.7	19.3	31.4	22.1	27.1

NOTES:

[1] Respondents are defined as eligibles who completed all 6 ADL questions.

SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004.

Computer Output: MNWIPHS2004_02h.

Table 8
Comparison of ADL categories for 2003 and 2004 PACE Health Survey in Minnesota and Wisconsin

	2004						2003					
		# ADL impairments						# ADL impairments				
Plan	Number of respondents[1]	Mean # of ADLs	No ADLs	1-2 ADLs	3-4 ADLs	5-6 ADLs	Number of respondents[1]	Mean # of ADLs	No ADLs	1-2 ADLs	3-4 ADLs	5-6 ADLs
			%	%	%	%			%	%	%	%
All programs	2,227	2.4	28.5	29.2	18.5	23.8	2,011	2.4	27.4	29.4	18.3	24.9
Minnesota	1,404	2.0	36.0	29.1	15.4	19.5	1,227	2.0	35.9	29.8	14.4	19.8
A	28	4.1	17.9	7.1	17.9	57.1	58	4.1	6.9	22.4	8.6	62.1
B	744	2.0	37.4	28.0	15.3	19.4	656	2.0	37.3	28.2	15.2	19.2
C	185	1.6	38.9	36.8	10.8	13.5	181	1.6	38.7	38.1	10.5	12.7
D	447	2.1	33.8	29.1	17.2	19.9	332	1.9	36.7	29.8	16	17.5
Wisconsin	823	3.0	15.6	29.5	23.9	31.0	784	3.0	14.2	28.7	24.4	32.8
E	38	3.5	5.3	26.3	34.2	34.2	97	3.6	5.2	24.7	30.9	39.2
F	322	3.0	14.6	30.1	21.7	33.5	225	2.9	15.6	31.6	21.3	31.6
G	183	3.2	13.7	26.2	28.4	31.7	177	2.9	15.8	25.4	27.1	31.6
H	280	2.7	19.3	31.4	22.1	27.1	285	3.0	15.1	29.8	22.8	32.3

NOTES:

[1] Respondents are defined as eligibles who completed all 6 ADL questions.

SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004.

Computer Output: MNWIPHS2004_02h.

For example, 39.3% of Minnesota enrollees have difficulty bathing compared to almost 63% in Wisconsin. Similarly, about 29.4% of Minnesota respondents have difficulty dressing, while over 46% in Wisconsin do. The pattern holds for other ADLs such as walking, transferring, eating and toileting. This consistency was also found in the 2003 survey.

As with overall level of functional impairment, individual demonstration programs also vary in the proportion of enrollees with limitations in each activity. For difficulty with bathing, the proportion of respondents with any difficulty ranges from 33% to 79%, for dressing- from 18% to 71%, for walking- from 54.6% to 89.5%, for transferring– from 30% to 75%, for toileting– from 17% to 64%, and for eating- from 6.5% to 39.3%.

Some of this variation reflects the varied eligibility requirements by state. Minnesota's plans enroll both community-well and nursing home certifiable (NHC) beneficiaries, while Wisconsin only enrolls NHC participants. To support a comparison by eligibility group, Minnesota program staff provided RTI with NHC status information to examine the differences in functional limitations by NHC status. Of the 1,404 beneficiaries enrolled in the Minnesota program, 660 are certified as nursing home eligible and 744 as community-well. ***Table 10*** presents this information and compares functional impairments of community-well Minnesota program enrollees with that of the NHC groups in Minnesota and Wisconsin.

As expected, the Minnesota NHC group has much higher functional impairment levels when compared to community-well with an average of 3 and 1 ADL respectively. Among NHCs, only 18.2% report no ADL limitations compared to 51.9% of the community-well. Twenty-one percent of NHCs report between 3 and 4 ADL limitations compared to about ten percent among community-well. Almost one third of NHCs belong to the most impaired group with 5 to 6 ADL impairments, and compared to only 9.5% of the community-well. These results are consistent with the 2003 survey data.

Within the Minnesota NHC group, enrollees in MnDHO UCare Complete presents substantially more impairment with about 4.1 ADLs on average and almost 60% with 5-6 ADLs, higher than in any other Minnesota or Wisconsin program. With the exception of MnDHO UCare Complete, NHCs in other Minnesota and Wisconsin plans present a relatively uniform group without much difference by state. This is interesting to note as Minnesota has more inclusive NHC eligibility guidelines that include individuals with only IADL impairments.

3.6 SF-12 Scores

We calculated raw unadjusted SF-12 Physical and Mental Component Scores (PCS and MCS) overall, by state and for each demonstration program that participated in the PHS. Unlike other PHS analyses conducted for the sample of survey participants who answered all 6 ADL questions, we calculated PHS and MCS scores for all survey participants who yielded sufficient data for score calculation (all 12 SF items with valid non-missing answers). As stated before, the SF-12 scores presented in this report are not adjusted for program case mix and thus cannot be compared to other published SF scores such as MCO program scores derived from the Health Outcomes Survey. However, these scores are useful as they illustrate the general health status of program participants.

Table 9
2004 PACE Health Survey in Minnesota and Wisconsin: ADL impairments

	% Impaired					
Plan	Bathing	Dressing	Walking	Transferring	Toileting	Eating
	%	%	%	%	%	%
All programs	47.9	35.6	65.7	44.1	28.5	16.6
Minnesota	39.3	29.4	58.4	38.5	23.2	15.3
A	78.6	71.4	82.1	75.0	64.3	39.3
B	38.4	30.0	56.2	37.5	23.3	16.7
C	33.0	18.4	54.6	30.3	16.8	6.5
D	40.9	30.4	62.2	41.4	23.0	15.2
Wisconsin	62.5	46.1	78.1	53.6	37.6	18.8
E	73.7	57.9	89.5	65.8	47.4	18.4
F	64.9	46.9	80.8	56.2	38.8	16.5
G	64.5	47.5	80.3	55.2	42.6	25.1
H	56.8	42.5	72.1	47.9	31.4	17.5

NOTES:

[1] Respondents are defined as eligibles who completed all 6 ADL questions.

SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004.

Computer Output: MNWIPHS2004_02c.

Table 10
Functional status of respondents[1] to the 2004 PACE Health Survey in Minnesota and Wisconsin: Comparison of Nursing Home Certifiable (NHC) and non-NHC[2]

Plan	NHC # of respondents[1]	NHC Mean # of ADLs	NHC No ADLs %	NHC 1-2 ADLs %	NHC 3-4 ADLs %	NHC 5-6 ADLs %	Non-NHC # of respondents[1]	Non-NHC Mean # of ADLs	Non-NHC No ADLs %	Non-NHC 1-2 ADLs %	Non-NHC 3-4 ADLs %	Non-NHC 5-6 ADLs %
All programs	1,483	2.9	16.7	29.8	22.6	30.9						
Minnesota	660	2.9	18.2	30.2	20.9	30.8	744	1.3	51.9	28.1	10.5	9.5
A	27	4.1	18.5	7.4	14.8	59.3	1	4.0	0.0	0.0	100.0	0.0
B	365	2.8	19.2	30.1	21.9	28.8	379	1.2	54.9	25.9	9.0	10.3
C	66	2.4	22.7	39.4	12.1	25.8	119	1.2	47.9	35.3	10.1	6.7
D	202	3.0	14.9	30.2	22.8	32.2	245	1.4	49.4	28.2	12.7	9.8
Wisconsin	823	3.0	15.6	29.5	23.9	31.0	---	---	---	---	---	---
E	38	3.5	5.3	26.3	34.2	34.2	---	---	---	---	---	---
F	322	3.0	14.6	30.1	21.7	33.5	---	---	---	---	---	---
G	183	3.2	13.7	26.2	28.4	31.7	---	---	---	---	---	---
H	280	2.7	19.3	31.4	22.1	27.1	---	---	---	---	---	---

NOTES:

[1] Respondents are defined as eligibles who completed all 6 ADL questions.

[2] All participants in Wisconsin are NHCs.

SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004.

Computer Output: MNWIPHS2004_02k.

Table 11
2004 PACE Health Survey in Minnesota and Wisconsin: ADL counts[1]

Plan	# of ADL impairments						
	No ADLs	1 ADLs	2 ADLs	3 ADLs	4 ADLs	5 ADLs	6 ADLs
	%	%	%	%	%	%	%
All programs	28.5	15.7	13.5	10.1	8.5	11.1	12.7
Minnesota	36.0	16.2	12.8	8.5	6.9	7.9	11.6
A	17.9	0.0	7.1	0.0	17.9	17.9	39.3
B	37.4	15.1	12.9	9.4	5.9	6.9	12.5
C	38.9	22.7	14.1	5.9	4.9	9.7	3.8
D	33.8	16.6	12.5	8.5	8.7	8.3	11.6
Wisconsin	15.6	14.8	14.7	12.8	11.2	16.5	14.5
E	5.3	10.5	15.8	10.5	23.7	21.1	13.2
F	14.6	13.7	16.5	9.9	11.8	20.8	12.7
G	13.7	11.5	14.8	18.0	10.4	11.5	20.2
H	19.3	18.9	12.5	12.9	9.3	14.3	12.9

NOTES:

[1] Respondents are defined as eligibles who completed all 6 ADL questions.

SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004.

Computer Output: MNWIPHS2004_02j.

Table 12 presents SF-12 scores for the sample of 1,942 of PHS participants in Minnesota and Wisconsin. The mean PCS score for the sample is 32.5 (34.0 for Minnesota and 29.8 for Wisconsin) and the mean MCS is 47.4 (47.8 for Minnesota and 46.6 for Wisconsin). These scores are consistent with the results from the 2003 survey, although the mean scores in 2004 are slightly lower. This implies that the 2004 survey population is less healthy than the 2003 sample. In 2004, there is slightly more variation than in 2003 between the PCS scores across the Minnesota programs; in 2004 PCS scores range from 29.8 to 34.6 as compared to 30.7 to 34.9 in 2003. Similarly, the differences in scores for Wisconsin are more pronounced in 2004, and range from 24.9 to 31.5 compared to 27.4 to 32.4 in 2003. While the MCS scores in 2003 were more uniform across states and across programs (from 44.9 to 48.4), more variation exists among the 2004 sample. In 2004, the MCS scores range from 43.1 to 49.0.

3.7 Respondent Type

Due to the high levels of frailty, cognitive impairment and other factors that might preclude program participants from responding to the PHS themselves, proxies were allowed to respond on behalf of the PHS eligibles. The PHS protocol permitted proxy respondents, including family members or friends, and paid professional caregivers including program staff and care coordinators. To compare the rate and nature of proxy respondents and to better understand the roles of proxies in completing the PHS, we incorporated a series of questions for proxy respondents in the survey instrument. These items asked:

- whether a proxy responded to the survey,
- why a proxy responded to the survey,
- what is the nature of help provided by proxy, and
- what is the position/affiliation of professional caregivers serving as proxies.

Paid caregivers or health professionals serving as proxies included both demonstration program staff (e.g., social workers, care coordinators or nurses) and non-program staff providing care for the participants in their homes or in alternative settings such as adult foster homes, residential care facilities, assisted living or nursing facilities.

Tables 13 through 15 exhibit the proxy information for the PHS overall, by state and individual demonstration program. ***Table 13*** presents the distribution of proxy respondents. About 45 percent of PHS respondents (45.3% in Minnesota and 45.8% in Wisconsin) were capable of responding to the survey without assistance. The rest (54%) responded by proxy, of whom about 40% were family members and friends and 8% were health professionals. About 5 percent of returned surveys did not provide a valid answer to this question or refused to answer it. In Minnesota, 40.2% were family proxies and 8.0% health professional, compared to 39.4% and 8.0% respectively in Wisconsin. These results are all very similar to those found in the 2003 survey. Given the evidence presented earlier that the 2004 sample is more impaired than the 2003 survey, it is not a surprise that the number of self-respondents in Minnesota decreased (from 47.6% to 45.3%). However, the number of self respondents actually increased in Wisconsin, up from 42.9% to 45.8%.

Table 12
2004 PACE Health Survey for Minnesota and Wisconsin:
SF-12 Physical (PCS) and Mental (MCS) Component
Unadjusted[1] mean scores

Plan	N[2]	PCS	MCS
All programs	1,942	32.5	47.4
Minnesota	1,242	34.0	47.8
A	28	29.8	48.0
B	659	34.6	47.0
C	161	34.0	48.3
D	394	33.4	49.0
Wisconsin	700	29.8	46.6
E	32	24.9	43.1
F	274	28.7	46.7
G	154	29.9	46.3
H	240	31.5	47.2

NOTES:

[1] SF-12 scores are not adjusted for case mix.

[2] SF-12 scores are presented only for those who responded to all of the SF-12 items, including participants who may not have answered all 6 ADL items.

SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004.

Computer Output: MNWIPHS2004_03a.

care for the participants in their homes or in alternative settings such as adult foster homes, residential care facilities, assisted living or nursing facilities.

Table 13
2004 PACE Health Survey for Minnesota and Wisconsin: Respondent[1] type

Plan	Self	Proxy		
		Family	Health professional	Missing[2]
	%	%	%	%
All plans	45.5	39.9	8.0	5.2
Minnesota	45.3	40.2	8.0	5.1
A	60.7	3.6	28.6	0.0
B	39.9	48.4	4.3	6.0
C	60.0	20.5	9.7	7.6
D	47.2	36.9	12.1	2.7
Wisconsin	45.8	39.4	8.0	5.3
E	73.7	21.1	0.0	2.6
F	46.6	38.5	8.4	5.3
G	36.6	50.8	7.7	4.9
H	47.1	35.4	8.9	6.1

NOTES:

[1] Respondents are defined as eligibles who completed all 6 ADL questions

[2] Missing includes respondents who wrote in an answer which could not be classified into a pre-existing category or refusals.

SOURCE: RTI analysis of the PACE Health Survey for MN and WI data, 2004

Computer Output: MNWIPHS2003_04a

The rate of self-response in 2004 varied substantially by program from a low of 36.6% to a high rate of 73.7%. Similarly, the family proxy rate ranged from 3.6% to almost 51%. For professional proxy response rates, the highest proxy response was 28.6% and the lowest was 0.0%. Similar variation also occurred in the 2003 sample.

To help understand the role of proxies and when they are needed, the survey included a question about the type of help provided by proxies. The answer choices offered the following: reading the survey to the individual; recording the individual's own responses; using the medical record information; translating the responses from another language; and using the proxy's own knowledge of the individual's health status. Proxies were instructed to indicate all that applied, so multiple categories could be coded and the response options were not mutually exclusive.

Table 14 describes reasons a proxy was needed by PHS respondents. For all demonstration program proxy survey participants, inability to speak or read English presented as

Table 14
2004 PACE Health Survey for Wisconsin and Minnesota: Reasons for proxy respondents[1]

Plan	Physical health	Memory loss or mental health	Unable to speak or read English	Other	Missing
	%	%	%	%	%
All plans	28.1	21.0	40.3	16.7	9.4
Minnesota	23.2	15.8	55.5	14.2	8.6
A	90.9	0.0	0.0	9.1	0.0
B	20.8	16.1	66.0	14.3	7.6
C	20.3	14.9	36.5	18.9	21.6
D	25.4	16.1	44.1	12.7	6.8
Wisconsin	36.5	30.0	14.1	21.1	10.8
E	50.0	40.0	10.0	10.0	10.0
F	39.0	30.8	7.0	26.2	11.6
G	37.9	33.6	18.1	17.2	6.0
H	31.8	25.7	19.6	18.9	13.5

NOTES:

[1] Proxy respondents are defined as proxies who completed all 6 ADL questions.

Percents do not sum to 100 because some respondents checked more than one answer.

SOURCE: RTI analysis of the PACE Health Survey for Minnesota and Wisconsin data, 2004.

Computer Output:

a major reason for requiring proxy help (40.3% in 2004 compared to 41.6% in 2003), mostly driven by a high proportion of foreign language speakers in Minnesota (56% in 2004 and 60% in 2003). In Wisconsin, 14.1% of proxy responders were in need of an interpreter, a small increase from 13.2% in 2003. In particular, the need for translation in 2004 was substantial in plans where anywhere from 44 to 66% of all proxies helped with English translations.

In 2004, physical health problems necessitated the use of help for about 28% of proxy respondents (23% in Minnesota and 36.5% in Wisconsin). Comparably, in 2003, 38% of proxy respondents helped because of physical health problems (30% in Minnesota and 51% in Wisconsin). Memory loss and cognitive and mental health problems also accounted for a large portion using proxies. In 2004, 21% reported this reason overall (down from 25% in 2003), and specifically 16% in Minnesota (versus 20% in 2003) and 30% in Wisconsin (versus 31.6% in

2003) provided this reason for the use of proxies. About 17% reported other reasons for needing proxy help. In summary, most often, a combination of language barriers, physical health, and cognitive problems required PHS respondents to seek help in filling out the survey instrument.

The proxy respondents were also asked to describe the type of help they had provided. The distribution of answers to this question for the total survey sample, by state and for each individual program is presented in ***Table 15***. As in other questions on proxy participation, respondents could check more than one answer. Over 43% of proxies read the questions to a sample member and one third of proxies wrote down answers for survey participants. In 2003, over 51% of proxies read the questions to a sample member and about 37% wrote down answers for survey participants. In 2004, 46.5% of proxies answered the survey based on their own experience in taking care of the respondent, as compared to 51% in 2003. Medical records were used to help by 9% in 2004 and 7% in 2003. Medical records can only used by professional proxies. Less than 1% supplied other help and 12% left this question unanswered (in 2003, about 3% of proxies supplied other help and 2% left this question unanswered).

As stated above, language barriers presented a substantial issue in Minnesota and less so in Wisconsin. Overall, when averaged across the states, about 21 percent of proxies provided language help with survey questions, which breaks down to almost 30% for Minnesota and only 6% for Wisconsin. This is consistent with the 2003 results, when 21% of proxies overall provided language help, with 31.3% in Minnesota and only 7% in Wisconsin. Consistent with previous findings on reasons for proxy involvement, the highest proportions of translations for survey questions as the type of help provided were 36% in 2003 and 2004.

3.8 Memory Loss

For the PHS in Minnesota and Wisconsin, participants were asked whether they experience memory loss that interferes with their daily activities. ***Table 16*** presents self-reported memory loss rates for the total survey sample, by state, and by individual program. In addition, we examined how memory loss varies by respondent type. Overall, about 36% of all PHS respondents across the programs reported having memory loss, a percentage similar to the one in 2003. Of this population, 10% of self-respondents report memory loss compared to 21% of respondents assisted by family proxies and just 2.8% of respondents helped by professionals. In 2003, however, 23% of self-respondents report memory loss compared to 53.2% of respondents assisted by family proxies and 36% of respondents helped by professionals. There is minimal variation across the programs in the rate of memory impairment by response status. The proportion of impairment is similar for self-respondents (9% for Minnesota and 11% for Wisconsin, compared to 21% for Minnesota and 26% for Wisconsin in 2003). Similarly, the difference is small among proxies. Family proxies in Minnesota reported memory loss for 20% of participants and in Wisconsin, for 23% of participants. In 2003, there was more variation among family respondents, with 48.8% in Minnesota reporting memory loss compared to 60.6% in Wisconsin. In 2004, there was very little difference for professional proxies. Minnesota reported memory loss for 3.0% of the sample and Wisconsin for 2.6% of the sample. Again, in 2003 there was more variation with Minnesota reporting 44.9% and in Wisconsin- 29.7%. Memory loss varies more when examined at the individual program level. Percentages ranged from 30.0 to 46.4% in 2004, and in 2003 ranged from 28.3 to 43.5% .

Table 15
2004 PACE Health Survey for Wisconsin and Minnesota:
Type of help provided by proxy respondents[1]

Plan	Read questions to sample member	Wrote answers for sample members	Answered based on experience	Used medical records	Translated survey questions	Other	Missing
	%	%	%	%	%	%	%
All plans	43.6	33.3	46.5	9.0	21.0	0.3	12.3
Minnesota	43.6	32.9	44.5	11.7	29.9	0.5	9.9
A	90.9	90.9	18.2	0.0	9.1	0.0	0.0
B	47.4	32.4	40.3	8.9	35.8	0.7	8.9
C	43.2	36.5	35.1	5.4	23.0	0.0	23.0
D	34.3	30.1	56.8	19.5	22.0	0.4	8.1
Wisconsin	43.5	33.9	49.8	4.3	5.6	0.0	16.4
E	60.0	40.0	50.0	0.0	0.0	0.0	10.0
F	46.5	37.2	52.3	3.5	4.7	0.0	14.5
G	33.6	25.9	54.3	6.0	3.4	0.0	17.2
H	46.6	35.8	43.2	4.1	8.8	0.0	18.2

NOTES:

[1] Proxy respondents are defined as proxies who completed all 6 ADL questions.

Percents do not sum to 100 because some respondents checked more than one answer.

SOURCE: RTI analysis of the PACE Health Survey for Minnesota and Wisconsin data, 2004.

Computer Output:

Table 16
PACE Health Survey for Minnesota and Wisconsin: Reported memory loss[1] by respondent type[2]

Plan	Total sample			Self-respondents		Proxies			
						Family		Health Professional	
	Sample size	Memory loss	Missing	Memory loss	Missing	Memory loss	Missing	Memory loss	Missing
		%	%	%	%	%	%	%	%
All plans	2,227	35.7	3.3	9.7	1.3	21.3	0.9	2.8	0.0
Minnesota	1,404	34.1	3.3	8.9	1.3	20.2	0.9	3.0	0.0
A	28	46.4	0.0	28.6	0.0	3.6	0.0	10.7	0.0
B	744	36.4	3.0	8.1	0.9	24.9	0.5	1.9	0.0
C	185	33.0	5.9	13.5	3.2	10.8	0.5	5.4	0.0
D	447	30.0	2.9	7.2	1.1	17.4	1.6	3.4	0.0
Wisconsin	823	38.5	3.4	10.9	1.5	23.2	1.1	2.6	0.0
E	38	44.7	5.3	26.3	5.3	15.8	0.0	0.0	0.0
F	322	37.0	2.5	11.2	0.9	21.7	1.2	3.1	0.0
G	183	44.8	2.7	7.7	0.5	33.3	1.1	1.6	0.0
H	280	35.4	4.6	10.7	2.1	19.3	1.1	2.9	0.0

NOTES:

[1] Memory loss that interferes with daily activities.

[2] For those who completed all 6 ADL questions.

SOURCE: RTI analysis of the PACE Health Survey for Minnesota and Wisconsin, 2004.

Computer Output:

3.9 Incontinence

Urinary incontinence is an additional important measure of frailty that is used to describe the NHC population. In the PHS, incontinence is defined as self-reported difficulty controlling urination daily or having a urinary catheter. ***Table 17*** presents incontinence rates overall, by state, and for individual demonstration programs. About 43% of PHS respondent reported incontinence, a marked increase from the 23% that reported incontinence in the 2003 survey. Rates for Minnesota increased sharply from 18% in 2003 to 49% in 2004, while Wisconsin increased from 30% in 2003 to just 31.7% in 2004. Rates of incontinence vary by program from 18.4 to 47.9% . The range in 2003 fell between 12.7 to 43.1%.

Table 17
2004 PACE Health Survey for Minnesota and Wisconsin:
Incontinence[1] rates for survey respondents[2]

Plan	Sample size	Incontinence	Missing
		%	%
All plans	2,227	42.6	4.0
Minnesota	1,404	49.0	3.8
A	28	32.1	3.6
B	744	50.8	3.2
C	185	47.0	4.9
D	447	47.9	4.3
Wisconsin	823	31.7	4.3
E	38	18.4	5.3
F	322	37.0	4.3
G	183	26.8	3.3
H	280	30.7	4.6

NOTES:

[1] Incontinence is defined as a daily difficulty controlling urination or catheter use.

[2] Respondents are defined as eligibles who completed all 6 ADL questions.

SOURCE: RTI analysis of the PACE Health Survey for Minnesota and Wisconsin data, 2004.

Computer Output:

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SECTION 4
CONCLUSIONS

In 2004, RTI International and the New England Research Institutes (NERI) administered the PHS to 8 Minnesota and Wisconsin dual demonstration programs. Based on the survey response rates and data analysis findings, we can conclude that this survey effort was successful as functional data information was collected for 75% of survey participants. Several major factors contributed to its success:

- RTI received support and cooperation from the program staff, who publicized and promoted the survey, collected contact information for program enrollees, updated RTI on deaths and disenrollments, assisted beneficiaries in filling out the questionnaires (served as proxies), and helped to mail surveys back to NERI;
- RTI collected extensive contact information for program enrollees, increasing the chance of family members' participation as proxies. Increased proxy rates lead to the increases in overall survey response rates;
- RTI collected death and disenrollment information from programs and via Medicare Enrollment Database continuously thought the survey process, further boosting the response rates by correctly identifying Medicare beneficiaries no longer eligible for the survey.

The major purpose of this contract was to collect self-reported functional status data from beneficiaries and their proxies participating in the dual demonstrations that are necessary for calculating frailty adjustors. As expected, we found a difference in functional impairment levels between MSHO and WPP due to the fact that dual demonstration programs enroll a mixture of community-well and nursing home certifiable (NHC) beneficiaries in Minnesota and only nursing home certifiable beneficiaries in Wisconsin.

RTI has also completed the analysis on the potential for bias due to nonresponse in the Dual Eligible Demonstrations. The findings from both 2003 and 2004 nonresponse analyses are presented elsewhere.

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REFERENCES

Minnesota Senior Health Options/Minnesota Disability Health Options Medicare Payment/Medicaid Waiver Demonstration Fact Sheet, 2004, CMS

Walsh, E.G., A. Nason, G. Khatutsky, et al.: Pilot Test of the Medicare Health Survey for PACE and EverCare, PACE Pilot Report, CMS Contract No. 500-00-0030-003, October, 30, 2003.

Wisconsin Partnership Program Fact Sheet, 2004, CMS

APPENDIX A
ORIENTATION MATERIALS

RTI INTERNATIONAL
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PACE Health Survey
Information for Participating Sites
March 8, 2004

Included in this packet are:

I. Wisconsin Partnership Program (WPP), the Minnesota Senior Health Options (MSHO) and Minnesota Disability Health Options (MnDHO) Instructions for 2004 Data Collection and Survey Administration

   A. Background
   B. Assistance needed from WPP, MSHO, and MnDHO sites prior to survey administration
   C. Assistance needed from WPP, MSHO and MnDHO sites during survey administration

II. Frequently Asked Questions

III. Research Triangle Institute (RTI), New England Research Institutes (NERI), and the Centers for Medicare and Medicaid Services (CMS) Staff Contact Information

Additional materials:

Attachment 1: Sample Participant and Family Member/Caregiver Contacts Data File (sent as a separate email attachment)
Attachment 2: Sample Handout to provide information for program Staff (included in this document)
Attachment 3: Sample Newsletter Insert (included in this document)
Attachment 4: Sample Letter to Staff of Adult Foster Homes, Assisted Living Facilities, Nursing Facilities or other congregate housing sites where program participants may reside. (included in this document)

I. WPP, MSHO, and MnDHO Instructions for 2004 Data Collection and Survey Administration

A. Background

This is the second year of a CMS contract with RTI International and New England Research Institutes (NERI) to conduct a survey to determine the health status of WPP, MSHO, and MnDHO participants. There are a number of ways to determine the frailty of an elderly population, however, CMS has decided to use a survey specially tailored to frail populations. This information is used as part of the CMS payment formula for each plan. The survey used asks a number of questions regarding the health of the program participant and will be distributed to all qualifying individuals enrolled in the programs.

The pilot phase and first year of this project have already been completed. In the pilot, four PACE sites served as test sites for the survey to determine the best way of collecting health status data from elderly participants. The survey was administered using three separate approaches for distributing the survey to PACE participants. CMS selected one of these based on the results of the pilot test for the first and second years of the survey. This approach involves getting up-to-date addresses and phone numbers for each participant and for family members or other responsible parties, and then completing a standard mailed survey with telephone follow-up. The family members or other responsible parties will be contacted when participants do not respond to the mailed survey or to telephone follow-up. Details about appropriate contacts, proxies, and the role of program staff are included in this packet.

Although beneficiary participation is voluntary, our goal is to get as many participants or their caregivers to respond to the survey as possible. One of the most important factors in achieving a high response rate is to have accurate addresses and phone numbers for each participant, and for family or other contacts who we can call if the participant does not respond. Publicity and information for your staff is also very important to the success of the survey, so that staff can respond to questions from participants and caregivers.

This package includes:

- instructions regarding the information we need about your participants and their family contacts or other responsible parties,
- suggested materials you can use to help publicize the survey and inform your staff about the survey, and
- contact information for RTI, NERI and CMS staff involved in this important project.

We anticipate fielding the survey to WPP, MSHO and MNDHO participants from **May through August, 2004.** At that time, the survey activities with the PACE participants will already be underway.

B. Assistance Needed from WPP, MSHO, and MnDHO Sites *Prior to* Survey Administration

1. Provide a staff contact person to work with CMS and RTI staff (please send name, email address, mailing address and phone number to amoore@rti.org. Sites that participated in the 2002 pilot recommend that the Program Director serve as the contact but delegate individual tasks to other staff members as appropriate.

   It will be important for the Program Director or their designee to track whether their designees are making progress on delegated tasks, such as the contact data file creation (see below). Some staff may be juggling multiple demands and not realize that this task is so time sensitive.

   PLEASE SUBMIT AT YOUR EARLIEST CONVENIENCE. (DEADLINE: March 15, 2004.)

2. If you have changed your logo since last year, please provide a new electronic logo for your specific program, to be used on mailings (i.e., on the envelopes that the surveys are mailed in). We would prefer to have the logo in black and white, but if this is not available, you may provide a color logo. Plans are not obligated to provide a logo, but it does help participants to recognize the survey as legitimate and it ultimately improves response rates. You may send this to amoore@rti.org also.

   PLEASE SUBMIT AT YOUR EARLIEST CONVENIENCE. (DEADLINE: March 15, 2004)

3. Provide ONE electronic data file with contact information for each participant and their family contacts or other caregiver contacts. We would prefer for this file to be in Excel format. The information must be sent on a diskette or CD-ROM to RTI (c/o Amber Moore) via FedEx delivery (RTI will pay for the FedEx charges; the FedEx charge code to put on the shipping label for this mailing is 08522). DO NOT EMAIL THIS INFORMATION. RTI staff will work with your site individually if you have any questions or face any technical challenges when creating the participant and caregiver contact data file. For example, please let us know if you have data files that are in a format other than specified below so that we can accommodate your needs.

   PLEASE SUBMIT AT YOUR EARLIEST CONVENIENCE. (DEADLINE: April 8)

DATA FILE SPECIFICATIONS

While we discussed sending you a file with all the information you provided us last year to update and return, we are unable to provide this due to a change that occurred in the Medicare Enrollment Database (EDB) used by CMS. Therefore, we are asking you to create a new file for your participants that meets the criteria described below.

The survey will be fielded to those participants for whom CMS is developing frailty adjusters. We will delete from your data files any individuals who are not Medicare beneficiaries and will only include participants meeting the following criteria for each plan:

WPP: All NHC enrollees 55 and older (NO institutional enrollees)
MSHO: All NHC and community well enrollees
MnDHO: All NHC and community well enrollees aged 55 and over

For each beneficiary enrolled in WPP, MSHO or MNDHO, as of March 1, 2004 we will need:

- First name, last name, middle name, Medicare number **(please make sure it is the Medicare number, not Medicaid, Social Security or other identifier)**, primary language, address, phone number, whether or not the participant normally receives his/her own mail from your program, and which center the participant attends (if site has more than one center). If possible, we would also like to know if the participant lives in a facility and if they share a phone line with other residents.

- First name, last name, middle name, address, home and work phone number, relationship to participant, and language of at least one, but up to four, contact person(s). NERI will contact these individuals for follow-up in case the beneficiary does not complete and return the mailed questionnaire. If you indicated that the participant does not normally receive his/her own mail from your program, NERI will send the mailed survey directly to participant's primary contact person.

- The contact person(s) should be those who are responsible for assisting the participant with making decisions about their health care. They are the persons who the site would normally call to discuss any changes in the service plan, health status, scheduling or any other typical client needs. ***If a beneficiary lives in foster care or in a congregate care facility, then the foster caregiver or congregate care facility staff may be one of the appropriate contacts.*** **These facility caregivers would only be listed as the *first* contact if the participant has no family or other identified or designated caregiver.**

- Minnesota plans should also provide care coordinator information for each participant, including the Care Coordinator's first name, last name and phone number.

- The second line for the address, labeled "building," can be used for the name of the apartment complex, trailer park, residential facility or other such identifier that comes before the street number and other address information. Such information was used in about 30% of the mailings in the pilot and was important to achieving good response rates.

- **IMPORTANT:** This data **must** be submitted to RTI by **April 8th**, so it is important to get started on this database as soon as possible to allow enough time to work out any potential problems before the deadline.

- See attached table for a sample of the datafile (Attachment 1: Sample Data File). Please note that each entry should appear in a separate field. If this is a challenge for your site, please contact RTI.

- After RTI receives your data files, we will conduct some simple quality checks of the data. For example, we will read across several randomly selected rows of the file and check with the site contact to be sure that each field indeed relates to the appropriate participant. (In the pilot, one site sent a list where the participant and family contacts were mismatched. The problem was easily corrected.) We will also call the sites if we have any additional questions about specific elements in the data files, such as incomplete Medicare numbers.

4. Publicize the survey to participants and educate staff about the survey before NERI begins to send out the surveys in the spring. Plans are not required to publicize the survey, but doing so will increase the response rate. We have included several samples of materials you can use for publicity and staff education. Feel free to revise these documents or replace them with others of your own design.

   - "Information for WPP, MSHO, and MnDHO Staff," can be distributed to staff members to help with this task. It may also be given to other groups at your discretion, such as any sort of participant council or board you may have. This fact sheet was developed and used by one of the pilot sites, we have modified and updated it slightly.
   - We have also attached a form letter which can be sent to facilities where your participants reside to provide information about the survey. This concept and letter was also developed and used by one of the pilot sites last year. We strongly encourage you to use these, inserting contact information for your site. Feel free to tailor these to best meet your needs.
   - Finally, we have attached an insert that may be included in your newsletters to alert participants of the survey. This is just a sample, feel free to create your own or change this one.

PUBLICITY DUE DATE: April, prior to when we will be sending out the survey.

C. Assistance Needed from WPP, MSHO, and MnDHO Sites *During* Survey Administration (May –September, 2004)

1. Respond to any questions from participants, their families or other caregivers about the legitimacy of the survey.
2. Encourage participants or their families to call NERI's toll-free number (1-800-775-6374 x 638) if they have any specific questions about completing the survey questionnaire that program site staff cannot answer. If participants bring their completed questionnaires to a PACE site, please send the completed questionnaires by mail to NERI. [NOTE: Please do not return blank questionnaires. These will be discarded. Also, please do not copy surveys to complete for more than one participant. If more than one copy of a survey is returned, all copies will be discarded. Each survey has a unique identification number so it is only appropriate for the addressee to fill it out].
3. Serve as proxy respondent if requested by the participant, family or caregiver and mail back the completed questionnaire to NERI in the postage-paid envelope provided. (This activity is voluntary: staff may choose not to serve as proxies or to offer other assistance to the participant.) It should take 10 minutes or less to complete the questionnaire for a participant. Please be sure to answer the questions specifically for the proxy at the end of the survey questionnaire. Staff may also assist in other ways: completing all or part of the survey as proxies, reading the questions to participants and marking the responses for the participants, translating the questions into the participant's language, etc. Staff are not required to assist in any way, however, staff assistance may contribute to a higher response rate. More information about the roles of staff as proxies is included in the FAQs attached.
4. Please inform RTI staff if a participant passes away or disenrolls from the program during the course of the survey so that we do not mail the materials or call the family. We would also like to be informed if death is imminent for a participant so that we do not bother the participant or their family with the survey during a sensitive time. For data security reasons, this information can be transmitted by telephone message (781-788-8100 ext 127) or by fax (781-788-8101, attn. Amber Moore), but not be email. When informing RTI of a death or disenrollment, please fax the following information to Amber Moore at 781-788-8101: name, Medicare number, date of death or disenrollment, and reason for disenrollment (indicate if it is death or other).
5. Contact RTI or NERI staff with any questions or problems.

II. Frequently Asked Questions

RTI staff will provide updated FAQs by email to all sites periodically. These are questions that came up during the first year of the survey.

Q: Why do you need so many contacts for the survey data files?

A: The survey must be conducted within a very short time frame (We have only three and one-half months for several thousand participants). If a participant cannot be reached by telephone within 10 days, NERI will then try each of the contacts that you provide until someone is reached (on behalf of the participant). The contact reached might then serve as a proxy respondent, or call the participant and encourage him or her to complete the mailed questionnaire or to participate in the telephone interview, or let NERI staff know who is the best person to call and when (what time of day or evening) is the best time to call that person. Also, the contact person might ask program staff or facility staff who are more familiar with the participant's health to complete the survey on behalf of the participant.

Q: Why do you need so much detail in the data files?

A: Some of the items, like middle names, are used to distinguish between two people who might have the same first and last name (e.g., two Mary Smiths). Some of the information allows NERI staff (who make the calls) to understand where they are calling (e.g., a facility versus a private residence), so that the call goes smoothly from the start. Some information, like the program site attended, is useful in case a participant associates their care with the name of the site, not with their health plan.

Q: What if my program has some of the information requested for the data files in an electronic format but not all of it?

A: If your site maintains any electronic client list please add the necessary additional information to create a complete electronic file. Of course there may be some information that you do not have in your records (e.g., middle names of contacts). Please include whatever information you do have about each participant and their family or caregiver contacts in the electronic file that you prepare (whether it comes from an electronic format or another format).

Q: What if my contact files do not have requested information in separate fields? For example, what if my files have both the first and last name in one field?

A: Please let RTI staff know about this problem as soon as possible. We will work with you to produce a usable data set.

Q: What if my site has separate electronic data files for beneficiaries and contacts?

A: If your data files each include a unique identifier (for example, if each data file includes the beneficiaries' name) then RTI staff can merge the files for you.

Q: What if a participant cannot fill out the survey questionnaire and there is no family member or other caregiver available to do so?

A: Program staff may fill out the survey questionnaire or complete the telephone interview at the request of the participant, family member or other caregiver. However, program site staff members should not be listed as a contact in the data file that you will provide to RTI. Staff are not required to fill out the survey, even if requested to by the participant, family or caregiver, if they consider it too burdensome.

Q: Who can serve as a proxy for the PACE Health Survey?

A: Family, close friends, other responsible parties, program staff, home health agency staff, staff at Adult Foster Homes, Assisted Living Facilities, Nursing Facilities or other congregate housing sites may serve as proxies. Staff members of any type of facility or of WPP, MSHO, or MnDHO programs should only serve as proxies at the request of the program participant, family member or other caregiver- for example, if they are asked to assist. WPP, MSHO, or MnDHO staff may also offer assistance, and provide it, if a participant, family member or other caregiver accepts this offer of assistance. While it is best to have as many participants represented in the survey as possible, housing, facility and staff are not required to do so if they consider it too burdensome.

Q: What should we tell the nursing and social work staff to do if they are asked by a participant to help fill out the survey?

A: Before the survey is administered, you should alert the nursing and social work staff that they may be asked for help. If staff are asked to fill out the survey and they are willing to do so, they do not have to answer any questions that they do not feel comfortable answering. For example, staff may be comfortable filling out the ADL questions, but not some of the psychosocial questions. Staff may also offer to help the participant by reading the questions to the participant, marking the responses for the participant, translating the questions into the participant's language, etc. Staff are not required to provide help or serve as proxies, but doing so will improve the accuracy of the survey results.

Q: Many of our participants do not speak or read English. What arrangements are being made to ensure they are represented in the survey?

A: At this time, the PACE Health Survey has been translated into Spanish and Chinese. NERI has bilingual Spanish/English translators, and will be adding Cantonese/English translators (the most common Chinese dialect in the PACE population). Many enrollees in all of these programs speak other languages, but it has

not been feasible to translate all of the surveys. Non-English speaking participants may respond to the survey through family or staff proxies. These proxies may translate the instrument verbally for participants and record their responses or complete the surveys on behalf of participants. The survey includes questions about the reason for proxy respondents and the types of help needed.

Q: What if an attorney is responsible for health decisions for a Participant who cannot complete the survey on his/her own, but the attorney is not knowledgeable enough of the patient's health to complete a survey?

A: Please list the attorney as the primary contact and be sure to indicate "Attorney" in the relationship column. Please be sure to list several other "contacts" since we will need to follow-up with them to complete the mailed questionnaire or telephone survey. If we decide that we need more information than can be provided by any of the listed contacts, we may contact the PACE center, however, please DO NOT list PACE staff as contacts.

Q: What if the currently listed primary contact for a Participant is the PACE Program because the individual does not have any family or caretakers?

A: If there is no "responsible party" for the Participant besides the PACE program/staff, please leave the contact information columns blank. We may contact the PACE Center for additional information, however, please DO NOT list PACE staff as contacts.

Q: What are the Health Insurance Portability and Accountability Act (HIPAA) implications of this survey?

A: HIPAA permits covered entities to disclose protected health information for the purposes of treatment, payment or health care operations. Since CMS will use this information for payment, the disclosure of this information to CMS is permitted by HIPAA.

III. PACE HEALTH SURVEY PROJECT STAFF

RTI STAFF

RTI is responsible for working with the program sites on a daily basis in preparation for the survey, developing the sampling frame, general oversight of the survey administration conducted by NERI, and for all analyses related to the survey.

Amber Moore
Primary Contact for Survey Implementation
(781) 788-8100 x127
email: amoore@rti.org
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411 Waverly Oaks Rd
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Edith Walsh
Project Director
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411 Waverly Oaks Rd
Waltham, MA 02452

NERI STAFF

NERI is responsible for fielding the survey. They will be mailing out all the surveys, prenotification postcards, thank you and reminder cards. NERI staff will also be calling those program participants and their contacts who do not return the mailed survey within a specific period of time. At this time, NERI staff will offer to complete the survey with the participant over the telephone.

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9 Galen Street
Watertown, MA 02472

CMS PROJECT OFFICER

This survey and the related analyses are being conducted for CMS (formerly HCFA). Any questions or concerns about the purpose of the survey or problems encountered may be directed to the CMS Project Officer.

Susan Radke
Project Officer for Survey Implementation
(410) 786- 4450
email: sradke@cms.hhs.gov

ATTACHMENT 1: SAMPLE PARTICIPANT AND FAMILY/RESPONSIBLE PARTY CONTACTS DATA FILE

THIS DOCUMENT IS BEING SENT AS A SEPARATE ATTACHMENT IN EXCEL.

PLEASE CONTACT AMBER MOORE (amoore@rti.org) or GALINA KHATUTSKY (gkhatutsky@rti.org) IF YOU DID NOT RECEIVE IT OR HAVE TROUBLE DOWNLOADING IT.

ALL OTHER ATTACHMENTS HAVE BEEN INCLUDED IN THE MAIN DOCUMENT.

Attachment 2: Q&A Re: The PACE Health Survey
Information for WPP, MSHO, and MnDHO Staff

What is it?	The PACE Health Survey is a survey that will be mailed to all Medicare beneficiaries enrolled in PACE, WPP (community residents only), MSHO (both NHC- nursing home certifiable- and community-well), and MnDHO participants and measures the health status of each individual participating in these programs.
Why is this survey being conducted?	CMS intends to implement a new Medicare payment approach for PACE, WPP, MSHO, and MnDHO beginning in 2004. The health status information collected via the survey will support this new payment approach.
When will it happen?	Beginning in May, 2004
How does it get to participants?	New England Research Institutes (NERI) will mail surveys to each participant's address.
What if a participant has questions about the survey?	Staff can encourage participants to complete the survey and explain that "Medicare would like to know more about you and what services you need." There will be a NERI 1-800 number printed on the survey to call for specific questions.
What if a participant wants help completing the survey?	A family member or caregiver may assist at anytime if they wish. A PACE, WPP, MSHO or MNDHO employee may assist with the survey **if asked by the participant or a family member or caregiver. Program staff are not required to assist participants with the survey.**
What happens if participants do not respond to the mailed survey?	If no response is received after mailing out the surveys, NERI will call the participant. If participants do not have their own phone, NERI will call the facility's phone number and ask for the participant. **If the participant is interested in participating in the survey, a phone should be made available to them for about 10-15 minutes.**
What if participants still do not respond?	NERI staff will contact the family or other caregivers and ask if they are willing to complete the survey. If none are available, NERI may contact program staff. Contract staff or program site staff may complete the survey on a participant's behalf at the request of the participant, family or other caregivers. Even if requested, caregivers and program staff may decline to complete the survey due to a lack of time.
Who can I contact with questions?	Site Contact: [INSERT SITE CONTACT INFORMATION HERE] FYI- External "Players" in The Survey • RTI International- CMS contracts with RTI to oversee survey project. Contacts: Amber Moore, Contact for Survey Implementation (amoore@rti.org) or Edith Walsh, Project Director (ewalsh@rti.org) • Centers for Medicare and Medicaid Services (CMS) staff Contact: Susan Radke, Project Officer (sradke@cms.hhs.gov) for WPP, MSHO and MNDHO • New England Research Institutes- NERI mails out surveys and follows up when no responses are received Contact: Kathleen Rogers, Contact for Survey Implementation (kathyr@neri.org)

Attachment 3: Newsletter Insert

Keep Your Eyes on the Mail!

This spring, all [insert your program here**] participants nationwide will be asked to complete a survey asking questions on your individual health. You should be expecting it to arrive at your residence with a self-addressed stamped envelope. Please complete and return this survey by mail, as it provides important information to Medicare. Staff members will be available to answer your questions as they arise, so don't hesitate to ask!**

Attachment 4: Sample Letter to Staff of Adult Foster Homes, Assisted Living Facilities, Nursing Facilities or other congregate housing sites where program participants may reside.

[INSERT YOUR ADDRESS HERE]
[INSERT DATE HERE]

Dear ,

In the near future, each of the [INSERT YOUR PROGRAM NAME HERE] participant(s) residing in your facility will receive a survey questionnaire entitled, "PACE Health Survey" in the mail. The Centers for Medicare & Medicaid Services (CMS) is conducting this survey in order to monitor the health of seniors who are covered by Medicare. This survey is Health Insurance Portability and Accountability Act (HIPAA) compliant because HIPAA permits covered entities to disclose protected health information for the purposes of treatment, payment or health care operations. Since CMS will use this information for payment, the disclosure of this information to CMS is permitted by HIPAA.

CMS has contracted with New England Research Institutes (NERI) to conduct the survey. If a participant does not respond to the mailed survey, NERI may contact you as the individual's caregiver to ask if you will complete the survey on your resident's behalf. Also, you may respond to the survey if the participant or a family member or other person responsible for the participant asks you to complete it for them. It takes ten minutes or less to complete the questionnaire or the telephone interview. Your assistance with completing the survey would be appreciated, however if it is too much of a burden or inconvenience, we understand that you may not be able to participate in the survey. Of course, the survey is voluntary and you are not required to complete it.

Thank you for your assistance. Please contact me if you have any questions.

Sincerely,

[INSERT YOUR SITE CONTACT INFORMATION HERE]

APPENDIX B
VARIABLES IN THE PACE HEALTH SURVEY CONTACT FILE

Variables in the Wisconsin and Minnesota Health Survey Datafile:

Variable	Meaning
MCARE	Participant Medicare Number
FNAME	Participant First Name
INITIAL	Participant Middle Name
LNAME	Participant Last Name
BUILDING	Participant Building
STREET	Participant Street Number/Name
CITY	Participant City
STATE	Participant State Code
ZIP	Participant Zip Code
HPHONE	Participant Home Phone Number
WPHONE	Participant Work Phone Number
CPHONE	Participant Cell Phone Number
LANGUAGE	Participant Primary Language
PACEMAIL	Does The Participant Receive His/Her Own Mail?
LIVE FACILITY	Does The Participant Live in a Facility?
PHONEST	Does the Participant Share a Phone Line with One or More Others?
PACECTR	Center Attended by Participant
PLANID	
CXFNAME*	Contact X First Name
CXINITIAL	Contact X Middle Name
CXLNAME	Contact X Last Name
CXBUILDING	Contact X Building
CXSTREET	Contact X Street Number Name
CXAPT	Contact X Apartment Number
CXCITY	Contact X City
CXSTATE	Contact X State Code
CXZIP	Contact X Zip Code
CXHPHONE	Contact X Home Phone Number
CXWPHONE	Contact X Work Phone Number
CXCPHONE	Contact X Cell Phone Number
CXRELATE	Contact X Relationship to Participant
CXLANG	Contact X Primary Language
CCLNAME†	Care Coordinator Last Name
CCFNAME†	Care Coordinator First Name
CCHPHONE†	Care Coordinator Phone Number
NOTE	Notes

* Where X = 1, 2, 3 or 4

† Care Coordinator information is only collected for the Minnesota programs

APPENDIX C
SURVEY PROTOCOL

New England Research Institutes, Inc.

Survey Research Center

Survey Administration Protocol for the PACE Health Survey for Dual Eligible Demonstrations in Wisconsin and Minnesota

The sampling frame was constructed from a list of participants in the programs, and included the name and address of individuals selected for the survey. RTI International provided NERI's Survey Research Center (SRC) with a datafile of the names, addresses (and telephone numbers, if available) for the sample. In many instances, the telephone number provided will be that of a ***facility***, such as an adult foster home or residential care facility. If additional information re: telephone numbers (for beneficiaries or their proxies) was needed, the SRC called the facility to obtain the required information.

Data Collection Protocol

In general, SRC staff implemented the following mixed-mode survey methodology:

- **T_0** — **Mailing of the pre-notification postcard to the beneficiary or the family proxy.**
- **T_0 +7 days** — **First mailing of the introductory cover letter, survey questionnaire, and postage-paid BRE (Business Reply Envelope). The program participant will receive a personalized cover letter, questionnaire and Business Reply Envelope with a unique Respondent Identification number for tracking purposes.**
- **T_0 +14 days** — **Reminder "thank you"/postcard sent to individual program participants or their family proxies**
- **T_0 +42 days** — **Second mailing of the cover letter; survey questionnaire; and postage-paid BRE (Business Reply Envelope) to** *non-Respondents only***.**

- **T_0 +49 days** **Second reminder "thank you"/postcard sent to individual program participants or their family proxies**

- **T_0 +56 days** **Initiate computer-assisted-telephone-interviews (CATI) for non-Respondents to the mailed survey component and for those returned with "missing" data. ('Missing' data would include questions that are left unanswered without a reasonable explanation; but would not include responses that were marked "Don't Know" or Refused. This first set of calls will serve two purposes: (1) Reminder calls for those who wish to complete the self-administered questionnaire and return it by mail; and (2) administration of the (CATI) telephone interview for those who prefer to complete the survey by telephone.**

- **T_0 +(56 – 90) days -Conduct up to 6 telephone attempts to reach the Respondent /proxy for return of the mailed questionnaire or completion of the telephone interview (as above).**

The introductory cover letter was personalized for each individual in the sample. The introductory letter states that the Respondent may call our (NERI) offices toll-free to speak directly with a member of our project staff. The 1-800 project telephone number was staffed Monday – Friday from 9:00 am –1:00 pm (20 hours per week); but also was operational (voicemail) 24 hours a day. Once the telephone information has been added to the database, the project's data management team developed a "batch" system for implementation of the above protocol for contacting each potential Respondent. The initial sample of 3,200 names (in round 1 of interviewing) were divided into 7 mailing "batches" of approximately 450 individuals per batch.

This "batch" method ensures adequate staff for all of the components of the mixed-mode survey: project mailing; log-ins and data entry of completed questionnaires; routing incomplete questionnaires to the SRC telephone staff; and data collection by telephone.

The introductory letter is the first attempt to enlist the cooperation of potential Respondents by offering an explanation of the rationale for the study and emphasizing its important contribution to research, an important topic for everyone. Project-specific stationery (letterhead; envelopes; etc.,) were designed and the project name and logo were used in all project correspondence and related materials. Each letter was personalized, printed on project

stationery and signed. The Respondent's address was printed on the envelope with a postage stamp affixed.

After the first mailing and the reminder postcards, SRC staff began telephoning the potential Respondents to conduct the telephone interviews. If telephone numbers have been disconnected or changed to nonpublished or unlisted numbers, SRC staff will conduct an in-house search for the new telephone number. The SRC has a well-established protocol for searching for telephone numbers for sampled individuals. First, the staff of the SRC contacts Directory Assistance to see if there is a new telephone number on file for the individual (or for the same last name at the same address). If the Directory Assistance search is unsuccessful, the next step is to conduct a search using resources on the Internet, (e.g., www.555-1212.com; www.databaseamerica.com; www.four11.com; www.infospace.com; or www.switchboard.com).

All Respondent letters were mailed with "Address Service Requested" printed on the outside envelope. This indicates to the post office that the letter should be forwarded, and in addition, the updated address will be provided to NERI. Forwarding information is usually kept on file at the post office in the zip code area of the place of former residence for one year after the Respondent moves.

At the time of the initial telephone contact, the Interviewers answered any questions that the individual may have about the research project. Assurances of confidentiality of all information and emphasis on the voluntary nature of participation were made. During the introductory telephone call, the Interviewers clearly described the nature of the proposed research, its sponsorship and the purpose of the study. At the time of the telephone call, NERI's telephone staff stresses the importance of each selected subject's participation. This practice consistently increases cooperation rates. The study's importance was specifically spelled out, and the subject was told what ultimately may be gained from participation in the study.

The Interviewer will proceed to the telephone interview (or schedule an appointment for a more convenient time if necessary). All Respondents will be identified ***only by an identification number***. Moreover, all project staff handling data will be required to sign an ***Oath***

of Confidentiality, to further emphasize this responsibility (standard NERI procedure). All subjects will be given a project staff member's toll-free telephone number as well as that of a NERI Institutional Review Board member, to verify that the study is legitimate.

Up to **six** telephone calls were made to conduct the telephone interview, thus ensuring telephone coverage at all possible times. These calls will be made at different times of the day and on different days of the week, in an attempt to maximize contact (with beneficiaries and/or proxy/caregivers) using assignment procedures already operating smoothly at SRC. Of the six calls, at least one was made on a weekday, one was on a weeknight (Monday through Friday) and one was made on the weekend (on Saturday between 9:00 a.m. and 7:00 p.m. or on Sunday between 12:00 noon and 9:00 p.m.). If the Beneficiary/proxy is not available at the time of the call, the Interviewers will request appropriate 'call-back' times to maximize efficiency. The remainder of the calls will be made in accordance with the beneficiaries' specific 'call-back' time requests (whenever this information is available). In addition, the SRC protocol specifies that calls should be made at least two days (48 hours) apart (unless a Beneficiary/proxy requests a specific call-back within 48 hours). This ensured adequate coverage over a span of at least 15 days. If the interviewer reached a beneficiary who was unable to respond due to physical limitations (e.g., hard of hearing), confusion or inability to understand English, the Interviewer called family contacts, when available.

Response Rates

It is critical to the aims of any research to obtain valid and reliable data. To ensure quality data, it is also important to obtain a high response rate. Based on the experience of senior investigators at NERI, the single most important factor in maximizing response rates is the effort contributed by project staff in contacting Respondents and enlisting their cooperation.

Refusal Conversion Protocol

The SRC closely monitored refusal rates so that high refusal rates for particular Interviewers could identified and appropriate corrective action taken. NERI is able to turn

around, on average, **30%** of initial refusals. In addition, some of those who initially refuse were not, in fact, eligible for the survey (due to plan disenrollment). At all times, great care is taken not to upset or otherwise irritate Respondents. The SRC's highly trained interviewing staff are experts in the art of separating out those Respondents who are absolutely unwilling to participate from those who have justifiable questions or concerns about the legitimacy of the Project and who simply want more information.

NERI's Data Management and CATI Systems

NERI's approach to data management and quality control is to fit the data system to the projects. For mixed-mode surveys, the responses to the mailed questionnaires and responses to telephone surveys are stored in the same database. Response items are keyed directly into the computer as the interview is administered on the CATI system. The system is supported by its own local area network and an automatic tape backup system. NERI designed a complex database management system to manage the mixed-mode data collection for this project. The data management system provided the following capabilities to the project:

- Establishment of a research database for a master file of all cases including 'site' identifiers (for approximately 12 sites);
- Monitoring (tracking) the process of all mailed and telephone contacts;
- Integration with the Computer Aided Telephone Interview (CATI) system at NERI;
- Full online edits for ranges, values, logical consistency checks; and
- Rapid production of cleaned and edited datasets for final transmission within 2 weeks after completion of data collection to RTI (and CMS).

This data management flow is designed to seamlessly integrate the CATI system with the standard research data systems NERI employs for its research projects, and also integrates the mix of direct electronic (the telephone interviews) with the data from the hard-copy (mailed questionnaire) survey components. The basic procedures to ensure the highest quality data and prevent data file degeneration include:

- Screen data entry with built-in logic and range checks programmed prior to the start of data collection;
- Built-in data redundancy checks to detect a duplicate form automatically: For example, on a mixed-mode mail/telephone survey, it is not uncommon for a

Respondent to complete and return a duplicate questionnaire; or complete a telephone interview the day before a completed questionnaire arrives in the mail. This process precludes the data entry of a second mailed questionnaire under the Respondent's unique identification number; and with pre-programmed project-specific criteria, automatically selects the **first** completed questionnaire/interview.

- Common interface to all microcomputer applications for the data management system.
- A mail-log system so that reports can be generated on a daily basis to track questionnaire status, participant response rates, etc.
- Password control of access to the system, and control via password of access to particular system functions (such as editing the data, etc.)
- Automatic audit trail capability which tracks changes to data, monitors usage of system features, and keeps track of which user is logged on at any given time.
- Quality Control on the complete sample. A sample of original forms will be selected for duplicate (quality control entry and verification). The system then compares the original data entry to the quality control entry version and corrections to original data entry errors are made during this process.

The NERI data management system provides for complete on-line editing of data as they are entered. The quality control system will include the use of the "editing function." This editing capability includes range checking, table look-up for value accuracy, and logical consistency checks. Under the project's quality control protocol, whenever an error occurs, the system automatically generates an "edit report" to trigger follow-up on the case ID#. Of course, each datapoint is programmed to accept a 'refused' or 'don't know' response on the part of a Respondent to a particular question or series of questions.

An error occurs when the value entered fails to meet the system's **imbedded** validation ranges (programmed prior to the start of data collection). The system contains both "hard" and "soft' validation ranges. "Hard" validations refer to verifications that flag data that are "unacceptable' to the system. For example, if a mailed questionnaire is returned with missing data, the data management system will produce an "edit report" to flag the case for assignment to a telephone interviewer for a call-back to obtain the missing data. The system will not allow the case to be assigned a final disposition of "INTERVIEWED" until the missing information is entered in the system. An edit report is generated to facilitate timely follow-up for error

resolution. Upon completion of data entry, all errors are printed out in hard copy edit reports for resolution by the project personnel.

The research staff documents the corrections on the edit reports and on the hard copy mailed survey form. The NERI data processing clerk then attaches the edit correction form to the original mailed survey and it is assigned for immediate telephone follow-up.

At the end of data collection, a final disposition was assigned to every Respondent ID# according to a Project-specific set of dispositions, and falling in one of the following major categories:

- Respondent (or Proxy) completed the mailed questionnaire or telephone interview;
- Refusal (Respondent or Proxy);
- No contact; or
- Ineligible (Deceased or “disenrolled” from the program).

APPENDIX D
SURVEY INSTRUMENT

PACE Health Survey

INSTRUCTIONS

This survey asks about your health, feelings, and ability to do daily activities. Please take the time to complete this survey. Your answers are very important to us. If you need help to complete this survey, a family member or a friend may fill out the survey about ***your*** health. If a family member or friend is NOT available, please ask your nurse or other health professional for help.

- Answer each question by putting an "**X**" in the box next to the best answer like this **example**:
  Are you male or female?
  MALE ..... ☐
  FEMALE ..... ☒
- Be sure to read **ALL** the answer choices before putting an "X" in the box next to the best answer.
- You may find some of the questions to be personal. It is important that you answer **EVERY** question on this survey. However, you do not have to answer a question if you do not want to. If you are unsure of the answer to a question or that the question applies to you, just choose the **BEST** available answer.

Please complete the survey *within two weeks* and return it in the enclosed *postage-paid* envelope.

IF YOU ARE FILLING OUT THIS SURVEY FOR SOMEONE ELSE

Please answer every question the way you believe best describes that person's health, feelings, and ability to do daily activities. Answer each question the way you think the person you are helping would answer about him or herself.

CONFIDENTIALITY PLEDGE

All information that would permit identification of any person who completes this survey will be kept strictly confidential. **Your answers to this survey will not change your Medicare services in any way.** This information will be used only for the purposes of this study and will not be disclosed or released for any other purpose without your permission.

If you have any questions or want to know more about the study, please call the New England Research Institutes at 1-800-775-6374, extension 638. For questions concerning your rights as a research subject, please contact Sarah Carolan of NERI's Institutional Review Board at 1-800-775-6374, extension 249.

1. In general, would you say your health is:

EXCELLENT ..... ☐1
VERY GOOD ..... ☐2
GOOD ..... ☐3
FAIR ..... ☐4
POOR ..... ☐5

2. How much difficulty, if any, do you have lifting or carrying objects as heavy as 10 pounds, such as a sack of potatoes?

NO DIFFICULTY AT ALL ..... ☐1
A LITTLE DIFFICULTY ..... ☐2
SOME DIFFICULTY ..... ☐3
A LOT OF DIFFICULTY ..... ☐4
NOT ABLE TO DO IT ..... ☐5

3. How much difficulty, if any, do you have walking a quarter of a mile—that is about 2 or 3 blocks?

NO DIFFICULTY AT ALL ..... ☐1
A LITTLE DIFFICULTY ..... ☐2
SOME DIFFICULTY ..... ☐3
A LOT OF DIFFICULTY ..... ☐4
NOT ABLE TO DO IT ..... ☐5

4. Because of a health or physical problem, do you have any difficulty doing the following activities **without special equipment or help from another person**?

		NO, I DO NOT HAVE DIFFICULTY	YES, I HAVE DIFFICULTY	I AM UNABLE TO DO THIS ACTIVITY
a.	Bathing or showering	☐1	☐2	☐3
b.	Dressing	☐1	☐2	☐3
c.	Eating	☐1	☐2	☐3
d.	Getting in or out of bed or chairs	☐1	☐2	☐3
e.	Walking	☐1	☐2	☐3
f.	Using the toilet	☐1	☐2	☐3

5. Do you receive **help from another person** with any of these activities?

		YES, I RECEIVE HELP	NO, I DO NOT RECEIVE HELP	I DO NOT DO THIS ACTIVITY
a.	Bathing or showering	☐1	☐2	☐3
b.	Dressing	☐1	☐2	☐3
c.	Eating	☐1	☐2	☐3
d.	Getting in or out of bed or chairs	☐1	☐2	☐3
e.	Walking	☐1	☐2	☐3
f.	Using the toilet	☐1	☐2	☐3

6. The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

	YES, LIMITED A LOT	YES, LIMITED A LITTLE	NO, NOT LIMITED AT ALL
a. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	☐1	☐2	☐3
b. Climbing **several** flights of stairs	☐1	☐2	☐3
c. Climbing **one** flight of stairs	☐1	☐2	☐3
d. Bending, kneeling, or stooping	☐1	☐2	☐3

7. During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health?** (If you are not able to do work or regular daily activities, please answer yes to both questions).

	YES	NO
a. **Accomplished less than** you would like	☐1	☐2
b. Were limited in the **kind** of work or other activities	☐1	☐2

8. During the **past 4 weeks**, have you had any of the following problems with your regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? (If you are not able to do work or regular daily activities, please answer yes to both questions).

	YES	NO
a. **Accomplished less than** you would like	☐1	☐2
b. Didn't do work or other activities as **carefully** as usual	☐1	☐2

9. During the **past 4 weeks**, how much did **pain** interfere with your regular daily activities?

NOT AT ALL ..... ☐1
A LITTLE BIT ..... ☐2
MODERATELY ..... ☐3
QUITE A BIT ..... ☐4
EXTREMELY ..... ☐5

10. These questions are about how you feel and how things have been with you. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the **past 4 weeks**:

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a. Have you felt calm and peaceful?	☐1	☐2	☐3	☐4	☐5	☐6
b. Did you have a lot of energy?	☐1	☐2	☐3	☐4	☐5	☐6
c. Have you felt downhearted and blue?	☐1	☐2	☐3	☐4	☐5	☐6

11. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

ALL OF THE TIME ..... ☐1
MOST OF THE TIME ..... ☐2
SOME OF THE TIME ..... ☐3
A LITTLE OF THE TIME ..... ☐4
NONE OF THE TIME ..... ☐5

12. Do you experience memory loss that interferes with daily activities?

YES..... ☐1
NO ..... ☐2

13. How often, if ever, do you have difficulty controlling urination (bladder accidents)?

NEVER..... ☐1
LESS THAN ONCE A WEEK ..... ☐2
ONCE A WEEK OR MORE OFTEN..... ☐3
DAILY..... ☐4
CATHETER ..... ☐5

14. Who completed this survey form?

PACE Participant..... ☐1 **STOP HERE**

Please return the survey. Thank you.

Family member, relative or friend of PACE Participant…. ☐2 **Please answer questions 15 and 16.**
(Includes Legal Guardian)

Nurse or other health professional..... ☐3 **Please answer questions 15, 16, and 17.**

15. What was the reason you filled out this survey for someone else? (Please answer **ALL** that apply.)

PHYSICAL PROBLEMS ..... ☐1
MEMORY LOSS OR MENTAL PROBLEMS..... ☐2
UNABLE TO SPEAK OR READ ENGLISH ..... ☐3
PERSON NOT AVAILABLE..... ☐4
OTHER (PLEASE SPECIFY BELOW) ..... ☐5

_____

16. How did you help complete this survey? (Please answer **ALL** that apply.)

READ THE QUESTIONS TO THE PERSON..... ☐1
WROTE DOWN THE PERSON'S ANSWERS ..... ☐2
ANSWERED THE QUESTIONS BASED ON MY EXPERIENCE WITH THE PERSON..... ☐3
USED MEDICAL RECORDS TO FILL OUT THE SURVEY ..... ☐4
TRANSLATED THE SURVEY QUESTIONS ..... ☐5
OTHER (PLEASE SPECIFY BELOW) ..... ☐6

_____

FOR PROFESSIONAL STAFF (CAREGIVERS) ONLY

17. Which of the following **best describes** your position? (Please choose **one** answer.)

NURSE ..... ☐1
SOCIAL WORKER OR CASE MANAGER ..... ☐2
GROUP/FOSTER HOME STAFF..... ☐3
NURSE'S AIDE, PERSONAL CARE ATTENDANT, HOME HEALTH AIDE, ETC. ..... ☐4
OTHER..... ☐5

INSTRUCTIONS FOR RETURNING THE PACE SURVEY

THANK YOU FOR COMPLETING THE PACE HEALTH SURVEY

Please return your completed survey **within two weeks** to:

PACE Health Survey
New England Research Institutes
9 Galen Street
Watertown, MA 02472

A postage-paid return envelope is enclosed for your convenience.

IF YOU HAVE QUESTIONS ABOUT THE SURVEY, PLEASE CALL

The New England Research Institutes *toll-free* at:

1-800-775-6374, extension 638

PACE Health Survey
New England Research Institutes
9 Galen Street
Watertown, MA 02472