Final Transcript

TRUVEN HEALTH ANALYTICS: January TEFT Grantee Training: Part I

January 10, 2017/11:00 a.m. EST

SPEAKERS

Teja Stokes
Mike Smith
Kerry Lida
Allison Weaver
Susan Raetzman
Elizabeth Frentzel
Coretta Mallery
Lisa Gold

PRESENTATION

Coordinator

Good day, ladies and gentlemen, and welcome to the CAHPS National Training Part Conference Call. During the presentation, your lines will remain on listen-only. [Operator instructions.] I would like to advise all parties this conference is being recorded for replay purposes.

Now, I would like to hand you over to your host today, Teja Stokes. Please go ahead.

Teja

Good morning and welcome to the Part I of the National Training Call on the CAHPS Home and Community Based Services survey. Next slide, please.

I would like to start this webinar with a few logistical points. First, please note that phone lines will be muted throughout the entire event. To pose questions for speakers, please submit them to all participants via the chat feature.

For help with any technical issues, you can use the chat feature to contact Lisa Gold, or through email at Lisa.Gold@TruvenHealth.com. Finally, this training is being audio recorded to serve as a web-based technical assistance module. In order to accommodate the recording, please anticipate a pause immediately after these announcements and prior to the question-and-answer portion of the event. Thank you. Next slide, please.

Mike

Hello, everybody, and as Teja was saying, welcome to the National Call. This is Mike Smith with the Division of Community Systems Transformation at CMCS. Welcome to Part I of the National Training on the CAHPS Home and Community Based Services survey. Next slide, please.

This section includes a brief description of the training, what we're going to do in the overview, an introduction of speakers and the survey itself and the discussion of what it is intended to accomplish. Next slide, please.

The overview of the training—there are going to be two web-based events as you can see on the slide—Part I and Part II. We're going to go over in Part I, as it states here, the need for the community based service tool, the research and development process, so you get an idea of how that it came to be and what went into it, lessons learned from that testing, and field testing as well as the endorsement of some of the measures from the survey itself.

In Part II of the presentation, which is going to be coming at a later date, we'll actually go over administering the survey and preparing and analyzing the data and state uses for the CAHPS survey.

I think this is just mentioned here how important this is in terms of we had so much material to go over, we wanted to make sure that we gave people background on the development of the tool before we just launched into administering it so that folks would have that material available to them moving forward and could understand how it was developed. Next slide, please.

I'm presenting the beginning of this presentation today. I'm Mike Smith as I stated before, and as well on the call is Kerry Lida, who's our team lead for the testing experience and functional tools demonstration. As well as Dr. Lida, we also have Allison Weaver, who's on the call today. She is a core for the technical assistance work that's going on to help us present this material today, so thank you to both of them and you'll be hearing from Dr. Lida in a minute here. Next slide, please.

In addition to our CMS staff, we have Susan Raetzman, who has helped develop the CAHPS tool with us, Elizabeth Frentzel, she also worked on the tool with us, and Coretta Mallery is on the call today. They'll be presenting some of the details around the development of the survey. Next slide, please.

Let's talk a little bit about the CAHPS survey and focusing on Home and Community Based Services. One of the things we want to talk briefly about is just the historical growth of Home and Community Based Services over time, and we thought it was important that we, as it grew to over 50% as everybody on the call is probably aware in 2013—we are now spending over 50% of the resources, expenditures for long-term services and supports are happening in the community.

We really wanted to try and develop a tool that would help states consider the possibility that they may want to look at a survey like this to improve the quality of their programs in the community moving forward. Next slide, please.

What are high-quality HCBS services? We wanted to talk a little bit about how they need to be person-centered and inclusive, sustainable and efficient as well as culturally competent. We're hoping that, in particular, that the person-centered and person-driven means that the system affords to individuals with disabilities, want to decide where they want to live and have control over their services and supports and who provides them and where they work and who would be included in their lives.

We're hoping that this survey helps us get a better picture of that individual's experience, and if you're familiar with the home and community-based rule, they even talk about the individual's experience of care and services, so we're hoping that this tool will help fulfill that survey's rationale or why we developed a tool.

In terms of person-centered effect, next slide, we want to talk a little bit about person-centeredness in terms of what that is so that people are thinking about that as we go through the presentation today and as we are thinking about developing the tool.

Person-centered thinking helps us establish the means for people to live a life that they and the people who care about them have good reason to value. We also wanted to assist people that need home and community-based services and supports to be able to describe what they want and need to bring purpose and meaning to their lives living in the community as well as person-centered practice, which really helps align the service resources to give a person full access to community integration and community living.

When we think about the experience, the care, again, the tool that we're going to be talking over the next two sessions about, it's really with this idea of person-centeredness at the focal point of what we're providing in terms of services and supports in the home and community-based setting that we bring this tool to the forefront so that we understand people's experience with the services and get the idea of what the value of those services are to them from their perspective.

Now I'm going to hand over the call to Kerry Lida. Dr. Lida is with CMS, and she's our team lead. Next slide, please.

Kerry

Thank you, Mike.

The HCBS CAHPS survey fills a critical need in long-term services and supports quality assurance because it focuses on Medicaid, the HCBS beneficiary experience outcome and quality of life as a result of receiving services and support.

What distinguishes it from other HCBS surveys is that it was designed and demonstrated with a broad range of beneficiaries through Medicaid HCBS programs, including individuals who are frail/elderly, individuals with a physical disability, individuals with an intellectual or developmental disability, individuals with a brain injury and individuals with serious mental illness. Next slide, please.

The entire development and testing process beginning in 2010 was funded by CMS under two different projects, the most recent being the demonstration grant for testing experience and functional assessment tools CAHPS in community-based long-term services and support. There's testing in HCBS programs using both fee-for-service and managed long-term services and supports.

In June 2016, it received the CAHPS trademark and was finalized. The National Quality Forum subsequently endorsed a set of measures derived from the survey.

Now I'm going to hand the next part of the presentation over to Elizabeth. Next slide, please.

Elizabeth

Thank you, Kerry. In this section, we will be discussing the research and development of the HCBS CAHPS survey. Next slide, please.

From the beginning, the process of developing and testing the HCBS CAHPS survey was attentive to requirements for receiving a CAHPS trademark. The development and approval process for CAHPS surveys emphasizes scientific rigor and frequent input from those who ultimately will be survey respondents and other key stakeholders.

Major steps in the survey development process include literature reviews and environmental scans, focus groups, input from providers and other key stakeholders, cognitive testing and survey questions and how the measures are to be reported and field testing. This process is designed to ensure that the survey will generate valid and reliable data to meet the information needs of healthcare consumers, care providers, health plans, purchasers, and policymakers.

CMS sponsors multiple CAHPS surveys nationwide that are focused on settings such as the hospital, home healthcare, hospice care, in-center hemodialysis and outpatient ambulatory care surgery. Next slide, please.

The process of developing and testing the HCBS CAHPS survey also was attentive to the requirements for receiving NQF endorsement of measures that might be derived from the survey instrument. The National Quality Forum or NQF endorses health quality measures. NQF-endorsed measures are considered the gold standard for healthcare measurement in the United States.

Under legislated authority, the NQF convene measure application partnership, MAP, advises the federal government and private sector payers on the optimal measures for use in specific payment and accountability programs. There are numerous NQF-endorsed measures derived from CAHPS surveys that can be used across a variety of settings and providers, including ones for clinician and group practice, in-center hemodialysis, home healthcare, child hospitals, health plans, behavioral health and surgical care. Next slide, please.

The development team followed the CAHPS survey development process, a rigorous and beneficiary involved process. It also is well-known and highly regarded by the developers of experience of care surveys. This diagram outlines the three major phases of the development process.

The process of developing and testing the survey instruments began with a formative research stage to identify key domains and constructs. This stage involved one, a literature review of similar surveys to identify items and measures; two, both one-on-one interviews and focus groups with individuals to learn what was most important to them when they receive HCBS; and three, input from experts, our technical expert panel or TEP. Then the team drafted the survey.

In phase II, survey development continued with multiple iterations of cognitive testing of the draft survey instrument in both English and Spanish. Once the items were refined, the survey was pilot tested in two states in 2013 and 2014 and field tested in nine states in 2014 and 2015.

In phase III, pilot and field test data were analyzed beginning in 2015 to determine which items worked or did not work, allowing the survey to be finalized. The survey instrument received the Consumer Assessment of Healthcare Providers and Systems or CAHPS trademark in June 2016.

National Quality Forum endorsement of the related measures occurred in October 2016. Survey and measure maintenance activities continued from those points in time. CMS is open to suggestions and other feedback. Next slide, please.

The formative research or phase I was an important first step to develop the survey. First, the team conducted a literature review and developed an item bank to identify topics for the survey. This included a database with over 1,000 potential survey questions from existing tools.

Then the team conducted focus groups and interviews with HCBS beneficiaries. These were critical to identifying topics that the HCBS beneficiaries were interested in and could report on and help to make the survey person-centered. The research team then conducted formative research interviews and focus groups with a range of HCBS recipients with different types of disabilities across several states to determine what services they use and how they use them, to identify and rank potential quality domains and constructs and to identify language that people typically use to describe services and providers.

These formative interviews revealed common quality domains and values across the participants with different types of disabilities. Next slide, please.

The interviews and focus groups included a diverse set of individuals with broad variations in disability type and education. Most participants were female and white, slightly less than half had not completed high school, and the study population were fairly evenly divided among individuals who had a physical disability, an intellectual or developmental disability, serious mental illness or frail/elderly. Next slide, please.

In all phases, the technical expert panel or TEP provided guidance. The TEP was made up of HCBS beneficiaries, state Medicaid HCBS staff, survey methodologists, representatives from advocacy organizations, national associations such as the National Association of Medicaid Directors, the National Association of State Directors of Developmental Disability Services, the National Association of States United for Aging and Disabilities, the National Association of State Mental Health Program Directors and the National Association of State Injury Administrators. Next slide, please.

As noted in the previous slide, the TEP met five times between 2010 and 2015. In 2010, the TEP provided input into the final domains and data collection modes. In 2011, they reviewed the cognitive testing results. In 2012, the TEP provided input on the emerging instrument and proposed field test methodology. In 2014, they heard about the progress of the pilot study and in 2015 they provided input and made final decisions about which items to include in the finalized survey, provided input on composites or groupings of items and made suggestions for future implementation. Next slide, please.

On the basis on the formative research conducted in 2010, which included the literature review and formative interviews as well as input from the TEP, the research developed ten domains, which are listed on this slide. These domains represent topics of importance to those receiving HCBS and include the quality of help received from personal assistance,

behavioral health staff, homemakers, case managers, transportation providers, as well as their experience in developing their service plans and whether the services they receive supports them to live the lives they want in the community. Next slide, please.

Findings from the formative research literature, interviews and focus groups also identified constructs that contribute to each domain. This slide presents three of the domains along with examples of constructs that contribute to each domain. For example, one of the domains was getting needed services from staff, and two of the constructs or concepts covered by that domain were unmet need in toileting, and unmet needs in taking medications. Similarly, communication by the homemaker focused on whether the homemaker's interaction with the person was individualized and responsive as well as whether the homemaker listened carefully to the person.

The case manager construct tapped into the responsiveness of the case manager to requests from the individual as well as how the person rated the services provided by the case manager. Next slide, please.

Here are three additional domains and some of their constructs. Choosing your services included a construct on whether the service plan included what is important to the individual. The personal safety domain included the assistance addressing physical abuse by paid staff. Community inclusion and empowerment included the construct of being able to get together with friends. Next slide, please.

In addition to identifying the domains and constructs, the formative research sought to identify the most common home and community-based services and supports and providers for use in a survey that would be appropriate for beneficiary input across the disability and HCBS program spectrums.

The services and providers listed on this slide are those that are common across Medicaid HCBS programs with one exception. Although employment assisted services are not offered across all programs, the TEP encouraged the inclusion of items on these services because they are so vitally important for full community participation, especially for working aged persons served in HCBS programs. Next slide, please.

In phase II of development and testing, the research team's next step was to create a draft survey that incorporated the information learned during the formative research stage that also addressed CAHPS principles. The survey underwent cognitive testing with HCBS beneficiaries, and items were refined based on their input. The TEP reviewed the cognitive testing findings and resulting revisions and also provided input on our analysis plan.

I'll provide more details about the cognitive testing process on the next slide. Once the survey was [audio disruption], it was piloted in two states from 2013 through 2014 and then the field test was conducted in nine states during 2014 and 2015. Next slide, please.

For those of you who are less familiar with cognitive testing, the cognitive testing interview process is valuable to identify whether a question is irrelevant to a respondent or needs to be crafted differently to make it more accessible and more relevant to future survey respondents. Specifically, is the information in the question relevant to the cognitive interview participant? Is the question person-centered? Can the respondent recall the information? Is the survey organized well or are some questions misplaced?

Cognitive interviews are one-on-one face-to-face interviews that can take up to one and a half hours in which a respondent is asked about each question on the survey. For example, an interviewer asks the actual survey question and the respondent answers, and then the interviewer follows up with a question, such as what makes you answer X response? Or, are there any words that could be confusing to someone? Or, is there another response option that you were expecting? Next slide, please.

The research team conducted three rounds of cognitive testing across six states with individuals with different types of disabilities. The first round was performed in January and February 2011. The research team made revisions, conducted a second round in March and April of 2011, made additional revisions and then conducted a third round in November of 2011 through January 2012.

Once these were finished, the survey was finalized for testing. On the basis of a recommendation from the CAHPS consortium after rounds one and two of the cognitive testing, we compared and tested different formats for questions and response options. For these experiments, we focused on individuals with intellectual and developmental disabilities. Next slide, please.

The individuals who participated in the cognitive testing represented a range of education levels and disability types. A large portion, more than 40%, had completed some college and slightly less than 40% had attained a high school diploma or completed some high school.

We interviewed slightly more females than males, and almost three quarters of participants were white. Slightly less than half of the participants had an intellectual or developmental disability, about a third were individuals with a physical disability or were individuals who were frail/elderly and about a quarter were individuals with a serious mental illness. Next slide, please.

Now I'd like to walk through some of the main feedback that we received from participants during the cognitive testing and the changes that resulted from their feedback. I'll discuss these findings in more detail over the next few slides.

Participants helped us identify and exclude questions that were less relevant, such as a question about provider handwashing. They also helped us determine instances when it's important to know what services a participant received in order to tailor the survey. Knowing the respondent's preferred staff titles also helps with tailoring the survey.

As a result of cognitive testing, we were able to refine most of the survey items to be more person-centered and accessible. For example, an initial question in the survey asked, "Do the people paid to help you where you live do things that you would rather do for yourself?" Interview participants indicated problems with the question. For example, they may want to walk but not be able to do so, so the question did not work. Ultimately, it was changed to "Do staff encourage you to do things for yourself if you can?" Next slide, please.

In order to make the survey as accessible as possible for individuals with an intellectual or developmental disability, an alternate response scale was tested. Alternative responses are simplified responses that can be used in lieu of the standard CAHPS responses when a beneficiary has difficulty responding with the standard CAHPS options.

For responses that address frequency, there were two types of response options: never, sometimes, usually and always or the response options of mostly yes and mostly no. The first set—never, sometimes, usually or always—is a CAHPS standard response option; however, this response option was not accessible to all so we created and tested the alternate version of mostly yes and mostly no. This slide illustrates some of the feedback that we received on the response scales.

When participants compared questions with different response scales, some preferred to have four response options, whereas others preferred two response options. Next slide, please.

On the basis of findings from cognitive testing as well as an experiment conducted as part of the field test, a simplified response option was determined to be accessible for some individuals. Using both response modes would allow more people to participate in the survey, including individuals with intellectual or developmental disabilities.

This slide shows the alternate response approach in the survey itself. The interviewer starts with the standard CAHPS response option of never, sometimes, usually or always. If the respondent has difficulty using the question-and-response format to answer, the interviewer then asks the alternate version. The interviewer does this three times and if the respondent prefers the alternate version each time, the interviewer then uses only the alternate version for the rest of the survey. Next slide, please.

The HCBS CAHPS survey asks respondents for feedback about specific types of service providers and when possible a specific individual. On the basis of the formative research, we knew that there were few uniform naming conventions for providers across programs and terms that individuals use in referring to their providers.

Some beneficiaries refer to a provider by their given name or as a friend. Thus, on the basis of the formative research and refined and cognitive testing, the survey was designed so that sponsors can incorporate program-specific terms for staff. You can see the bracketed italicized text that alerts the person administering the survey to insert program specific terms for these types of staff, which allows the interviewer to modify the term on the basis of the respondent's choice of the term.

The preferred term for a provider can be used throughout the survey. State administrative information facilitates the use of program specific terms. These data can include agency names, titles of staff members who provide care, names of staff who provide care and the activities that each staff member provides. Next slide, please.

To help respondents answer the relevant questions, the instrument was developed with skip patterns embedded throughout. The HCBS CAHPS survey asks about several categories of HCBS services, some of which respondents do not receive; therefore, skip instructions based on services received were developed for interviewers.

The survey also was developed with additional skips related to screener questions. This helps to ensure that specific experiences could be identified on which programs would be able to act.

In the example shown on this slide, there is a set of questions focused on whether the individual goes without help in bathing or getting dressed because personal assistance staff

are not there to help. The first screener question in the series asks whether the person needs help from the personal assistance staff to bathe, shower or get dressed. If the person says no, in other words that he or she has no need for help, the interviewer is instructed to skip the next three items and move on to an item on personal privacy.

If the beneficiary says yes to the screener question about needing help, then up to two additional follow-up questions are asked to elicit information on an unmet need. Next slide, please.

CAHPS also requires a translation of the survey. All CAHPS surveys must be available in one additional language other than English. The developer team chose Spanish because that is the second most commonly spoken language in the United States.

The CAHPS translation process was followed. This involves two independent simultaneous translations by certified translators, reconciliation of differences between the two translators, cognitive testing in Spanish and final reconciliations. The Spanish cognitive testing findings led to some small wording changes in the English translation of the survey to make sure that the English and Spanish surveys matched. Next slide, please.

Once the cognitive testing rounds were done, the survey was finalized and the next phase of assessing the survey began, piloting and field testing the survey. The HCBS CAHPS survey was tested on over 3,200 individuals in 10 states and 26 HCBS programs, using both fee-for-service and managed long-term services and supports.

Two experiments were conducted. One was a mode experiment in which we tested in-person interviewing against phone interviewing. CAHPS requires testing in more than one mode and the TEP advised using in- person and phone modes. Random assignment allocated 80% of respondents to an in-person survey and 20% to a phone survey.

The second experiment was testing the comparability between the standard CAHPS response items of never, sometimes, usually and always as well as the alternate response pattern of mostly yes and mostly no. Half of the respondents were assigned to each of the response options. In addition, eight hypothesized structures for composites were tested. Next slide, please.

The sampling frame for the field test consisted of the participants of the home and community based service programs within the states. The ten states selected were either TEP grantees or selected by CMS as pilot states. Louisiana was both, but Tennessee was a pilot only.

Then, states selected Medicaid HCBS programs that served individuals with a variety of disabilities, including individuals who are frail/elderly, individuals with a physical disability, individuals with an intellectual or developmental disability, individuals with a brain injury, and individuals with a serious mental illness.

Now, I'm going to hand it over to Coretta. Next slide, please.

Coretta

Thank you, Elizabeth. Beginning in 2015, the research team analyzed the data from the pilot and field tests and solicited feedback from the TEP on our analysis. The results of the data analyses and expert input helped us finalize the survey instrument.

In 2016, the developer team applied for and received the CAHPS trademark for the finalized survey as well as NQF endorsement of measures derived from the survey. Next slide, please.

This table provides information on the respondents for the pilot and field tests. Of the 3,226 total respondents, 3,003 were identified as complete, meaning that they answered at least half of all items in the survey that everyone was eligible to answer. This is the standard CAHPS procedure for identifying complete.

Midway through the survey, because of a low response rate, we included proxies or individuals that helped respondents complete the survey. We ultimately retained proxies for analysis. The third column of the table shows that there were 691 proxies accounting for about 23% of the total analyzed surveys. There was a range in number of participants in each disability group who were included in the analyses, from 228 for individuals with a brain injury to 1,178 for individuals who are frail/elderly.

The disability group with the largest portion of surveys by proxy was people with an intellectual or developmental disability for whom nearly 50% of respondents were proxy respondents. Next slide.

The next few slides lay out the steps taken by the research team in analyzing the pilot and field test results. The initial analytic steps were to understand how well the questions worked in eliciting survey responses and whether the data we received were clean.

First, it was important to identify language that could have been confusing to respondents or questions that were burdensome because they were either unnecessary or took too long to complete. To assess this, the team examined the data for instances in which people skipped questions or did not follow instructions, either intentionally or unintentionally.

The cleaning phase involved checking to see that all respondents were eligible for the survey; that is received home and community based services to identify and exclude incomplete surveys, and to appropriately recode any responses that violated skip patterns. Next slide, please.

Once the data had been cleaned, the team turned to conducting a psychometric analysis. Psychometric testing consists of a series of analyses to ensure that scores produced by a survey are as reliable and valid as possible. These analyses are geared towards answering the following questions: Do the responses group together on a basis of the draft domains, for example, communication or access? Confirmatory factor analysis was the analytic technique used to address this issue. We then used exploratory factor analysis to answer whether there might be a better way to group the items.

Good measures have the ability to discriminate between programs. In order to assess this, the team tested the unit level reliability. To examine the accuracy and consistency of responses, the team evaluated the reliability, validity and variability of composite and single item scores. Next slide, please.

The last steps in our analyses were to construct composite scores by combining individual items and adjusting for case mix, in other words, adjusting for differences in the respondent's demographics. We then developed estimated program level scores for the composites and single survey items. We tested the significance of unit rankings; that is

whether a program score was significantly higher or lower than the average score across a participating states' HCBS programs. Finally, we reported program level results to the states participating in the pilot and field tests. Next slide.

As a result of the pilot and field tests analyses, as well as feedback from the TEP and the CAHPS consortium, the finalized survey includes the items and measures depicted in this slide. First is a set of three cognitive screening items that help identify individuals who may not be able to provide reliable information.

Next, service identification items and screening items ensure that the beneficiary answers only questions about the services that they've received. Because not every beneficiary answers all questions, the average survey administration time is 30 minutes.

There are 34 items that make up composite measures that will be described later in this presentation. Stakeholders deemed some single item measures as important to retain even though they did not fit into a composite. These include a series of questions that assess a person's unmet needs and physical safety.

Six global rating and recommendation items provide information on the person's overall experience with three main types of staff. There are 15 items that collect demographic information, some of which are used for case mix adjustment. Finally, a 21-item supplementary employment module is an option for programs that provide employment services. Next slide, please.

The HCBS CAHPS survey is the only survey focused on home and community based services that has received a CAHPS trademark from the CAHPS consortium. Next slide, please.

The 19 measures derived from the HCBS CAHPS survey are the only HCBS specific measures that are currently endorsed by NQF. Next slide, please.

In this part of the presentation, we will discuss lessons learned from the pilot test conducted between October 2013 and April 2014 and the field test conducted between July 2014 and February 2015. Next slide, please.

In this map, yellow shows the pilot test only site, blue shows field test sites and green indicates the site of both pilot and field tests. Individuals from three Medicaid HCBS programs in two states, Louisiana and Tennessee, participated in the pilot test between October 2013 and April 2014. All the programs included served individuals who are frail/elderly and individuals with a physical disability.

Field testing took place in Louisiana, New Hampshire, Connecticut, Maryland, Minnesota, Colorado, Arizona, Kentucky, and Georgia with individuals from over 20 Medicaid HCBS programs between July 2014 and February 2015. These programs served individuals who are frail/elderly, individuals with a physical disability, individuals with a brain injury, individuals with an intellectual or developmental disability, and individuals with serious mental illness. Next slide, please.

During the pilot and field tests, the research team conducted an experiment on the mode of administration. All CAHPS surveys must be administered in at least two modes. Stakeholder input suggested that the in-person mode would be the most appropriate for these populations.

The research team also included the phone mode on the basis of stakeholder input and cost consideration. The team did not consider a mail survey because of the complexity of the survey with its skip patterns and program-specific insert and because the TEP agreed and noted that it was not a feasible option for persons served in HCBS programs.

Participants were randomized to the two modes but had the option of switching modes if they preferred the other mode. There was an overall higher response rate for the in-person mode; however, there was a higher response rate by phone for individuals with an intellectual or developmental disability and individuals with a brain injury.

The phone respondents reported better overall physical health, whereas the in-person respondents reported worse health. The TEP recommended that because there was no difference in how respondents rated care between the survey modes that were administered in-person and by phone, it would be extremely valuable for states to have the phone option in addition to the in-person option. One of the advantages of phone surveys is that they are more cost effective than in-person surveys. Next slide, please.

Because survey response rates are an important issue, we want to share pilot and field test results. This slide shows the portion of participants who completed surveys compared to all who were asked to take the survey.

The overall response rate was about 22%, with the highest response rate, over 30%, among participants of programs serving individuals who are frail/elderly and individuals with a physical disability. The lowest response rate, about 10%, was among participants of programs serving individuals with an intellectual or developmental disability. Although it is not surprising that these rates are lower than for populations without disabilities, the presence of guardians for some of these individuals pose a particular challenge.

The survey vendors indicated that guardians could act as gatekeepers by refusing on behalf of the beneficiary or wanting to be their proxy. Note that in the pilot and field tests, proxy respondents were not allowed consistently.

In the pilot and field tests, participants of different programs preferred different modes. Among programs serving individuals who are frail/elderly, individuals with a physical disability and both groups of individuals, response rates were higher when the survey was administered in-person.

Among programs serving individuals with an intellectual or developmental disability and those serving individuals with a brain injury, response rates were slightly higher when the survey was administered by phone. Next slide, please.

In addition to the mode experiment, the research team conducted an experiment between the standard CAHPS response options and the alternate response options. The survey had two response options included in this field test: the standard CAHPS never, sometimes, usually, always and a simplified response of mostly yes or mostly no.

Participants were randomized to the two response options, and respondents who had difficulty with the standard set were switched into the simplified response set. For example, if a participant had trouble differentiating between sometimes and always, they were administered the more simplified response.

A significantly higher percentage of alternate option respondents were of Hispanic ethnicity compared with standard CAHPS respondents, 6% versus 4% respectively. Our results showed that there were no additional differences in respondent characteristics between response types. Next slide, please.

Next, we will present the composites included in the HCBS CAHPS survey. Composites are a series of questions that measure an underlying concept. The research team identified seven valid composites out of the eight that were hypothesized. These include staff are reliable and helpful, staff listen and communicate well, case manager is helpful, choosing the services that matter to you, transportation to medical appointments, personal safety and respect and planning your time and activities. Next slide, please.

The research team tested these composites using confirmatory factor analysis. Some items were not included in the analysis because they applied to too few participants or the variance among answers was too low.

The TEP advised that some individual items were important to retain as standalone items not part of a composite. Examples of these include questions about personal safety of the beneficiary. There were good statistics for this group of composites, indicating that these are an appropriate group of composites.

We also examined the program level reliability. One of the purposes of the CAHPS survey is to be able to detect variability across units; thus, one of the major goals for the composites and other survey items from this measure is to be able to discriminate across reporting units measured by unit level reliability. Next slide, please.

For the next few slides, we are going to go over some important concepts related to sample design, some of which were informed by the results of the pilot and field test analyses. This survey is intended to result and report about a particular program's performance vis-à-vis beneficiary reported outcomes. The unit of analysis is either the HCBS program or the accountable entity.

An accountable entity is an operating entity responsible for managing and overseeing a specific HCBS program within a given state. Although Medicaid HCBS programs are administered by state Medicaid agencies under various legal authorities, they frequently are operated by other entities including non-Medicaid state agencies, for example the Department of Aging or a non-state governmental entity, for example the county or managed care organizations under managed long-term services and support programs.

In those cases, the operating entities then contract with direct service and support providers and case managers. The HCBS CAHPS survey was developed so that comparisons about the quality of services and support can be made across programs or between managed care organizations or other subgroups. Next slide, please.

Stratified random sampling is a sampling method that can be used for answering questions, comparing subgroups or strata, such as managed care organizations, case management agencies, or regions within a state. A stratum is a technical term to designate a subgroup from a larger unit.

One might also stratify at the program level if the intent is to compare programs. Examples of research questions that use stratified random sampling design include, how do

beneficiaries in the brain injury program in my state rate their case managers? How do beneficiaries enrolled in different HCBS programs in my state rate their case managers? This would be a program comparison.

New beneficiaries and managed care organization, one, rate their case manager differently from the way that beneficiary is served by all managed care organizations on average rate their case manager. Note that it's always possible to generate an estimate for the program as a whole even if one is stratifying by subgroup. Next slide, please.

Effective sample size is the number of completed responses needed to obtain a reasonable level of reliability. Field test data suggested the effective sample size should be about 400 respondents per stratum. This means that you will need 400 respondents per stratum or subgroup to reliably compare scores across strata.

It is especially important that states considering using measures derived from the HCBS CAHPS survey for incentivizing providers—that is value-based purchasing—have 400 responses per sub-group to ensure the reliability of survey metrics. Next slide, please.

One important concept to understand for fielding the survey is the total response rate. This is a percentage of people who are offered the survey who responded to the survey. To calculate the total response rate, divide the number of surveys completed by the number of people who are offered the survey and then multiply this number by 100. Next slide, please.

Another important concept is stratum response rate. This is the percentage of people from the drawn sample in a single stratum, for example, a managed care organization who were offered the survey that responded to the survey. The equation presented is very similar to the calculation for the total response rate but instead focuses on the stratum sample rather than the entire sample. Next slide, please.

Because not everyone who was offered the survey will become a respondent, it is important to poll a sample large enough to achieve an effective sample size of 400 per program or stratum depending on your analytic goals. To determine the stratum poll size or number of people per stratum you may offer the survey, divide the effective sample size of 400 by the expected response rate for the stratum.

If you don't use any stratification, substitute the expected program response rate and the denominator. If you do use stratification, just sum the poll sizes from all strata to obtain total program sample size. Next slide, please.

There is some flexibility in the response rates used and the sample poll size calculation. The response rates from the field test can be used as a guide. If survey sponsors believe their survey efforts will result in a higher response rate and future administrations because of increased outreach efforts or use of proxies, or from prior experience, adjust the value used in the calculations accordingly. Also, make sure to take into account the survey mode used because response rates generally vary within the mode. Next slide, please.

Here are two examples of calculating the sample poll size. If you plan to compare programs within your state, your sampling scheme will look more like the first table. The first table shows a state administering the HCBS CAHPS survey to beneficiaries in three different programs.

If you plan to make comparisons within a program, your sampling scheme will look more like the second table. The second table shows a state with a managed long-term services and support program with three different managed care organizations providing services.

Which table most closely matches your state sampling method will depend on how you plan to use the survey results. Both tables show the effective sample size, example of response rates and sample poll size for each program in the top table or managed care organization in the bottom table.

The response rate column shows a program-specific or managed care organization specific response rate. Survey sponsors should determine and use the response rate that is most appropriate for their program or stratum. This rate should reflect what was observed in the HCBS CAHPS field test and any projected differences that the survey sponsors expect when they field the survey. The last column shows a calculated sample poll size calculation. Next slide, please.

Some HCBS programs have very few people enrolled. Surveying a program with fewer than 400 people may not yield enough completed responses to produce reliable results for some measures.

For small programs, either take a census; that is offer the survey to all program enrollees or combine small programs serving a similar HCBS population. If you choose to combine small programs, you will not be able to generalize the survey results to individual programs. You will only be able to generalize the results to the small program serving that population.

Consider combining programs for purposes of the survey only if they are similar in providers, program operation and quality oversight. Next slide, please.

Another special consideration for planning is the inclusion of proxy responses. As mentioned earlier in this presentation, the HCBS CAHPS survey was designed to be person-centered and allow as many beneficiaries as possible to be respondents. The survey was intentionally designed to be as accessible as possible; however, survey vendors in the pilot and field tests reported difficulty in successfully administering the survey to all beneficiaries. They reported that other individuals in the person's life were willing to respond to the survey as proxy respondents; thus, partway through the field test we began allowing proxy respondents.

For the purposes of the pilot and field tests, a proxy respondent refers to any help that the respondent received in completing the survey. This ranged from answering all questions for the respondent to providing prompts, translation or help with communication technology.

Proxy respondents are allowed by CMS and can help to improve the response rate; however, the survey sponsor needs to consider which types of proxies they will allow. The TEP suggested that a proxy be anyone with regular interaction with the respondent and who is not paid to provide services to the respondent.

If you decide to allow proxy respondents, it will be important that you take respondent types into account when you case mix adjust your results. Next slide, please.

This table presents numbers and percentages of proxies for each HCBS population represented in the field test. As you can see, across the board, proxies were used to some extent and there was a substantial variation in use by population and state. Because the

decision to include proxies was not made until midway through the field test, these results are likely an underestimate of proxy respondent participation had they been allowed throughout the entire data collection period.

Now, I'm going to hand it over to Susan. Next slide, please.

Susan

Thank you, Coretta. This section describes the 19 measures from the HCBS CAHPS survey that received NQF endorsement on October 25, 2016. These are the first NQF-endorsed measures specific to the HCBS setting. As previously mentioned, NQF-endorsed measures are considered the gold standard for healthcare measurement in the United States and NQF endorsement provides assurance to the user that measures were rigorously tested.

For more details about the HCBS CAHPS measures, go to NQF #2967 in the NQF Quality Positioning System. Next slide, please.

Last March, the HCBS measures were submitted to an NQF standing committee that oversees the person and family-centered care family of measures. The standing committee shapes a project scope and ensures that input is obtained from relevant stakeholders. In June, the committee conducted an initial detailed review of the measures and did not recommend endorsement. The developer team was invited to submit additional information and request a reconsideration.

During the summer, the results from the meeting were posted for the public to provide comments. During this public comment period, multiple stakeholders submitted feedback in support of the measures.

At the beginning of August, the developer team submitted additional information and analyses of the measures, and the committee voted to recommend endorsement of the measures.

This past fall, the NQF general membership and the Consensus Standards Approval Committee also voted to endorse the measures and final board ratification occurred on October 25, 2016. The process concluded in November after a 30-day appeal process that yielded no appeals. Measures are endorsed for a three-year period. CMS has begun activities to support maintenance of this endorsement. Next slide, please.

As noted earlier, the HCBS CAHPS survey items provide information about specific domains of the HCBS experience. The HCBS CAHPS survey has 34 items that support 7 composite or scale measures and 12 items that support single item measures from the domains shown here.

After the composites were identified in the analyses, the developer team went back to a group of beneficiaries and talked with them about the best labels for each of the composites. The slide shows the resulting labels for the final set of composites.

In these next several slides, I will describe each composite and the survey items that make up each of them as well as the single item measures. Each of these composites and single item measures are NQF endorsed measures derived from the HCBS CAHPS survey. Next slide, please.

This slide shows that the first composite, staff are reliable and helpful, has six items that pertain to the personal care attendant, behavioral health staff and/or homemaker. Items include whether staff come to work on time, whether staff work as long as they are supposed to, how often staff make sure the beneficiary has enough privacy when bathing or dressing. Next slide, please.

The next composite, staff listen and communicate well, has 11 items. Items focus on aspects of service and support such as how often staff show courtesy and respect, whether explanations staff give are hard to understand because of language barriers, how often staff treat the beneficiary the way he or she wants to be treated, how often staff explain things in a way that's easy to understand, how often staff listen carefully to the beneficiary, whether staff know what kind of help the beneficiary needs with everyday activities. Next slide, please.

This slide shows that there are three items in the case manager is helpful composite. These address whether the beneficiary can contact the case manager when needed, whether the case manager works with the beneficiary when he or she asks for help with getting or fixing equipment, whether the case manager works with the beneficiary when he or she asks for help with getting changes to services. Next slide, please.

This slide shows that the composite on choosing the services that matter to you consist of items on whether the person's service plan includes things that are important to the beneficiary, whether staff know what's in the person's service plan, including the things that are important to the beneficiary. Next slide, please.

This slide shows that the transportation to medical appointments composite consists of items about how often the beneficiary has transportation to medical appointments, whether the beneficiary is able to get in and out of the ride easily, how often the ride arrives on time. Next slide, please.

This slide shows that the three items in the personal safety and respect composite ask the beneficiary about whether there is a person with whom they can talk if someone hurts them or does something to them that they do not like, whether any staff takes the beneficiary's money or their possessions without first asking, whether they have staff who yell, swear or curse at them. Next slide, please.

This slide shows that the composite titled 'planning your time and activities' is a community integration measure that asks about how often the beneficiary gets together with family members who live nearby if they want to do so, how often the beneficiary gets together with friends who live nearby if they want to do so, how often the beneficiary does things in the community that he or she likes when he or she wants to do so, whether the beneficiary needs more help to do things in the community, whether the beneficiary takes part in deciding what to do with his or her time each day, whether the beneficiary takes part in deciding when he or she does things each day, for example, get up, eat, go to bed. Next slide, please.

In addition to the seven composite measures, the measures endorsed by NQF include three global rating measures and three recommendation measures that are supported by the HCBS CAHPS survey. Both the global ratings and the recommendations are specific to three different types of service providers. Next slide, please.

In addition to the seven composite measures and the six global rating or recommendation measures, the NQF endorsed measures include single item measures. In the psychometric analyses, there were 13 items that were not part of a composite. The technical expert panel felt that these items were important enough to retain in the survey as standalone items. For example, the TEP told the developer team that questions about unmet needs in bathing, dressing, meal preparation, toileting and medication should be included.

The same was true about questions that follow up on whether someone is working with you to fix the problem if the beneficiary reports currently experiencing verbal abuse or financial exploitation. This slide shows the subset of six standalone items that were submitted to NQF and endorsed as measures. Next slide, please.

These next few slides show the pilot and field test values for some measures. These slides also illustrate some options for how to present such results at a very high level.

This first slide shows the differences in global ratings across HCBS populations. The values are calculated as mean scores. In part II of the training, we'll describe a second way to present scores for measures.

The only service that had a statistical difference across populations was case manager services, with participants with brain injury reporting the lowest ratings, 81.2, and individuals who are frail/elderly reporting the highest rating, 86.8. It should be noted that all ratings are quite high, so although there is a statistically significant difference, that difference may not be meaningful. Next slide, please.

This slide presents the pilot and field test values for composites and global ratings. The values are calculated as mean scores and ranked from highest to lowest. In part II of this training, we'll describe a second way to present the scores.

On this slide, all scores are above 82. The highest scores were for personal safety; however, that is expected because most people reported no, the individual did not steal, hit or curse at them. The second highest scores were for case management. The lowest scores were for community inclusion and choosing services. Next slide, please.

This slide shows the ratings of the case management services by HCBS population. Again, the values are calculated as mean scores and in part II of the training, we'll describe a second way to present scores. All scores here were above 87, with individuals with a brain injury reporting the lowest rating and individuals who are frail/elderly reporting the highest rating. Next slide, please.

We realize that a lot of information was presented in this training. The HCBS CAHPS webpage on the CMS site is a key resource for individuals who want more information about the survey. Resources that can be accessed through this webpage include the survey instruments in English and Spanish, both the core and the employment supplement, and technical assistance documents.

Questions about the HCBS CAHPS survey or requests for technical assistance related to the survey can be directed to the HCBS CAHPS mailbox. This link is on the CMS webpage. Mailbox staff will answer generic questions about the survey, including identifying relevant available resources. Next slide, please.

Thank you for participating in this training module. Now, I'm going to hand it over to Lisa. Next slide, please.

Lisa

Great. Thank you, Susan, and thank you to all of our presenters today. This is Lisa Gold with Truven Health Analytics. We will now take some time to answer questions from attendees.

As a reminder, to pose questions for our speakers, please send your questions to all participants, all participants via the chat function. We've been getting some questions through our operator and through all panelists. We want them, please, to go to all participants so that everyone is able to see what's coming in.

We have gotten several questions regarding the slide deck and a recording of this presentation, and we will be posting the slide deck at a minimum and we will send a link to everyone who has registered. We have your email addresses. We will send an email notice to you when that is available for you to access.

Alright, we have some questions that have come in. The first question is pertaining to the states that piloted and tested the survey. Which states piloted and tested the survey?

Coretta

Hi. This is Coretta Mallery. I'm looking for the slide that has the information on it that maybe we could go back to.

Elizabeth

Hi. The field test included Arizona, Colorado, Connecticut, Georgia, Kentucky, Louisiana, Maryland, Minnesota and New Hampshire, and the pilot included Louisiana and Tennessee. Operator, if you could bring up slide 46, that depicts the states that participated in the pilot and field test. There it is. Thank you.

Lisa

The next question is sort of a follow-up regarding the states that pilot tested, were they also part of the field testing and how were these states selected?

Coretta

Sure. Tennessee and Louisiana were included in the pilot test, and then Louisiana went on to also be included in the field test, but Tennessee was not. There was the one state overlap and perhaps, Beth, maybe you could answer how the states were determined?

Beth

Yes. For the field test, they were all states participating in the TEFT demonstration program, and for the pilot, prior to the beginning of the TEFT demonstration, CMS allocated some funds through another grant for the pilot test and put a call out to states who might want to participate. Tennessee and Louisiana answered that call. That's how the states came to be either in the pilot or the field test.

Lisa

Another question that has come in is asking about the reading level of the survey.

Elizabeth

Hi. This is Elizabeth. One of the reasons why we do cognitive testing is to assess ability to understand. One of the concerns we have when we use reading levels, such as a Flesch-Kincaid, which most people can do using Microsoft Word, is that the reading level may be fine but it may not actually work with an audience because the reading level really measures the number of words in a sentence or question and the number of syllables in the words. That's why we do cognitive testing. It's another level up beyond reading level. Thank you.

Lisa

Another question that's come in has multiple parts. How is the disability level defined and by whom? Was it decided via enrollment application, claims, self-reported data, health risk assessment completion upon enrollment? How is that determined?

Beth

The survey was fielded to individuals in programs, in state HCBS Medicaid programs, targeting certain groups of people with different types of disability. The survey was not in any way targeted to certain levels of disability but more types of disabilities through the various programs, through the various HCBS programs of the states that participated in the pilot and the field tests. Thanks, Lisa.

Lisa

Another question was asking, what were some of the reasons why surveys were not completed? Someone wondered if the length, perhaps, was a factor, thinking that perhaps 30 minutes is quite a long time to spend.

Beth

Elizabeth, can you address the non-response rate, or Coretta?

Elizabeth

I think Coretta can address the non-response rate, but I can also add that most CAHPS surveys are around 20 minutes long, and we had looked at prior research that had even suggested even longer surveys would be okay with this particular population.

In terms of reasons for non-response, Coretta, do you think you could help out on that?

Coretta

Sure. There were multiple reasons. I do think that we could provide the exact data on how many people started and then stopped because the survey was too long, but that really wasn't a substantial percentage of the non-responses.

We do have disposition reports that show if they refunded or broke off, but unfortunately if they chose to decline or they didn't answer the phone to schedule an appointment, we don't have the data collected to say why they declined. We would just have the information that we had a hard time reaching them or that we weren't able to schedule an appointment or that they declined, but then we won't be able to say why they declined. We could provide those specific percentages.

Lisa

Another question asks if were there any differences in the proxy responses versus direct survey to the beneficiaries?

Coretta

Hi. We did look at this, and I would like to say that because proxies were not administered consistently throughout the process, I think as we noted that we started allowing them partway through. We're very hesitant to compare proxies versus non-proxies because it wasn't consistently administered.

We have looked at that, and I believe that there were not major differences, but again, I'm hesitant to report results on that because we didn't allow proxies consistently. I think it would be very interesting to see in uses of the survey moving forward, those that permit proxies to see if proxies rate care better or worse than beneficiaries.

Lisa

Someone also asked if the survey can be used for children.

Elizabeth

I'm going to ask or suggest that Beth respond to that.

Beth

Sure. Programs for children, the services are different. Medicaid has different requirements for those services, and it would have been a much more complicated survey if it were targeted to children as well.

Early on, CMS made the decision that this CAHPS survey would be developed for adults receiving HCBS services, age 18 and over, so no this is not applicable, not to be used with children and in programs that serve children. That would require another development process, testing and development process and obviously would include parents and to some extent, perhaps, children when they get into the adolescent years. It's a different beast, if you will.

Lisa?

Lisa

Alright. Thank you. I still have some more questions rolling in. As a reminder, please send them through the chat feature to all participants. I'm going through them as best I can. The next question I have is was there any thought of using emojis or some sort of graphic for respondents to use instead of the text responses, perhaps something like a smiley face scale to be used for a pain indicator?

Elizabeth

Hi. Since the survey is verbally or orally administered, there was no thought, in part because of the skip pattern issue again, so interviewers ask the questions to a respondent verbally and the expectation is that they will be able to respond in kind, unless they need some assistance.

Lisa

Alright. Thank you. Another question is would there be an electronic version of the CAHPS survey available?

Susan

There is an electronic version of the survey available on the website that we mentioned. When the slides are posted, you'll be able to get the address from that, but if you go to Medicaid.gov and if you do a search just for CAHPS Home and Community Based Services survey, it should bring you to the webpage.

Lisa

Another question that's come in is is there a question as to whether or not a respondent uses a hearing aid? This person said it might be important to analyze the communication results.

Elizabeth

There is no question related whether a respondent uses a hearing aid. The communication questions are much more about rapport rather than literally the ability to hear well, and it's also addressing the behaviors of the staff and not the respondent.

Lisa

Someone has asked if you think there is a bias in case managers' performance?

Susan

Are they asking whether there's a bias in the responses?

Lisa

I wondered about responses as well, but the question specifically says performance. I will try to reach out to that person privately and try to get clarification.

The next question is can you please talk about next steps for using the survey within states?

Susan

I'll say two things. First of all, on our next training which is in two weeks, we do have quite a bit of material about state uses that will provide some information about the ways in which states might use the survey instrument. It will also include information about how states are already using the survey instruments.

You'll hear from states that are already doing it and some summaries of what we know about others. If the question is about at the individual state level, how to proceed, again I would encourage you to use the survey web page to look at the resources that are already there, and if you have a specific question about where you are and what you want to do next or need to do next, please use that mailbox and we can communicate with you about your specifics.

Beth

This is Beth Jackson. I see the question, in what states and/or what programs in the HCBS CAHPS survey expected to be used. My understanding, and I will punt this back to the folks

at CMS, is that this is voluntary. Using this survey in HCBS programs by states is voluntary and Kerry, Allison, Melanie, Mike, would you like to say anything more about that?

Mike

That's correct. It is something that states can use. What we were trying to accomplish in providing this was to give states a valid and reliable tool that they could use to look at the experience of people in HCBS services, so the adoption of it is within their purview.

I will say, I think we're going to be posting more materials over time about different best practices with the tool in using it as well as this training that will be posted for folks to see and modify to their programs that they want to use the tool.

Lisa

Alright. Thank you. I see we're really almost out of time, so we did have a couple of questions that did not get answered. Questions that were sent to chat but we didn't have time to answer will be responded to directly via email to the person who submitted it, and if participants have additional questions that were not posed, please contact the HCBS CAHPS mailbox on the CMS webpage for the HCBS CAHPS survey.

Now, we will go to the final slide. As we prepare to conclude Part I of the national training, we have just a couple of reminders for all of our attendees. Part II of the national training will be held on January 24th at the same time 11:00 to 12:30 Eastern. Please make sure that you register in advance for that in order to receive the call and web details.

Also, please take a few minutes to answer the poll questions that you'll soon see coming up. We do value your input, and we use your feedback, so please do take a few minutes to thoughtfully respond to those questions.

Thank you, again, to everyone for attending. Have a great day.

Coordinator

Thank you, Lisa. Ladies and gentlemen, that concludes your conference for today. You may now disconnect. Thank you for joining and have a very good day.