

Technical Assistance Guide for Administration of the CAHPS[®] Home and Community-Based Services Survey

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Appendix B: [Disability sensibility: The diversity of disability](https://event.on24.com/eventRegistration/EventLobbyServlet?target=reg20.jsp&referrer=&eventid=1083366&sessionid=1&key=9AD1D48C2C28AE94041D78E2F5B8805C®Tag=&sourcepage=register). Online training module. (https://event.on24.com/eventRegistration/EventLobbyServlet?target=reg20.jsp&referrer=&eventid=1083366&sessionid=1&key=9AD1D48C2C28AE94041D78E2F5B8805C®Tag=&sourcepage=register)

Appendix C: CAHPS Home and Community-Based Services Surveys

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2. [CAHPS Home- and Community-Based Services Survey 1.0, Spanish language \(https://www.medicaid.gov/medicaid/quality-of-care/downloads/cahps-home-and-community-based-services-survey-10-spanish.pdf\)](https://www.medicaid.gov/medicaid/quality-of-care/downloads/cahps-home-and-community-based-services-survey-10-spanish.pdf)
3. [CAHPS Home- and Community-Based Services Survey 1.0: Supplemental Employment Module, English language \(https://www.medicaid.gov/medicaid/quality-of-care/downloads/cahps-home-and-community-based-services-survey-10-supplemental-employment-module-english.pdf\)](https://www.medicaid.gov/medicaid/quality-of-care/downloads/cahps-home-and-community-based-services-survey-10-supplemental-employment-module-english.pdf)
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Appendix E: Sample of introductory scripts for the CAHPS Home and Community-Based Services Survey

1. [English introductory scripts](https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppE-IntroScript-Eng.pdf) (<https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppE-IntroScript-Eng.pdf>)
2. [Spanish introductory scripts](https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppE-IntroScript-Spa.pdf) (<https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppE-IntroScript-Spa.pdf>)

Appendix F: Sample of in-person consent form for the CAHPS Home and Community-Based Services Survey

1. [English in-person consent form](https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppF-Consent-Eng.pdf) (<https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppF-Consent-Eng.pdf>)
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Appendix G: [Sample of frequently asked questions about the CAHPS Home and Community-Based Services Survey for survey vendors](https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppG-VendorFAQ.pdf) (<https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppG-VendorFAQ.pdf>)

Appendix H: [Sample of guardian and provider update telephone script for the CAHPS Home and Community-Based Services Survey](https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppH-GuardianUpdate.pdf) (<https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppH-GuardianUpdate.pdf>)

Appendix I: [Vendor materials associated with the administration of the CAHPS Home and Community-Based Services Survey](https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppI-VendorMaterials.pdf) (<https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppI-VendorMaterials.pdf>)

1. Sample of Minimum Business Requirements
2. Sample of Survey Vendor Quality Assurance Plan

Appendix J: [Technical Assistance Guide for Analyzing Data from the CAHPS Home and Community-Based Services Survey](https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-Data-Analysis-Guide.pdf) (<https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-Data-Analysis-Guide.pdf>)

I. PURPOSE OF THE GUIDE

A. Origin of the CAHPS® Home and Community-Based Services Survey

The Centers for Medicare & Medicaid Services (CMS) is responsible for the oversight and financing of Medicaid home and community-based services (HCBS), which enable chronically ill and disabled Medicaid beneficiaries to receive care at home instead of being institutionalized. With the majority of Medicaid long-term services and supports provided in the community, mechanisms for ensuring the quality of care delivered in those settings is imperative. The CAHPS Home and Community-Based Services Survey, hereinafter referred to as the HCBS CAHPS Survey, was designed to provide standard performance metrics for HCBS programs.¹ Specifically, the survey is intended to gather direct feedback from Medicaid beneficiaries receiving HCBS about their experiences and the quality of their long-term services and supports.

B. Overview of the Survey Administration Guide

This *Technical Assistance Guide for the Administration of the CAHPS® Home and Community-Based Services Survey* (Survey Administration Guide) serves as an orientation to the data collection process for survey sponsors. Survey sponsors include state Medicaid agencies that administer HCBS programs as well as operating entities that are responsible for managing and overseeing a specific HCBS program within a state (e.g., managed care organizations [MCOs], non-Medicaid state agencies such as departments of aging, non-state governmental entities such as counties). The Survey Administration Guide is a comprehensive guide to enable sponsors to administer a survey, from planning to receiving survey results from the survey vendor. Table 1 lists the main sections of the guide with a brief description for each section.

Table 1. Description of the Survey Administration Guide

Section	Description
Overview of the HCBS CAHPS Survey	Presents the key features of the survey and describes the roles and responsibilities of the sponsor and survey vendor
Roles and Responsibilities	Outlines customary roles and responsibilities for sponsors of the HCBS CAHPS Survey as well as survey vendors
Planning the Survey	Provides guidance on selecting a survey vendor, overseeing and coordinating the survey, selecting a survey mode, avoiding survey incentives, understanding core versus supplemental items, adding supplemental items, tailoring the survey, modifying the survey title, using proxy respondents, and administering the survey in other languages
Sampling Specifications and Sample Frame	Describes the information needed to develop the list and number of individuals who are eligible to be surveyed (i.e., the sample frame)

¹ CAHPS® is a registered trademark of the Agency for Healthcare Research and Quality.

Section	Description
Information Security and Beneficiary Confidentiality	Communicates necessary data security for the survey sponsor and vendor to be compliant with the Health Insurance Portability and Accountability Act
Reporting Abuse, Neglect, and Exploitation	Describes obligation toward state mandatory reporting laws on abuse, neglect, and exploitation
Fielding the Survey	Explains prenotification letters, maximizing response rates, interviewer training, customer support, recruitment calls, consent and assent (if applicable), proxy respondents (if applicable), maximizing privacy, beneficiary selection criteria, beneficiary identification of problems with a program, and beneficiary behavioral concerns
Survey Vendor Updates	Provides recommendations on survey reporting timing and content
Final Data File	Communicates recommended file format and transmission method as well as suggested quality checks on the file
Oversight of the Survey Vendor	Provides guidance on quality oversight, the quality assurance plan, and sponsor oversight of the survey vendor
Survey Timeline	Presents a sample timeline for the entirety of the survey administration project and a sample timeline for the survey administration to the beneficiaries

C. Key Resources to Implement the Survey

The appendices to the Survey Administration Guide, which include materials useful for administering the survey and for background resources, are listed below. A link to each resource is in the Table of Contents.

Appendix A: Interviewer Guidelines for Administering the CAHPS Home and Community-Based Services Survey

Appendix B: Disability Sensibility: The Diversity of Disability

Appendix C: CAHPS Home and Community-Based Services Survey

1. CAHPS Home and Community-Based Services Survey 1.0, English language
2. CAHPS Home and Community-Based Services Survey 1.0, Spanish language
3. CAHPS Home and Community-Based Services Survey 1.0: Supplemental Employment Module, English language
4. CAHPS Home and Community-Based Services Survey 1.0: Supplemental Employment Module, Spanish language
5. Translating CAHPS® Surveys

Appendix D: Sample of beneficiary and guardian prenotification letter for administration of the CAHPS Home and Community-Based Services Survey

1. English beneficiary and guardian prenotification letter
2. Spanish beneficiary and guardian prenotification letter

Appendix E: Sample of introductory scripts for the CAHPS Home and Community-Based Services Survey

1. English introductory scripts
2. Spanish introductory scripts

Appendix F: Sample of in-person consent form for the CAHPS Home and Community-Based Services Survey

1. English in-person consent form
2. Spanish in-person consent form

Appendix G: Sample of Frequently Asked Questions for the CAHPS Home and Community-Based Services Survey

Appendix H: Sample of Guardian and Provider Update Telephone Script for the CAHPS Home and Community-Based Services Survey

Appendix I: Vendor Materials Associated With the Administration of the CAHPS Home and Community-Based Services Survey

1. Sample of Minimum Business Requirements
2. Sample of Survey Vendor Quality Assurance Plan

Appendix J: Technical Assistance Guide for Analyzing Data from the CAHPS Home and Community-Based Services Survey

The following webpages include additional information about the survey and related programs.

- [CMS HCBS CAHPS Survey Website](#). This site includes additional information and materials to conduct the survey and analysis, including a mailbox for technical assistance questions.
- Agency for Healthcare Research and Quality [CAHPS Website](#). This site provides general information on the CAHPS program and other CAHPS surveys.
- [National Quality Forum Website](#). This site provides National Quality Forum measure specifications.

II. OVERVIEW OF THE HCBS CAHPS SURVEY

A. Context for the HCBS CAHPS Survey

The goal of the HCBS CAHPS Survey is to provide standard individual experience metrics for HCBS programs that are applicable to all populations served by these programs. The survey was field tested with a large sample of people receiving Medicaid HCBS and related supports, specifically people served in programs targeting the following populations:

- Individuals who are frail elderly
- Individuals with a physical disability
- Individuals with an intellectual or developmental disability
- Individuals with a brain injury
- Individuals with serious mental illness

States provide HCBS to allow Medicaid beneficiaries to receive services in their own homes or communities rather than in institutional or other isolated settings. The results from the HCBS CAHPS Survey enable HCBS programs to identify areas in which quality can be improved and to provide stakeholders with comparisons across HCBS programs. Although several other beneficiary surveys have been developed and tested and are currently in use with HCBS recipients in various states, none has the ability to provide comparable information on HCBS program beneficiaries across the spectrum of disability-related and federally funded services.

CMS is working with states, consumers and advocates, providers, and other stakeholders to create a sustainable, person-driven, long-term support system. This system provides people with disabilities and chronic conditions with choice, control, and access to a full array of quality services that ensure optimal outcomes, such as independence, health, and quality of life. CMS is responsible for the oversight of and, in partnership with states, payment for Medicaid HCBS, which enable Medicaid beneficiaries to receive care and support at home and in the community instead of in institutional settings. As the primary funder of HCBS through Medicaid, CMS sponsored the development of a mechanism to measure HCBS experience and outcomes across the various HCBS populations. CMS used CAHPS principles² to inform HCBS CAHPS Survey development.

B. Key Features of the Survey

The HCBS CAHPS Survey received the CAHPS trademark on June 22, 2016. Nineteen measures derived from the survey also received endorsement from the National Quality Form on October 25, 2016.

² Agency for Healthcare Research and Quality. About CAHPS. Rockville, MD: Agency for Healthcare Research and Quality; updated October 2016. <http://www.ahrq.gov/cahps/about-cahps/index.html>.

The HCBS CAHPS Survey includes a maximum of 69 core items that providers developed to accurately and reliably measure beneficiary experience with the Medicaid HCBS delivered. Core questions cover the following areas:

1. Staff are reliable and helpful
2. Staff listen and communicate well
3. Case manager is helpful
4. Choosing the services that matter to you
5. Transportation to medical appointments
6. Personal safety
7. Planning your time and activities
8. Ratings of providers

The survey also begins with a set of three cognitive screening questions and then poses a second set of nine questions to identify the relevant HCBS services that the beneficiary uses. The instrument ends with a set of 15 demographic questions.

Many of the items in the HCBS CAHPS Survey are preceded by screener or gate questions. These questions confirm that only those sampled beneficiaries for whom a particular item is relevant are eligible to answer the pertinent subsequent items following each specific-screener question.

The survey elicits feedback from beneficiaries on the most common service and support providers across the Medicaid HCBS authorities and programs, as listed below:

- Personal assistants
- Behavioral health staff
- Homemakers
- Case managers
- Medical transportation providers

A 21-item module on experience with employment support services focusing on job coaches is offered as a separate supplement. The supplemental survey covers the following areas:

- Help finding employment
- Selection of employment
- Reliability and helpfulness of job coach
- Ability of job coach to listen and communicate well
- Satisfaction with and recommendations for job coach

The HCBS CAHPS Survey is intended for Medicaid beneficiaries who are at least 18 years of age and have received HCBS services for at least 3 months. The survey was developed to be

administered by an interviewer in person or by telephone. English and Spanish versions of the instrument are available with links provided in Appendix C.

The survey is designed so that sponsors can tailor it to refer to the names of programs and providers used by the state. Furthermore, the survey can be tailored to include the names, terms, or titles that the respondent prefers to use to refer to the service provider. At the beginning of the survey, there are questions asking for the name, term, or title for the paid staff who provide a specific service. That name, term, or title then is used during the interview for that specific person.

The survey has two types of response options to increase accessibility. The standard CAHPS 4-point response scale (e.g., “never,” “sometimes,” “usually,” and “always”) is used as the primary response option. However, if a respondent finds these options challenging, the simpler alternative response option (“mostly yes” and “mostly no”) is used.

In some cases, even with an alternate response, eligible respondents cannot answer for themselves. In those situations, proxy respondents may answer questions for the beneficiaries. Although self-reporting is always preferred, allowing proxies can help HCBS programs obtain important feedback from the full range of beneficiaries.

The survey includes complex skip patterns and embedded names, terms, or titles for staff throughout. The survey is intended to be used with a computer-assisted telephone interview (CATI) system or computer-assisted personal interview (CAPI) system. The use of the CATI or CAPI system enables interviewers to skip questions automatically as appropriate and use respondents’ preferred and understood terms throughout the survey. To minimize the risk of incomplete surveys that result from instructions not being followed as intended, sponsors are cautioned about using paper surveys—those administered by an interviewer as well as those mailed to respondents.

III. ROLES AND RESPONSIBILITIES

This section outlines customary roles and responsibilities for sponsors of the HCBS CAHPS Survey as well as survey vendors. The actual survey vendor responsibilities should be determined by each survey sponsor.

A. Survey Sponsor Roles and Responsibilities

- Engage a survey vendor with experience in conducting surveys with HCBS or similar populations to administer the survey
- Work with survey vendor to customize the survey materials such as the prenotification letter, introduction scripts, and interview scripts
- Produce a complete, accurate, and up-to-date HCBS CAHPS Survey sample frame (i.e., list of eligible respondents from which the sample will be drawn)
- Select—or ensure that the survey vendor selects—the HCBS CAHPS Survey sample from the sample frame consistent with the approved sample design

- Designate a staff member as the HCBS CAHPS Survey administrator to serve as the survey vendor’s main point of contact for the HCBS CAHPS Survey. This person also should provide oversight before and during the survey administration and be able to respond to questions and work with the survey vendor to resolve any problems that may arise throughout survey administration.
- Provide the following materials to the survey vendors for review, and then confirm that the vendors can meet these essential elements:
 - Survey administration protocol
 - Timeline
 - Description of the secure data transfer protocol from the sponsor to the vendor and from the vendor to the sponsor
- Review vendor’s Quality Assurance Plan (QAP) and final survey materials
- Notify HCBS program beneficiaries that they may be contacted to participate in a survey via a prenotification letter that has been approved by the sponsor. A prenotification letter should be sent by either the sponsor or the survey vendor.
- Provide protocols for survey staff to use to identify and report abuse, neglect, or exploitation
- Provide survey vendors with the tools, format, and procedures for submitting the collected data
- Process, review, and analyze data files submitted by survey vendors (see Appendix J for the technical assistance guide for analyzing data)
- Provide survey results to stakeholders (e.g., participating HCBS providers, CMS, the public)

B. Survey Vendor Roles and Responsibilities

- Meet the Minimum Business Requirements articulated by the survey sponsor (see Appendix I-1)
- Comply with the requirements established by the sponsor noted in the business associate agreement, data use agreement, and contract to administer the HCBS CAHPS Survey
- Establish and maintain a Survey Management System to track survey cases while the survey is fielded
- Create a QAP (see Appendix I-2)
- Provide customer support for beneficiaries with questions about the survey
- If selecting the survey sample, receive and perform checks of the sponsor’s sample frame data file to verify that the sample frame data file includes all required data variables, and draw the eligible sample from the validated sample frame provided by the sponsor using the specifications provided in the contract
- If delegated by the sponsor, notify HCBS program beneficiaries that they may be contacted to participate in a survey via a prenotification letter approved by the sponsor
- Train interviewers on the protocol for administering the HCBS CAHPS Survey

- Administer the HCBS CAHPS Survey and oversee the quality of work performed by staff and subcontractors according to the protocols and procedures established by the sponsor and described in the contract
- Successfully submit a test data file by the deadline established by the sponsor
- Successfully submit all data files to the sponsor in accordance with the data file specifications in the contract by the data submission deadline established by the sponsor
- Meet all HCBS CAHPS Survey due dates (including submission of QAP and survey materials for review) or risk revocation of approval to administer the HCBS CAHPS Survey
- Conduct all business operations for the HCBS CAHPS Survey within the continental United States, Hawaii, Alaska, or U.S. territories so that the sponsor can perform the required quality oversight activities. This requirement also applies to all staff and subcontractors.

IV. PLANNING THE SURVEY

This section provides information about a number of topics that survey sponsors will need to consider in preparing to administer the HCBS CAHPS Survey.

A. Survey Vendor Selection

Survey sponsors will need to decide how to accomplish the data collection. Survey sponsors may use two major options for data collection: (1) in-house data collection directly by the survey sponsor, for example, state or other organization, or (2) data collection performed by an external vendor under a contract with the state. In-house data collection for state survey sponsors may involve using existing state employees or existing HCBS program staff, or hiring contract staff. Data collection through an external vendor can involve contracting with a survey research center (such as a university-based or for-profit organization) or contracting with a stakeholder group. Each option has potential benefits and challenges.

Table 2 provides information on factors for survey sponsors to consider when selecting a survey vendor.

Table 2. Questions for Sponsors to Ask During Vendor Selection

Topic	Questions to Ask	Recommendations
Survey Modes	What experience does the survey vendor have in administering in-person and telephone surveys?	Survey vendors should have at least 2 to 3 years of experience in administering in-person and telephone surveys.
Experience Surveying HCBS Populations	Does the survey vendor have experience conducting surveys with populations who receive HCBS, such as individuals with intellectual or developmental disabilities, physical disabilities, serious mental illness, or some combination?	The survey vendor should have experience administering surveys to individuals with a variety of disabilities, cognitive impairment, and serious mental illness.

Topic	Questions to Ask	Recommendations
Organizational Capabilities and Capacity	Does the survey vendor <i>currently</i> have the capabilities and capacity to administer the survey during the desired time frame?	Ensure that the survey vendor has the capabilities and capacity to administer the survey during the desired time frame. This includes ensuring that the survey vendor has both the correct software and a sufficient number of interviewers.
Survey Management System	Does the survey vendor have a survey management system and established procedures to track the progress of the survey?	Survey vendors should have an established survey management system that they will use to track the status of each sampled patient throughout survey administration.
Professional Organizations	Is the survey vendor or their staff a member of a survey research professional society such as the American Association for Public Opinion Research?	Members of professional society are required to adhere to a code of conduct.

Abbreviation: HCBS, Home and Community-Based Services.

B. Survey Sponsor Oversight and Coordination

Survey sponsors should identify one staff member to serve as the primary point of contact with the survey vendor. This person should work with the survey vendor to review survey materials, resolve any issues that may arise during data collection, and oversee the quality of the survey vendor’s work.

C. Survey Mode Selection

A key decision about fielding the HCBS CAHPS Survey is what mode or modes to use. Stakeholder input during the development of the instrument suggested that the in-person mode would be most appropriate for these populations. A telephone mode also was tested on the basis of stakeholder input and cost considerations. Telephone surveys typically are substantially less expensive because they take less time and do not involve travel. The field test results supported both modes as options for future use of the HCBS CAHPS Survey.

Depending on the population served, survey sponsors may consider choosing a mixed-mode approach that uses both telephone and in-person data collection methods to reduce the cost of data collection while ensuring the quality of the data collected. One version of this approach is for recruiters to offer participants their choice to take the survey either in person or over the telephone. Under another version of this approach, survey vendors would initially offer to administer the survey by telephone but would allow beneficiaries to request an in-person interview. Alternatively, the survey sponsor could request that individuals with one type of disability be interviewed only in person, whereas other beneficiaries would receive the survey by telephone. If mixed-mode data collection is desired, survey sponsors should work with their survey vendor to develop a protocol that works best for their state’s population.

D. Survey Incentives

The use of incentives—whether financial or otherwise—to encourage participation in the survey by HCBS program beneficiaries is not recommended. The survey was developed and tested to be conducted without incentives. Although there is considerable research indicating that incentives enhance response rates, the best practice is to not compensate survey respondents for their participation, because it could lead to more favorable evaluation of providers or the program and run the risk of biasing survey results. Most consumer experience of care surveys, including other CMS-administered CAHPS surveys, do not provide incentives to respondents.

E. Core Versus Key Survey Items

CAHPS surveys are designed to achieve standardization through the use of a core set of items that all survey sponsors use. The core items consist of all questions prior to the “About You” section of the HCBS CAHPS Survey (see Appendices C-1 and C-2, respectively, for the core English and Spanish surveys). As long as the sponsor retains all core items of the CAHPS questionnaire and does not modify or reorder the questions or response options, the HCBS CAHPS Survey qualifies as a CAHPS survey and can be referred to as such.

Although both terms are used to refer to CAHPS survey items, *core items* and *key items* have different meanings. In order to analyze the data, the Agency for Healthcare Research and Quality (AHRQ), which is responsible for the Consumer Assessment of Health Providers and Systems (CAHPS) program, recommends that analysis of CAHPS surveys be limited to “complete” surveys. The CAHPS definition of a *complete survey* is one in which a respondent provided a substantive response³ to at least half of the items that all respondents are eligible to answer in the survey. These substantive items that are considered when assessing complete surveys are referred to as *key items*. The set of survey items that all respondents are eligible to answer does not include items in the “About You” section. Furthermore, identification of key items for the HCBS CAHPS Survey should take into account that respondents are eligible to answer different survey questions on the basis of the HCBS services they receive. Some survey sponsors may use this definition of a complete survey to pay survey vendors for the number of complete surveys for which they submit data.

F. Supplemental Survey Items

CAHPS surveys also are designed to support customization through optional supplemental items that sponsors can use to gather whatever additional information they may need beyond the core survey items.

Supplemental items may be added before the “About You” section. Survey sponsors may add as many questions as they desire. However, additional items likely will result in greater data collection costs because of increased administration time. Also, adding questions may decrease

³ Substantive responses include all responses *other than* “don’t know,” “refused,” or “unclear.” A response of “no” is considered a substantive response.

response rates because of the increased length of the survey. The potential for a lower response rate may warrant an increase in the sample size to ensure that a sufficient number of responses to the key items are obtained to conduct analyses, which also increases the cost of the survey.

A particularly relevant example of additional questions is the 21-item supplementary item set regarding employment support services, which may be used by survey sponsors who provide these services through their HCBS programs (see Appendix C-3 and C-4, respectively, for the supplemental modules in English and Spanish).

G. Alternate Response Options

One of the unique features of this survey is that it includes two types of response options. First, there are the standard CAHPS response options for behavioral frequency (“never,” “sometimes,” “usually,” or “always”) and ratings of staff (rating of 0 to 10, 0 being the best and 10 being the worst). The second are alternate response options for behavioral frequency (“mostly yes” and “mostly no”) and for ratings of staff (“excellent,” “very good,” “good,” “fair,” or “poor”).

The purpose of including alternate response options is to facilitate more beneficiaries responding to the survey. In the development of the survey, it was found that some beneficiaries, particularly individuals with an intellectual or developmental disability, found the standard CAHPS response options challenging or were nonnumerate. Therefore, the alternate response options were developed to enable more beneficiaries to participate in the survey.

The process that was and is recommended for survey vendors is to start with the standard response options, which are shown first, and if a beneficiary cannot respond, ask the alternate question and response options. If a beneficiary needs the alternate question and response options three times, all further questions should be asked using the alternate question and response format.

H. Tailoring Features of the HCBS CAHPS Survey

To keep the CAHPS brand (i.e., be able to use the CAHPS name), neither a sponsor nor a survey vendor may omit a HCBS CAHPS Survey question or change the wording of the questions, the response categories, or the order of the questions in any of the surveys.

At the same time, the survey allows for tailoring to help the beneficiary focus on the correct provider. There are few uniform naming conventions for providers across programs and terms that individuals use in referring to their providers. Thus, the survey was designed so that sponsors can incorporate the name of the HCBS program from which the person receives services as well as *program-specific* terms for *categories* of staff and *provider-specific* terms for *individual* staff. The survey questionnaire denotes where the interviewer should use the appropriate term by setting it off in italics and curly brackets (e.g., {*program-specific term for these types of staff*}).

1. Data Necessary for Tailoring

Survey sponsors have and can provide the following information to survey vendors to facilitate tailoring of the survey by interviewers and to help sampled beneficiaries focus their answers to the survey. This information should be used by interviewers at the beginning of the survey, particularly during recruitment and in the eligibility questions of the survey.

The beneficiary-specific information to help tailoring includes the following:

- Beneficiary name, first and last
- Mailing address (address, city, state, and ZIP Code)
- Telephone number(s)
- Sex
- Date of birth
- Name and contact information of guardian (if applicable, as this would be used to contact the guardian to obtain survey participation consent)
- Services that beneficiary receives (personal care, behavioral health, homemaker, case management, employment) along with program-specific name for each of the services (this information can be used to assess appropriate responses to the cognitive screener)
- Names for each service provider (e.g., John Smith) for each service (this information can be used to remind respondents about services they receive by provider name in the identification questions of the survey)
- Preferred language (this would be used to send an appropriate prenotification letter and conduct the interview in the language preferred)

The program- or state-specific information to help tailoring includes the following:

- Name of the HCBS agency(ies) (this is used to tailor the prenotification letter and to remind the beneficiaries that the survey is about the staff from these agencies)
- Name of waiver program under which the beneficiary receives services (this also should be linked to each respondent primarily for analysis purposes because it can be an indicator of subgroups, e.g., individuals who are frail elderly or individuals with a serious mental illness)
- Program-specific title for each staff category (e.g., personal care assistant [PCA], staff) (this information is used in the identification questions of the survey)
- Program-specific title for “service plan”
- Program-specific term for “staff”
- State-specific language related to mandated reporting of abuse, neglect, or exploitation

The survey vendor’s CATI/CAPI programmer will tailor the survey as noted below:

- Where the survey states, “{*program-specific term for personal assistance*},” program in the administrative data for that term.

- Where the survey states, “{*program-specific term for behavioral health services*},” program in the administrative data for that term.
- Where the survey states, “{*personal assistance/behavioral health staff*},” program in the administrative data for program-specific terms for personal assistant and behavioral health staff (e.g., PCA or counselor). In addition, the program should allow for modification by the interviewer that changes the rest of the survey on the basis of the response to Question 5 and Question 7. For example, if a respondent states that he or she calls the personal assistant something else, such as “a worker” (or “my friend” or “Sally”) for Q5, the CATI/CAPI program should use “worker” (or “my friend” or “Sally”) in lieu of personal assistance staff. The survey vendor should be instructed to program the CATI/CAPI to autofill the respondent’s title wherever an item specifies “*personal assistance / behavioral health staff*.”
- Where the survey states, “{*program-specific term for homemaker services*},” program in the administrative data for that term.
- Where the survey states, “{*homemaker*},” program in the administrative data for that term. As noted in the bullet on personal assistance/behavioral health staff, allow for interviewer changes on the basis of respondent’s response to Question 9 on a title for the homemaker.
- Where the survey states, “{*program-specific term for case manager services*},” program in the administrative data for that term.
- Where the survey states, “{*case manager*},” program in the administrative data for that term. As noted in the bullet on personal assistance/behavioral health staff, allow for interviewer changes on the basis of respondent’s response to Question 12 on a title for the case manager.
- Where the survey states, “{*service plan*},” program in the administrative data for that term.
- Where the survey states, “{*staff*},” program in the administrative data for that term.
- Where the survey states, [ADD STATE-SPECIFIC LANGUAGE HERE REGARDING MANDATED REPORTING, IF APPROPRIATE]—“I want to remind you that, although your answers are confidential, I have a legal responsibility to tell {STATE} if I hear something that makes me think you are being hurt or are in danger,” program in the language for state-specific language related to mandated reporting of abuse, neglect, or exploitation.

2. Identification of Administrative Data for the Survey Vendor

Ideally, the survey sponsor would provide the administrative data necessary to tailor the survey, for example, the name of the HCBS agency and services provided. In other cases, sponsors may need to have the data updated. Sponsors may elect to update the data themselves; for example, a case manager could do so on behalf of the state or request a survey vendor to do so. If the administrative data are updated, and if guardian information needs to be updated, it is

recommended to update both at the same time. Appendix H includes a sample guardian and provider update telephone script. It is recommended that updating be accomplished at least 3 months before survey administration to decrease bias in responses. It is also recommended to update the entire sample frame, should the survey vendor need to obtain more sample for the field test. If the survey sponsor is not an MCO, the sponsor can ask the MCO or a coordinating agency who may have more up-to-date or more specific information to provide the data.

During the call to update information, it may be discovered that the services that a sponsor lists for a beneficiary are different than what the beneficiary, guardian, or proxy respondent perceives he or she is receiving. In the sample guardian and provider script, there is a place to capture those discrepancies for purposes of reporting back to the sponsor. A sponsor should inform the vendor about how to handle discrepancies in perceptions of services received for purposes of conducting the survey.

I. Survey Title and Branding

Although the official title of the survey is the “CAHPS Home and Community-Based Services Survey,” or HCBS CAHPS Survey for short, survey sponsors may make some modifications to the title to be more meaningful to those being surveyed while retaining use of the CAHPS trademark. According to AHRQ, the agency that provides the CAHPS trademark, there are no restrictions on the survey’s title. If a survey sponsor does not use “CAHPS” in the title of the questionnaire, AHRQ strongly recommends that the questionnaire be attributed to CAHPS in some way. For example, a survey sponsor might attribute it to CAHPS by stating, “This questionnaire includes the CAHPS Home and Community-Based Services Survey, which was developed and funded by the Centers for Medicare & Medicaid Services.” For more information on survey naming, refer to AHRQ’s “Modifying and Naming Your CAHPS Survey.”⁴

Sponsors may choose to add their logo to the prenotification letter and the envelope to help sampled beneficiaries more easily identify the source of the survey.

J. Decisions Regarding Proxy Respondents

Feedback on services received by Medicaid beneficiaries in HCBS programs is most useful when it reflects the experiences of program participants as communicated directly by those individuals. Although the survey was designed to be accessible to as many HCBS beneficiaries as possible, because of the nature of physical or cognitive challenges, some service recipients are not able to participate on their own in efforts to elicit their feedback. In that event, rather than excluding these individuals and their experiences or viewpoints from surveys and other information-gathering activities, one alternative is to rely on a proxy respondent to provide the input on behalf of the person with a disability. Although self-reporting always is preferred, using proxies

⁴ Agency for Healthcare Research and Quality. Modifying and Naming Your CAHPS Survey. Rockville, MD: Agency for Healthcare Research and Quality; last reviewed April 2017. <http://www.ahrq.gov/cahps/surveys-guidance/helpful-resources/modifying/index.html>

can help HCBS programs obtain important feedback from the full range of beneficiaries and will likely result in a higher response rate.

Survey sponsors should consider the following aspects regarding proxy respondents in the HCBS CAHPS Survey:

- Decision to use proxy respondents if a beneficiary is otherwise unable to participate in the survey, or to include beneficiaries who can complete the cognitive screening questions
- The types of individuals who can act as proxies, such as guardians, family members, and friends
- In the event that there is no institutional review board, whether to require guardian consent and/or beneficiary assent
- If a guardian or proxy may respond on behalf of the beneficiary, whether to require beneficiary assent to have a proxy respondent and who that proxy will be. From a person-centered perspective, users should consider prohibiting a proxy if the beneficiary does not agree to it.
- If a sponsor decides to allow proxies to respond, how to tailor the training materials (Appendix A), introductory script (Appendix E), and the survey (Appendix C) for proxies. For example, one opportunity to inquire about a potential proxy respondent occurs if a program participant does not pass the brief cognitive screener at the start of the survey.
- Tailoring the survey questions given that “you” is intended to refer to the beneficiary, not the proxy respondent.

If a sponsor decides to allow proxies to respond, include only one respondent in the numerator and denominator. Thus, when a beneficiary cannot respond because of not passing the initial cognitive screening items and a proxy completes the survey, the proxy is counted as the respondent. If both the beneficiary and the proxy fail the cognitive screener, only the beneficiary is counted. Sponsors should decide whether they want the survey vendor to capture whether a proxy was used because a beneficiary failed the cognitive screener or because the proxy answered the phone during the introductory call and stated that the beneficiary could not answer because of physical or cognitive reasons.

A prenotification letter and a telephone recruitment script that accommodates proxy respondents have been developed for survey sponsors to use for their HCBS programs (see Appendices D and E).

If proxies are allowed, it is recommended that the survey sponsor case-mix adjust the survey results for the proxy status of respondents (see Appendix J for specifications on case-mix adjusting).

1. Proxy Respondent Criteria

The survey sponsor should decide on the types of individuals who are allowed and not allowed as proxy respondents in the HCBS CAHPS Survey. In general, a person who is familiar with the services and supports that the beneficiary receives and has regular, ongoing contact with the beneficiary is more likely to be a good proxy respondent. Unpaid family members, friends, or neighbors may meet these criteria. A beneficiary's wishes should be honored if he or she chooses not to participate. In this case, no proxy should be used.

Excluding anyone who is paid to provide care or services to the sampled beneficiary as a proxy is strongly encouraged because it is inappropriate for a person who provides services to a beneficiary to provide feedback on his or her own performance. This exclusion also applies to family members and friends who are paid to help the beneficiary. Because the HCBS CAHPS Survey asks about the performance of paid staff, allowing paid staff to answer performance questions increases the potential bias and any perceived conflict of interest. It is also best that paid staff members are not present during the actual interview, unless the beneficiary specifically requests this. In addition, guardians or conservators whose only responsibility is to oversee the beneficiary's finances are less likely to be good proxy respondents, because they are unlikely to have sufficient knowledge of the quality of service and supports delivery and whether the beneficiary's preferences are addressed and goals are met.

K. Survey Administration Languages

In addition to English, the HCBS CAHPS Survey questionnaire is available in Spanish (see Appendix C-2 and Appendix C-4). One of the considerations for sponsors is whether to support a telephone and in-person version of the Spanish survey, and that will depend on the number of Spanish-speaking HCBS beneficiaries a sponsor has.

Translation services must be provided in accordance with federal and state requirements.⁵ The survey vendors are responsible for providing all required certified translators and translation services to interview non-English speaking sampled beneficiaries, regardless of the language the beneficiary speaks. Sponsors may choose to have the survey translated into other languages. For guidance on translation, see Appendix C-5.

V. SAMPLING SPECIFICATIONS AND SAMPLE FRAME

Sponsors should generate a complete, accurate, and valid sample frame data file that is representative of the entire eligible population for each reporting unit (defined below). Generating accurate and complete sample frames is important for data collection activities and the representativeness of survey results.

⁵ For more information, see the webpage on Translation and Interpretation Services on Medicaid.gov at <https://www.medicaid.gov/medicaid/finance/admin-claiming/translation/index.html>.

A. Unit of Analysis

The unit of analysis is the level for which survey results (scores) will be produced. The unit of analysis for the HCBS CAHPS should be the accountable entity (e.g., HCBS program, the MCO). An accountable entity is the 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 (e.g., department of aging), non-state governmental entities (e.g., county), or MCOs under managed long-term services and supports programs. In those cases, the operating entities then contract with direct service and support providers and case managers.

B. Survey Population and Sample Frame

A sample frame is a list of all eligible individuals in the HCBS unit being analyzed (e.g., a HCBS program, an MCO as part of a Medicaid managed long-term services and supports program).

Below are recommended criteria when determining which HCBS beneficiaries to include in the HCBS CAHPS Survey sample frame file:

- Individuals 18 years or older, because the survey audience is intended for adults
- Individuals continuously enrolled in an HCBS program for at least the last 3 months to ensure they have enough experience to answer the questions
- Individuals who have received at least one qualifying HCBS service (personal care, behavioral health support, homemaker services, case management, and medical transportation) because the survey is about these services

Individuals residing in an institution (i.e., individuals who are long-term nursing home residents or are expected to be in a nursing home in excess of 90 days) should be excluded from the survey sample, and, if identified during data collection, should be excluded from the survey. Survey sponsors should make efforts to exclude individuals who are known to be institutionalized when the sample frame is produced.

C. Sample Frame Generation

Sponsors can generate the sample frame and provide the appropriate random sample (i.e., number of individuals to sample from the frame) to the survey vendor. Alternatively, the survey sponsor can provide the entire sample frame data file to the survey vendor, who can then draw the random sample of HCBS beneficiaries. However, from a data confidentiality perspective, it is best to provide as little data to the survey vendor as possible to avoid potentially compromising confidentiality.

The sponsor should consider what data to provide the survey vendor as part of the sample frame. Table 3 summarizes the recommended data elements to generate for the sample frame and additional data elements that the survey vendor will need for tailoring the survey. Additionally,

these variables may be used in any analyses that the survey vendor may perform on behalf of the survey sponsor.

Table 3. Data Elements for Sample Frame and Tailoring

Data Elements for Sample Frame	Data Elements for Tailoring the Survey
<ul style="list-style-type: none"> • Beneficiary name, first and last • Mailing address (address, city, state, and ZIP Code) • Telephone number(s) • Sex • Date of birth • Name and contact information of guardian • Name of the HCBS agency(ies) • Name of waiver program under which the beneficiary receives services 	<ul style="list-style-type: none"> • Services that beneficiary receives (personal care, behavioral health, homemaker, case management, employment) and program-specific name for each of the services • Names for each service provider (e.g., John Smith) for each service • Preferred language • Program-specific title for each staff category (e.g., PCA, staff) • Program-specific title for “service plan” • Program-specific term for “staff” • State-specific language related to mandated reporting of abuse, neglect, or exploitation

Abbreviations: PCA, personal care assistant; HCBS, home and community-based services.

Sample files may be provided as a flat, ASCII fixed-width file, CSV, or Microsoft® Excel file. Survey sponsors should work with their survey vendor to determine the preferred and most feasible format in advance. Survey sponsors should ensure that the sample frame is transferred to the survey vendor using methods that are compliant with the Health Insurance Portability and Accountability Act and only through encrypted email.

D. Sample Size Determination

A primary function of CAHPS measures is to distinguish among the performance of entities being surveyed. Likewise, one use of the HCBS CAHPS Survey by sponsors will be to compare quality of services and supports across HCBS programs, other accountable entities (e.g., MCOs), or providers of HCBS services. A statistic called *unit-level reliability* indicates whether the measures in the survey are able to detect differences among these HCBS groups. Unit-level reliability is partly a function of the number of respondents used in the analysis, taking into consideration the measure-level response rate. Therefore, different measures will require different numbers of completed surveys per program to achieve an acceptable unit-level reliability. The estimated number of completed surveys needed to achieve acceptable unit-level reliability is the effective sample size (ESS). The ESS estimates from the HCBS CAHPS Survey field test for the composite measures ranged from 70 for *Choosing the Services That Matter to You* composite to 376 for the *Case Manager Is Helpful* composite. Thus, 400 is the recommended target ESS for future administrations.

To calculate the sample size, the survey sponsor will need to consider the ESS for the desired measures and the anticipated response rate. Data from the HCBS CAHPS Survey field test or the survey sponsor's experience with similar surveys and respondent populations can inform these predictions. The response rate is the percentage of people from the sample who complete the survey out of those who were offered the opportunity to take the survey. The sample size is the number of people asked to participate in the survey. The sample size will be larger than the ESS. The sample size accounts for the fact that not all people who are contacted about the survey will complete it. To determine the sample size, or number of people who should be offered the survey, divide the effective sample size of 400 by the expected response rate. In the field test, response rates varied by program type and survey mode.

For any subgroup comparisons (e.g., programs within states, MCOs within programs), obtaining 400 completed responses for each subgroup is important to ensure reliability of results. It is especially important that states considering using measures derived from the HCBS CAHPS Survey for incentivizing providers (i.e., value-based purchasing) follow this to ensure reliability of survey metrics used for payment incentives.

E. Drawing a Sample for the HCBS CAHPS Survey

Survey sponsors should discuss with their vendor the specific sampling method to be used. The steps for drawing a random sample follow a common structure, regardless of whether it is a simple random sample or a stratified random sample. First, identify the subgroups to be compared. This may be the different MCOs, case management agencies, or programs. Then, divide the population into the different subgroups of interest. Next determine the sample size for each stratum that will produce reliable estimates. Then, give each participant in each subgroup an identification number. Finally, select a random sample from an unsorted list from the frame until the desired sample size is met.

VI. INFORMATION SECURITY AND BENEFICIARY CONFIDENTIALITY

The Health Insurance Portability and Accountability Act (HIPAA) protects information about patients, which is referred to as protected health information (PHI). HIPAA also applies to electronic records, regardless of whether they are being stored or transmitted. For purposes of a Medicaid beneficiary survey, the survey sponsor is a covered entity under HIPAA and must adhere to HIPAA requirements for PHI. Thus, survey sponsors need to make sure that both they and survey vendors safeguard all information collected from sampled beneficiaries, as required by HIPAA.

A sponsor must develop and implement a data use agreement and a business associate agreement with the data collection entity that describes, in detail, plans for data security and confidentiality. Such a document would require that survey vendors adhere to the following requirements when conducting the HCBS CAHPS Survey:

- Keep confidential data secure, both physically and electronically
- Limit access to confidential data to authorized staff members only

- Prohibit sharing any information that can identify a sampled beneficiary with any individual or organization, including sponsors
- Implement procedures for identifying and handling breaches of confidential data

In addition, sponsors should require data collectors and survey vendors to provide the following assurances of confidentiality in all communications with sampled beneficiaries (written or verbal):

- Survey responses will never be reported with a sampled beneficiary's name or other identifying information.
- All survey responses will be reported in aggregate; neither the sponsor nor HCBS providers will be able to identify a sampled beneficiary's individual answers.
- Sampled beneficiaries can skip or refuse to answer any question they do not feel comfortable answering. Participation in the study will not affect the benefits that sampled beneficiaries currently receive or may receive in the future.
- In addition, all HCBS CAHPS Survey project staff will sign affidavits of confidentiality and are prohibited by HIPAA from using survey information for anything other than this research study.

VII. REPORTING ABUSE, NEGLECT, AND EXPLOITATION

If the data collector/survey vendor, typically an interviewer, observes or suspects abuse, neglect, or exploitation of the beneficiary, there are state laws that mandate reporting of these concerns. The survey sponsor should specify the protocol for the data collector or survey vendor to follow when potential or actual beneficiary abuse, neglect, or exploitation is encountered. The protocol should include whom to contact, how, and in what time frame. For example, the protocol may indicate that an interviewer who identifies potential abuse, neglect, or exploitation should contact a supervisor at the survey vendor. Someone from the survey vendor should then contact the appropriate state or program representative within the required time frame (e.g., same day, within 24 hours) as determined by the sponsor. If required, a description of the event also should be forwarded to the appropriate institutional review board.

VIII. FIELDING THE SURVEY

A. Prenotification Letter

The agreement between the survey sponsor and the survey vendors will include an overall communication plan to Medicaid beneficiaries receiving HCBS services, delineating the roles and responsibilities of the vendor and the sponsor. As part of the communication plan, a prenotification letter may be sent by the survey vendor or the sponsor to all sampled beneficiaries to provide information about the purpose of the HCBS CAHPS Survey.

1. Information Included in the Prenotification Letter

A sample prenotification letter can be found in Appendix D. Letters must be reviewed and approved by the sponsor before dissemination. Sending the letter using sponsor letterhead and envelopes may add to the credibility of the survey. Prenotification letters typically have the following features:

- Include the sampled beneficiary’s full name and address in the address block
- Contain a personal salutation (i.e., “Dear [Mr. / Ms. Beneficiary Name]”)
- Include the signature of a senior executive of either the survey vendor or the sponsor
- Insert the HCBS program name in designated fill locations
- Include the survey vendor’s toll-free customer support telephone number and project-specific email address
- Display the survey vendor’s logo, the sponsor’s logo, or both logos in the header
- Include the return address of the survey vendor
- Fit on one page and are printed using a font size equal to or larger than 12 points of a readable font (e.g., Times New Roman or Arial)

Survey sponsors may include additional requirements for the letter to which the survey vendor is expected to adhere. For example, it is strongly encouraged that survey vendors include tracking codes on prenotification letters to assist with quality assurance activities as long as the codes are unobtrusive and do not obscure the standard prenotification letter text.

Survey vendors should use address standardization techniques to verify that address information is current and is formatted to enhance deliverability. Survey vendors may use commercial tools such as the National Change of Address database to update addresses provided by the sponsor for sampled beneficiaries and to standardize addresses to conform to U.S. Postal Service formats.

If a prenotification letter is returned by the U.S. Postal Service as undeliverable, indicating a “bad address,” then survey vendors may not contact the sampled beneficiary by telephone for updated address information. However, survey vendors may begin the telephone interviews early (if desired) for a sampled beneficiary if confirmation of a bad address is received.

2. Timing of the Prenotification Letter

The prenotification letter should be mailed to beneficiaries 7 days before the initial recruitment telephone call. This allows for delivery time and provides time for the beneficiary to review information about the survey before the initial phone contact. The prenotification letter adds credibility to future contact attempts and has been shown to increase response rates.

3. Production and Mailing of Prenotification Letters

Survey sponsors will need to determine whether they would prefer to produce and mail the prenotification letters or whether this will be a responsibility of the survey vendor.

One key consideration is whether the survey sponsor has the capability to print and mail large numbers of letters efficiently. Survey vendors will have the capability to perform this work

in house or will have partnered with a print vendor who can easily and securely provide these services.

Another consideration is the timing of mailing the prenotification letter. Because the initial phone contact occurs 7 days after the prenotification letter is mailed, the prenotification letters may need to be mailed in waves to ensure that the survey vendor can contact all beneficiaries 7 days after the mailing. If this is the case, the survey sponsor would need to track which beneficiary letters are mailed on each day to ensure that the survey vendor conducts the telephone contacts at the appropriate time.

4. Contacting Guardians

The preferred respondent is always the HCBS beneficiary. Some beneficiaries have legal guardians. Having a legal guardian does not mean that an HCBS beneficiary cannot respond for him- or herself, but it does mean that the sponsors should follow state requirements regarding legal guardians, which typically involve contacting the legal guardian before the beneficiary respondent.

Survey sponsors should provide a list to the survey vendor of all beneficiaries with names, addresses, and phone numbers of guardians. Sponsors may contact guardians for consent or may ask survey vendors to contact guardians to obtain consent for beneficiaries to respond, and beneficiaries can then be contacted to obtain assent to participate in the survey. A sample guardian prenotification letter can be found in Appendix D, and a sample guardian and provider update script can be found in Appendix H.

As noted under tailoring the survey, the sponsor may have the data necessary to provide guardian information. In other cases, sponsors may need to ask staff such as case managers or the survey vendors to update the entire sample frame or just the sample. Appendix H presents a sample script to update guardian information. It is recommended that updating be accomplished at least 3 months before survey administration to decrease bias in responses. Updating the entire sample frame also is recommended, should the survey vendor need to obtain more sample for the field test.

For survey administration and working with the vendor, sponsors will need to take into consideration the extra time it may take to obtain guardian information and consent (if required).

B. Maximizing Beneficiary Participation

It is strongly recommended that the survey sponsor determine how beneficiaries will be notified that they may be asked to participate in the survey. As an example, before and during survey administration, it is helpful if the importance of the survey is communicated to beneficiaries. This could include indicating that their survey responses will be used to improve home and community-based services. Additionally, it may be helpful to communicate that the beneficiary was randomly chosen from all HCBS recipients in this program to provide his or her feedback.

Sometimes respondents may try to avoid completing the survey by providing a generic response at the outset. For example, a respondent might indicate that he or she has had excellent experiences or, alternatively, has had a poor experience. It is important to communicate to the beneficiary that completing the survey is critically important so that the program and state agency know about the parts of the program that are working well or, alternatively, the parts that are not working well.

Although it is important to encourage beneficiaries to participate, as previously discussed, it is important that staff not attempt to influence the beneficiary's responses.

Certain types of promotional communication—either oral, written, or in the survey materials (e.g., survey cover letters and telephone scripts)—are strongly discouraged, because these communications may introduce bias to the survey results. It is strongly suggested that survey sponsors and their vendors or other agents should not—

- Attempt to influence or encourage beneficiaries to answer survey questions in a particular way
- Imply that the sponsor, HCBS program providers will be rewarded or gain benefit from positive feedback provided by beneficiaries by asking beneficiaries to choose certain responses or indicating that the HCBS program is hoping for a given response

In order to avoid overburdening beneficiaries who receive invitations to take more than one survey, it is strongly recommended that survey sponsors avoid administering any other surveys during the 4-week period prior to the HCBS CAHPS Survey administration and while the survey is being fielded.

Sponsors can use a variety of strategies for recruiting beneficiaries who may have a greater risk of refusal. Examples of strategies include the following:

- Informing case managers of the survey's purpose and letting them know that a beneficiary may ask the case manager about the legitimacy of the survey. Case managers should be directed to acknowledge the legitimacy of the survey if they receive inquiries from beneficiaries, but not to engage the beneficiary in any conversations about how the person should respond to survey items (so as not to bias survey results).
- Enlisting advocacy groups to inform beneficiaries and their informal caregivers of the survey and to communicate the benefits of participating in the survey
- For beneficiaries with guardians, accessing up-to-date information on guardians before the initial contact to increase the efficiency of field operations and, ultimately, aid increased response rates
- Sending prenotification letters on state or program letterhead to sampled beneficiaries within 7 days of phone recruitment of the same beneficiaries
- Having the survey vendor make at least five call attempts to eligible sampled beneficiaries on different days of the week and at various times of day

- Leaving up to two voice mail messages to sampled beneficiaries who cannot be reached when making recruitment calls. Survey sponsors should work with their survey vendor to ensure that these messages are HIPAA compliant.
- Using two modes of administration—phone and in person
- Using the alternate response option to provide program beneficiaries with more opportunities to participate in the survey. Some participants may find the standard response options (“never,” “sometimes,” “usually,” or “always”) challenging; thus, allowing for the alternate responses of “mostly yes” and “mostly no” can enhance participation.
- Allowing beneficiaries to receive assistance from another person to complete the survey
- Allowing an appropriate proxy respondent to complete the survey on behalf of the beneficiary
- Describing how their responses will be kept private

Sponsors should work with survey vendors to determine which of these options, if any, they plan to implement.

C. Interviewer Training

Interviewer training is essential to ensure that interviewers are following protocols and procedures and that survey data are collected accurately and efficiently. Properly trained interviewers are thoroughly familiar with survey protocol and procedures and skilled in general interviewing techniques, including how to make initial contacts, deal with reluctant sampled beneficiaries, conduct interviews in a professional manner, and avoid influencing or biasing responses. Appendix A includes interviewer guidelines for administering survey. It also may be valuable for interviewers to review the disability sensibility online training module (see Appendix B). Interviewers should follow verbatim the survey scripts provided by the survey sponsor, use nondirective probes, record responses accurately, and maintain a neutral and professional relationship with the respondent. The survey is expected to take 30 minutes.

Although interviewers will receive general training on how to administer surveys, interviewers should receive project-specific training before they begin administering the HCBS CAHPS Survey. This project-specific training is particularly important given the complexity of the survey, as well as the vulnerable populations that are interviewed.

Survey vendors should train interviewers on how to conduct the survey depending on which mode is used. If interviewers are conducting only telephone surveys, training them on the use of CATI, telephone interview techniques, and issues relevant to the survey and populations are sufficient. If the interviewers are conducting in-person interviews, the same logic applies, focusing on the use of CAPI, in-person interview techniques, and issues relevant to the survey and population.

During this project-specific training, the survey sponsor and survey vendors should familiarize interviewers with the survey questions, the data collection specifications, and any project-specific scenarios that may arise during administration. It may also be beneficial for interviewers

to receive a copy of the prenotification letter that is sent so that they are aware of the contents of this letter. Survey sponsors should ensure that interviewers are trained on how to handle the following situations:

- Beneficiary is unable to answer the survey.
- Beneficiary has significant problems with the HCBS Program.
- Beneficiary has a legal guardian.
- Beneficiary's behavior poses a safety concern for beneficiary or interviewer.
- Beneficiary does not meet the selection criteria for the survey.

It may be beneficial for a staff member from the survey sponsor to participate in a project-specific interviewer training to answer questions that may arise during training regarding the HCBS program(s).

D. Respondent Support From Survey Vendors

Survey sponsors must determine how to provide respondent support throughout the process to beneficiaries, their caregivers, and guardians. This can be accomplished directly or by requiring survey vendors to establish a respondent support toll-free telephone number for sampled beneficiaries who have questions about the HCBS CAHPS Survey and/or the survey administration process. A sponsor should require survey vendors to demonstrate ability to provide these services and to meet requirements and/or milestones such as the following:

- Respondent support capabilities are operational by the start of the mailing of the prenotification letter. It is recommended that survey vendors test the functionality of the respondent support toll-free telephone number and email address before the start of survey fielding.
- Staff should be able to answer questions from English-speaking respondents and potentially from individuals using other languages determined by the sponsor. If the survey is funded by Medicaid dollars, for respondents who cannot speak English or other languages determined by the sponsor, enlist a translator to support the process.
- Respondent support telephone lines must be staffed live during the survey vendor's regular business hours.
- A voicemail mailbox must be available after hours and on weekends and federal holidays, and voicemail messages must be returned within 24 hours or on the next business day if the message is received during the weekend or on a federal holiday.
- Survey vendors should document and track respondent support phone calls and emails for quality assurance purposes and periodically assess the reliability and consistency of phone and email responses provided by customer support staff.

The sponsor must ensure that customer support staff are properly trained on the HCBS CAHPS Survey specifications and methodology, as well as have access to frequently asked questions (FAQs, in Appendix G) and corresponding responses. Customer support staff also must have a thorough

understanding of the rights of sampled beneficiaries and receive training to work with their supervisor or other appropriate staff to provide responses to questions that they are unsure how to answer. Escalation procedures should be identified for handling questions or issues. In addition, staff should understand how to implement the procedures. Customer support staff also must be able to handle questions via the toll-free telephone number in other languages as designated by the sponsor (if applicable). If customer support staff are not trained to administer telephone interviews, then they must be trained in procedures to transfer calls to telephone interviewers or to schedule callbacks.

E. Introductory and Recruitment Telephone Call

Survey sponsors should require survey vendors to make an introductory call after sending the prenotification letter to introduce the survey, explain the survey's purpose, and schedule the interview date and time for those who agree to participate. The sponsor and the vendor should agree on the timeline for the survey, and it should be specified in the agreement with the vendor. Vendors will use separate scripts and procedures for beneficiaries who have guardians. Additionally, during the introductory call, survey vendors should subscribe to the following procedures:

- Telephone interviews can be completed during this introductory call, pending verbal consent (if required) and respondent availability. Otherwise, telephone interviews should be scheduled for a future time that will work for the respondent.
- In-person interviews should be scheduled at a future time that will work for a respondent (and an interviewer).

See Appendix E for sample introductory script for the recruitment, set-up, and consent.

1. Number of Telephone Attempts

As directed by survey sponsors, survey vendors will attempt to reach sampled beneficiaries to conduct the telephone survey or schedule the in-person survey. Repeated telephone attempts are made until the sampled beneficiary is contacted or found ineligible, or the sponsor-determined number of contact attempts has been exhausted. After telephone attempts have been exhausted, no further attempts are made to contact the sampled beneficiary.

All sampled beneficiaries must be called at least the number of times agreed on with the sponsor, unless they are found to be ineligible, are away for the duration of the data collection period, or explicitly refuse to complete the survey. If a sampled beneficiary is found to be ineligible for the survey, the survey vendor must *not* continue to attempt to complete the survey.

If a survey vendor reaches a sampled beneficiary on the final call attempt and the respondent requests a callback, then survey vendors may call the respondent back. This may be done as long as the telephone data collection protocol is still open.

If a sampled beneficiary requests the survey vendor's inbound customer support line number during an outbound call attempt, the survey vendor provides the sampled beneficiary with its customer support line number.

If a sampled beneficiary calls customer support to complete an inbound telephone interview after the maximum telephone attempts have been reached, survey vendors still may administer the survey by telephone as long as the outbound telephone phase of the protocol is still open.

2. Leaving Messages on Answering Machines

Survey sponsors should work with their survey vendor to determine whether interviewers should leave messages for the sampled beneficiary on their voicemail or with another individual who answers the telephone. It is recommended to leave no more than two messages to avoid burdening beneficiaries. All voicemail messages must be HIPAA compliant; for example, voicemail messages should be specific enough for sample members or other individuals answering the phone to understand the purpose of the survey and how to respond but should not mention clinical diagnoses or procedures. Below is sample voicemail language.

Hello, this is {interviewer name} calling from {survey vendor} on behalf of {sponsor} to ask you to take part in a study about your experiences with {HCBS program name}. Your answers are very important and will be used to help improve the {HCBS program name} in the future. It is your choice to answer the questions, and how you answer will not affect any benefits you get. We will call you back in the next few days. If you would like to call us, our telephone number is {XXX-XXX-XXXX}.

3. Refusal Conversion

It is assumed that survey sponsors will conduct the survey on a voluntary basis and cannot do otherwise when surveying Medicaid beneficiaries.⁶ At the same time, survey vendors typically train interviewers in the use of refusal avoidance and conversion techniques.

Although implementing refusal avoidance and conversion techniques can improve response rates, using these techniques in certain scenarios is strongly discouraged. These situations include the following:

- When a sampled beneficiary indicates that he or she is currently at work and cannot answer the survey at work
- When a sampled beneficiary indicates that he or she is driving

In these situations, survey vendors may attempt to recontact the sampled beneficiary at a later time. In these situations, the follow-up call does not count as a separate attempt.

⁶ Sections 440.230-440.240 of 46 FR 47993 on Sufficiency of amount, duration and scope, and comparability of services for groups.

However, if a sampled beneficiary declines after the survey vendor uses conversion techniques, the survey should be ended.

F. Consent and Assent

Depending on the use of the survey findings, sponsors may or may not seek to obtain review and approval by an institutional review board. Institutional review boards may require (or sponsors may request) consent of guardians and/or beneficiaries and assent of beneficiaries with guardians. For telephone interviews, consent is verbal and typically is requested at the beginning of the survey before the respondent answers questions. For in-person interviews, written consent typically is presented and requested at the beginning of the interview and a copy of the consent form is given to the respondent (see Appendix F for the sample written consent form for in-person interviews). The beneficiary may withdraw consent at any time and end the interview. If that occurs, interviewers should thank the beneficiary and end the interview.

If a beneficiary has a legal guardian, sponsors should follow state laws regarding consent and assent. In all cases in which there is a legal guardian, regardless of state law, beneficiary assent is highly desirable.

G. Interacting With Proxy Respondents

Interviews involving proxy respondents may take place under a range of scenarios. A proxy may listen and support a beneficiary to respond, may respond on behalf of the beneficiary for some questions, or may respond on behalf of the beneficiary for all questions. Interviewers first should seek to conduct the interview with the beneficiary. However, there are three main situations that occur in which proxy respondents may respond according to specific instructions.

1. Upon calling to introduce the survey, a proxy may indicate that the beneficiary is physically or mentally unable to respond to the survey and suggest that the proxy respond. If a proxy indicates that the beneficiary is unable to respond because of physical or mental reasons, interviewers should be directed to ask the proxy the survey, including the cognitive screening questions at the beginning of the survey.
2. A beneficiary may start answering the cognitive screening questions and fail at least one of the questions. The survey vendor should capture this information and then seek to identify and interview a proxy. The survey vendor should include only one set of responses. Thus, if the proxy is reached and passes the cognitive screening questions, include only the proxy set of responses, not the failure of the beneficiary.
3. During the interview, a proxy also may be present and/or listen to the interview and provide answers to some or all of the questions. If the beneficiary and the proxy both are present during the survey administration, interviewers should be directed to state that they will first start asking questions to the sampled beneficiaries. If a response comes from both the beneficiary and the proxy and the responses are different, the vendor should use the beneficiary's response. If the beneficiary cannot answer, the vendor will use the proxy's response.

In all scenarios, in the fields specified at the end of the survey the interviewer should indicate who answered the survey and whether a proxy responded to all questions or only some of the questions.

H. Maximizing Beneficiary Privacy During Interview

The presence of HCBS staff, including paid family or friends, while the survey is being administered may bias the results. A sponsor should decide how to handle this situation. At a minimum, if the HCBS staff are present for the interview, the interviewer should indicate this in the field specified at the end of the survey. The following are some other options:

- Interviewers may speak with the respondent and the HCBS staff person to explain that it is important to conduct the survey privately.
- A respondent may feel more comfortable with an HCBS staff at the interview, may need 24-hour care, and/or the staff may be required to be present. If that is the case, the interviewer should ask whether he or she could conduct the interview in a room separate from the HCBS staff.
- Include all responses and adjust for differences.
- Continue with the interview but exclude the data from analysis.

I. Beneficiary Reports of Problems With the Program

The survey sponsor should determine the appropriate protocol for an HCBS beneficiary reporting any problems with the program. For example, if the respondent indicates during the initial phone call that he or she has significant concerns or problems with HCBS program services, survey vendors should provide the sampled beneficiary with contact information for the HCBS program and/or state, such as the phone number, email, or mailing address. Significant concerns with HCBS program services may include issues such as a worker routinely does not show up to provide services or equipment repairs have gone unheeded for an extended length of time. The survey vendor should receive sponsor-specific contact information before conducting any surveys, in the event that such issues are disclosed during the survey.

J. Interviewer Safety During In-person Interviews

The survey sponsor should determine the appropriate protocol if a beneficiary presents behavioral challenges that the interviewer perceives as compromising his or her safety. If there are some questions during the introductory call, the sponsor should consider requiring that the survey vendor send two individuals to the in-person interview. Interviewers never should be put in a situation in which they perceive that they may be in danger. Additional recommendations include the following:

- Matching the sex of the interviewer with the respondent
- Suggesting that interviewers seat themselves in a place from which they can easily leave
- Supporting interviewers to follow their instincts and leave if necessary
- Ensuring that interviewers bring cell phones with them to interviews

- Requesting that interviewers inform supervisors when they are at the place of the interview and when they are finished with the interview.

IX. SURVEY VENDOR UPDATES

Throughout data collection, vendors must maintain up-to-date, accurate disposition information for each sampled beneficiary to monitor the survey's progress. Survey vendors track progress using disposition codes that indicate the outcome of the most recent contact attempt. The survey sponsor should indicate whether the survey vendor must use the disposition codes developed by the American Association for Public Opinion Research (AAPOR)⁷ or disposition codes that have been developed internally.

Sponsors may wish to require that the survey vendors provide weekly updates of the number of completed surveys as well as other outcomes by survey disposition to the sponsor to monitor progress. Sponsors may wish to require that this report also include information on the number of proxy responses, the mode in which the survey is completed (if using both phone and in-person modes), or information on the status of sampled cases broken out by HCBS program or other variables relevant to the targeted number of complete surveys.

Survey sponsors should use this information to determine the progress of data collection and can use information from these reports to make decisions regarding the success of the survey or whether, if possible, additional sample beneficiaries may need to be added to the survey.

Throughout survey administration and prior to data submission, the sponsor may consider requesting that survey vendors conduct quality control measures on the data included in submission files to verify that data from completed phone and in-person surveys have been captured accurately. The sponsor also may want to conduct a quality assurance check on the interim data files. If the sponsor's review reveals any errors, he or she should consider requiring the survey vendor to correct the error and prevent it from happening during the rest of the survey.

X. FINAL DATA FILE

Working with the survey vendor, sponsors should specify when the final data and the final disposition codes are to be submitted to the sponsor and how. Along with survey data, the survey vendor should provide a final disposition report using disposition categories defined by AAPOR or developed by the survey vendor to meet the survey sponsor's information needs. This final

⁷ ESOMAR. AAPOR Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys. 2016. <https://www.esomar.org/what-we-do/code-guidelines/AAPOR-Standard-Definitions-Final-Dispositions-of-Case-Codes-and-Outcome-Rates-for-Surveys>

disposition for all sampled cases indicates the final outcome in terms of whether the beneficiary responded to the survey and, if not, why they did not respond.

A. File Format and Transmission Method

Survey sponsors should work with their survey vendor to request that vendors provide the final data file in a format that is most convenient for sponsors. The preferred file format likely will depend on the analysis software that will be used, such as SAS (SAS Institute Inc), SPSS (IBM), Stata (StataCorp), or R. Alternatively, the data file can be provided as flat, ASCII fixed-width file, CSV, or Microsoft Excel file, which can be used in a variety of software tools.

Depending on the arrangements the survey sponsor and the survey vendor make, the survey data may or may not have identifiers removed before submission to the sponsor. If the sponsor chooses to deidentify the data, the vendor should remove anything that identifies the information (name, address, phone number) from the data set.

Survey sponsors also should coordinate with their survey vendor to determine the preferred method to securely transmit the data file. Depending on the data elements that the survey sponsor requests be included in the data file, this file may contain PHI. Given the sensitive nature of these data, final data files should *not* be transmitted via email unless encrypted.

B. Quality Checks on Final Data File

Before submission of the final data file, the survey sponsor should request that the survey vendor perform a variety of checks on the final data file to ensure the quality and accuracy of the information in the data file. The following are examples of these checks:

- Requesting that the survey vendor randomly select 5–10 records and compare the information in the data file against the data in the vendor’s survey management system
- Ensuring that the data file includes records for the number of cases that were sampled
- Reviewing the frequency of the disposition codes in the file to determine the reasonableness and consistency with information from the survey management system

The sponsor also may want to conduct a quality assurance check on the final files. If the sponsor’s review reveals any errors, the sponsor should consider requiring the survey vendor to correct the error and resubmit the revised data.

XI. OVERSIGHT OF SURVEY VENDOR

To facilitate compliance with the sponsor-specified HCBS CAHPS Survey protocols, the sponsor should conduct oversight of all participating survey vendors. Examples of oversight-related activities that survey sponsors may choose to require of their survey vendor are described below. Specific oversight requirements that survey sponsors intend to implement should be noted in the survey vendor’s scope of work.

A. Quality Oversight Requirements for Survey Vendor

A survey sponsor can require a survey vendor to create and submit an HCBS CAHPS Survey Quality Assurance Plan (QAP). The QAP is a comprehensive document that is revised periodically by survey vendors to describe and document implementation of and compliance with all required HCBS CAHPS Survey protocols. The QAP also details the quality oversight and assurance processes that a survey vendor uses to verify high-quality data collection and continuity in survey processes. A sample HCBS CAHPS Survey QAP is in Appendix I-2.

B. Sponsor Oversight of the Survey Vendor

It is strongly encouraged that survey sponsors request that survey vendors submit for final review and approval all electronic versions of all survey materials for each survey mode and for each language in which the survey is being fielded. This may include English and Spanish survey materials and print-ready templates for prenotification letters.

Survey sponsors may require that survey vendors submit electronic copies of all materials for approval before volume printing and survey administration. All materials submitted to the sponsor for review should appear as they would to a survey respondent or interviewer.

The sponsor reviews survey materials and responds to survey vendors to request any necessary revisions on an agreed-on schedule. Survey vendors must submit revised materials within an agreed amount of time.

The survey sponsor should require that all survey materials in all applicable modes and languages be approved by the sponsor before the survey vendor may begin survey administration.

1. Telephone Monitoring

The survey sponsor also may conduct live monitoring of telephone interviews to assess various quality control criteria for each monitored interviewer (e.g., script adherence, probing, intonation, professionalism, neutrality, coding). Silent monitoring is useful for providing instant feedback to telephone staff. The sponsor may schedule remote telephone interview monitoring sessions with survey vendors during mutually convenient times.

To allow the survey sponsor to hear a variety of telephone interviews, monitoring sessions should be scheduled for a 2-hour duration. If the sponsor cannot observe a sufficient number of interviews during the initial telephone interview monitoring session, the sponsor may request an additional monitoring session at its discretion.

Another way to monitor is to request that the survey vendors record all interviews and review a fraction of the recordings. Another method is for the sponsor to contact a small portion of the completed survey respondents and ask a few of the questions from the survey to see whether they are the same or very similar. Finally, a sponsor could analyze the final data by interviewer and assess how many similarities there are. If the skips and responses are the same for a number of surveys, that would suggest that that fraudulent surveys were submitted.

As part of monitoring and quality assurance, survey sponsors may call a survey vendor’s telephone customer support line to ask standard questions. This customer support review allows the sponsor to assess whether responses provided by staff members are appropriate. The sponsor can also verify that calls to the customer support line are answered live during regular business hours and responses to email inquiries are received within the agreed-on time frame, for example, 24 hours or next business day. The sponsor provides feedback to the survey vendor as appropriate.

2. Review of Submitted Data

The survey sponsor may review and analyze all survey data submitted during and immediately following the data submission period to verify the integrity of the data. This review may include, but is not limited to, statistical and comparative analyses. If significant issues are identified, survey vendors may be asked to resubmit data.

XII. SURVEY TIMELINE

Table 4 is a sample timeline for planning the logistics to support the administration of the survey and to provide a sense of the length of time sponsors may need for the entirety of the survey project. The timing for each task will depend heavily on the specific directions set by the sponsor.

Table 4. Sample Planning Timeline for Survey Project

Task	Timeline
Sponsor provides all materials to survey vendor. <ul style="list-style-type: none"> • Final scope of work • Model Quality Assurance Plan (QAP) • Prenotification letter • Introductory recruitment script including a proxy script, if applicable • Survey in English and Spanish (if applicable) • Sample frame file layout • State mandatory reporting requirements 	Day 0
Survey vendor reviews materials.	Days 1 to 10
Survey vendor and sponsor meet or email regarding any necessary clarifications or refinements relating to administering the survey.	Days 10 to 20
Sponsor reviews interviewer guidelines for administering the HCBS CAHPS Survey with survey vendor management.	Day 23
Sponsors generate and submit a sample frame for each subgroup (HCBS program).	Days 30 to 40
Survey vendors submit QAP.	Day 40

Task	Timeline
<p>Survey vendor submits final survey materials to the sponsor for review. The sponsor responds to the survey vendor within 10 business days.</p> <p>In-person: Survey vendors submit CAPI screenshots to the sponsor for review and approval before in-person administration. Survey vendors submit CAPI screenshots for each language in which they are administering the survey (English and/or Spanish [if applicable]).</p> <p>Telephone: Survey vendors submit CATI screenshots to the sponsor for review and approval before telephone administration. Survey vendors submit CATI screenshots for each language in which they are administering the survey (English and Spanish, if applicable).</p>	Days 50 to 80
Survey vendor trains interviewers using the interviewer guidelines for administering the HCBS CAHPS Survey.	Days 70 to 80

Abbreviations: CAPI, computer-assisted personal interview; CATI, computer-assisted telephone interview; HCBS, home and community based services.

Table 5 is a sample timeline for the administration of the HCBS CAHPS Survey that can change based on the sponsor’s directions and needs.

Table 5. Sample Planning Timeline for Survey Administration

Task	Timeline
<p>Survey vendors sample beneficiaries according to sampling protocols.</p> <p>Confirm that samples meet specifications identified by the sponsor for telephone and/or in-person protocols.</p>	Days 0 to 30
Mail prenotification letter to sampled beneficiaries (English and/or Spanish [if applicable]).	Day 31
Open customer support phone center (toll-free phone number required).	Day 32
<p>Survey vendor initiates telephone interviews of sampled beneficiaries, including the following:</p> <ul style="list-style-type: none"> • Conducting at least five call attempts • Leaving voicemail messages • Ensuring that call attempts are scheduled to occur at different times of the day on different days of the week to maximize the likelihood of contacting the sampled beneficiary • Survey sponsors should consider requesting that call attempts should occur over a minimum of 2 different weeks during an 18-calendar-day telephone interview period. • Scheduling call attempts must be at different times of the day on different days of the week. 	Days 38 to 56

Task	Timeline
<p>Survey vendor initiates in-person interviews of sampled beneficiaries, including the following:</p> <ul style="list-style-type: none"> • Making at least five call attempts to set up interview • Leaving voicemail messages • Survey sponsors should consider requesting that call attempts should occur over a minimum of 2 different weeks during an 18-calendar-day telephone recruitment period. • Scheduling call attempts must be at different times of the day on different days of the week. • Survey sponsors should consider requesting that in-person interviews should be set up during an 18-calendar-day in-person interview period. • Scheduling call attempts must be at different times of the day on different days of the week. 	Days 38 to 74
<p>Review status of survey administration</p> <p>Review whether survey vendor will likely meet response rate goals or whether additional samples will be needed.</p> <p>If an additional sample is needed, follow the same time frames for the telephone and in-person time frames.</p>	Day 47 to up to 91 days