

# **Technical Assistance Guide for Administration of the Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services (HCBS CAHPS<sup>®</sup>) Survey**

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Appendix B: CAHPS Home and Community-Based Services Surveys

1. [CAHPS Home- and Community-Based Services Survey 1.0, English language \(https://www.medicaid.gov/medicaid/quality-of-care/downloads/cahps-home-and-community-based-services-survey-10-english.pdf\)](https://www.medicaid.gov/medicaid/quality-of-care/downloads/cahps-home-and-community-based-services-survey-10-english.pdf)
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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2. [Spanish participant pre-notification letter \(https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppC-Prenotif-Spa.pdf\)](https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppC-Prenotif-Spa.pdf)

Appendix D: Sample of Guardian Pre-Notification Letter for Administration of the CAHPS Home and Community-Based Services Survey

1. [English guardian pre-notification letter \(https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppD-Prenotif-Eng.pdf\)](https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppD-Prenotif-Eng.pdf)
2. [Spanish guardian pre-notification letter \(https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppD-Prenotif-Spa.pdf\)](https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPS-AppD-Prenotif-Spa.pdf)

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 Consent Form for the CAHPS Home and Community-Based Services Survey

1. [English 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>)
2. [Spanish consent form](https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPs-AppF-Consent-Spa.pdf) (<https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPs-AppF-Consent-Spa.pdf>)

Appendix G: Sample of General Frequently Asked Questions about the CAHPS Home and Community-Based Services Survey (<https://www.medicaid.gov/medicaid/quality-of-care/downloads/HCBSCAHPs-AppG-FAQs.pdf>)

Appendix H: [Sample of Guardian and Provider 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>)

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

Appendix J: 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-AppJ-VendorFAQs.pdf>)

Appendix K: 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-AppK-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) oversees and finances Medicaid home and community-based services (HCBS), which enable Medicaid participants with chronic illness or a disability to receive services in their own home or community rather than institutions or other isolated settings. These programs serve a variety of targeted population groups, such as older adults and people with intellectual or developmental disabilities, physical disabilities, and/or mental health or substance use disorders.<sup>1</sup> HCBS programs provide services and supports that allow these individuals to reside outside of institutions (e.g., home), get the assistance needed to perform basic activities of daily living (e.g., bathing, dressing, eating, toileting), and help them participate in community life including employment. Medicaid participants may also receive home health services (e.g., nursing, home health aide, medical supplies, equipment, physical or occupational therapy services) at their place of residence based on written medical orders.<sup>2</sup> With the majority of Medicaid long-term services and supports (LTSS) now provided in the community, mechanisms for measuring the quality of care delivered in those settings become imperative. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) Home and Community-Based Services Survey, hereinafter referred to as the HCBS CAHPS Survey, provides standard performance measures for HCBS programs.<sup>3</sup> Specifically, the survey gathers direct feedback from Medicaid participants receiving HCBS about their experience with the program.

### B. Overview of the Survey Administration Guide

This *Technical Assistance Guide for the Administration of the HCBS CAHPS Survey* (Survey Administration Guide) serves as an orientation to the data collection process for survey sponsors. Survey sponsors include state agencies that administer Medicaid and other state-funded HCBS programs as well as other entities that manage and oversee a specific HCBS program within a state (e.g., Medicaid state agencies, other state agencies such as departments of aging, non-state governmental entities such as counties, and managed care plans [MCP]). This comprehensive Survey Administration Guide supports sponsors in the administration of a survey, from planning to contracting with a survey vendor to receiving survey results. For more information about analyzing and interpreting the results, please see the [Technical Assistance Guide for Analyzing Data from the HCBS CAHPS Survey](#) (Data Analysis Guide). *Exhibit 1* lists the main sections of this guide with a brief description for each section.

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<sup>1</sup> For more information, visit <https://www.medicaid.gov/medicaid/quality-of-care/quality-of-care-performance-measurement/cahps-home-and-community-based-services-survey/index.html>.

<sup>2</sup> For more information on Medicaid home health services, visit <https://www.govinfo.gov/app/collection/cfr/2018/title42/chapterIV/subchapterC/part440/subpartA>.

<sup>3</sup> CAHPS<sup>®</sup> is a registered trademark of the Agency for Healthcare Research and Quality.

## Exhibit 1: Description of the Survey Administration Guide

Section	Description
II. 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
III. Roles and Responsibilities	Outlines customary roles and responsibilities for sponsors of the HCBS CAHPS Survey as well as survey vendors
IV. 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
V. 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)
VI. Information Security and Participant Confidentiality	Communicates necessary data security for the survey sponsor and vendor to be compliant with the Health Insurance Portability and Accountability Act (HIPAA)
VII. Reporting Abuse, Neglect, and Exploitation	Describes obligation to abide by state mandatory reporting laws on abuse, neglect, and exploitation
VIII. Fielding the Survey	Explains pre-notification letters, maximizing response rates, interviewer training, customer support, recruitment calls, consent and assent (if applicable), maximizing privacy, participant selection criteria, participant identification of problems with a program, and participant behavioral concerns
IX. Survey Vendor Updates	Provides recommendations on survey reporting timing and content
X. Final Data File	Communicates recommended file format and transmission method as well as suggested quality checks on the file
XI. Oversight of the Survey Vendor	Provides guidance on quality oversight, the quality assurance plan, and sponsor oversight of the survey vendor
XII. Survey Timeline	Presents a sample timeline for the entirety of the survey administration project and a sample timeline for the survey administration to the participants

## C. Key Resources to Implement the Survey

Introduced in *Exhibit 2*, the appendices to the Survey Administration Guide include materials useful for administering the survey and for background resources. If you have any questions or would like to request technical assistance, please email The Lewin Group (Lewin) at [HCBSmeasures@Lewin.com](mailto:HCBSmeasures@Lewin.com). For specific questions about the HCBS CAHPS Database or questionnaire, please contact Westat at [HCBSCAHPSDatabase@westat.com](mailto:HCBSCAHPSDatabase@westat.com).

### Exhibit 2: Survey Administration Guide Appendices

Support Type	Resource(s)
General Technical Assistance	CMS contracted Lewin to provide technical assistance to states related to the administration of the HCBS CAHPS Survey. For assistance, email: <a href="mailto:HCBSmeasures@Lewin.com">HCBSmeasures@Lewin.com</a>
HCBS CAHPS Database Technical Assistance	The Agency for Health Research and Quality (AHRQ) contracted Westat to provide technical assistance to states related to the HCBS CAHPS Database. For assistance, email: <a href="mailto:HCBSCAHPSDatabase@westat.com">HCBSCAHPSDatabase@westat.com</a>
Published Materials	<ul style="list-style-type: none"> <li>• Appendix A: Interviewer Guidelines for Administering the CAHPS Home and Community-Based Services Survey</li> <li>• Appendix B: CAHPS Home and Community-Based Services Survey <ul style="list-style-type: none"> <li>○ CAHPS Home and Community-Based Services Survey 1.0, English language</li> <li>○ CAHPS Home and Community-Based Services Survey 1.0, Spanish language</li> <li>○ CAHPS Home and Community-Based Services Survey 1.0: Supplemental Employment Module, English language</li> <li>○ CAHPS Home and Community-Based Services Survey 1.0: Supplemental Employment Module, Spanish language</li> </ul> </li> <li>• Appendix C: Sample of participant pre-notification letter for administration of the CAHPS Home and Community-Based Services Survey <ul style="list-style-type: none"> <li>○ English participant pre-notification letter</li> <li>○ Spanish participant pre-notification letter</li> </ul> </li> <li>• Appendix D: Sample of guardian pre-notification letter for administration of the CAHPS Home and Community-Based Services Survey <ul style="list-style-type: none"> <li>○ English guardian pre-notification letter</li> <li>○ Spanish guardian pre-notification letter</li> </ul> </li> <li>• Appendix E: Sample of introductory scripts for the CAHPS Home and Community-Based Services Survey <ul style="list-style-type: none"> <li>○ English introductory scripts</li> <li>○ Spanish introductory scripts</li> </ul> </li> <li>• Appendix F: Sample of consent form for the CAHPS Home and Community-Based Services Survey <ul style="list-style-type: none"> <li>○ English consent form</li> <li>○ Spanish consent form</li> </ul> </li> </ul>



Support Type	Resource(s)
Published Materials	<ul style="list-style-type: none"> <li>• Appendix G: Sample of Frequently Asked Questions about the CAHPS Home and Community-Based Services Survey</li> <li>• Appendix H: Sample of Guardian and Provider Telephone Script for the CAHPS Home and Community-Based Services Survey</li> <li>• Appendix I: Vendor Materials Associated with the Administration of the CAHPS Home and Community-Based Services Survey <ul style="list-style-type: none"> <li>○ Sample of Minimum Business Requirements</li> <li>○ Sample of Survey Vendor Quality Assurance Plan</li> </ul> </li> <li>• Appendix J: Sample of Frequently Asked Questions about the CAHPS Home and Community-Based Services Survey for Survey Vendors</li> <li>• Appendix K: Technical Assistance Guide for Analyzing Data from the CAHPS Home and Community-Based Services Survey</li> </ul>
Additional Online Resources	<ul style="list-style-type: none"> <li>• <a href="#">CMS HCBS CAHPS Survey Website</a>. This site includes additional information and materials to conduct the survey and analysis, including the <a href="mailto:HCBSmeasures@Lewin.com">HCBSmeasures@Lewin.com</a> mailbox for technical assistance questions.</li> <li>• <a href="#">AHRQ CAHPS Website</a>. This site provides general information on the CAHPS program and other CAHPS surveys, including the <a href="#">HCBS CAHPS Database</a>.</li> <li>• <a href="#">National Quality Forum Website</a>. This site provides National Quality Forum (NQF) measure specifications. NQF convenes multi-stakeholder Standing Committees in topical areas that review and recommend submitted measures for endorsement.</li> <li>• <a href="#">National Quality Forum Measure 2967</a>. This page provides information about NQF HCBS CAHPS measures.</li> </ul>

## II. OVERVIEW OF THE HCBS CAHPS SURVEY

### A. Context for the HCBS CAHPS Survey

CAHPS Surveys measure participant experience instead of satisfaction. Participant experience measures whether something that should have happened in a healthcare experience did occur, and how often.<sup>4</sup> This is in contrast with participant satisfaction, which measures whether a participant's expectations were met or not; two participants receiving the same care may have different participant satisfaction levels if their expectations and experiences are different. CAHPS uses measurements to objectively assess participant experience. As outlined in *Exhibit 3*, the CAHPS Consortium defined the underlying principles that are also crucial to all CAHPS Surveys.<sup>5</sup>

#### Exhibit 3: Underlying CAHPS Principles

Underlying CAHPS Principles
CAHPS questions focus on aspects of care for which the participant is the best or only source of information. For example, only a participant can tell whether a provider communicated in a way the participant could understand or whether the participant felt treated with respect.
CAHPS questions are understood and interpreted consistently by a range of consumers.
CAHPS questions ask participants to report on only care they have experienced and/or can observe.
CAHPS questions ask about aspects of healthcare delivery that are important to participants.
CAHPS questions are consistent with existing standards of healthcare delivery.
CAHPS reporting questions provide an explicit time frame (e.g., in the past six months) or event reference (e.g., during your hospitalization).
CAHPS questions include an explicit reference to the clinician, organization, or facility that is the focus of the survey.
CAHPS Surveys consist of a core set of questions that are administered to all respondents in a standardized manner.
CAHPS Surveys are suitable for comparisons across heterogeneous populations.
CAHPS Surveys can be self-administered.

The CMS works with states, consumers and advocates, providers, and other stakeholders to create sustainable, person-driven, LTSS systems. These systems provide people with disabilities and chronic conditions with choice, control, and access to a full array of quality services that promote optimal outcomes, such as independence, health, and quality of life. CMS is responsible for the oversight of and, in partnership with states, financing of Medicaid HCBS programs. The HCBS CAHPS Survey was developed by CMS, the largest funder of HCBS through Medicaid, for voluntary use by state Medicaid programs, including both fee-for-service HCBS programs as well as managed LTSS (MLTSS) programs. States with adequate sample sizes may consider using the HCBS CAHPS Survey measures in value-based purchasing initiatives.

<sup>4</sup> Agency for Healthcare Research and Quality. What Is Patient Experience? Rockville, MD: Agency for Healthcare Research and Quality; updated Marcy 2017. <https://www.ahrq.gov/cahps/about-cahps/patient-experience/index.html>.

<sup>5</sup> Crofton C, Lubalin JS, Darby C. Consumer Assessment of Health Plans Study (CAHPS®): Foreword. Medical Care 1999 March 37(3):MS1-MS9

The goal of the HCBS CAHPS Survey is to provide standard experience measures for HCBS programs that apply 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:

- Older adults;
- Individuals with physical disabilities;
- Individuals with intellectual or developmental disabilities;
- Individuals with an acquired brain injury; and
- Individuals with serious mental illness.<sup>6</sup>

The results from the HCBS CAHPS Survey enable HCBS program administrators to identify areas for quality improvement and to provide stakeholders with comparisons across HCBS programs within a state or across states. Although other participant experience of care surveys has been developed and tested and are currently in use with HCBS recipients in various states, no other survey has the ability to provide comparable information on HCBS program participants across the spectrum of disability-related and federally funded services. In addition, use of HCBS CAHPS allows program administrators to participate in the HCBS CAHPS Database. This participation provides programs with useful data comparing programs within and across states.

## **B. Key Features of the Survey**

The HCBS CAHPS Survey received the CAHPS trademark in June 2016. Nineteen measures derived from the survey also received endorsement from NQF in October 2016. Among other measures, the survey items support scale measures, which are composed of multiple questions that ask about related topics or areas of care. Composite measures summarize overall quality of care that cross multiple measures through the use of one value or piece of information. CMS provides information on staff reliability, communication, support, choice of services, safety, community inclusion, and empowerment using scale and composite measures that rely on data from HCBS CAHPS.

The HCBS CAHPS Survey is designed for Medicaid participants who are at least 18 years of age and have received HCBS services for at least three 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 B. The Spanish version was developed using two translators to each produce a forward translation from English to Spanish and then having the two forward translations reviewed (by a separate bilingual reviewer) against each

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<sup>6</sup> The pilot group included individuals with serious mental illness served by HCBS programs. The Survey Administration Guide expands use of the HCBS CAHPS Survey to individuals with mental health and substance use disorders.

other and compared to the original English survey. This process, along with testing by non-English speakers, ensures linguistic and cultural relevance.

HCBS programs, services, and providers are called different things in different states. The survey is designed so that sponsors can tailor the overall survey to use the names of programs and providers that are used in the state, so they are recognizable to participants. Furthermore, the survey can be tailored for each individual respondent to include the names, terms, or titles that the respondent prefers to use to refer to specific service providers. However, survey items and response options cannot be modified. At the beginning of the survey, respondents are asked 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 includes 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.

The survey has two types of response options to increase accessibility. The standard CAHPS 4-point response scale (i.e., "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 (i.e., "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 participants. Although self-reporting is always preferred, allowing proxies can help HCBS programs obtain important feedback from the full range of participants.

## **1. Survey Structure**

The HCBS CAHPS Survey includes a maximum of 69 core items that accurately and reliably measure participant experience with the Medicaid HCBS delivered. The core items ask participants to report on their experiences with getting needed services, communication with providers, case managers, choice of services, medical transportation, personal safety, and community inclusion and empowerment. A set of supplemental items asks participants about experience with employment services. As long as the survey retains all core items 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. Many of the items in the HCBS CAHPS Survey are preceded by screener or gate questions. These questions determine what questions will be asked next, so that only those participants for whom a particular set of questions is relevant are asked to answer those questions. While the survey has 69 questions, many participants will answer fewer questions because they do not receive all services covered in the survey.

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; and
8. Ratings of providers.

The survey begins with three cognitive screening questions that the individual should answer in a meaningful way in order to continue the interview:

1. Does someone come into your home to help you?
2. How do they help you?
3. What do you call them?

These questions are referred to as cognitive screening questions because they generally assess a participant's cognitive ability to participate in the survey. The questions anchor the respondent and interviewer to complete the relevant sections of the survey. The HCBS CAHPS Survey does not contain traditional cognition-related questions.

Then, the survey includes a set of nine questions that identify the following types of providers from which the participant could receive services, as listed below:

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

Based on the participant's responses to the types of providers in their home from above, the survey introduces skip patterns which individualize the questions to elicit feedback from participants on the most common services in the Medicaid HCBS authorities and programs. For example, if a participant receives personal assistance services, the survey asks about help with everyday activities such as dressing or cooking meals. In comparison, if a participant responds that they have medical transportation providers, the survey asks about timeliness of the transportation and accessibility.

The instrument ends with a set of 15 demographic questions. The demographic questions include health status, age, gender, education level, race, ethnicity, language, and who participants live with.

The survey takes most respondents about 30 minutes to complete. It will take longer for respondents who receive all of the types of services asked about in the survey than for those who only receive one or two types of services.

A 21-item Supplemental Employment Module on experience with employment support services focusing on job coaches is offered as a separate supplement and can be added before the demographic questions. The Supplemental Employment Module covers the following:

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

### **C. HCBS CAHPS Database Participation**

The HCBS CAHPS Database is a CMS and AHRQ initiative that provides program-level data to assess participant experience as well as de-identified data for research purposes. Survey sponsors that conduct the HCBS CAHPS Survey have the opportunity to submit their data to the HCBS CAHPS Database. Participating in the database offers sponsors access to valuable data that can help with analysis and quality improvement. Some specific benefits of submitting to the database include:

- A private, customized feedback report comparing sponsor's results to overall HCBS CAHPS Database results;
- Inclusion in other reporting products: online reporting system, chartbooks, and data set for research; and
- Technical assistance with the submission process.

Survey sponsors may participate in and administer the HCBS CAHPS Survey in all HCBS programs, provided the questionnaires are administered independently and survey data are submitted according to CAHPS specifications. The CAHPS Database supports and collects the HCBS CAHPS Survey 1.0 and the HCBS CAHPS Survey 1.0 with the Employment Module Item Set.

Users must use the original version of the HCBS CAHPS Survey to be able to submit to the database. If a survey sponsor intends to submit their data to the database, they are strongly encouraged to submit the questionnaire they plan to use to the HCBS CAHPS Database mailbox ([HCBSCAHPSDatabase@westat.com](mailto:HCBSCAHPSDatabase@westat.com)) before fielding the survey to check that it meets the qualifications for inclusion in the database.

The HCBS CAHPS Database Online Submission System opens once a year in October. Survey sponsors that choose to participate follow four simple steps:

1. Register and provide state information via an online database registration form;
2. Sign and upload a data use agreement (DUA) to the HCBS CAHPS Database;
3. Submit a copy of the HCBS CAHPS Survey instrument used for data collection; and
4. Submit data files according to the required database specifications.

For more information, sponsors can visit <https://www.ahrq.gov/cahps/cahps-database/submitting-data/index.html> or contact [HCBSCAHPSDatabase@westat.com](mailto:HCBSCAHPSDatabase@westat.com) for additional technical assistance from Westat.

### 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. Hiring a Vendor for a CAHPS Survey

Users of CAHPS Surveys typically seek out and contract with a survey vendor to administer the survey and sometimes to analyze and report the results. Unless specified by an external organization, the use of survey vendors is recommended but not required.<sup>7</sup>

Neither the HCBS CAHPS program nor the HCBS CAHPS Database has a vendor certification process. Any vendor who administers the appropriate version of a survey and follows HCBS CAHPS data collection and submission protocols may submit data to the HCBS CAHPS Database.

To find a vendor in your area, you may want to consult with:

- National Committee for Quality Assurance (NCQA), which certified vendors for two CAHPS Surveys:
  - CAHPS Health Plan Survey: [NCQA Certified CAHPS 5.0H Survey Vendors](#);
  - CAHPS Patient-Centered Medical Home (PCMH) Survey: [CAHPS PCMH 2018 Certified Survey Vendors](#);
- The Centers for Medicare & Medicaid Services:
  - For the [CAHPS Hospital Survey](#);
  - For the [CAHPS Home Health Care Survey](#);
- A local university, which may have a survey research center or can recommend local vendors; and
- Other departments in your organization that may have used survey vendors for other purposes.

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<sup>7</sup> For more information, see <https://www.ahrq.gov/cahps/surveys-guidance/helpful-resources/hiring/index.html>.

## B. Survey Sponsor Roles and Responsibilities

Survey sponsor roles and responsibilities include the following:

- Engage a survey vendor with experience in conducting surveys with HCBS participants or similar populations to administer the survey;
- Work with the survey vendor to customize the survey materials such as the pre-notification 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; and
  - 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;
- Submit final survey materials for review to the CMS HCBS CAHPS Technical Assistance Contractor, Lewin at [HCBSmeasures@Lewin.com](mailto:HCBSmeasures@Lewin.com), and the AHRQ CAHPS Database Contractor, Westat at [HCBSCAHPSDatabase@westat.com](mailto:HCBSCAHPSDatabase@westat.com), if planning to submit data to the HCBS CAHPS Database (*Note:* It is recommended that the proposed questionnaire be submitted to the Lewin and Westat teams before conducting the survey to ensure that it meets standards for participation in the HCBS CAHPS Database);
- Notify HCBS program participants that they may be contacted to participate in a survey via a pre-notification letter that has been approved by the sponsor. A pre-notification 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 to the sponsor;
- Ensure that responses recorded fall within the expected responses for each question;
- Process, review, and analyze data files submitted by survey vendors and submit data to the HCBS CAHPS Database (see Appendix K for the technical assistance guide for analyzing data); and



- Provide survey results to stakeholders (e.g., participating HCBS providers, CMS, the public).

### **C. Survey Vendor Roles and Responsibilities**

Survey vendor roles and responsibilities include the following:

- 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, DUA, 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 participants 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 participants that they may be contacted to participate in a survey via a pre-notification 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;
- Ensure that responses recorded fall within the expected responses for each question, if delegated by the sponsor;
- Process, review, and analyze data files submitted by survey vendors, if delegated by the sponsor (see Appendix K for the technical assistance guide for analyzing data);
- Successfully submit a test data file by the deadline established by the sponsor;
- Successfully submit all data files to the sponsor following 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; and
- 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 several 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 choose between two primary strategies 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 sponsor. 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.

*Exhibit 4* provides information on factors for survey sponsors to consider when selecting a survey vendor.

**Exhibit 4: 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. States that are less familiar with CAHPS Survey administration should select a vendor with experience administering CAHPS 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, mental illness and substance use disorders, or some combination?	The survey vendor should have experience administering surveys to individuals with a variety of disabilities, cognitive impairment, and mental health and substance use disorders. Vendors may employ people with disabilities to conduct surveys.
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 person throughout survey administration.

Topic	Questions to Ask	Recommendations
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 a professional society are required to adhere to a code of conduct.
HCBS CAHPS Database Participation	Is the survey vendor able to plan on aligning data and transferring it to the HCBS CAHPS Database?  Are there any DUAs that need to be completed by the survey sponsor and survey vendor?	Survey sponsor should make the vendor aware of database participation and any associated requirements.

Survey sponsors should also work to make the vendor aware of any HCBS CAHPS Database requirements during the contract process to ensure proper planning. Vendors should understand that participation in the HCBS CAHPS Database is an expectation.

**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**

Stakeholder input during the development of the instrument suggested that the in-person mode is the most appropriate for these populations. Telephone surveying has also been tested and both modes have been determined to be valid options for use of the HCBS CAHPS Survey. Telephone surveys typically are substantially less expensive because they take less time and do not involve travel.

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 participants to request an in-person interview. Alternatively, the survey sponsor could request that individuals with a specific disability be interviewed only in person, while other participants 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 the population being surveyed.

Because of the importance of the interviewer being able to tailor the terminology so it is understandable to each respondent and the importance of following the complex skip patterns correctly, sponsors are cautioned against using paper surveys – either those administered by an interviewer or those mailed to respondents.

#### **D. Survey Incentives**

The use of incentives—whether financial or otherwise—to encourage participation in the survey by HCBS program participants 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 a more favorable evaluation of providers or the program and may bias the 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 before the “About You” section of the HCBS CAHPS Survey (see Appendix B for the core English and Spanish surveys).

Although both terms are used to refer to CAHPS Survey items, *core items* and *key items* have different meanings. To analyze the data, AHRQ, which is responsible for the 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 response<sup>8</sup> 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 *reportable items*. Furthermore, the identification of reportable items for the HCBS CAHPS Survey should take into account that respondents will answer different survey questions on the basis of the HCBS they receive. Due to skip patterns built into the survey based on HCBS received, some participants (or proxies) may not answer many questions. A survey is considered complete if the participant (or proxy) provides information on at least half of the reportable items that participants are eligible to answer. The reportable items that participants are eligible to answer will depend on responses to items 4, 6, 8, and 11 and parent questions throughout the remainder of the HCBS CAHPS Survey instrument.

Complete surveys should also have a response to at least one *key item*. Key items are the survey questions that all respondents should answer, including:

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<sup>8</sup> Substantive responses include all responses *other than* “don’t know,” “refused,” or “unclear.” A response of “no” is considered a substantive response.

- Questions confirming eligibility for the survey;
- The screeners for the questions included in the core composite measures;
- The primary rating question; and
- Demographic and other background items.

Some survey sponsors may use this definition of a complete survey to pay survey vendors for the number of complete surveys for which the vendor submits data.

## F. Supplemental Survey Items

As shown in *Exhibit 5*, CAHPS Surveys also are designed to support customization through optional Supplemental Items that sponsors can use to gather additional information beyond the survey items.

**Exhibit 5: CAHPS Survey Model**



### CAHPS Survey Trademark

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. For the HCBS CAHPS Survey, this means that all 69 core items must be included.

As shown in *Exhibit 6*, Supplemental Items can be added to the HCBS CAHPS core survey to create a customized survey. **Supplemental Items or questions may only be added immediately before the “About You” section.** However, sponsors should be cautious because the HCBS CAHPS Survey generally takes 30 minutes to administer. Adding more items will result in greater data collection costs and may decrease 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.

Supplemental Items should not be confused with added questions in general. Supplemental Items are questions that are part of an approved CAHPS Survey. Adding any questions to the survey beyond the Core Survey and approved Supplemental Items eliminates the potential to participate in the HCBS CAHPS Database. Additionally, the HCBS CAHPS Survey has only been validated for use in its entirety (plus any approved Supplemental Items) and not in parts or with additional questions included.

A particularly relevant example of additional questions for the HCBS CAHPS Survey is the 21-item Supplemental Employment Module regarding employment support services, which may be used by survey sponsors who provide these services through their HCBS programs (see

Appendix B-3 and B-4, respectively, for the Supplemental Employment Module in English and Spanish). Below is an example of Supplemental Items added to the HCBS CAHPS Survey by the state of Florida. It includes an item from the Supplemental Employment Module added before the About You section.

**Exhibit 6: Sample Supplemental Survey Questions**

Question	Response
Question from Supplemental Employment Module	In the last 3 months did you work for pay at a job? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> DON'T KNOW <input type="checkbox"/> REFUSED <input type="checkbox"/> UNCLEAR RESPONSE

**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 (i.e., “Never,” “Sometimes,” “Usually,” or “Always”) and ratings of staff (i.e., rating of 0 to 10, 10 being the best and 0 being the worst). The second is alternate response options for behavioral frequency (i.e., “Mostly yes” and “Mostly no”) and for ratings of staff (i.e., “Excellent,” “Very good,” “Good,” “Fair,” or “Poor”).

The purpose of including alternate response options is to help more participants to respond to the survey. In the development of the survey, some participants, particularly individuals with an intellectual or developmental disability, found it challenging to select from the standard CAHPS response options. Interviewers can use alternate response options to enable more participants to complete the survey.

It is recommended that survey vendors start with the standard response options, which are shown first, and if a participant cannot respond, ask the alternate question and response options. If a participant 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 trademark (i.e., to be able to use the CAHPS name), neither a sponsor nor a survey vendor may omit an 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 tailored wording to help the participant 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 should provide the following information to survey vendors to facilitate tailoring of the survey by interviewers and to help participants understand what they are being asked. 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 program- or state-specific information to help with tailoring the survey includes the following:

- Name of the HCBS provider agencies (this is used to tailor the pre-notification letter and to remind the participant that the survey is about the staff from these provider agencies);
- Name of program under which the participant receives services (this also should be linked to each respondent primarily for analysis purposes because it can be an indicator of subgroups, [e.g., older adults, persons with physical disabilities, persons with intellectual or developmental disabilities, persons with acquired brain injury, and persons with mental health or substance use disorders];
- Program-specific title used 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 used for “service plan;”
- Program-specific term used for “staff;” and
- State-specific language related to mandated reporting of abuse, neglect, or exploitation.

The participant-specific information to help with tailoring the survey includes the following:

- Participant 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 (e.g., legal representative, legal guardian) if applicable, as this would be used to contact the guardian to obtain survey participation consent;
- Services that participant receives (e.g., personal care, behavioral health, homemaker, case management, employment) along with the 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); and
- Preferred language (this would be used to send an appropriate pre-notification letter and conduct the interview in the language preferred).

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 a personal assistant and behavioral health staff (e.g., PCA or counselor). Also, the program should allow for modification by the interviewer that changes the rest of the survey based on the response to Question 5 and Question 7. For example, if a respondent states that they call the personal assistant something else, such as “a worker” (or “my friend” or “Sally”) for Question 5, the CATI/CAPI program should use “worker” (or “my friend” or “Sally”) instead 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 based on the 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 based on the 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; and
- 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**

The survey sponsor should provide the HCBS program’s administrative data necessary to tailor the survey. However, if the respondent provides another term, that term should be used in place of the program-specific term wherever indicated. For example, some respondents may refer to their case manager by another title, which should be used instead throughout the survey.

Appendix H includes a sample telephone script for guardians. It is recommended that updating the administrative data be accomplished at least three months before survey administration to decrease bias in responses. This helps reduce bias in two ways. First, using administrative data to update the survey with the most recent program terminology can reduce risk of response bias if the participant does not recognize outdated terminology when asked about the services they receive. Second, including current administrative data for participants ensures that the proper pool of potential respondents is available for sampling, thus reducing risk of a bias in sampling. It is also recommended to update the entire sample frame, should the survey vendor need to obtain a larger sample for the field test. If the survey sponsor is not an MCP, the sponsor can ask the MCP 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 participant are different than what the participant, guardian, or proxy respondent perceives they receive. 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. For example, the [State or MCP] HCBS CAHPS Survey. 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](#).”<sup>9</sup> Sponsors are encouraged to add their logo to the pre-notification letter and the envelope to help sampled participants more easily identify the source of the survey.

## **J. Decisions Regarding Proxy Respondents**

Feedback on services received by Medicaid participants 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 participants as possible, because of the nature of physical or cognitive challenges, some service recipients are not able to participate on their own. 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. Direct participation from the person with a disability is preferable because it best captures the firsthand participant experience. Survey sponsors and vendors should ensure that interviewers are trained to appreciate the experiences and responses of people with disabilities and to only use a proxy when absolutely necessary. Although self-reporting always is preferred, using proxies can help HCBS programs obtain important feedback from the full range of participants and will likely result in a higher response rate. In order to follow person-centeredness best practices, users should prohibit a proxy if the participant does not agree to it. In this case, the participant is excluded from the survey.

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

- Decision to use proxy respondents to support participant response if a participant is otherwise unable to respond to the survey on their own, to include participants who cannot complete the cognitive screening questions in a meaningful way, or to exclude participants who cannot complete the cognitive screening questions in a meaningful way with no proxy response option;
- The types of individuals who can act as proxies, such as guardians, family members, and friends;
- If there is no institutional review board, how to record guardian consent and/or participant assent if the guardian and participant are cognitively able to provide it;
- If the participant and/or guardian are cognitively unable to provide assent and consent, respectively, whether to include the participant in the survey;
- If a guardian or proxy may respond on behalf of the participant, how to record participant assent to have a proxy respondent and who that proxy will be;

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<sup>9</sup> 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>

- 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 B) 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); and
- Tailoring the survey questions given that “you” is intended to refer to the participant, 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 participant 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 participant and the proxy fail the cognitive screener, only the participant is counted as a non-response. Sponsors should decide whether they want the survey vendor to capture whether a proxy was used because a participant did not pass the cognitive screener or because the proxy answered the phone during the introductory call and stated that the participant could not answer because of physical or cognitive reasons.

A pre-notification letter and a telephone recruitment script that accommodates proxy respondents have been developed for survey sponsors to use for their HCBS programs (see Appendix C, Appendix D, and Appendix E).

If proxies are allowed, survey sponsors should case-mix adjust the survey results for the proxy status of respondents (see Appendix K for specifications on case-mix adjusting).

For more guidance around using proxies, please see [Section VIII.G \(\*Interacting with Proxy Respondents\*\)](#).

### **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 participant receives and has regular, ongoing contact with the participant is more likely to be a good proxy respondent. Unpaid family members, friends, or neighbors may meet these criteria. A participant’s wishes should be honored if they choose not to participate. In this case, no proxy should be used.

Anyone who is paid to provide care or services to the participant should not be used as a proxy. It is inappropriate for a person who provides services to a participant to provide feedback on their own performance. This exclusion also applies to family members and friends who are paid to help the participant. 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 participant specifically requests their presence. In addition,

guardians or conservators whose only responsibility is to oversee the participant'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 participant's preferences are addressed and goals are met. This is a standard practice for many states to avoid any conflict of interest on the part of the guardian or conservator.

## **K. Survey Administration Languages**

In addition to English, the HCBS CAHPS Survey questionnaire is available in Spanish (see Appendix B-2 and Appendix B-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 participants.

Translation services must be provided per federal and state requirements.<sup>10</sup> The survey vendors are responsible for providing all required certified translators and translation services to interview non-English speaking sampled participants, regardless of the language the participant speaks. Sponsors may choose to have the survey translated into other languages. For guidance on translation, see Appendix B-5. Sponsors interested in offering the survey in an additional language should contact the AHRQ CAHPS technical assistance phone line at 1-800-492-9261 or the Lewin Group's technical assistance email at [HCBSmeasures@Lewin.com](mailto:HCBSmeasures@Lewin.com).

## **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.

### **A. Unit of Analysis**

The unit of analysis is the unit for which survey results (scores) will be produced. The unit of analysis for the HCBS CAHPS Survey should be the accountable entity (e.g., HCBS program, MCP). 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, these programs frequently are operated by other entities including non-Medicaid state agencies (e.g., State Unit on Aging), non-state governmental entities (e.g., county), or MCPs under MLTSS programs. In those cases, the program's operating entities then contract with direct service and support providers and case managers.

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<sup>10</sup> 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>.

## B. Survey Population and Sample Frame

A sample frame is a list of all eligible participants in the HCBS unit being analyzed (e.g., HCBS program, a MCP as part of a Medicaid MLTSS program).

The criteria below should be used when determining which HCBS participants 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 three months to ensure they have enough experience to answer the questions; and
- Individuals who have received at least one qualifying HCBS service (i.e., personal care, behavioral health support, homemaker services, case management, and medical transportation) because the survey is about these services.

Some HCBS program participants will spend a short time in an institutional setting for more intensive care or rehabilitation and then return to a home or community-based setting. If an HCBS program participant is staying in an institutional setting at the time when the survey is fielded, they may still be eligible to participate if their stay is expected to be short term. However, individuals who have resided in a rehabilitation hospital, nursing home, or other institution for more than three months or are expected to stay in an institutional setting for longer than three months should be excluded from the survey sample. If these individuals are identified during data collection, they should be excluded from the survey.

## 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 participants. However, from a data security and confidentiality perspective, the sponsor and vendor should coordinate on determining the data elements to be shared based on survey vendor sample selection protocol.

The sponsor should carefully consider what data to provide the survey vendor as part of the sample frame. *Exhibit 7* presents the data elements that should be used to generate the sample frame and additional data elements that the survey vendor will need to tailor the survey. Additionally, these variables may be used in analyses that the survey vendor performs for the survey sponsor.

## Exhibit 7: Data Elements for Sample Frame and Tailoring

Data Elements for Producing Sample Frame	Data Elements for Tailoring the Survey
<ul style="list-style-type: none"> <li>• Participant name (first and last);</li> <li>• Mailing address (address, city, state, and ZIP code) (consider identifying institutional settings to exclude in the sample);</li> <li>• Telephone number(s);</li> <li>• Sex;</li> <li>• Date of birth;</li> <li>• Name and contact information of guardian;</li> <li>• Name of program under which the participant receives services;</li> <li>• Names of the participants’ HCBS service provider agencies for each kind of service provided; and</li> <li>• Length of time in the program.</li> </ul>	<ul style="list-style-type: none"> <li>• Services that participant receives (personal care, behavioral health, homemaker, case management, employment) and program-specific name for each of the services;</li> <li>• Names for each service provider (e.g., John Smith) for each service;</li> <li>• Preferred language;</li> <li>• Program-specific title for each staff category (e.g., PCA staff);</li> <li>• Program-specific title for “service plan;”</li> <li>• Program-specific term for “staff;” and</li> <li>• State-specific language related to mandated reporting of abuse, neglect, or exploitation.</li> </ul>

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

Sample files may be provided as a flat, ASCII (American Standard Code for Information Exchange) fixed-width file, CSV (comma-separated values), 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 (HIPAA) such as through encrypted email, FTP (file transfer protocol) server, or other HIPAA-compliant file-sharing services.

### 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 the quality of services and supports across HCBS programs, other accountable entities (e.g., non-Medicaid state agencies, non-state governmental entities, MCPs), 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 future recommended target ESS for survey administrations.

To calculate the sample size, the survey sponsor will need to consider the ESS for the desired measures and the anticipated response rate. 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. Response rates vary but tend to be between 5 and 30 percent for the HCBS CAHPS Survey. The survey sponsor should consider their past experience with other surveys or other states' experience with the HCBS CAHPS when estimating what response rate to expect. 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 will complete the survey. 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. Therefore, when selecting the sample size consider desired response rates for the program type and survey mode and consider oversampling.

For any subgroup comparisons (e.g., programs within states, MCPs within programs), obtaining 400 completed responses for each subgroup is important to ensure the reliability of results. For states that are considering using measures derived from the HCBS CAHPS Survey to calculate incentive payments for providers (i.e., value-based purchasing), it is especially important to ensure reliability of survey measures.

For additional information regarding the sample size for the HCBS CAHPS Survey, please see the [\*Technical Assistance Guide for Analyzing Data from the CAHPS Home and Community-Based Services Survey\*](#).

### **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 MCPs, case management agencies, or programs. Then, divide the population into 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 PARTICIPANT CONFIDENTIALITY**

HIPAA protects information about participants, which is referred to as protected health information (PHI). HIPAA also applies to electronic records, regardless of whether they are being stored or transmitted. As a government program that pays for healthcare, Medicaid qualifies as a health plan under HIPAA. Therefore, for purposes of a Medicaid participant survey, the survey sponsor is a covered entity under HIPAA and must adhere to HIPAA requirements for PHI. Survey sponsors and vendors must safeguard all information collected from sampled participants, as required by HIPAA.

A sponsor must develop and implement a DUA and a business associate agreement (BAA) with the survey vendor that requires the vendor to 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 participant with any individual or organization, including sponsors;
- Implement procedures for identifying and handling breaches of confidential data;
- Ensure alignment with HCBS CAHPS Database and submit survey instrument used and data files to the database; and
- Sign and abide by the DUA as set forth by the survey sponsor.

Also, sponsors should require survey vendors to provide the following assurances of confidentiality in all communications with sampled participants (written or verbal):

- Survey responses will never be reported with a sampled participant'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 participant's answers;
- Sampled participants 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 participants currently receive or may receive in the future; and
- 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/interviewer observes or suspects abuse, neglect, or exploitation of a participant, they must follow state laws about mandated reporting of these concerns. The survey sponsor should specify the protocol for the data collector or survey vendor to follow when participant abuse, neglect, or exploitation is suspected. 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. Pre-notification Letter**

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

#### **1. Information Included in the Pre-notification Letter**

Sample pre-notification letters for participants and guardians can be found in Appendix C and 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. Pre-notification letters typically have the following features:

- Include the sampled participant’s full name and address in the address block;
- Contain a personal salutation (i.e., “Dear [Mr. / Ms. Participant Name]”);
- Include the signature of a senior executive of either the survey vendor or the sponsor;
- Insert the HCBS program name in designated fields;
- 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;
- Include information about how the survey data will be used (e.g., “Your answers will help us to improve the services we provide”);
- Include a statement about confidentiality; and
- Fit on one page, printed using a font size equal to or larger than 12 points of a readable font (e.g., Times New Roman or Arial), and use plain language when appropriate.

Survey sponsors may include additional requirements for the letter to which the survey vendor is expected to adhere. For example, survey vendors should include tracking codes on pre-notification letters to assist with quality assurance activities. The codes should be unobtrusive and not obscure the standard pre-notification 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 participants and to standardize addresses to conform to U.S. Postal Service formats.

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

## **2. Timing of the Pre-notification Letter**

The pre-notification letter should be mailed to participants seven days before the initial recruitment telephone call. This allows for delivery time and provides time for the participant to review information about the survey before the initial phone contact. The pre-notification letter adds credibility to future contact attempts and has been shown to increase response rates.

## **3. Production and Mailing of Pre-notification Letters**

Survey sponsors may produce and mail the pre-notification letters or delegate this responsibility to 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 should have the capability to perform this work or contract it out.

Another consideration is the timing of mailing the pre-notification letter. Because the initial phone contact should occur seven days after the pre-notification letter is mailed, the pre-notification letters may need to be mailed in waves to ensure that the survey vendor can contact all participants seven days after the mailing. If this is the case, the survey sponsor would need to track which participant letters are mailed on each day so telephone contacts occur at the right time.

## **4. Contacting Guardians**

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

Survey sponsors should provide a list to the survey vendor of all participants 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 participants to respond, and participants can then be contacted to obtain assent to participate in the survey. A sample guardian pre-notification letter can be found in Appendix D, and a sample guardian and provider update script can be found in Appendix H.

As noted earlier, when 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 the contact information be updated at least three months before survey administration to decrease bias in responses. Updating the entire sample frame also is recommended, should the survey vendor need to obtain a larger sample for the field test.

In planning for survey administration and working with a survey vendor, sponsors should account for the extra time it may take to obtain guardian information and consent (if required).

## **B. Maximizing Participant Participation**

The survey sponsor must determine how participants will be notified that they may be asked to participate in the survey. As an example, before and during survey administration, it is helpful to communicate to participants the purpose and the importance of the survey. This could include an explanation of how their survey responses will be used to improve HCBS in their state. Additionally, it may be helpful to communicate that the participant was randomly chosen from all HCBS recipients in this program to provide their 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 they had an excellent experience or had a poor experience. It is important to communicate to the participant that answering the specific questions on the survey is important so that the program and state agency know about the parts of the program that are working well or, alternatively, the parts of the program that are not working well.

It is important to encourage participants to participate, as previously discussed. However, it is also important not to influence the participants' 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. Survey sponsors and their vendors or other agents should not:

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

However, certain promotional communication can help improve response rates. These messages should only promote participation and should not encourage either positive or negative responses. *Exhibit 8* provides a list of example appropriate and inappropriate promotional messages as a guide when developing communications.

### Exhibit 8: Promotional Communication Examples

Appropriate Promotional Communication	Inappropriate Promotional Communication
We carefully review the results of the surveys to figure out how to provide better services.	Help your service provider get a good rating by answering these questions.
We are committed to providing you the best quality services available, and your input will help us.	We need your support to get a good rating.
<p>We want to know:</p> <ul style="list-style-type: none"> <li>• How easy it was for you to get services;</li> <li>• How well you feel treated; and</li> <li>• Whether you feel listened to.</li> </ul> <p>These are the kinds of things that only you can tell us.</p>	We want to hear the compliments you have for the people paid to help you at home.

To avoid overburdening participants who receive invitations to take more than one survey, it is strongly recommended that survey sponsors avoid administering any other surveys during the four-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 participants who may have a greater risk of refusal. Examples of appropriate strategies to increase participation include the following:

- Informing case managers of the survey’s purpose and letting them know that a participant 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 participants, but not to engage the participant in any conversations about how the person should respond to survey items (so as not to bias survey results);
- Enlisting advocacy groups to inform participants and their informal caregivers of the survey and to communicate the benefits of participating in the survey;
- For participants 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 pre-notification letters on state or program letterhead to sampled participants within seven days of phone recruitment of the same participants;
- Having the survey vendor make at least five call attempts to eligible sampled participants on different days of the week and at various times of day;
- Leaving up to two voicemail messages to sampled participants 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 participants 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 participants to receive assistance from another person to complete the survey;
- Allowing an appropriate proxy respondent to complete the survey on behalf of the participant; and
- Describing how participant 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. Interviewers should be thoroughly familiar with survey protocol and procedures and skilled in general interviewing techniques, including how to make initial contacts, deal with reluctant sampled participants, conduct interviews in a professional manner, and avoid influencing or biasing responses. Appendix A includes interviewer guidelines for administering the survey. It will also be valuable for interviewers to complete disability training. Interviewers should follow the survey scripts provided by the survey sponsor verbatim, use nondirective probes, record responses accurately, and maintain a neutral and professional relationship with the respondent.

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 populations.

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 be familiar with the pre-notification letter that is sent so that they are aware of what this letter looks like and its contents. Interviewers should also know how to handle the following situations:

- Participant is unable to answer the survey;
- Participant has significant problems with the HCBS program;
- Participant has a legal guardian;
- Participant's behavior poses a safety concern for the participant or interviewer; and
- Participant does not meet the selection criteria for the survey.

It may be beneficial for a staff member from the survey sponsor to participate in 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 participants, 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 participants 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 should be available by the start of the mailing of the pre-notification letter. Survey vendors should 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; and
- 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 (FAQ) (see Appendix G) and corresponding responses. Respondent support staff should also have a thorough understanding of the rights of sampled participants 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. Respondent 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 administrators should make an introductory call after sending the pre-notification 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 should use separate scripts and procedures for participants 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; and
- In-person interviews should be scheduled at a future time that will work for the respondent (and an interviewer).

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

### **1. Number of Telephone Attempts**

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

All sampled participants should 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 participant 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 participant 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 participant requests the survey vendor's inbound customer support line number during an outbound call attempt, the survey vendor should provide the sampled participant with its customer support line number.

If a sampled participant calls respondent 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 and survey vendors must determine whether interviewers should leave messages for the sampled participant on their voicemail or with another individual who answers the telephone. In general, no more than two messages should be left to avoid burdening participants. 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 Avoidance and Conversion Techniques**

It is assumed that survey sponsors will conduct the survey voluntarily and cannot do otherwise when surveying Medicaid participants.<sup>11</sup> At the same time, survey vendors typically train interviewers to avoid or minimize refusals.

Although implementing refusal avoidance and conversion techniques can improve response rates, in certain scenarios these techniques are discouraged. These situations include:

- When a sampled participant indicates that they are currently at work and cannot answer the survey at work; and
- When a sampled participant indicates that they are driving.

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<sup>11</sup> Sections 440.230-440.240 of 46 FR 47993 on sufficiency of amount, duration and scope, and comparability of services for groups.



In these situations, survey vendors may attempt to contact the sampled participant at a later time and the follow-up call does not count as a separate attempt. However, if a sampled participant 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 participants and assent of participants 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, 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 participant may withdraw consent at any time and end the interview. If that occurs, interviewers should thank the participant and end the interview. Survey vendors and sponsors should remove survey responses provided by participants who withdraw consent.

If a participant 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, participant assent is highly desirable.

## **G. Interacting with Proxy Respondents**

As mentioned earlier in the guide, involving proxy respondents may take place under a range of scenarios. A proxy may listen and support a participant to respond, may respond on behalf of the participant for some questions, or may respond on behalf of the participant for all questions. Interviewers first should seek to conduct the interview with the participant. 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 participant is unable to respond to the survey and suggest that the proxy respond. If a proxy indicates that the participant 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 participant may start answering the cognitive screening questions and be unable to answer 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 can answer the cognitive screening questions, include only the proxy set of responses, not the participant's; and
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 participant 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 participants. If a response comes from both the participant and the proxy and the responses are different, the vendor should use the participant's response. If the participant cannot answer the question, 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 Participant 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. It is not recommended to conduct an interview with HCBS staff present, but some situations may occur that make it impossible to conduct the interview with the participant alone. These situations may include:

- The respondent feels more comfortable with an HCBS staff at the interview and requests their presence; and
- The respondent needs 24-hour care.

At a minimum, if the HCBS staff must be present for the interview, the interviewer should indicate this in the field specified at the end of the survey. The following are some additional actions that the interviewer may take:

- Speak with the respondent and the HCBS staff person to explain that it is important to conduct the survey privately;
- Ask the respondent if they feel comfortable conducting the interview in a room separate from the HCBS staff;
- Include all responses and adjust for differences; and
- Continue with the interview but exclude the data from the analysis if directed to do so by the sponsor.

For more information about the presence of family or friend proxy respondents, please see [Section VIII. G. Interacting with Proxy Respondents](#).

## **I. Participant Reports of Problems with the Program**

The survey sponsor should determine the appropriate protocol for an HCBS participant reporting any problems with the program. For example, if the respondent indicates during the initial phone call that they have significant concerns or problems with HCBS program services, survey vendors should provide the sampled participant 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 unanswered 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 and survey vendor should work together to identify potential physical and mental safety risks and mitigation strategies. The survey sponsor should determine the appropriate protocol if a participant presents behavioral challenges that the interviewer perceives as compromising their safety. If there are any concerns 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:<sup>12</sup>

- Matching the sex of the interviewer with the respondent;
- Training interviewers to provide no personal details beyond their name, the survey vendor, and/or sponsor they are there on behalf of, and the contact phone number;
- Scheduling interviews only during daylight hours if possible;
- Training interviewers to observe the environment and identify safe exits when arriving to conduct the interview;
- 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 fully-charged cell phones with them to interviews;
- Carrying minimum necessary equipment and no unnecessary valuable items or cash to the interview;
- Leaving the full details of the location, interview time, and interviewer contact information with the supervisor; and
- Requesting that interviewers inform supervisors when they are at the place of the interview, how long they expect to be at the interview, and when they are finished with the interview. If the supervisor does not hear from the interviewer within a reasonable time after the interview is expected to end, the supervisor should attempt to contact the interviewer.

## **IX. SURVEY VENDOR UPDATES**

Throughout data collection, vendors must maintain up-to-date, accurate disposition information for each sampled participant 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

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<sup>12</sup> Interviewer safety recommendations informed by <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3964461/>

the American Association for Public Opinion Research (AAPOR)<sup>13</sup> 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 participants may need to be added to the survey.

Throughout survey administration and before 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, they should consider requiring the survey vendor to correct the error and prevent it from happening during the rest of the survey. Additionally, sponsors should ensure that the vendor is properly preparing data for submission to the HCBS CAHPS Database throughout the process.

## **X. FINAL DATA FILE**

Working with the survey vendor, sponsors should specify when and how the final data and the final disposition codes are to be submitted to the sponsor. Along with survey data, the survey vendor should provide a final disposition report using disposition categories defined by the AAPOR or developed by the survey vendor to meet the survey sponsor's information needs. This final disposition for all sampled cases indicates the final outcome in terms of whether the participant responded to the survey and, if not, why they did not respond.

The survey sponsor should also work with the vendor to submit the data to the HCBS CAHPS Database in ASCII/flat-file format. The HCBS CAHPS Database will review each file submitted for approval, which can take up to three business days. For more information about data submission requirements for the HCBS CAHPS Database, please see the [Data File Specifications](#) or contact Westat at [HCBSCAHPSDatabase@westat.com](mailto:HCBSCAHPSDatabase@westat.com).

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<sup>13</sup> 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>

After submission to the database, survey sponsors will receive a customized report comparing their state and individual program type responses to overall HCBS CAHPS Database results.

### **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 and that is compatible with submission to the HCBS CAHPS Database. The preferred file format likely will depend on the analysis software that will be used, such as SAS<sup>®</sup> (SAS Institute Inc.), SPSS<sup>®</sup> (IBM), Stata<sup>®</sup> (StataCorp), or R. Alternatively, the data file can be provided as flat, ASCII fixed-width file, CSV, or Microsoft<sup>®</sup> 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 de-identify the data, the vendor should remove anything that identifies the respondent (e.g., 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 to 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; and
- 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.

### **C. Submission of Data to the HCBS CAHPS Database**

Survey sponsors should work with the survey vendor to submit the final data file to the HCBS CAHPS Database. The HCBS CAHPS Database supports and collects the following questionnaires:

- CAHPS Home and Community-Based Services Survey 1.0; and
- CAHPS Home and Community-Based Services Survey 1.0 with the Employment Module Item Set.

It is imperative that the survey question wording, response options, and skip patterns remain intact and unaltered for the survey instrument to be approved for data submission. Any Supplemental Items or customized questions must be added immediately before the About You section of the instrument, so that they do not alter the preceding core survey questions.

**Questions that are not part of the Supplemental Employment Module must be removed before preparing a data file for submission.**

The following steps are necessary to participate in the HCBS CAHPS Survey Submission System:

1. **Registration:** New users must complete an online registration form including the name of the program, program identification number, survey type (HCBS or HCBS with Employment Module), and program State. After completing the form, users will receive an email with a link to activate the account;
2. **Data Use Agreement:** Each participating organization is required to sign a DUA and upload a copy of the [DUA](#) onto the submission site. Please do not email or fax the DUA;
3. **HCBS CAHPS Survey Questionnaire:** Upload a copy of the HCBS CAHPS Survey questionnaire administered. The HCBS CAHPS Database will review the submitted questionnaire, and then users will receive an approval/rejection email. To ensure the data collected can be accepted by the HCBS CAHPS Database, a copy of the survey instrument should be provided for review before data collection begins;
4. **HCBS CAHPS Survey Data File:** Data files submitted to the HCBS CAHPS Database must conform to the [2020 Data File Specifications](#); and
5. **Approval Process:** Each questionnaire, DUA, and data file is reviewed by the HCBS CAHPS Database team. The review process can take up to three business days. Users are notified of the outcome by email.

For technical assistance please contact the HCBS CAHPS Database at [HCBSCAHPSDatabase@westat.com](mailto:HCBSCAHPSDatabase@westat.com) or 1-855-580-4657.

## **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 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. For more information about data quality, please review [Section X. Final Data File](#).

## **B. Sponsor Oversight of the Survey Vendor**

Survey sponsors may require that survey vendors submit electronic copies of all materials for approval before volume printing and survey administration. This submission is strongly encouraged for any sponsors who wish to participate in the HCBS CAHPS Database. All materials submitted to the sponsor for review should appear as they would to a survey respondent or interviewer. This submission may include English and Spanish survey materials and print-ready templates for pre-notification letters (note that Westat can only approve materials in English and Spanish). In addition to the survey sponsor's review and approval, all materials used to field the survey should be submitted to the HCBS CAHPS Database at [HCBSCAHPSDatabase@westat.com](mailto:HCBSCAHPSDatabase@westat.com) for pre-approval to ensure submission eligibility before the survey begins.

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**

Using appropriate privacy protocols, 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 two-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 the interviewer and assess how many similarities there are. If the skips and responses are the same for several surveys, that would suggest that fraudulent surveys may have been 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 the 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

*Exhibit 9* includes 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.

**Exhibit 9: Sample Planning Timeline for Survey Project**

Task	Timeline
Sponsor provides all materials to survey vendor. <ul style="list-style-type: none"> <li>• Final scope of work;</li> <li>• Model QAP;</li> <li>• Pre-notification letter;</li> <li>• Introductory recruitment script including a proxy script, if applicable;</li> <li>• Survey in English and Spanish (if applicable);</li> <li>• Sample frame file layout; and</li> <li>• State mandatory reporting requirements.</li> </ul>	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 11 to 22



Task	Timeline
Sponsor reviews interviewer guidelines for administering the HCBS CAHPS Survey with survey vendor management.	Days 23 to 29
Sponsors generate and submit a sample frame for each subgroup (e.g., HCBS program, MCPs).	Days 30 to 39
Survey vendors submit QAP and sponsor reviews QAPs.	Days 40 to 49
Survey vendor submits final survey materials to the sponsor for review. The sponsor responds to the survey vendor within 10 business days.  The survey vendor and sponsor work together to submit the survey materials to AHRQ/Westat for review before administering the survey ( <i>optional, but recommended</i> ).  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]).  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/or Spanish [if applicable]).	Days 50 to 80
Survey vendor trains interviewers using the interviewer guidelines for administering the HCBS CAHPS Survey.	Days 70 to 80

Abbreviations: QAP – quality assurance plan; CAPI – computer-assisted personal interview; CATI – computer-assisted telephone interview; HCBS – home and community-based services.

**Exhibit 10** includes a sample timeline for the administration of the HCBS CAHPS Survey that can change based on the sponsor’s directions and needs.

### Exhibit 10: Sample Planning Timeline for Survey Administration

Task	Timeline
Survey vendors sample according to sponsor’s sampling protocols.  Confirm that samples meet specifications identified by the sponsor for telephone and/or in-person protocols.	Days 0 to 30
Mail pre-notification letter to sampled participants (English and/or Spanish [if applicable]).  Sponsors may choose to mail on a rolling basis if low response rates.	Day 31
Open customer support phone center (toll-free phone number required).	Day 32
Survey vendor initiates telephone interviews of sampled participants, including the following: <ul style="list-style-type: none"> <li>• Conducting at least five call attempts;</li> <li>• Leaving voicemail messages;</li> <li>• 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; and</li> <li>• 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.</li> </ul>	Days 38 to 56

Task	Timeline
<p>Survey vendor initiates in-person interviews of sampled, including the following:</p> <ul style="list-style-type: none"> <li>• Making at least five call attempts to set up an interview;</li> <li>• Leaving voicemail messages;</li> <li>• 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;</li> <li>• Scheduling call attempts must be at different times of the day on different days of the week; and</li> <li>• Survey sponsors should consider requesting that in-person interviews should be set up during an 18-calendar-day in-person interview period.</li> </ul>	Days 38 to 74
<p>Review the status of survey administration</p> <p>Review whether the 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 Day 91
<p>HCBS CAHPS Database DUA and data submission</p> <ul style="list-style-type: none"> <li>• Register for an account with the HCBS CAHPS Database;</li> <li>• Provide a signed DUA;</li> <li>• Submit a copy of the survey instrument;</li> <li>• Submit data files matching the HCBS CAHPS Database specifications;</li> <li>• Receive reports from the HCBS CAHPS Database; and</li> <li>• Analyze results to set quality improvement initiatives.</li> </ul>	Annually in October