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Pilot Test of the Medicare Health Survey for PACE and EverCare

PACE Pilot Report

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Symbols

*Statistically Significant at 10% Level

** Statistically Significant at 5% Level

*** Statistically Significant at 1% Level

EXECUTIVE SUMMARY

The Centers for Medicare & Medicaid Services (CMS) contracted with RTI International to conduct a pilot test of the Medicare Health Survey for PACE and EverCare (MHSPE). The MHSPE is a potential source of health status measures that have been linked to Medicare costs and could be used to risk adjust payments to specialty plans serving frail Medicare beneficiaries. Developed and pretested under a previous CMS contract, the MHSPE 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. Under contract to CMS, RTI International and the New England Research Institutes fielded the MHSPE to 1,500 Medicare beneficiaries enrolled in four PACE plans and one EverCare plan, and analyzed the resulting data. This report is focused on the PACE pilot. EverCare results will be reported separately.

The project had two main goals:

- pilot test the MHSPE, and
- compare three survey distribution approaches in order to determine the best approach for use in a national roll-out of the survey.

E.1 Background

The BBA mandated that Medicare capitated payments to PACE organizations be based on M+C payment rates, adjusted to account for the comparative frailty of PACE enrollees. Initially, CMS considered using the annually required HOS to collect frailty information for PACE. To assess the feasibility of this approach, the HOS was administered to PACE in 1999, 2000 and 2001. However the annual response rates across all PACE organizations averaged only 37 to 50 percent. These response rates were considered too low to be useful for risk adjustment.

To address this issue, we developed the Medicare Health Survey for PACE and Evercare (MHSPE). This survey instrument was much shorter than the HOS. It included questions worded identically to those in 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 and general M+C organizations. The instrument was pre-tested on 9 frail beneficiaries enrolled in either PACE or Evercare.

Based on the results of the pre-test, we further simplified and revised the survey instrument. In addition, we realized that the survey administration protocol might play an important role in achieving higher response rates. Thus, we developed a pilot test to evaluate the impact of the simpler survey instrument and several approaches to survey administration on response rates, on burden to participating sites and on the proportion of proxies that are PACE staff. This report describes the pilot test and its results.

E.2 Methods

The pilot test used three approaches for administering the survey (PACE staff, as well as family/friends, were allowed to serve as proxies for all approaches):

- Approach 1: Similar to HOS, surveys were mailed directly to the beneficiary;
- Approach 2: The surveys were mailed to PACE organizations for distribution to the beneficiaries;
- Approach 3: PACE organizations were asked to determine the most appropriate respondent (self, family, staff) and the surveys were mailed directly to the selected respondent.

We conducted several analyses with the primary goal of evaluating the impact of the MHSPE and the various distribution approaches on response rates. The analyses included:

- descriptive analyses of the health status of the sample as a whole, by respondent type, and by survey distribution approach;
- comparison of Activities of Daily Living ratings from the survey to those in the PACE medical records for the sample as a whole, by respondent type, and by survey distribution approach;
- multivariate analyses to evaluate the factors related to the congruence between the Activities of Daily Living ratings derived from the survey and those derived from the medical records; and
- a nonresponse analysis, comparing the Activities of Daily Living information from the medical record for survey respondents and nonrespondents.

E.3 Key Findings

E.3.1 Characteristics of respondents

Over all 3 approaches 26 percent of the respondents were the enrollees themselves, 46 percent were family or friends, and 28 percent were health professionals. The health professional proxies included paid caregivers at adult foster homes, assisted living facilities and other congregate housing facilities, as well as PACE staff. While 75 percent of the health professional proxies drew on their own knowledge of the enrollees' health and 18 percent consulted the medical record, only about one third of the health professional proxies (i.e., about 10 percent of the total respondents) relied totally on their own knowledge or the medical record in responding to the survey. The rest assisted by reading the survey to the beneficiary, writing down the beneficiary's own responses, translating the survey, or by providing some combination of these types of assistance.

Based on survey responses, the mean number of Activities of Daily Living impairments in the pilot sample was 3.7, with 12 percent of the sample reporting 0 Activities of Daily Living impairments, 20 percent reporting one to two Activities of Daily Living impairments, 18 percent reporting three to four Activities of Daily Living impairments, and 49 percent reporting five to six Activities of Daily Living impairments.

As expected, Activities of Daily Living impairments differed by respondent type, with those able to respond for themselves reporting the least impairment (mean Activities of Daily Living=2.5), those with family proxies reporting the most impairment (mean Activities of Daily

Living= 4.5) and those for whom health professionals served as proxies reporting mean Activities of Daily Living impairments of 3.7.

Survey respondents reported substantially higher rates of health problems compared to the general Medicare population, including nearly half that report having been depressed, about 40 percent that have Alzheimer's Disease or other dementia, a third of the sample that had a stroke and a quarter that had diabetes. About half of the sample reported memory loss which interferes with daily activities, more than 40 percent suffer from daily bladder incontinence, and about 90 percent have difficulty walking two to three blocks, or lifting or carrying 10 pounds.

E.3.2 Comparison of the three survey distribution approaches

Table ES-1 provides a comparison of the three survey distribution approaches on selected factors: response rates, the percent of responses by health care professionals, the subset of the professional proxies who were PACE staff, and the burden on PACE staff associated with each approach. In addition, we conducted a nonresponse analysis, comparing Activities of Daily Living information derived from medical records of survey respondents to nonrespondents. Professional proxies include both PACE plan staff and staff at facilities where PACE participants reside (e.g., adult foster homes, assisted living facilities and nursing facilities). For example, 25% of respondents under Approach 1 were professionals serving as proxies. Under every approach, a much smaller percentage were the subset of professionals directly employed by PACE, 0% in Approach 1, 4% in Approach 2, and 53% of respondents in Approach 3.

We also evaluated the burden on the PACE sites by approach. Overall, Approach 1 was the least burdensome on PACE staff. Beyond creation of the datafile and ongoing communication with RTI staff (required in every approach), Approach 1 imposed no burden on the PACE staff. The burden for Approach 2 was roughly 10 minutes for each beneficiary in the sample. The burden for the two organizations that participated in Approach 3 was 10 minutes per beneficiary and 16 minutes per beneficiary, respectively, for a weighted average of 14 minutes.

E.3.3 Comparison of Survey and Medical Record ADL Ratings

When we compared the individual ADL ratings reported in the survey to the ADL ratings for the same individuals in their medical records, we found only a 36% match rate. Self or proxy reported ADL counts and those reported in the medical record were moderately correlated. The match rate increased to 56% based on ADL categories, i.e., 0 ADLs, 1-2, 3-4, and 5-6. The highest match rates were for those with 5-6 ADL impairments and for those surveys completed by health professionals based on the medical records or their own knowledge of the PACE enrollee.

Table ES-1
Comparison of survey approaches on key selection criteria

	Approach 1	Approach 2	Approach 3
Response rates	68%	67%	86%
Professional proxies (including staff at Adult Foster Homes, Assisted Living Facilities, and other congregate housing facilities, as well as PACE staff)	25%	8%	53%
PACE staff serving as proxies (a subset of the professional proxies including PACE social workers and nurses)	0%	4%	53%
Burden on PACE ¹ (minutes/enrollee)	0	10	14
Nonresponse bias	none	none	none

¹ Excluding time spent creating a beneficiary data file which was required of all plans prior to survey administration. The time it took plans to create these data files was a function of the information systems available at each plan, and was unrelated to the pilot survey distribution approaches.

NOTE: Nonresponse bias was evaluated by comparing assessed number of impairments in Activities of Daily Living in the medical record for survey respondents and nonrespondents.

The low match rate does not necessarily mean that the survey responses were inaccurate. Survey responses may differ from the medical record for two main reasons. First, the survey questions are worded differently than the medical record assessment. Second, various types of respondents may have different interpretations regarding what constitutes having difficulty with a task. Therefore, these results do not have direct implications for survey-based payment.

E.3.4 Nonresponse Analysis

The nonresponse analysis, which compared the ADL ratings from the medical records for respondents and nonrespondents, showed no significant difference between the two groups.

E.4 Conclusions

Each of the survey distribution approaches resulted in a substantial increase in response rates over the PACE HOS response rates. We attribute the improvement in response rates over the HOS to several factors, including: receipt of detailed and up-to-date contact information for each enrollee from the PACE sites; the use of a shorter, more targeted instrument; efforts by the sites to inform their participants, caregivers and PACE staff about the survey effort; and aggressive telephone follow-up by the survey subcontractor, the New England Research Institutes.

Based on the results of the pilot, CMS selected Approach 1 for program implementation.

SECTION 1 INTRODUCTION

1.1 Overview

The Centers for Medicare & Medicaid Services (CMS) contracted with RTI International to conduct a pilot test of the Medicare Health Survey for PACE and EverCare (MHSPE). The MHSPE is a potential source of health status measures that have been linked to Medicare costs and could be used to risk adjust payments to specialty organizations that enroll Medicare beneficiaries. Developed and pretested under a previous CMS contract, the MHSPE 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. RTI International and the New England Research Institutes (NERI) administered the Medicare Health Survey for PACE and EverCare to 1500 Medicare beneficiaries enrolled in four PACE plans and one EverCare plan, and analyzed the resulting data. This report is focused on the PACE pilot. EverCare results will be reported separately.

The key objectives of the pilot were to

- determine the impact on response rates of the MHSPE, as a replacement for the Health Outcomes Survey (HOS);
- determine the impact on response rates associated with various approaches to distributing the survey;
- measure the burden on program staff under each approach;
- compare the consistency of responses by approach and determine the extent of nonresponse bias under each approach;
- determine how the survey instrument might be refined for national implementation.

The pilot test was fielded using three methods of survey administration to a sample of 1,025 Program of All-inclusive Care for the Elderly (PACE) participants at four sites. As a result of this pilot, CMS selected an approach for national implementation of this survey to PACE participants nationwide.

1.2 Background

PACE—PACE is a health care delivery model integrating long-term and chronic care with the standard Medicare acute care benefit package. PACE serves a functionally impaired population that resides primarily in the community. Eligibility is based on state-by-state determinations of nursing home certifiability (NHC), i.e., whether the applicant meets his or her state's criteria for nursing home admission under Medicaid. Care is provided through centers operated by PACE staff comprised of physicians, nurses, social workers, rehabilitation therapists, and other ancillary providers. Most PACE participants live at home, or in other community-based settings with which PACE contracts, such as group homes, assisted living facilities, adult foster homes, and residential care facilities, and attend the PACE adult day facilities to receive much of their medical and nursing care. A small proportion of PACE

enrollees become residents of nursing facilities when they can no longer be supported adequately in other settings. Most PACE enrollees are Medicare/Medicaid dual eligibles for whom PACE plans receive monthly capitation payments from both Medicare and Medicaid. PACE organizations are small, with an average enrollment of less than 300 beneficiaries. At the time of the pilot there were 27 PACE organizations nationwide serving roughly 7,000 beneficiaries.

1.2.1 Risk Adjustment Implementation for M+C Organizations

The Balanced Budget Act of 1997 (BBA) mandated the implementation of risk adjustment for M+C organizations no later than January 1, 2000. As an initial step under BBA authority, CMS began collecting inpatient hospital diagnosis data from M+C 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 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. Out of concern for the administrative burden on the M+C organizations collecting and submitting these data, CMS redesigned its data collection and submission process. As a result, M+C organizations are no longer required to submit encounter data, but instead are only required to submit a minimum number of data elements in addition to the relevant diagnoses that populate the model and trigger an increased payment. CMS will implement the CMS-HCC model for M+C organizations in 2004.

1.2.2 PACE Program Payment

The BBA mandated that Medicare capitated payments to PACE organizations be based on M+C payment rates, adjusted to account for the comparative frailty of PACE enrollees. But preliminary research suggested that early diagnosis-based risk adjustment models (such as those that rely on hospital inpatient diagnoses) did not necessarily account for the Medicare costs of frail populations. CMS therefore exempted PACE from M+C risk adjustment and maintained the current PACE payment adjuster through the 2003 payment year.

Although the CMS-HCC model performed well for M+C 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 PACE and certain demonstrations. Thus, PACE organizations will be required to submit diagnosis data to support this payment approach.

Frailty Adjustment for PACE

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. When implemented, the frailty adjuster will modify each organization's risk adjusted payment amount depending upon the organizations enrollees' level of functional impairment.

CMS will need to collect functional impairment information about enrollees in PACE organizations to support the application of the frailty adjuster to their Medicare payments. A 'frailty factor' will be assigned to each community-based survey respondent based on his or her number of ADL difficulties. The average factor across all community-based respondents in an organization will be calculated, and this organization-level frailty score will be applied to the payment for each community based enrollee for that organization.

Collection of Functional Impairment Data

Initially, CMS considered using the annual required HOS to collect frailty information for PACE. 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.

In 2000, CMS developed the Medicare Health Survey for PACE and Evercare. 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 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 program 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 evaluate burden on the individual PACE programs, the role of PACE staff serving as proxies,

potential nonresponse bias across the various approaches, and to compare functional status ratings derived from the survey responses to those found in beneficiaries' medical records.

This report describes the survey pilot methodology, and compares the various approaches in terms of response rates achieved, nonresponse bias, and plan burden.

SECTION 2 METHODS

2.1 Survey Distribution Approaches

We tested three different approaches to distributing the MHSPE surveys to enrollees or their proxies and their effects on survey response rates. The three approaches varied in the degree of program staff involvement. In all three approaches, we printed plan logos, as well as the CMS logo, on materials to associate the survey with the plan familiar to the participant or their family. In all three approaches, plan staff were permitted to assist participants to complete the survey or to serve as proxies. The degree of staff involvement varied by approach.

The MHSPE survey (Appendix A) was administered to participants using the following three distribution approaches (See Appendix B for detailed approach protocols):

Approach 1 was modeled after the HOS approach, with slight modifications. Similar to HOS, surveys were mailed directly to the sampled beneficiaries and telephone follow-up interviews were conducted for beneficiaries who did not respond to the mailing. Unlike HOS (where PACE organizations voluntarily provided some beneficiary contact information), PACE was required to provide up-to-date addresses and contact information for all of the sample members. Medicare beneficiaries were encouraged to complete the survey on their own or with some assistance from a family member, friend, or their health care provider. Proxy responses were considered acceptable if the beneficiary were unable to respond to the survey. The survey instrument instructed beneficiaries to seek help from a family member or friend if they were unable to complete the survey. If a family member or friend was unavailable, the beneficiary was instructed to ask a nurse or other health professional for help. Given its similarity to the HOS methodology, this approach also tested the effect of the MHSPE instrument compared to the HOS on response rates, and of getting more detailed and up-to-date beneficiary contact information.

Approach 2 was designed to test the effect of the PACE organization staff personally distributing the surveys to their participants as a way to encourage responses to the survey and avoid problems associated with incorrect mailing addresses. The surveys were mailed in batches to the PACE organization for hand distribution. The contact information provided by the site was used for telephone follow-up as needed. The beneficiary was responsible for seeking the assistance of a family member, friend, or professional proxy if they were unable to complete the survey. The beneficiary was encouraged to return their completed survey to the local program; however, the beneficiaries and/or proxies could mail them to the vendor if they chose.

Approach 3 was designed to test the effect of predetermining whether a beneficiary would be capable of completing a survey and assigning an appropriate proxy if needed. The local PACE and EverCare programs decided if a proxy was appropriate and determined the most appropriate proxy (family, friend, or professional). Program staff used a decision tree (Appendix C) to determine who would be the most appropriate proxy respondent. The local program distributed the survey to that proxy. The beneficiary/proxy was encouraged to return their completed survey to the local program; however, the beneficiaries and/or proxies could mail them to the vendor if they chose. Telephone follow-up was conducted as needed.

The level of staff involvement in the three approaches may be summarized as follows:

Approach 1: Minimal staff involvement; staff may serve as professional proxy if asked by the respondent.

Approach 2: Greater staff involvement since the plan was responsible for survey distribution to and collection from the enrollees; staff may serve as professional proxy if asked.

Approach 3: The greatest level of staff involvement since the plan was responsible for determining the appropriate respondent and distributing the surveys to the enrollees or an appropriate proxy and collecting the completed surveys; staff may serve as professional proxy.

Approach 1 was considered the baseline against which the other approaches would be measured. The greatest opportunity to increase response rates for PACE was expected for Approach 2 where staff involvement was at a moderate level with staff responsible for distributing and collecting the surveys. Since PACE enrollees are not as impaired as EverCare enrollees, the additional staff involvement for Approach 3 was not hypothesized to have as large an effect on the PACE response rates.

2.2 Site Selection

Four PACE organizations and one EverCare organization participated in the pilot MHSPE survey. A fifth PACE site had been selected but was unable to participate due to that site’s lengthy Institutional Review Board (IRB) process. The organizations were selected so that the response rates to the 2000 HOS were approximately the same for each approach (i.e., about 47 to 48 percent, see Table 1). This provided a level playing field for assessing the impact of each approach on response rates. As Approach 3 was expected to be most burdensome for the sites, we split the Approach 3 sample across two small sites. The number of PACE enrollees assigned to each approach is shown in the last column. PACE Approach 1 had 372 participants, Approach 2 had 419, and the two sites in Approach 3 had a total of 234 participants.

Table 1
Characteristics of PACE sites selected for the MHSPE

Approach	# of participants eligible in 2000	HOS 2000 response rate	# of participants at time of MHSPE Pilot
Approach 1	302	47.7%	372
Approach 2	199	46.7%	419
Approach 3 (site A)	134	45.5%	163
Approach 3 (site B)	67	50.7%	71

2.3 Sampling

We used a sampling methodology similar to that for the pretest of the MHSPE survey. We used PLAN ID numbers for the four PACE plans to construct a finder file of beneficiary Medicare Health Insurance Claim Numbers (HICNUMs). This finder file was used by RTI to access Medicare’s Enrollment Data Base (EDB) through WORKBENCH to identify

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

- be enrolled in the selected PACE or EverCare plan for at least a month by February 1, 2002,
- be alive,
- be enrolled in both Medicare parts A and B,
- be 65 years old or older,
- have a Medicare status code 10 only (AGED without ESRD), and
- have Medicare as the primary payer.

To create a sample frame file, we used the EDB to obtain each beneficiary's name and HICNUM, as well as demographic information such as race, age, sex, and first and last names. Then, this file was appended by adding supplemental information received from plans, such as updated/verified mailing addresses and phone numbers for the beneficiaries and names, mailing addresses, and telephone numbers of up to four additional contacts that could be used for proxy responses. We used this sampling frame file to select the actual sample. However, since sample members were not randomized across specific survey implementation approaches, the interaction of site-specific characteristics (such as casemix) with survey approach could affect results. The lack of randomization limits the inferences that can be drawn about the effects of different survey approaches.

2.4 Staff Burden

In each distribution approach protocol, we asked PACE staff to track the amount of staff time it took to participate in the preliminary preparation activities and actual survey administration. PACE staff at each site participated in preparation activities, including participating in phone calls with RTI staff to determine the logistics of each distribution approach, creating a beneficiary datafile, and for Approach 3 sites, determining the appropriate respondent for the survey (either self, family, or staff). Prior to fielding the survey, we sent each site a Staff Time Log (See Appendix D1) to record the amount of time by position type (administrative, clinical, clerical, and other) spent participating in the pilot survey administration. Approach 2 and 3 sites were also sent a Survey Log, containing the date we sent the surveys to the site, to assist the site staff in tracking each survey by indicating the date each survey was distributed to the respondent, returned, and sent to NERI (see appendix D2). Each site was asked to fax the logs to NERI weekly. In addition to the site logs, the project team conducted a conference call to discuss staff burden with each PACE site at the conclusion of the pilot survey administration and solicit suggestions for minimizing burden in the future.

2.5 Data Collection Procedures

NERI determined a standard procedure for survey implementation. Initially, NERI sent a prenotification 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. NERI fielded the survey in several batches beginning in March and ending in July of 2002. Please see Appendix B for a detailed description of the approach-specific procedures and Appendix E for general survey procedures used by NERI for this study.

2.6 Medical Record Comparison Analysis

PACE organizations maintain medical records for each of their enrollees. These records include nursing staff assessments of the beneficiary's need for assistance in ADLs at the time of PACE enrollment and are updated periodically. The ADL assessments are used to determine care needs that PACE provides or arranges, such as whether help is needed to dress, bathe, etc. Further assessments are conducted by rehabilitation therapists and physicians regarding any potential for improvement, but the focus is on underlying pathology, not the level of ADL. We compared MHSPE survey responses with the nursing ADL assessments to evaluate whether these sources differ and to compare the differences across approaches. We also wanted to determine if the consistency of the responses differed significantly by approach.

The level of ADL impairment for each beneficiary was available from most sites electronically, using similar assessment instruments. One small Approach 3 site did not have this data available electronically. For that site, RTI staff abstracted the information directly from each beneficiary's medical record and entered the information into a data file.

2.7 Nonresponse Analysis

As medical record information was available for both survey respondents and nonrespondents, we were also able to use this data to evaluate potential nonresponse bias. Using this data, we compared mean number of ADL impairments, individual ADL impairments, and categorical ADL impairment levels for survey respondents and nonrespondents.

2.8 Estimation of Response Rates

Historically, PACE organization response rates to the HOS have ranged from about 30 to 60 percent. Since we were measuring the effect of each approach on response rates, we needed to control for known site-to-site differences in response rates. One way would have been to use multiple approaches in each site, or to use multiple sites for every approach. However, we were constrained to use only one approach per site for logistical and budgetary reasons. Specifically, the training needs of various site staff to accommodate more than one approach per site would have created additional burden for the sites, and there was a risk of spillover effects from one approach to another within the same site. To address this issue we selected individual PACE plans that had similar response rates to the HOS, suggesting that the response rates to the MHSPE would be similar if the same data collection approach were used.

SECTION 3 SURVEY FINDINGS

In this section, we report findings regarding the PACE pilot sites' response rates (unit and item), health and functional status as reported by survey respondents, the role of proxies in completing the surveys, and burden on the individual PACE plans participating in the pilot. These analyses are reported by survey distribution approach. In addition, we compare results by respondent type (self, family, or health professional)—overall and by survey distribution approach. The comparison between the survey findings and information in the medical records are reported in Section 4. Because the instrument has elements in common with the HOS, the data reported here may also be used in the future to compare PACE enrollees to the general population of beneficiaries enrolled in regular M+C plans.

In the course of this project, we decided to focus on impairments in Activities of Daily Living (ADLs) as the most likely measure to be used for payment adjustment. For completeness, we show the descriptive results for all of the health status variables in the MHSPE but provide additional detail regarding ADL impairments, response rates, and the role of proxies.

3.1 Survey Results

3.1.1 Response Rates

We calculated both survey (i.e., unit) response rates and item response rates. Table 2 shows the survey response rate by approach, calculated in two ways. The first definition reports the percentage of eligible sample members who answered at least one question of the health status items in the survey (items 1-16). This more liberal response rate is useful for understanding what proportion of the sample responded at all, and provides the denominator for various item response rates. The second definition is more conservative. Sample members are only considered respondents if they or their proxies responded to all of at least the following items, which were (at one time) under consideration for payment adjustment: difficulty lifting 10 pounds, difficulty walking two to three blocks, difficulty ratings for each of the six Activities of Daily Living, receipt of help for each of the six Activities of Daily Living, and bladder incontinence.¹ The denominator for each approach was the total sample minus ineligible, whereas in other tables we use the number answering the required risk adjustment items as the denominator.

Using the more stringent definition (the minimum required items), Approaches 1 and 2 yielded similar response rates of close to 70 percent, while Approach 3 was clearly higher, at 86 percent. As shown, most who responded to any of the health and functional status questions responded to all of the items under consideration for payment adjustment. In addition, every approach generated a higher response rate than did the HOS for PACE participants. We attribute the improvement over the HOS response rates to several things, including a substantially shorter and more targeted survey instrument, the up-to-date contact information provided by the sites

¹ Other items in the MHSPE have been used in survey-based risk adjustment models, such as the health conditions and self-rated general health, and hence were included in this survey. However, at the time of these analyses, these items were not considered as the best candidates for payment adjustment

(including detailed information about proxy contacts for each individual), NERI’s aggressive telephone follow-up (particularly in Approaches 1 and 2), and the enlistment of PACE staff in Approach 3 to identify the appropriate respondents and serve as proxies.

Table 2
PACE analysis: Response rates by approach

	Approach 1	Approach 2	Approach 3
Sample Size	379	327	222
	%	%	%
Respondents to at least 1 health status question	72	73	89
Respondents to potential risk adjustment questions	67	68	86

NOTE: The Minimum required questions necessary to be counted as a respondent included survey questions 10, 11, 12, 13, 16 (lifting 10 pounds, walking two to three blocks, ADL difficulties, ADL help, and urinary incontinence).

Table 3 shows the distribution of respondent types for the entire PACE sample and across survey distribution approaches for those answering the minimum required questions. In the PACE sample as a whole, 26 percent of the sample members responded themselves, 46 percent had family proxies, and 28 percent had health professionals serving as proxy respondents. In addition, there was substantial variation in respondent type by approach. The percentage of beneficiaries who answered the survey independently was similar in Approaches 1 (29 percent) and 2 (35 percent) but much lower in Approach 3 (9 percent) where staff predetermined who was cognitively able to complete the survey themselves and where there were many non-English speaking enrollees. In one of the Approach 3 sites, 32% of those for whom proxies responded could not speak or read English; 15% in the other Approach 3 site. In comparison, only 7% and 11% of the Approach 1 and 2 sites, respectively, responded by proxy for this reason (not shown). Variation in the kind of proxy is also evident across the three approaches. Forty-four percent of respondents in Approach 1 were family proxies, compared to 54 percent in Approach 2 and 36 percent in Approach 3. Health professional proxies included PACE center staff (most often social workers) or paid caregivers such as assisted living or adult foster home providers. These proxies represented a quarter of all respondents in Approach 1, and over half in Approach 3, but only represented 8 percent of respondents in Approach 2. The greater number of health professional proxies in Approach 1 compared to Approach 2 may reflect a higher proportion of participants living in assisted living facilities, adult foster homes, or other congregate living arrangements among Approach 1 enrollees so that telephone follow-up calls reached facility staff rather than family members.

Table 3
PACE analysis: Respondent types by approach

	Total sample	Approach 1	Approach 2	Approach 3
Sample Size	691	266	231	176
Respondent:	%	%	%	%
Self	26	29	35	9
Family	46	44	54	36
Health Professional	28	25	8	53

Table 4 shows response rates to subcategories of survey items for the sample as a whole and by respondent type. Of the 708 respondents who answered at least one item on the survey, only 62 percent answered all of the health status questions (items 1–16 of the survey), nearly 80 percent responded to all the SF-12 component items, and 96 percent answered all of the ADL difficulty questions needed to calculate the mean number of ADL impairments. Clearly, the response rate was higher for all items when the respondent was a health professional. In debriefing discussions held with the sites at the end of the pilot, PACE staff reported that respondents had the most trouble responding to the medical conditions list. In this series of questions, respondents are asked “Has a doctor ever told you that you have” and then a series of health conditions are listed and responded to individually. Not only was this item difficult for the PACE enrollees themselves to answer, but professional proxies often had to consult the medical record to answer this series.

Table 4
PACE: Item response rates by respondent type

	Total sample	Respondent Type		
		Self	Family	Health professional
Sample Size	708	180	320	191
Mean # of All Health Status Questions Answered	14.9	14.8	14.6	15.6
	%	%	%	%
% with all Health Status Questions Answered	62	62	57	75
% responding to all SF-12 items	78	77	73	92
% with Overall Health, Other Impairments, & ADL Difficulty Questions Answered	91	87	90	98
% with Overall Health, Other Impairments, & Complete ADL Series Questions Answered	85	82	81	96
% with ADL Difficulty & Walking 2-3 Blocks Questions Answered	95	93	95	99
% with all parts of ADL Difficulty Question Answered (Question 11)	96	95	96	99

Table 5 shows similar results by approach, rather than by respondent type. Approach 3 yielded the highest item response rates (e.g., 15.5 items), with Approach 1 performing slightly better than Approach 2 (e.g., 14.6 items). Again, this table is based on the population of 708 respondents who answered at least one question.

Table 5
PACE: Item response rates by approach

	Approach 1	Approach 2	Approach 3
Sample Size	272	239	197
Mean # of All Health Status Questions Answered	14.6	14.6	15.5
	%	%	%
% with all Health Status Questions Answered	56	59	75
% with SF-12 score	72	77	89
% with Overall Health, Other Impairments, & ADL Difficulty Questions Answered	90	87	98
% with Overall Health, Other Impairments, & Complete ADL Series Questions Answered	81	81	95
% with ADL Difficulty & Walking 2-3 Blocks Questions Answered	96	92	98
% with all parts of ADL Difficulty Question Answered (Question 11)	97	94	99

3.2 Health Status

SF-12 Scores—The physical and mental component scores of the SF-12 range from 0–100 with a score of 100 representing perfect health. Table 6 shows SF-12 scores based on our survey results. We were able to calculate scores for 78 percent of the respondents. The mean Physical Components Score (PCS) of the total sample was 30.4 with a range of 27.7–31.9 across all sites. The mean Mental Components Score (MCS) was 43.9 with a range of 42.5–45.1 across all sites.

Table 6
PACE: SF-12 Scores

	<u>Mean</u>	<u>(Range)</u>
Sample Size	559	
Mean Physical Components Score (PCS)	30.4	(27.7-31.9)
Mean Mental Components Score (MCS)	43.9	(42.5-45.1)

Table 7 shows the age distribution for the PACE participants for whom we were able to calculate SF-12 scores. The mean age of females is older than that of males, and more females responded than males. This is indicative of the predominately female PACE population.

Table 7
PACE: Age by gender

		<u>Mean</u>	<u>(Range)</u>
Sample Size		559	
Mean age males	n=147	77.90	(56-95)
Mean age females	n=412	82.1	(56-103)

3.3 Difficulty in Activities of Daily Living

In Tables 8 and 9, we focus on the items that will be used for frailty adjustment in 2004, the ADL impairments. In the total sample, the mean number of ADLs that beneficiaries have difficulty doing or are unable to do without special equipment or help from another person is 3.7.² The mean number of ADL difficulties reported differ substantially by respondent type. As we expected, the self respondent group reported the least impairment, with a mean of 2.5 ADL difficulties. We expected those who had any type of proxy to be more impaired, compared to the self respondents. We found those with family proxies reporting the highest level of impairment

² The ADL series is taken from the Medicare Current Beneficiary Survey. We made minor changes in wording to adapt the questions and response options for use in a mail survey.

(mean of 4.5 ADLs), perhaps because these family caregivers were aware of the ADL difficulties experienced by their family members.

PACE is enrolling a substantially impaired population. In the total sample, 78 percent have difficulty bathing, 63 percent have difficulty dressing, 34 percent have difficulty eating, 63 percent have difficulty getting out of bed or chairs, 77 percent have difficulty walking, and 57 percent have difficulty using the toilet without special equipment or help from another person. Half of the sample has difficulty performing five to six ADLs independently.

Table 8
PACE: Difficulty in ADLs by respondent type

	All	Self	Family	Health Professional
Sample Size	708	180	320	191
Mean ADL impairments	3.73	2.54	4.47	3.70
Percent of respondents with ADL impairments:				
Types of ADL impairments	%	%	%	%
Bathing	78	51	90	84
Dressing	63	36	79	64
Eating	34	13	48	29
Transfers	63	45	76	59
Walking	77	70	84	74
Toileting	57	34	69	61
Percent of respondents by Number of ADL impairments				
0 ADLs	12	26	5	8
1-2 ADLs	20	27	13	25
3-4 ADLs	18	22	18	18
5-6 ADLs	49	25	64	49

NOTE: The percentage reported is of the number of beneficiaries who responded to the individual ADL question.

The differences across respondent groups are logical. Beneficiaries who responded to the survey themselves have fewer ADL limitations on average at least in part because they represent the least disabled of the PACE population. It is not surprising that beneficiaries whose family served as proxies are the most impaired, as very impaired people participating in a community-based program would require substantial family involvement to enable participation even with the extensive types of assistance available from PACE plans.

Table 9 presents ADL impairments by approach. There are fewer differences across approaches than across respondent groups; for example, the mean number of ADL difficulties are all between 3.6 and 3.9. The observed differences by approach likely reflect underlying case mix differences across the participating sites; however, they may also be due to differences in response rates across approaches.

Table 9
PACE: Difficulty in ADLs by approach

	Approach 1	Approach 2	Approach 3
Sample Size	272	239	217
Mean ADL difficulties	3.89	3.57	3.69
Percent of respondents with ADL impairments			
Types of ADL difficulties	%	%	%
Bathing	82	72	80
Dressing	64	60	65
Eating	35	35	29
Transfers	67	57	63
Walking	80	77	74
Toileting	59	53	59
Percent of respondents by Number of ADL difficulties			
0 ADL	11	14	10
1-2 ADLs	17	21	25
3-4 ADLs	19	19	16
5-6 ADLs	52	46	50

NOTE: The percentage is based on the number of beneficiaries who responded to the specific question.

Table 10 shows a summary of ADL impairments for the entire PACE sample. The mean number of ADL impairments is 3.7 (using difficulty to define impairment). Only 12 percent report zero ADL difficulties, while 49 percent report five to six ADL difficulties. We also looked at the mean number of ADLs with which respondents used special equipment or help (not shown), following the measurement convention in the MCBS. In the MCBS, only those who indicate they have difficulty or are unable to perform an ADL are asked about the use of special equipment or receipt of help with that ADL. While we did not format the survey with a similar skip pattern, we achieved the same result by tabulating use of equipment or receipt of help only

for respondents who first indicated they had difficulty with or were unable to do each ADL. Using this approach, respondents reported a mean use of special equipment for 2.0 ADLs, and received help with 2.7 ADLs.

Table 10
PACE: ADL summary

	<u>Difficulty</u>
Sample Size	682
Mean # of ADL impairments	3.73
	%
Number of ADL impairments	
0 ADLs	12
1-2 ADLs	20
3-4 ADLs	18
5-6 ADLs	49

3.4 Clinical Diagnoses

The MHSPE instrument includes the clinical condition list from the MCBS item, which begins, “Has a doctor ever told you that you had...” While this question does not provide an exhaustive list of medical conditions, the item attempts to capture major diagnoses prevalent in the older population. The list was included in the MHSPE as a potential alternative or supplement to plan-reported diagnostic information based on earlier work comparing alternative risk adjustment models (Pope et al., 1998). CMS has since dropped these variables from further consideration and from future versions of the MHSPE instrument (in part because diagnosis data are being collected for PACE enrollees and because of difficulties reported by proxy respondents in this pilot study discussed under Site Burden later in this section). As illustrated in Table 11, the majority of the PACE population sampled has arthritis and has heart disease, nearly half report having been depressed, and about 40 percent have Alzheimer’s Disease or other dementia. A third of the sample has had a stroke and a quarter has diabetes. These rates are substantially higher than those in the general Medicare population. Analyses of the MCBS find only 14 percent of the general Medicare population reporting strokes and 17 percent reporting diabetes (RTI analysis of the MCBS data). Eighteen percent of the respondents reported having a hip fracture and 15 percent have some degree of paralysis.

Table 11
PACE: Has a doctor ever told you that you had...

	Yes	Missing
Percentage of respondents whose physician has told them that they have:	%	%
Arthritis	61	8
High blood pressure or hypertension	52	9
Depression	46	9
Alzheimer's or other dementia	39	7
Stroke	32	9
Diabetes	27	8
Angina	21	10
Congestive heart failure	16	10
Heart attack or myocardial infarction	13	11
Other heart conditions	21	11
Emphysema, COPD, asthma, chronic bronchitis	18	10
Hip fracture	18	9
Paralysis	15	8
Parkinson's disease	5	9

NOTE: The “Missing” column displays the item nonresponse rate for each condition. Each row does not add up to 100% as the percentage who answered in the negative to each condition is omitted from the table.

3.5 Other Impairments and Conditions

Table 12 includes other impairments associated with increased risk for Medicare costs (lifting, walking two to three blocks, and incontinence) and a question about cognitive function included as a descriptor of the PACE population. In addition to their potential use for risk adjustment, impairments in lower body function (e.g., lifting, bending/kneeling/stooping and walking two to three blocks) are risk factors for future ADL impairment and hence useful population descriptors. For each item, the denominator includes only those who responded to that item. Hence the denominator varies from item to item. Had every respondent who answered any one of these questions responded to all of them, the denominator of the total sample would have been 708.

As seen in Table 12, over half of those responding to this question (n=674) reported memory loss which interferes with daily activities, 44 percent suffer from daily bladder incontinence (n=683), about 90 percent have difficulty walking 2-3 blocks (n=696), or lifting or carrying 10 pounds (n=675). Eighty-four percent have difficulty bending, kneeling, or stooping, and half the sample indicated that they have fair or poor health compared to others their age. Consistent with the ADL ratings, self respondents reported a higher level of physical function

Table 12
PACE: Other impairments and conditions, by respondent type

	Total Sample	Self	Family	Health Professional
Q8 In general, compared to other people your age, would you say that your health is...	n=669	n=167	n=299	N=189
	%	%	%	%
Excellent	4	5	4	3
Very good	11	17	8	10
Good	31	36	21	43
Fair	31	31	35	26
Poor	23	11	32	17
Q9 How much difficulty, if any, do you have lifting or carrying objects as heavy as 10 pounds, such as a sack of potatoes?	n=675	n=166	n=306	N=190
	%	%	%	%
No difficulty at all	8	17	3	7
A little difficulty	8	11	6	8
Some difficulty	11	20	8	8
A lot of difficulty	16	18	16	15
Not able to do it	57	34	67	62
Q10 How much difficulty, if any, do you have walking a Quarter of a mile—that is about 2 or 3 blocks?	n=696	N=175	n=317	N=191
	%	%	%	%
No difficulty at all	7	14	4	7
A little difficulty	8	13	4	9
Some difficulty	14	17	11	16
A lot of difficulty	15	18	16	12
Not able to do it	56	38	65	57

Table 12 (continued)
PACE: Other impairments and conditions, by respondent type

	Total Sample	Self	Family	Health Professional
Q15 Do you experience memory loss that interferes with daily activities?	n=674	N=171	n=301	N=187
	%	%	%	%
Yes	59	27	73	66
Q16 How often, if ever, do you have difficulty controlling urination (bladder accidents)?	n=683	n=178	n=304	N=189
	%	%	%	%
Never	25	34	17	29
Less than once a week	16	25	10	16
Once a week or more often	15	15	18	11
Daily	43	25	54	43
*Catheter	1	1	0	1

NOTE: Percentages may not sum to 100 due to rounding.

*Not a response option; added when respondents wrote in “catheter” or told telephone interviewer they had a catheter.

than those for whom the survey was completed by proxies. Among proxy respondents, family proxies reported the lowest level of physical function. For example, 73 percent of beneficiaries who had family proxies indicated that the beneficiary had memory loss which interfered with daily activities (n=301), whereas only 27 percent of self respondents reported this impairment (n=171).

3.6 Analysis of the Use of Proxies

Overview—Due to the high levels of cognitive impairment and other factors that might preclude PACE participants from responding to the MHSPE themselves, proxies responded on behalf of many of the PACE participants. The MHSPE protocol permitted proxy respondents, including family members or friends and paid caregivers including PACE staff. However, to compare the rate and nature of proxy respondents across approaches and to understand the roles of proxies in completing the MHSPE, we included a series of questions regarding proxy respondents in the survey instrument. These items included:

- whether a proxy responded to the survey,

- why a proxy responded to the survey,
- the nature of the help provided by the proxy, and
- the relationship of the proxy to the sample member.

We also asked paid caregivers or health professionals serving as proxies how they came to serve as a proxy respondent to the MHSPE. Paid caregivers or health professionals serving as proxies included both PACE plan staff (e.g., social workers or nurses) and others providing care for the participants in their homes or in alternative settings such as adult foster homes, residential care facilities, assisted living facilities, or nursing facilities.

One goal of the proxy analysis was to determine the proportion of professional proxies under each approach and to determine the proportion of these that are PACE staff proxies. A smaller proportion of PACE proxies is considered preferable for several reasons. First, proxies in the MCBS community sample, with which the relationship of frailty measures to costs have been calibrated, are assumed to be family members or friends, not clinicians or other professionals. Second, staff serving as proxies is one element of burden for the sites, so lower rates of PACE staff serving as proxies is also desirable. Finally, PACE staff may be perceived as having an incentive to code to a higher level of frailty since the frailty level of respondents will drive the payment.

There are several ways proxies may have been identified and have responded to the MHSPE. In each of the approaches, but especially Approach 1 or 2, the beneficiary may have received the survey and passed it on to a family member or caregiver. In addition, the mailing information provided by the PACE plans included individuals whose mail is routinely sent to a family member, for example, to Mrs. Jones in care of Daughter of Mrs. Jones. In these instances, the proxy might actually have received the mailed survey directly. In the telephone follow-up process, for those who had not responded to the survey by mail or who provided incomplete responses, both family and professional caregivers might either answer the telephone for the beneficiary or be contacted at another number after unsuccessful attempts were made to reach the beneficiary by telephone. By this route, non-PACE professional caregivers came to serve as proxies, for example, adult foster home providers. Under Approaches 1 and 2, PACE staff would only serve as proxies at the request of the beneficiary, family, or other caregiver.

Under Approach 3, PACE staff predetermined the appropriate respondent to the survey. Any beneficiary capable of responding was assigned to the self-respondent group. Those who could not respond for themselves, either due to impairments or language barriers, were sorted into those who had knowledgeable family members who could serve as proxies and those who did not—in which case the PACE program staff served as proxies. PACE staff might also serve as proxies under this approach if the beneficiary or family members asked them to.

Findings—Seventy-four percent of all survey responses involved someone other than the beneficiary. Tables 13, 14, 15, and 16 provide details about proxy respondents. As seen in Table 13, most proxies assisted in completing the survey because the beneficiary was unable to answer questions due to physical (48%) or mental (63%) problems.

To help understand the role of proxies during the pilot, the survey included a question about the type of help that was provided by proxies. Possible responses included the following: reading the survey to the individual; recording the individual’s own responses; using the medical record information; or using the proxy’s own knowledge of the individual. Proxies were instructed to indicate all that applied, so the response options are not mutually exclusive. As seen in Table 14, proxies wrote down the respondent’s own answers (to at least some of the items) 27 percent of the time; proxies used their own experience in 75 percent of the cases, and consulted the medical record in 18 percent.

Table 13
PACE: Reasons for proxy respondents

Reasons for proxy respondent	<u>n=500</u> %
Physical problems	48
Memory loss or mental problems	63
Unable to speak or read English	13
Subject not available	2
Subject’s request	18
Other	2

NOTE: Reasons are not mutually exclusive.

Table 14
PACE Proxies: How did you help complete the survey?

Proxy assistance provided	%
Read the questions to the subject	33
Wrote down the subject's answers	27
Answered based on experience	75
Used medical record	18
Translated the survey questions	4

NOTE: Responses are not mutually exclusive.

Finally, Table 15 shows why a professional served as the proxy instead of family members. In over 60 percent of cases, family members were not available or able to serve as proxies, and in 26 percent, the PACE participant asked a professional to complete the survey.

Table 15
PACE: Why did a professional complete the survey?

Reasons for professional as proxy	%
Subject's request	26
Family members not familiar with subject's health	20
Family members could not be reached, or none available	42
Family members declined	3
Other	18

NOTE: Responses are not mutually exclusive.

3.7 Plan Burden

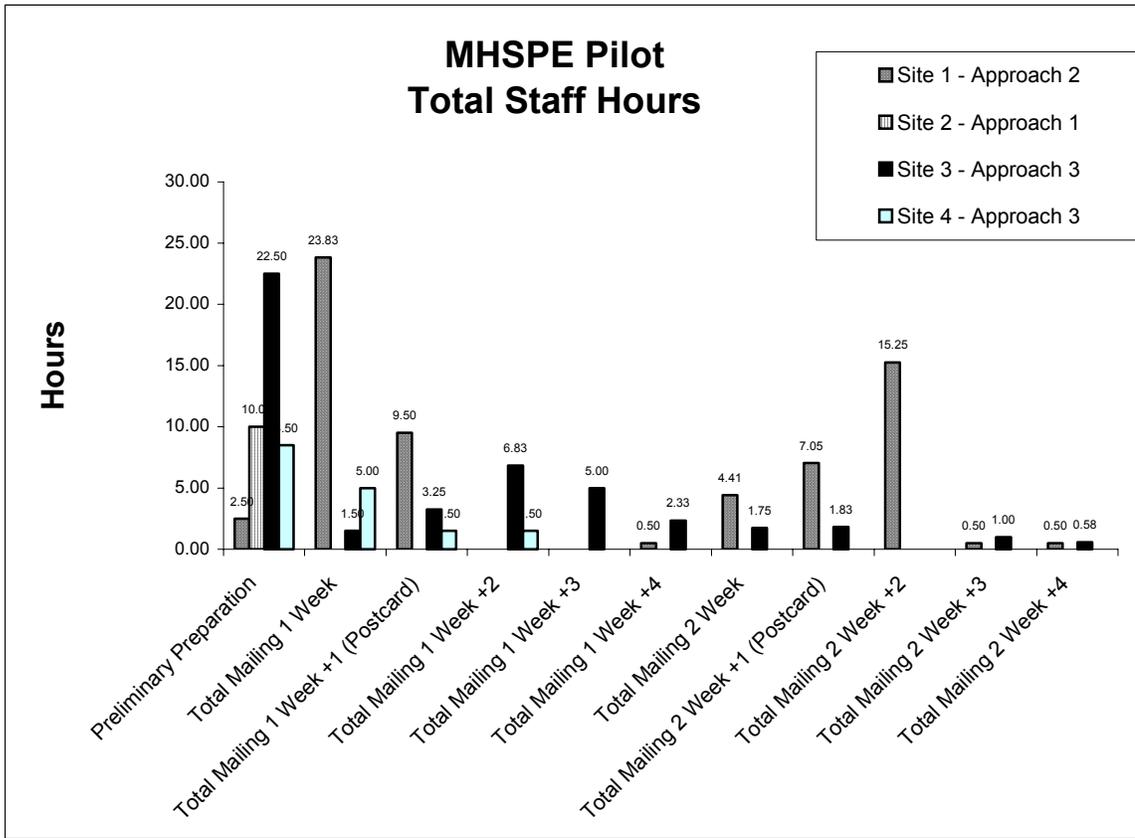
One goal of this pilot was to identify and compare the burden on PACE plans associated with each survey distribution approach. There were a few types of burden that sites experienced with the administration of the MHSPE. Plans spent time preparing the datafile with participant and family contact names, addresses, and telephone numbers. Survey administration activities were another potential source of burden, varying by approach. Finally, there was burden associated with site staff helping participants complete the survey or serving as their proxies.

3.7.1 Reported Preparation Time

In Figure 1, we show the staff time each site reported spending on activities related to this pilot. Staff involvement occurred in two general categories: (1) preliminary preparations for the survey (i.e., data file creation and conference calls with RTI staff) that were required of all sites regardless of approach; and (2) tasks associated with the actual survey distribution and assistance with survey completion which did vary by approach. The burden associated with data file creation, while no different by approach, did vary by site due to differences in their respective information systems and the size of the site. For example, one site reported minimal preliminary preparation time (2.5 hours) as the data technician at that site could easily export the contact information into a readily usable format. Another site spent 10 hours on these tasks and on developing and distributing information to the PACE center staff, assisted living facility personnel and adult foster home providers to increase awareness of the survey and encourage survey assistance or completion if asked by a beneficiary.³

³ This site's contact information arrived in an unusable format requiring RTI staff to enter all the data by hand. Considering this was a large site (500 participants) this was a considerable burden to RTI (requiring about 40 hours of data entry). In the future, the burden would fall on each site to ensure the data file was in the proper format.

FIGURE 1



Reported staff time prior to survey administration was considerably higher for the Approach 3 sites since they were required to determine the appropriate survey respondent for each beneficiary before the surveys were sent to the sites. One of the Approach 3 sites reported nearly 23 hours in these activities, whereas the second Approach 3 site reported 9 hours in staff time, even though each site was quite small. This difference between the two sites is at least in part due to the greater number of participants in one of the sites and the involvement of more staff who had to be oriented to the protocol as well as applying it to determine the appropriate respondents.

3.7.2 Reported Survey Administration Time

The Approach 1 site staff reported no staff time in any survey activities once the actual survey administration began. To our knowledge, no staff members at the PACE site were approached regarding the survey or asked to help complete it, making this the least burdensome approach for PACE staff overall.

As noted in Figure 1, the first week of the survey administration was most intense for the Approach 2 site since the postcards and survey packets arrived at one of the three centers, requiring nearly 24 hours in staff time to appropriately sort the survey materials and deliver them to the appropriate center. In the second mailing, we presorted all materials by center, therefore decreasing the amount of distribution time in this approach.

The Approach 3 sites reported less time overall than the Approach 2 site, partly because of the higher sample size at the Approach 2 site as well as the fact that the Approach 3 sites had only to distribute a segment of the sample since a large portion of the surveys at each site were sent directly to family members assigned by the site as proxies. Again, due to the smaller size of one of the Approach 3 sites, there was higher reported staff time required in fielding the survey in the larger Approach 3 site.

3.7.3 Burden on Staff Serving as Proxies

Actual survey completion did not appear to be overly burdensome for the pilot sites. Few beneficiaries asked for assistance in Approach 2, therefore most of the staff time reported on the log was time spent sorting and distributing surveys and not necessarily completing them. Approach 3 sites reported taking about 10 minutes of staff time per case to complete or help complete each survey and noted that they were able to incorporate it into the daily activities of the program.

Summary

Overall, Approach 1 was the least burdensome on PACE staff (see Table 16). Beyond creation of the datafile and ongoing communication with RTI staff, Approach 1 imposed no burden on the PACE staff. The burden for Approach 2 was roughly 10 minutes for each beneficiary in the sample. The burden for the two organizations that participated in Approach 3 was 10 minutes per beneficiary and 16 minutes per beneficiary, respectively, for a weighted average of 14 minutes.

Table 16
Burden on PACE staff

<u>Approach</u>	<u>Total Staff Time to Categorize the Sample</u>	<u>Total Staff Time to Distribute Surveys</u>	<u>Total Staff Time to Serve as Proxies</u>	<u>Staff Time per Sample Member</u>
Approach 1 (sample=419)	0	0	0	0 minutes
Approach 2 (sample=372)	0	61 hours	1.5 hours	10 minutes
Approach 3 (site A, sample=71)	4 hours	0	8 hours	10 minutes
Approach 3 (site B, sample=163)	20 hours	4 hours	19.5	16 minutes

SECTION 4 MEDICAL RECORD COMPARISONS

We compared survey responses with medical record information to determine if survey answers were consistent with health status as recorded in the medical record. If responses were not consistent, we determined whether the survey or the medical record reported a higher level of impairment. Although this analysis cannot be used to determine which method (survey or medical record) is more accurate, it does provide information on consistency across data collection approaches.

Survey and medical record information may differ for two main reasons. First, the survey questions are worded differently than the medical record assessment. The survey (which is designed to measure health status) defines ADL impairment based on whether or not the respondent reported having difficulty or is unable to perform a task, “without special equipment or the help of another person”. In the medical record (which is designed to support care planning), impairment is defined based on whether the person “needs” the help of another person or uses an assistive device. Second, there are differences in how various types of respondents might interpret each activity of daily living and what constitutes having difficulty with that task. Medical record data completed by nurses or rehabilitation therapists is based on clinical definitions that can differ from how beneficiaries, their families, and even other professionals such as social workers, interpret an everyday task. For example, an eating impairment is clinically defined by a wide range of needs for assistance. This includes the need for cueing or supervising an individual who might not remember to eat or needs to be kept on task, and special food preparation such as blending the food or cutting it into small pieces to allow the person to self-feed. However, most survey respondents define eating more narrowly, and would only indicate an impairment if the beneficiary required feeding by another person, tube feeding or other special methods.

Therefore, there will be some discrepancies between the MSPHE and the medical record under any approach. Regardless of which is “correct,” i.e., self-report or clinical assessment, analyses linking ADL status to Medicare costs are calibrated based on self-reported responses to the MCBS; hence, any inaccuracies in the clinical accuracy of these self-reports are not important for the development of frailty adjusters based on survey data.

We had two conflicting hypotheses about frequency of ADL impairments in the survey compared to the medical record. Depending on the respondent-type (i.e., self vs caregivers or types of proxies) and individual interpretations for each ADL:

- 1) “Need” for assistance may be defined more broadly by caregiving professionals than “difficulty” is defined by respondents. If this is true, then the medical record would show higher levels of impairment than the survey responses. As described in the previous paragraph, ratings of difficulty with eating might fall into this category.
- 2) “Need” can be interpreted as a subset of “difficulty” for those whose difficulty is severe enough to require assistance. Indeed, the MCBS structure only asks respondents about need for help if they already indicated difficulty.

Since these two hypotheses go in opposite directions, it is not clear *a priori* whether to expect the medical record frequencies by ADL impairment to be less than or greater than the survey frequencies.

In Table 17, we compare the mean number of ADLs, individual ADL ratings, and ADL categories reported in the surveys and medical records for all respondents. We define ADL impairment in the survey using the most inclusive measure: a response of “having difficulty or being unable” to perform the task without help or special equipment. This definition of impairment includes people who perform a task independently but have difficulty and those whose degree of difficulty is severe enough to require help from another person. In contrast, the medical record definition distinguishes between independence and need for help.

In general, the survey data produced slightly lower rates of impairment than found in the medical record. For example, the mean number of ADLs as reported in the survey is 3.7, compared to 4.1 in the medical records ($p < 0.01$). Looking at each ADL task separately, there are no significant differences between the survey and medical record ratings for dressing (63 percent vs. 66 percent) or walking (78 percent vs. 79 percent), substantially lower levels of impairment in ADL levels for bathing (78 percent vs. 94 percent) and toileting (57 percent vs. 72 percent), and to a lesser extent, eating (34 percent vs. 39 percent). Only difficulty with transfers are reported more often in the survey data than in the medical record data (63 percent of survey respondents compared to 58 percent in the medical record, $p < 0.01$). The cumulative effect of these differences in individual ADL ratings is evident in the distribution across ADL categories. A substantially higher proportion of survey respondents report zero ADL difficulties (12 percent) compared to their own medical records (3 percent) and fewer report three to four ADL difficulties (18 percent compared with 26 percent). However, there is no significant difference in the one to two and five to six ADL categories.

Table 17
PACE: Comparison of ADLS in the survey and medical record: total sample

	Survey Response	Medical Record
Mean # ADLs	3.7	4.1 ***
	%	%
Bathing	78	94 ***
Dressing	63	66
Eating	34	39 **
Transfers	63	58 ***
Walking	78	79
Toileting	57	72 ***
0 ADLs	12	3 ***
1-2 ADLs	20	22
3-4 ADLs	18	26 ***
5-6 ADLs	49	49

In Table 18, we compare the mean number of ADLs and the distribution across ADL categories by Approach. Different patterns are found across the three approaches. In Approach 1, the survey results indicate lower levels of impairment than the medical records for the ADL means, in the proportion reporting 0 ADL impairments, and to a lesser extent in the proportion reporting five to six ADL impairments. In Approach 2, the small difference observed in mean ADLs is not statistically significant, but there are substantial differences in the distribution across ADL categories and the pattern of differences is less consistent. For example, under Approach 2, the medical record shows fewer individuals with five to six ADL impairments (34 percent) than reported in the survey (46 percent). For the Approach 3 respondents, the medical records generally report a greater level of impairment, with the exception of the one to two ADL group in which the survey shows a greater level of impairment and the five to six ADL group in which there is no significant difference between the two.

Table 18
PACE: Comparison of ADLs in the survey and medical records by approach

	Approach 1			Approach 2			Approach 3		
	Survey	Medical Records		Survey	Medical Records		Survey	Medical Records	
Mean # ADLS	3.9	4.3	***	3.6	3.5		3.7	4.2	***
% with Difficulty in	%	%		%	%		%	%	
0 ADLs	11	2	***	14	4	***	10	3	***
1-2 ADLs	17	18		21	33	***	25	16	***
3-4 ADLS	19	23		19	29	**	16	28	***
5-6 ADLs	52	57	**	46	34	***	50	53	

NOTE: Significance testing is between ADL measurement by survey and medical record within each Approach.

In Table 19, we evaluate the differences between these two data sources a different way, focusing on the respondent types. We report match rates, i.e., the percent of the cases in which the survey responses and medical record agree, for the sample as a whole and by respondent type (self, family, or professionals). We also identify the percent of cases in which the medical record or the survey findings report a higher level of impairment. We report the professional proxy results in two ways: for all professionals serving as proxies and among those, for those who answered the questions based only on their own knowledge of the individual or by consulting the medical record.

While the differences in mean ADLs shown in Table 17 were small, in Table 19 we see that only 36 percent of all respondents had the same number of ADL impairments in both their medical record and in the survey, ranging from only 16 percent of the self-respondents to 53 percent of the cases with professionals serving as proxy respondents relying solely on their

professional judgment or the medical record. The match rate was higher, 56 percent, when ADLs were grouped into categories (zero, one to two, three to four, or five to six), reaching 74 percent in the professional proxy group. This finding suggests that among nonmatching respondents, a significant number had medical records and survey responses that were non-matching by only one ADL.

Table 19
PACE: Match rates between survey and medical record

	Match	MR> MHSPE	MHSPE> MR
ALL	%	%	%
ADL Count	36	40	24
ADL Categories	56	28	16
SELF			
ADL Count	16	58	26
ADL Categories	35	48	17
FAMILY			
ADL Count	46	28	27
ADL Categories	65	17	19
PROFESSIONALS			
ADL Count	40	43	18
ADL Categories	62	28	10
HEALTH PROFESSIONAL (using medical record or their own knowledge only)			
ADL Count	53	32	15
ADL Categories	74	17	9

Where cases do not match, the medical record more often reports a higher level of impairment than the survey. However, nonmatches between family proxy-reported ADL impairment and the medical records were evenly divided between those reporting higher or lower levels of impairment compared with the medical record.

Because we had expected the match rates to be higher for health professionals, especially when relying on their own judgment or the medical record, we asked the plans to investigate what might have accounted for the differences observed. The PACE plans reported that the professional proxies were most often non-PACE staff (such as adult foster home providers or

staff at other types of congregate housing facilities) or PACE center social workers, not the registered nurses who would have made the assessments in the records. Interviews with PACE social workers provided some insight into why their assessments might be different from those in the medical record. The differences appear to be related to using a more “colloquial” interpretation of function rather than the standard definitions of ADL impairments. For example, while the clinical definition used by nurses to rate difficulty in eating would include the need for cutting, individuals, family members and other staff would rate a person who is able to self-feed as independent.

To understand more about the relationship between the survey responses and the medical record information, we analyzed the correlation between ADL ratings between the two data sources. Using the frailty adjustment categories of 0, 1-2, 3-4 and 5-6 ADL impairments, we compared the results in each category as shown in Table 20. In Table 21, we report the correlation coefficients for the sample as a whole and by respondent type. The columns in Table 21 are based on the survey ADLs. The rows are defined by the information noted in the medical records. For example, for those whose survey responses showed 5-6 ADL impairments, 2 had 0 ADL impairments noted in their medical records, 25 had 1-2 noted in their medical records, 46 indicated 3-4, and 244 (or 77 percent) had 5-6 ADL impairments noted in their medical records. Thus we see that the extent of match is highest among the most impaired.

Table 20
Comparison of ADL counts based on surveys and medical records

ADLs from Medical records	ADLs from Survey				Match as % of <u>row total</u>
	<u>0</u>	<u>1 to 2</u>	<u>3 to 4</u>	<u>5 to 6</u>	
0	9	4	1	2	56.3
1 to 2	36	52	22	25	38.5
3 to 4	21	46	49	46	30.2
5 to 6	7	21	44	244	77.2
Match as % of column total	12.3	42.3	42.2	77.0	

Marks matching records

Table 21 shows correlation coefficients for the sample as a whole and by respondent type between the medical record ADLs and the survey-reported ADLs, coded as continuous variables 0-6. As seen in the table, the ADL ratings from the two data sources are moderately correlated. The correlation between the two for all respondents is about 0.61, ranging from 0.44 for the self respondents to 0.68 for the professionals serving as proxies.

Table 21
Correlation between ADL counts reported in the survey and medical records by type of respondent

	Pearson Coefficient (p-value)
Total sample (N=629)	0.606 (<0.0001)
Self-respondents (N=154)	0.436 (<0.0001)
Family proxies (N=282)	0.588 (<0.0001)
Professional proxies (N=181)	0.676 (<0.0001)

4.1 Regression analysis

In an attempt to explain the cause of nonmatching between the survey and medical record, we performed a regression analysis (results shown in Table 22), including age, gender, underlying health status as defined by ADL impairments from the medical record, approach, respondent type, and “lag time” as predictors of match. Lag time refers to the number of days between the survey response and the latest available medical record data.

Respondent types and increasing ADL impairment were the strongest predictors of match between the survey and medical record. Compared to self respondents, family respondents were more than three times as likely to report ADL impairments matching those in the medical record, and health professional respondents were two and a half-times more likely to produce matching results.

Compared to those with five to six ADL impairments (as reported in their medical records) lower levels of impairment (i.e., three to four and one to two ADLs) decreased the likelihood of the survey and medical record matching. Having zero ADL impairments was not a significant predictor or match.

Contrary to expectations, greater lagtime was associated with increased match, for those with a lag of greater than 90 days, although this finding is only marginally significant. We found no significant differences in any of these measures.

Although we observed differences in match rate by approach when we looked at the descriptive data, this finding did not hold up in the multivariate model. As shown in the table, there was no significant impact on match associated with the survey distribution approach. In

summary, only respondent type and functional status were significant predictors of match in this model.

Table 22
PACE: Logistic model estimating ADL matching

<u>Parameter</u>	Odds Ratio (95% Confidence Interval)	
Gender		
Male	Omitted	
Female	1.17	(0.76-1.80)
Approach		
Approach 1	Omitted	
Approach 2	0.90	(0.55-1.45)
Approach 3	0.84	(0.54-1.32)
Respondent type		
Self	Omitted	
Family	3.27***	(1.94-5.52)
Health professional	2.54***	(1.41-4.58)
Lag time		
Lagtime \leq 30 days	Omitted	
Lagtime 31-60 days	1.33	(0.84-2.11)
Lagtime 61-90 days	0.75	(0.44-1.30)
Lagtime greater than 90 days	1.58	(0.93-2.68)
Number of ADLs from medical record		
5 or 6 ADLs	Omitted	
3 or 4 ADLs	0.15***	(0.09-0.25)
1 or 2 ADLs	0.25***	(0.15-0.41)
0 ADLs	1.38	(0.47-4.10)
Age		
Age 65-74	Omitted	
Age < 64	0.93	(0.31-2.79)
Age 75-84	0.61	(0.35-1.05)
Age > 85	0.75	(0.43-1.28)

SECTION 5 NONRESPONSE ANALYSIS

CMS' proposed frailty adjusters would use information from the survey respondents to determine the payment adjustment for the entire organization. If the respondents are significantly different than the nonrespondents (i.e., "biased"), then this could result in an inaccurate payment to the organization.

The purpose of the nonresponse analysis was to determine whether the nonrespondents were significantly different than the respondents on the measures that might affect payment. Data that were available for all PACE enrollees included demographic data from the Medicare Enrollment Data Base and functional status data (ADLs) from the medical records. To evaluate response bias, these data were compared for respondents and nonrespondents. For this analysis, respondents (n=679) were defined as individuals who completed all of the ADL items in the survey necessary to calculate ADL scores. Those who either did not respond to the survey at all or who responded to the survey but did not complete all of the necessary ADL items were considered nonrespondents (n=253) in this analysis.

We compared respondents and nonrespondents on age, gender, mean number of ADL impairments according to the medical record, and the distribution across ADL categories per the medical record (zero impairments, one to two impairments, three to four impairments, and five to six impairments). As ADL assessments from enrollees' medical records were used for both respondents and nonrespondents, ADLs are measured the same way for both groups. As seen in Tables 24 and 25, the "mean age" and "percent female" categories were a near match for respondents and nonrespondents, for the sample as a whole, and by approach. In the full sample, the mean number of ADLs (based on the medical records) was 4.10 for survey respondents, and 4.08 for nonrespondents. When the ADL information in the medical records was analyzed as a categorical variable, 3 percent of the respondents reported zero ADL impairments, 21 percent reported one to two ADL impairments, 26 percent reported three to four ADL impairments, and 50 percent reported five to six ADL impairments. This was almost identical to the percent of nonrespondents who reported these numbers of ADL impairments. The percentages in each category were also very close for each approach.

In summary, the nonresponse analysis shows that the characteristics of nonrespondents were very similar to those of respondents in the pilot. This suggests that the respondents accurately represent the population, and, therefore, the survey was an accurate means for measuring the health of the frail elderly population.

Table 23
PACE: Nonresponse analysis

	Respondents ¹	Non Respondents ²
Sample Size	679	253
Mean Age	81	81
	%	%
Female	73	72
Race		
Asian	1	0
Black	14	19
Hispanic	5	7
White	77	72
Other	2	1
Unknown	1	0
Mean ADL Difficulties per Medical Record	4.10	4.08
ADL Categories %		
0	3	3
1-2	21	20
3-4	26	28
5-6	50	49

NOTES:

¹ Respondents are defined as those who responded to all six ADLs

² Nonrespondents are defined as those who did not respond at all or who responded to less than six ADLs.

Table 24
Pace: Nonresponse analysis by approach

	Total		Approach 1		Approach 2		Approach 3	
	Responded to all 6 ADLs	Nonrespondent or responded to less than 6 ADLs	Responded to all 6 ADLs	Nonrespondent or responded to less than 6 ADLs	Responded to all 6 ADLs	Nonrespondent or responded to less than 6 ADLs	Responded to all 6 ADLs	Nonrespondent or responded to less than 6 ADLs
Sample Size	679	253	263	117	223	111	193	25
	%	%	%	%	%	%	%	%
Female	73	72	75	76	67	66	77	76
Race								
Asian	1	0	0	0	0	1	4	0
Black	14	19	6	11	12	21	26	44
Hispanic	5	7	0	0	9	14	6	12
White	77	72	90	88	78	62	59	36
North American Native	0	1	0	0	0	1	1	4
Other	2	1	2	0	0	2	3	4
Unknown	1	0	1	1	0	0	2	0
Mean ADL Difficulties per Medical Re	4.10	4.08	4.37	4.44	3.54	3.53	4.27	4.20
ADL Categories	%	%	%	%	%	%	%	%
0	3	3	2	0	3	7	3	4
1-2	21	20	18	15	32	29	16	16
3-4	26	28	21	30	29	27	29	20
5-6	50	49	59	56	35	37	53	60

SECTION 6 CONCLUSIONS

In this project, we fielded the MHSPE to 1,500 Medicare beneficiaries enrolled in four PACE plans and one EverCare plan. The project had two main goals:

- to pilot test the Medicare Health Survey for PACE and EverCare, and
- to compare three survey distribution approaches in order to determine the best approach for use in a national survey.

6.1 Pilot Results

Key findings

- Response rates substantially increased compared to that under the HOS for all three approaches: 68% for Approach 1, 67% for Approach 2, and 86% for Approach 3.
- We demonstrated the feasibility of achieving response rates at the a level that was simliar to the HOS response rates achieved for M+C organizations.
- The burden associated with distributing the survey and assisting with survey completion was lowest for Approach 1 and highest for Approach 3.
- The nonresponse analysis, which compared the ADL ratings from the medical records for respondents and nonrespondents, found no significant difference between the two groups.
- When we compared individuals' number of ADL impairments reported in the survey to the number of ADL impairments for the same individuals in their medical records, we found only a 36% match rate. Self or proxy reported information and that in the medical record were moderately correlated. The match rate increased to 56% based on ADL categories, i.e., 0 ADLs, 1-2, 3-4, and 5-6.⁴

6.2 Revisions to the Survey Instrument

6.2.1 Removing the conditions list

The MHSPE included the MCBS series of questions about health conditions. We had originally included this series because it has been calibrated to Medicare costs in the MCBS and had potential utility for risk adjustment. However, in debriefings with PACE staff after the survey was administered, we learned that this item was particularly difficult for PACE proxy respondents, who often needed to consult the medical record for this information. Presumably other proxies, such as adult foster home providers, might also have limited information about

⁴ Survey responses may differ from the medical record due to differences in wording or interpretation. Therefore, these results do not have direct payment implications.

medical conditions previously diagnosed but not currently active and might not have access to the medical record.

6.2.2 Removing the MCBS Self-rated General Health Item

The MHSPE included both the general health item that is part of the SF-12 and the MCBS item that has been associated with the risk of Medicare costs. This item is not currently being considered for use in risk adjustment so we dropped the MCBS version. The SF-12 items remain, as does the rest of the SF-12 to enable the comparison of health outcomes between PACE and M+C organizations.

6.2.3 Reordering the Questions

The key items for risk adjustment in the PACE Health Survey are the ADL questions, and there is still some possibility that other functional impairments, such as difficulty lifting or walking 2-3 blocks may be incorporated in future models. In keeping with survey design principles, we moved these forward to the beginning of the instrument to increase the likelihood that respondents would at least answer these questions. After consulting with the developers of the SF-12, we determined that the best placement for the functional impairments was directly after the self-rated health question.

Because of the sensitivity of questions about incontinence and memory loss, we kept those items toward the end of the survey, as we did in the MHSPE. While these items are not currently candidates for risk adjustment purposes, we kept these items as they are important descriptors of the PACE population. We also added a response option to the incontinence question to indicate use of catheters.

6.2.4 Additional Information about Proxy Respondents

The MHSPE did not ask proxies to report their affiliation and we realize that different types of professionals (e.g., nurses and social workers) might interpret ADL impairments differently. As a result, we added an item to gather additional detail about professionals serving as proxy respondents.

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

PACE STAFF

- NURSE 1
- SOCIAL WORKER..... 2
- OTHER PACE STAFF 3

NON-PACE STAFF:

- GROUP/FOSTER HOME STAFF 4
- CASE MANAGER, MEDICAL OR CLINICAL SOCIAL WORKER..... 5

6.3 Epilogue: Selection of the Approach

The purpose of the pilot test was to determine the best approach to administer the survey. Using the results of this pilot, CMS looked at a number of criteria to make this determination.

Approach 1 imposed significantly less burden on PACE. It also was the best at meeting CMS' needs with respect to the proportion and role of professional proxies. In addition, Approach 1 was the only approach that did not rely on the availability of PACE staff to help with survey distribution and collection.

Approach 2 did not perform significantly better than the other approaches on any of the criteria. Clearly, Approach 1 was superior to Approach 2.

Approach 3 yielded a higher response rate than the other approaches. However, there was no response bias under any of the approaches. Therefore, the response rates for all approaches were considered adequate for the purpose of adjusting payment. The higher response rate achieved under Approach 3 would not significantly improve the accuracy of the payments to PACE organizations while imposing a higher burden on the PACE plans. Approach 1 was as good as or better than Approach 3 (in terms of meeting CMS' needs) on all criteria.

As a result of the pilot test, CMS determined that the best approach for collecting the survey information was Approach 1.

REFERENCES

Pope, G.C., Adamache, K.W., Walsh, E.G., and Khandker, R. Evaluating alternative risk adjusters for Medicare. Health Care Financing Review. 20(2):109-129, 1998.

APPENDIX A
MEDICARE HEALTH SURVEY FOR PACE AND EVERCARE

Medicare Health Survey for PACE and Evercare

INSTRUCTIONS

This survey asks about your health. 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.
- It is important that you answer **EVERY** question on this survey. If you are unsure of the answer to a question or that the question applies to you, please answer the question anyway, choosing 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.

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

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

2. 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..... | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ |
| b. Climbing several flights
of stairs..... | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ |
| c. Climbing one flight
of stairs..... | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ |
| d. Bending, kneeling, or stooping | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ |

3. 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).

- | | NO | |
|---|---------------------------------------|---------------------------------------|
| a. Accomplished less than
you would like..... | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| b. Were limited in the kind
of work or other activities | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |

4. 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

5. 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

6. 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**:

			A		A	
			Good		Little	
	All	Most	Bit of	Some	of the	None
	of the	of the	the	of the	Time	of the
	Time	Time	Time	Time		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

7. 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 TIME2
- SOME OF THE TIME3
- A LITTLE OF THE TIME4
- NONE OF THE TIME5

8. In general, **compared to other people your age**, would you say that your health is...

- EXCELLENT1
- VERY GOOD.....2
- GOOD.....3
- FAIR.....4
- POOR5

9. 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 DIFFICULTY2
- SOME DIFFICULTY.....3
- A LOT OF DIFFICULTY4
- NOT ABLE TO DO IT.....5

10. 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 DIFFICULTY2
- SOME DIFFICULTY.....3
- A LOT OF DIFFICULTY4
- NOT ABLE TO DO IT.....5

11. 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.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
b. Dressing.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
c. Eating.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
d. Getting in or out of bed or chairs.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
e. Walking.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
f. Using the toilet.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

12. Do you use **special equipment** to help you do any of the following activities?

Special equipment includes a cane, walker, wheelchair, raised toilet seat, lift chair, grab bars, etc.

	YES, I USE SPECIAL EQUIPMENT	NO, I DO NOT USE SPECIAL EQUIPMENT	I DO NOT DO THIS ACTIVITY
a. Bathing or showering.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
b. Dressing.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
c. Eating.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
d. Getting in or out of bed or chairs.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
e. Walking.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
f. Using the toilet.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

13. 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.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
b. Dressing.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
c. Eating.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
d. Getting in or out of bed or chairs.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
e. Walking.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
f. Using the toilet.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

14. Has **a doctor** ever told you that you had:

	YES	NO
a. High blood pressure or hypertension.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
b. Angina or coronary heart disease.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
c. Congestive heart failure.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
d. Heart attack or myocardial infarction.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
e. Other heart conditions such as problems with heart valves or the rhythm of your heartbeat.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
f. A stroke.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
g. Emphysema, asthma, chronic bronchitis or COPD (chronic obstructive pulmonary disease).....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
h. Diabetes, high blood sugar, or sugar in the urine.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
i. Cancer — other than skin cancer	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
j. Arthritis.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
k. Complete or partial paralysis.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
l. Parkinson's disease.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
m. A broken hip or hip fracture.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
n. Depression.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂
o. Alzheimer's disease or dementia.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂

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

YES..... ₁

NO..... ₂

16. 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

17. Who completed this survey form?

Person to whom the survey was addressed..... ₁ **STOP HERE and DO NOT answer questions 18 and 19.**
Please return the survey. Thank you.

Family member, relative or friend..... ₂ **Please answer questions 18 and 19.**

Nurse or other health professional..... ₃ **Please answer questions 18, 19, 20, and 21.**

18. 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
-

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

READ THE QUESTIONS TO THE PERSON.....1

WROTE DOWN THE PERSON'S ANSWERS2

ANSWERED THE QUESTIONS BASED ON MY EXPERIENCE
WITH THE PERSON.....3

USED MEDICAL RECORDS TO FILL OUT THE SURVEY4

TRANSLATED THE SURVEY QUESTIONS5

OTHER (PLEASE SPECIFY BELOW).....6

FOR HEALTH PROFESSIONALS (CAREGIVERS) ONLY

20. Who decided that a health professional should complete or help to complete this survey?

PERSON TO WHOM THE SURVEY WAS ADDRESSED.....1

FAMILY OR FRIENDS2

NURSE, HEALTH PROFESSIONAL OR OTHER PLAN STAFF ...3

21. Why did a professional complete this survey instead of a family member or friend?

ADDRESSEE'S REQUEST OR PREFERENCE.....1

FAMILY MEMBERS/FRIENDS ARE NOT FAMILIAR WITH
RESPONDENT'S HEALTH2

FAMILY MEMBERS/FRIENDS DECLINED TO FILL OUT
THIS SURVEY3

FAMILY MEMBERS/FRIENDS COULD NOT BE REACHED
THERE ARE NO FAMILY/FRIENDS AVAILABLE4

OTHER (PLEASE SPECIFY BELOW).....5

INSTRUCTIONS FOR RETURNING THE SURVEY

**THANK YOU FOR COMPLETING THE MEDICARE HEALTH SURVEY
FOR PACE AND EVERCARE**

Please return your completed survey **within two weeks** to:
Medicare Health Survey for PACE and Evercare
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

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-0844. Public reporting burden for this collection of information is estimated to average 13 minutes per questionnaire, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Health Care Financing Administration, ATTN: John Burke, Department Forms Clearance Officer, Room N2-17-23, 7500 Security Boulevard, Baltimore, Maryland 21244-1850.

Medicare Health Survey for PACE and Evercare
New England Research Institutes
9 Galen Street
Watertown, MA 02472

APPENDIX B
MEDICARE HEALTH SURVEY FOR PACE AND EVERCARE PILOT
PROTOCOLS

Approach 1 Protocol

PARTICIPANT LISTS:

1. The Approach 1 PACE sites provided a data file to RTI via FedEx delivery (COD) with the following information:

For each Beneficiary enrolled in their program:

- Name, Medicare number, address and phone number - if possible site indicated if phone number is a personal or a shared (facility) number; date of enrollment in PACE and which of 4 sites, the participant attends.
 - Name, address, and phone number of a contact person (of the Beneficiary) for New England Research Institutes (NERI) to contact for follow-up in case the BENEFICIARY does not complete and return the mailed questionnaire. The contact person/(Proxy) should be the person that the site would normally contact to discuss any changes in the service plan, health status, scheduling or any other typical client needs. ***For instance, if a Beneficiary lives in foster care or in a congregate care facility, then the foster caregiver or congregate care facility staff would be the appropriate contact person/(proxy).***
 - The participant and contact information can be in 2 separate files as long as there is a unique identifying number (such as the Medicare # or PACE ID if Medicare # is not available) in both files allowing RTI to link the 2 files. The data file may be provided in any electronic format that can be put on a diskette or CD-Rom.
- RTI linked the files if applicable and (if necessary) convert them to an ASCII file format.
 2. RTI created a data file with participant information such as race, age, gender, first and last names, mailing address and phone numbers as well as contact name, address, and phone number for each participant.
 3. RTI contacted the PACE site and site staff informed RTI of any Beneficiaries/families who should not be contacted due to the Beneficiary's precarious health status.
 4. After removal of any participants identified in step 4, RTI sent the data file to NERI.

SURVEY PROCESS:

NERI sent all mailings (with site specific and CMS logos) addressed to the Beneficiary. *For those Beneficiaries with Responsible Parties (RP) as indicated in the EDB, all mailings were addressed to the Beneficiary, C/O the RP and were mailed to the RP's address.* The following data collection protocol was implemented over 3 months with production of the final data file for RTI (and CMS) within 3 ½ months:

T ₀	Mailing of the pre-notification postcard to the Beneficiary.
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T ₀ +7 days	First mailing of the personalized introductory cover letter; survey questionnaire; and a postage-paid Business Reply Envelope (BRE) . The survey questionnaires and the BRE had a unique Respondent Identification number for tracking purposes.
T ₀ +14 days	Reminder/thank you postcard sent to Beneficiary.
T ₀ +42 days	Second mailing of the personalized introductory cover letter; survey questionnaire; and a postage-paid BRE for Non-respondents only.
T ₀ +49 days	Second reminder/"thank you" postcard sent to Beneficiary.
T ₀ +56 days	NERI initiated computer-assisted-telephone-interviews (CATI) for Beneficiaries who are non-Respondents to the mailed survey component and for those whose questionnaire was returned with several "missing" datapoints. ('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 questionnaires and return it by mail; and 2) administration of the telephone interview (CATI) for those who prefer to complete the survey by telephone.
T ₀ +(56-74) days	Conducted up to 6 telephone attempts to reach the Beneficiary/Responsible Party or contact person designated by the site in the data file. These calls will be made to enlist cooperation for return of the mailed questionnaire or to complete the (CATI) telephone survey (as above).

NOTES ON SURVEY ADMINISTRATION:

- If site staff were approached by a Beneficiary, Responsible Party, (or another family member/caregiver) regarding the legitimacy of the survey, the staff confirmed the legitimacy of the survey and encouraged the Beneficiary, Responsible Party, (or another family member/caregiver) to complete the survey.
- Sites encouraged Beneficiaries, Responsible Parties or another family member/caregiver to call NERI's **toll-free** 800 number (1-800-775-6374, extension 638), if they had any specific survey questions (that site staff cannot answer).
- Site staff may have completed the survey for the Beneficiary, but **only if directly asked to do so by the** Beneficiary, Responsible Party or another family member/caregiver. If serving as a "Proxy" Respondent, staff must have been sure to fill out items 17, 18, 19, 20, and 21 of the survey.
- Completed surveys were mailed back to NERI by the Respondent in the **postage-paid** Business Reply Envelope (BRE).
- Staff time was tracked for each type of staff (administrative, clinical, clerical, etc.) involved in answering questions, assisting, and completing the survey in order to evaluate burden on staff in this approach.

Approach 2 Protocol

PARTICIPANT LISTS:

1. The Approach 2 site provided a data file to RTI via FedEx (COD) with the following information:

For each participant enrolled in their program to date:

- Name, Medicare number, address and phone number - if possible site indicated if phone number is a personal or a shared (facility) number; date of enrollment and PACE ID number.
 - Name, address, and phone number of a contact person for New England Research Institutes (NERI) to contact for follow-up in case the Beneficiary or Responsible Party (if applicable) does not complete and return the mailed questionnaire. The contact person/(Proxy) was be the person that the site would normally contact to discuss any changes in service plan, health status, scheduling or any other typical client needs. *For instance, if a Beneficiary lived in foster care or in a congregate care facility, then the foster caregiver or congregate care facility staff was the appropriate contact person/(proxy).*
 - The participant and contact information could have been in two separate files as long as there is a unique identifying number (such as the Medicare # or PACE ID if Medicare # is not available) in both files allowing RTI to link the 2 files. The data file was provided in any electronic format that can be put on a diskette or CD-Rom.
 - RTI then linked the files if applicable and (if necessary) and converted them to an ASCII file format. RTI linked the file with information from the EDB
2. RTI created a data file with participant information such as race, age, gender, first and last names, mailing address and phone numbers as well as contact name, address, and phone number for each participant.
3. RTI contacted the site and the site informed RTI of any Beneficiaries/families who should not be contacted due to the Beneficiary's precarious health status.
4. After removal of any beneficiaries identified in step 4, RTI sent the data file to NERI.

SURVEY PROCESS:

NERI sent all mailings (with site specific and CMS logos) by overnight courier directly to the contact person at the Denver site. **The site staff then hand distributed all mailings directly to the Beneficiary.** NERI also provided Federal Express packaging materials for the site to return any completed surveys (at no cost to the site). These materials were returned from the site to NERI in weekly batches.

The following data collection protocol will be implemented over 3 months with production of the final data file for RTI (and CMS) within 3 ½ months:

T ₀	NERI first sent bulk mailing of the personalized introductory cover letter; survey questionnaire; outside envelope and a postage-paid B usiness R eply E nvelope (BRE) to the contact person at the site for distribution to Beneficiaries. The survey questionnaire and the BRE
----------------	---

	<p>had a unique Respondent Identification number for tracking purposes.</p>
	<p>Site Staff followed the following steps to distribute the survey:</p> <ol style="list-style-type: none"> 1) Hand out survey materials personally to each Beneficiary at first contact with Beneficiary. 2) Confirm the legitimacy of the survey and encourage each Beneficiary to fill it out or take it home for completion by a family member or another caregiver. [NOTE: Participation in the survey is voluntary.] 3) Encourage Beneficiaries, Responsible Parties, (or other family members or caregivers) to call NERI’s <i>toll-free</i> 800 number (1-800-775-6374, extension 638), if they have any specific survey questions (that the site staff cannot answer). 4) Help Beneficiaries fill out the questionnaire if directly asked to do so. 5) Keep track of which Beneficiaries have been given the survey materials and on what date they were distributed to the Beneficiary. 6) Collect any completed questionnaires returned to the site or filled out by site staff. [NOTE These should be returned in batches to NERI in the packaging materials described in the “Overview” above.] 7) Track staff time for each type of staff (administrative, clinical, clerical, etc.) involved in distributing, answering questions, assisting, and completing the survey in order to evaluate burden on staff in this approach. <p>NOTE: If asked for help, site staff may have <i>assisted</i> the Beneficiaries in completing the questionnaire. The assistance may have included reading the questions, recording the Beneficiary’s responses on the questionnaire, translating, and explaining the questions (within the guidelines provided by RTI and NERI). If a staff member assisted a Beneficiary, they were asked to record the Beneficiary’s own answer to each survey item even if the staff member would answer the question differently. Also, if a staff member assisted the Beneficiary in completing the questionnaire, they were then considered a “Proxy” Respondent and asked to fill out items 17, 18, 19, 20, and 21 of the survey.</p> <p>Example 1 Assisting: Mr. Khatutsky is competent but does not read English. Mrs. Peasely is competent but legally blind. Ms. Liu is competent but does not speak or read English at all. In each of these cases, site staff may assist the Beneficiary <i>if s/he requests assistance.</i></p>

	<p>Example 2 Completing the survey on behalf of the Beneficiary: Mrs. Brown is moderately cognitively impaired, but can maintain a conversation and asks the staff: “Dear, I’d like to help out, but why don’t you go ahead and take care of this for me?” In this case, the staff person used his or her <i>own</i> judgement/assessment of the Beneficiary’s status and <i>completed</i> the survey accordingly. Again, please be sure to fill out items 17, 18, 19, 20, and 21 of the survey.</p>
T ₀ +42 days	NERI sent the second bulk mailing of the personalized introductory cover letter; survey questionnaire; outside envelope and a postage-paid BRE for non-Respondents only. Again, these were sent directly to the contact person at the PACE site for manual re-distribution to the Beneficiaries within 2 days of receipt of the bulk mailing.
T ₀ +56 days	NERI initiated computer-assisted-telephone-interviews (CATI) for Beneficiaries who were non-Respondents to both manually distributed surveys and for those whose questionnaire was returned with several “missing” datapoints. (‘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 served 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 telephone interview (CATI) for those who prefer to complete the survey by telephone.
T ₀ +(56-74) days	NERI conducted a specific number of telephone attempts to reach the Respondent or if unsuccessful, to reach the contact person designated by the site in the data file. These calls were made to enlist cooperation for return of the completed ailed questionnaire or to complete the (CATI) telephone survey (as above.)

Approach 3 Protocol for PACE

A. PARTICIPANT LISTS:

1. The two Approach 3 PACE sites each provided a data file to RTI via FedEx delivery (COD) with the following information:

For each Beneficiary enrolled in their program:

- Name, Medicare number, address and phone number - if possible site indicated if phone number is a personal or a shared (facility) number; date of enrollment and PACE ID number.
- Name, address, and phone number of a contact person for New England Research Institutes (NERI) to contact for follow-up in case the BENEFICIARY or other designated Respondent does not complete and return the mailed questionnaire. Please refer to instructions below for the criteria to determine if the Respondent needs/has a FAMILY PROXY. In general, the contact person/(Proxy) should have been the person that the site would normally contact to discuss any changes in the service plan, health status, scheduling or any other typical client needs. **For**

instance, if a Beneficiary lived in foster care or in a congregate care facility, then the foster caregiver or congregate care facility staff would be the appropriate contact person/(proxy).

- The participant and contact information could be in 2 separate files as long as there was a unique identifying number (such as the Medicare # or PACE ID if Medicare # is not available) in both files allowing RTI to link the 2 files.
 - ***For each participant***, sites indicated **in the data file** if s/he is the designated Respondent (CODE = “**B**”), if s/he will have a FAMILY PROXY as the designated Respondent (CODE = “**P**”), or if a PACE/EverCare STAFF person is designated as the Respondent (CODE = “**S**”). The Decision Tree (Appendix C) was used to determine appropriate contact. RTI put in the appropriate codes if the site has already created the file.
 - The data file may have been provided in any electronic format that can be put on a diskette or CD-Rom. [NOTE: An ASCII file is the preferred format.]
2. RTI linked the files (if applicable) and (if necessary) converted them into an ASCII file format.
 3. RTI created a data file with participant information such as race, age, gender, first and last names, mailing address and phone numbers as well as contact name, address, and phone number for each participant and indicated whether the Respondent should be the **B**ENEFICIARY (B), **F**AMILY PROXY (F) or **S**TAFF PROXY (S). RTI then sent this file to NERI.

APPENDIX C
DECISION TREE FOR DETERMINING THE APPROPRIATE RESPONDENT FOR EACH
PARTICIPANT IN APPROACH 3

Types of Respondents

THERE ARE THREE CATEGORIES OF POSSIBLE RESPONDENTS

- BENEFICIARY (B): The Beneficiary him or herself is the designated Respondent.
- FAMILY/CAREGIVER/RESPONSIBLE PARTY (F): A family member, caregiver, guardian or other party responsible is the designated Respondent for the participant.
- STAFF (S): A PACE or EVERCARE staff member is the designated Respondent for the participant.

The site should determine the appropriate respondent using the following criteria:

1. GOALS for determining Respondent selection:

- Accurate information, i.e. the questionnaire should be completed by someone who is capable of answering the questions in the survey with the most accuracy.
- First preference should be given to the BENEFICIARY if s/he is capable of providing accurate information.
- Secondly, preference should be given to family or other (non-PACE/EVERCARE) caregivers if the Beneficiary is not capable, but there is a family member or another caregiver who *is* capable of completing the questionnaire on behalf of the Beneficiary.
- A PACE/EVERCARE program staff member is completely acceptable as the designated Respondent, if s/he is the *only available source of accurate information*, or if the Beneficiary or Family/Caregiver/Proxy requests the staff person's help in completing the questionnaire.

2. Steps for determining proper respondent

STEP 1: Determining if the Beneficiary can be the Respondent (him/herself)

Can the Beneficiary understand the survey questions and provide accurate answers?

IF YES → The Beneficiary is the designated Respondent, even if s/he might need help reading the survey or marking his/her answers, or would need someone to verbally translate the questions. Beneficiaries who are cognitively able to complete the survey, but will need a translator should still be designated as the Respondent. **[NOTE:** Staff members who are able to translate may do so but are not required to (unless requested by the Beneficiary) and it is not necessary to recruit any outside translators.]

Beneficiaries who are designated as (SELF)- Respondents are free to refuse to participate or to ask someone else to answer for them. **[NOTE:** If staff members are asked to help, they should be sure to fill out Questions 17, 18, 19, 20, and 21.]

IF NO- go to Step 2



STEP 2: Determining if there is an *appropriate* FAMILY member or other Responsible Party to act as a “Proxy” Respondent.

Family/Friends or Responsible Parties are the only appropriate Respondents in some circumstances.

Review these questions:

- a. Does the Beneficiary have a family caregiver, friend, or other Responsible Party (such as an Adult Foster Home provider or a legal guardian)?
- b. Is that family caregiver, friend or other Responsible Party knowledgeable about the Beneficiary’s health and functional status?
- c. Is the family caregiver, friend or other Responsible Party cognitively intact him or herself?

IF YES TO ALL (a-c, above), then the “Proxy” Respondent should be the FAMILY or FRIEND or RESPONSIBLE PARTY.

IF NO TO ONE OR ALL (a-c, above), go to Step 3

↓ Example of a “NO” response to “a-c” above: Mrs. Smith is a PACE participant who has dementia, and lives with her husband, Mr. Smith. Although Mr. Smith sees her every day, he has also has dementia and could not be a reliable “Proxy” Respondent. Their children and grandchildren do not call or visit them often, and they are not up to date on Mrs. Smith’s health and functional status.

STEP 3: STAFF Respondents

STAFF RESPONDENTS are appropriate if the Beneficiary is cognitively impaired or too sick to complete the survey **AND** there is no **appropriate** Family member, Friend or other Responsible Party or the family should not be contacted due to the Beneficiary’s precarious health status. [NOTE: This is different from the HOS survey - in which staff were **only** appropriate Respondents in the **absence** of anyone else.]

It is up to the staff at the site to determine who is the appropriate staff member to serve as the Respondent “Proxy” for each Beneficiary.

[NOTE: Staff may also fill out the survey at the request of the Beneficiary or the Beneficiary’s Family or other Responsible Party.]

**APPENDIX D
DRAFT
PACE HEALTH SURVEY**

INSTRUCTIONS

This survey asks about your health. 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.
- It is important that you answer **EVERY** question on this survey. If you are unsure of the answer to a question or that the question applies to you, please answer the question anyway, choosing 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.

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.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
b. Dressing	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
c. Eating.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
d. Getting in or out of bed or chairs.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
e. Walking.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
f. Using the toilet.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> 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.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
b. Dressing	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
c. Eating.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
d. Getting in or out of bed or chairs.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
e. Walking.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
f. Using the toilet.....	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> 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? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ | <input type="checkbox"/> ₆ |
| b. Did you have a lot of energy? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ | <input type="checkbox"/> ₆ |
| c. Have you felt downhearted and blue? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ | <input type="checkbox"/> 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....
(Includes Legal Guardian)

₂ **Please answer questions 15 and 16.**

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 ANSWERS2
 - ANSWERED THE QUESTIONS BASED ON MY EXPERIENCE WITH THE PERSON.....3
 - USED MEDICAL RECORDS TO FILL OUT THE SURVEY4
 - TRANSLATED THE SURVEY QUESTIONS5
 - OTHER (PLEASE SPECIFY BELOW)6
-

FOR PROFESSIONAL STAFF (CAREGIVERS) ONLY

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

PACE STAFF

- NURSE1
- SOCIAL WORKER2
- OTHER PACE STAFF.....3

NON-PACE STAFF:

- GROUP/FOSTER HOME STAFF.....4
- CASE MANAGER, MEDICAL OR CLINICAL SOCIAL WORKER 5
- OTHER NON-PACE STAFF (HEALTH PROFESSIONAL, etc.).....6

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

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is XXXX-XXX. Public reporting burden for this collection of information is estimated to average 10 minutes per questionnaire, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Health Care Financing Administration, ATTN: John Burke, Department Forms Clearance Officer, Room N2-17-23, 7500 Security Boulevard, Baltimore, Maryland 21244-1850.

PACE Health Survey
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Watertown, MA 02472