APPENDIX G. FREQUENTLY ASKED QUESTIONS ABOUT THE CONSUMER ASSESSMENT OF HEALTHCARE PROVIDERS AND SYSTEMS HOME AND COMMUNITY-BASED SERVICES (HCBS CAHPS®) SURVEY
INTRODUCTION TO THE HCBS CAHPS SURVEY

What is the purpose of the HCBS CAHPS Survey?

The Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Services (HCBS CAHPS) Survey elicits feedback from HCBS participants (sometimes called members or Medicaid beneficiaries) who are enrolled in Medicaid-funded HCBS about their experiences with the provision of services and supports. The survey covers a range of services and supports that are often provided through HCBS programs by personal care assistants, behavioral health assistants, homemakers, case managers, medical transportation, and employment services (as a supplemental module). The HCBS CAHPS Survey focuses on the experiences of participants in their specific program, including services provided by HCBS provider agencies or independent HCBS providers. The survey also is a vehicle for HCBS participants to provide feedback on their involvement in planning their services, whether they ever go without needed services important for community living, their control over day-to-day activities, and their personal safety.

How was the HCBS CAHPS Survey developed?

The HCBS CAHPS Survey was designed to align with the family of CAHPS surveys and followed the standard CAHPS process. This process began with formative research that included a literature review, interviews with participants who receive Medicaid HCBS, and input from stakeholders via a Technical Expert Panel (TEP). The resulting draft survey went through multiple rounds of cognitive testing with HCBS participants, additional input from stakeholders, a pilot test in two states in 2013, and a field test in eight states concluding in 2015. Over 3,200 participants from 26 Medicaid HCBS programs participated in the pilot and field tests. Psychometric analysis of the pilot and field test results helped to further refine the instrument and produce practical information about its use. The HCBS CAHPS Survey received the CAHPS trademark on June 22, 2016. CAHPS is a registered trademark of the Agency for Healthcare Research and Quality (AHRQ). Because each survey is the result of a systematic and thorough research and development process, the CAHPS brand has come to signify a high level of scientific rigor, reliability, and credibility.

How was the HCBS CAHPS Survey validated and over what approximate timeframe?

The HCBS CAHPS Survey was validated using both qualitative research (e.g., interviews, focus groups, literature review, TEP input, and four rounds of testing the draft instrument with target audiences) and quantitative research (e.g., confirmatory factor analysis, multi-trait analysis, scaling success statistics using pilot and field test results) conducted between 2010 and 2016.

Is HCBS CAHPS mandatory for any program? Is anyone required to use the survey?

The Centers for Medicare & Medicaid Services (CMS) has made the survey available for states and programs to use on a voluntary basis. States may decide to require its use by HCBS program administrators with whom the state contracts, such as managed care plans (MCP). Participation by respondents is always entirely voluntary. The HCBS CAHPS Survey 1.0 (English, Spanish) and Supplemental Employment Module (English, Spanish) are available at no cost on the

What are common similarities and differences between the HCBS CAHPS and Home Health CAHPS (HH-CAHPS) Surveys?

The HCBS CAHPS Survey elicits feedback on the experiences of Medicaid HCBS program participants with the provision of their HCBS services and supports. The HH-CAHPS Survey measures experiences of people receiving home health care from Medicare-certified home health agencies. The HH-CAHPS is conducted for home health agencies by approved HH-CAHPS Survey vendors. HCBS CAHPS Survey sponsors will most likely be state Medicaid HCBS programs or the MCP(s) that states contract with to serve participants in managed long-term services and supports program (MLTSS). Services and supports covered by the HCBS CAHPS Survey include those provided by personal care assistants, behavioral health assistants, homemakers, case managers, medical transportation, and employment services providers. The HCBS CAHPS Survey focuses on the performance of these providers, whether associated with agencies or operating as independent providers. The survey also is a vehicle for HCBS participants to provide feedback on (1) their involvement in planning their services, (2) whether they ever go without needed services that are important for community living, (3) their control over day-to-day activities, and (4) their personal safety.

One important difference between the HCBS CAHPS Survey and HH-CAHPS is that the HCBS CAHPS Survey has been made available by CMS for voluntary use and the HH-CAHPS was required by CMS beginning in 2010 for the Medicare annual payment update requirements.

States may limit their HCBS programs by the amount, duration, and scope of the benefits, as well as the population served. Medicaid HCBS programs commonly serve older adults, individuals with a physical disability, individuals with an intellectual or developmental disability, individuals with an acquired brain injury, and individuals with mental health or substance use disorders. These 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. HCBS may include Medicaid home health services that are provided to a participant at their place of residence based on written orders from a medical provider (i.e., physician, nurse practitioner). Medicaid home health services may be encompassed in a state’s HCBS program or separately. Medicaid home health services include nursing services, home aide services provided by a home health agency, medical supplies and equipment, and therapy services (e.g., physical, occupational). For more information on Medicaid home health services, visit https://www.govinfo.gov/app/collection/cfr/2018/title42/chapterIV/subchapterC/part440/subpartA.

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1 For more information on HH-CAHPS, visit: https://homehealthcahps.org/
2 For more information on HH-CAHPS, visit: https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/CAHPS/HHCahps
Can a provider association sponsor the HCBS CAHPS Survey or is this only intended for states?

Provider associations can sponsor the HCBS CAHPS Survey. To date, states and MCPs are the primary entities that have administered the HCBS CAHPS Survey. If a provider association, such as an HCBS provider group, is interested in administering the HCBS CAHPS Survey, we recommend speaking with your state Medicaid agency or MCP(s) in your state to serve as a survey sponsor to help meet the state quality goals such as collecting participant experience data across HCBS programs.

Can the HCBS CAHPS Survey be used for combined programs that serve multiple populations? For example, can a state that has a combined section 1915(c) elderly and physical disability waiver program use the survey?

Yes. The survey is designed to collect experience data from participants in many different kinds of Medicaid HCBS waiver 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 a physical disability;
- Individuals with an intellectual or developmental disability;
- Individuals with an acquired brain injury; and
- Individuals with serious mental illness.3

Can the HCBS CAHPS Survey be used by self-directed programs (sometimes called participant-directed or consumer-directed)?

Yes. The survey asks participants about their experience with services they receive, regardless of who is directing those services so most questions will be applicable. If the participant does not receive a service included in the survey, the survey is designed so the interviewer skips those questions.

Is HCBS CAHPS designed and tested for settings other than the participant’s home, such as group living settings including group homes or personal care homes? Is it designed and tested for nursing facilities, brain-injury residential programs, or Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID)?

The HCBS CAHPS Survey was designed and tested for individuals receiving HCBS. Specific categories of services that the survey elicits feedback about are personal assistance, behavioral health services, homemaker, case management, and transportation. The key criterion is whether the individuals are receiving services in their homes or communities. This could include persons with intellectual or developmental disabilities and others who live in shared quarters; if the

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3 The pilot group included individuals with serious mental illness served by HCBS programs. The HCBS CAHPS Survey Administration Guide expands use of the HCBS CAHPS Survey to individuals with mental health and substance use disorders.
person is receiving HCBS, then wherever they live is considered "home." For example, HCBS may be provided by the entity who runs the small group home.

**USE OF PROXIES**

**Should we include or exclude people whose cognition is below a certain level?**

All participants in an HCBS program should be considered eligible to include in the sample to be surveyed, regardless of what type of disability they have or their cognitive status. There are three questions at the beginning of the HCBS CAHPS Survey that are designed to determine whether the respondent is aware of the services and supports they receive. If the participant does not confirm their use of HCBS in those three questions, the interviewer will not continue with the survey. The survey vendor may try to find an eligible proxy respondent who could complete the survey on behalf of the participant (generally with the participant). For more information about the cognition and the use of proxies, see the complete Technical Assistance Guide for the Administration of the HCBS CAHPS Survey at: https://www.medicaid.gov/medicaid/quality-of-care/downloads/hcbscahps-admin-ta-guide.pdf.

**Can proxies be used to respond on behalf of program participants?**

Yes. Proxies may be used. A proxy is someone who answers on behalf of the program participant and represents participants’ experiences, not their own experiences. If a participant chooses not to participate, the participant’s wishes should be honored and no proxy should be used. A proxy may respond for the participant when the participant agrees and is willing to participate but unable to respond to the questions. Unpaid family members, friends, or neighbors may meet this criterion. Proxies may not be paid providers of participants’ services. Survey sponsors should decide whether to allow proxy respondents.

**What should we do if we have difficulty finding proxy respondents who are not paid providers for the participant?**

The person's program record or case file should indicate who a potential proxy responder might be. If a potential participant agrees to have a proxy respond on their behalf but you cannot identify anyone who could serve as a proxy and who is also not a paid provider for the respondent (including family members and friends who are paid to help the participant), that participant should not complete the survey.

**STAKEHOLDER INPUT AND PARTICIPATION**

**What kind of input did stakeholders have into the development and the value of the HCBS CAHPS Survey?**

Refer to the response to the earlier question: “How was the HCBS CAHPS Survey developed?” The HCBS CAHPS Survey was developed, field tested as part of the Testing Experience and Functional Tools Demonstration, revised, and finalized with input from a TEP of federal, state, program, participant, and family stakeholders. The National Quality Forum (NQF) Measure Applications Partnership (MAP) recommended and in 2017 NQF endorsed the 19 measures.
derived from the HCBS CAHPS Survey (NQF #2967) to address a measurement gap in services provided through long-term care programs. It generally has been viewed favorably by stakeholders throughout its development. Key features that may contribute to this include (1) its orientation toward person-centeredness; (2) the ability to use a single instrument with a broad range of individuals with disabilities, such that results can be compared; (3) that it was designed to be as accessible as possible to all HCBS participants; (4) that it aligns with CAHPS principles; (5) that the survey supports 19 quality measures endorsed by the NQF; and (6) there is no cost to access the instrument or related resources. During the public comment period of the NQF measure endorsement process, stakeholders submitted 11 of 21 total comments regarding the HCBS CAHPS quality measures under consideration by the committee. It was noted during the post-comment call that the majority of public comments supported the endorsement of the HCBS CAHPS Survey and related to the NQF criteria as they applied to the measures derived from the survey.

Have you received feedback from people with intellectual and/or developmental disabilities and their caregivers about the readability of the HCBS CAHPS Survey?

Individuals with intellectual and/or developmental disabilities made up a substantial share of the participants in the formative research and cognitive testing that informed the survey’s design. In addition, several key survey features were included to increase accessibility to the survey, such as allowing alternate response options.

Does the HCBS CAHPS Survey include questions about autonomy, choice, decision-making, and similar issues?

Yes. There are several questions designed to assess how much autonomy, choice, and control the program participant has, such as in the development of the service plan and in how services are delivered.

How can the HCBS CAHPS Survey support efforts to increase emphasis on person-centeredness in HCBS?

The HCBS CAHPS Survey includes several items designed to rate how person-centered a program (or sub-program unit) is in the planning and delivery of HCBS, as well as whether participants experience outcomes of choice, control, and participation in community life that Medicaid HCBS programs are intended to foster. The HCBS CAHPS Survey instrument includes questions about the individuals’ participation in service planning; whether the service package includes the things that are important to the participants; whether participants have the opportunity to socialize with whom and when they want; whether participants have the opportunity to participate in community life; and whether participants have control over daily life activities.
SURVEY ADMINISTRATION

How is the HCBS CAHPS Survey administered?

The HCBS CAHPS Survey is designed to be administered by an interviewer, asking the questions by telephone or in person. The developer team decided not to design a paper-based or online version of the survey based on stakeholder feedback that in-person or telephone administration would be preferable and because of the complexity of the survey with its skip patterns and program-specific terminology. At this time, survey users are cautioned against administering it in written form—either paper-based or online—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.

Does CMS prefer one administration mode over another (telephone or in-person)?

The field tests for the survey demonstrated that both modes were appropriate. Ideally, potential respondents should be offered a choice of responding by telephone or in person. In the experience of existing survey sponsors, the vast majority of participants will elect to take the survey by telephone. The survey sponsor should decide which mode(s) will be used.

Can the HCBS CAHPS Survey be completed by the respondent via the internet?

No. Only the in-person and telephone modes of the instrument were tested. The developer team decided not to design a paper-based or online version of the survey based on stakeholder feedback that in-person or telephone administration would be preferable and because of the complexity of the survey with its skip patterns and program-specific terminology. 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 in the survey correctly, survey users are cautioned against administering it in written form—either paper-based or online.

Can the HCBS CAHPS Survey be administered by mail?

No. Only the in-person and telephone modes of the instrument were tested. The developer team decided not to design a paper-based or online version of the survey based on stakeholder feedback that in-person or telephone administration would be preferable and because of the complexity of the survey with its skip patterns and program-specific terminology. At this time, survey users are cautioned against administering it in written form—either paper-based or online—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.

Does the HCBS CAHPS Survey allow for video-call survey implementation?

At this time, the HCBS CAHPS Survey has not been tested and validated with video-calls. Given the COVID-19 public health emergency and the increase in use of video-calls related to HCBS to avoid in-person interaction, CMS may consider exploring this option in the future.
Would it work for us to administer the HCBS CAHPS Survey as part of regular service plan monitoring activities wherein case managers would conduct HCBS CAHPS with each waiver participant annually? The case managers would not ask questions about their own services.

It is not advisable for anyone who is paid to provide HCBS for participants to serve as an interviewer administering the survey. This could make the participants feel pressure to respond to survey questions positively and bias or invalidate survey responses. To increase response rates, it is helpful for case managers to know in advance that the survey will be administered so they can let participants know it is legitimate. Case managers should be advised to acknowledge the legitimacy of the survey but not engage in any conversation about how the participant should respond.

What are strategies we could use to increase response rates for the HCBS CAHPS Survey?

Response rates for most surveys of older adults and adults with disabilities tend to be relatively low. Response rates tend to be between 5 and 30 percent for the HCBS CAHPS Survey, but they may be higher. During the HCBS CAHPS Survey testing in 2016, Connecticut reported a 63 percent response rate across HCBS programs. In estimating what the response rate will be, survey users should consider their past experience administering other surveys with their HCBS program participants. There are several things users can do to maximize response rates: using promotional communications, such as pre-notification letters on state or program letterhead; informing case managers so they can verify the legitimacy of the survey; making calls to schedule interview appointments; making several telephone attempts; allowing for proxies to respond as appropriate; and other methods described in the complete Technical Assistance Guide for the Administration of the HCBS CAHPS Survey:


Do you have a recommended sample size for the HCBS CAHPS Survey?

Field test data suggests that the effective sample size should be a minimum of 400 participants who respond per stratum (a stratum is one subgroup being included in the survey, such as all participants with the same disability). This means that you will need 400 respondents per stratum to reliably compare scores across strata. Effective sample size is the number of completed responses needed to obtain a reasonable level of reliability.

How long do people take to complete the HCBS CAHPS Survey?

The HCBS CAHPS Survey is designed to be administered by a trained interviewer over the phone or in person. While there are a number of items in the survey, because of the skip patterns, it took most respondents approximately 30 minutes to complete the survey during the pilot and field tests.
COST TO ADMINISTER SURVEY

What does it cost to administer the HCBS CAHPS Survey?

There is no charge for using the survey instrument and technical assistance supporting survey use. All of the survey materials, forms, interviewer scripts, and guidance are publicly available on the CMS website: https://www.medicaid.gov/medicaid/quality-of-care/quality-of-care-performance-measurement/cahps-home-and-community-based-services-survey/index.html

In addition, there is no charge to use the HCBS CAHPS Database and technical assistance supporting the database use. The HCBS CAHPS Database is publicly available on the AHRQ website: https://www.ahrq.gov/cahps/surveys-guidance/hcbs/index.html.

Some information about cost to implement was collected when the survey was field tested between 2014 and 2015. The costs for the states that field tested the survey ranged from $12,500 to $26,525. Some survey vendors charge an additional, one-time “startup” cost for fixed expenses, such as staff time to program the survey. In addition to the cost to administer the instrument, conducting a survey requires resources to plan, implement, monitor, and analyze the results.

The National Committee for Quality Assurance (NCQA) notes about CAHPS Surveys in general, that when vendors use “methods for increasing the number of responses (e.g., making sure all the phone numbers and email addresses are accurate, training interviewers on how to deal with gatekeepers) it will likely add to the costs of conducting a survey, but users need to weigh these extra costs against the risk of obtaining low response rates and less representative data.” For more considerations related to the cost of administering the HCBS CAHPS Survey, please visit the “Clear and Realistic Expectations for Costs and Timing” page on AHRQ.gov.

If you have questions or would like to request technical assistance about the HCBS CAHPS Survey, you can write to the CMS/Lewin team at: HCBSmeasures@lewin.com.

If you have questions or would like technical assistance about the HCBS CAHPS Database or the broader CAHPS family of surveys, you can write to the AHRQ/Westat team at: HCBSCAHPSDatabase@Westat.com.

Is there a difference in cost per completed survey for surveys administered by phone and in-person?

During field testing for the survey in 2014 and 2015, survey vendors were paid an average of $119 ($60-$250 range) per completed phone survey and $377 ($225-$686 range) per completed in-person survey. The median cost was a little lower due to a few high-cost vendors.
SURVEY VENDORS

Please provide some clarity on the use of vendors instead of staff of state agencies or providers. Is vendor utilization a requirement or a best practice?

It is possible for the survey data to be collected by “in-house” staff of a state agency or other sponsor or through a commercial survey research organization. Regardless of which approach is taken, however, there are basic competencies that must be present. For example, the data collection effort requires the data collection entity to have computer-assisted telephone interviewing (CATI) and/or computer-assisted personal interviewing (CAPI) capabilities. For more information on these basic competencies, please see the Promising Practice Paper entitled “Vendor Selection Strategies for the HCBS Experience of Care Survey” used by states for the Testing Experience and Functional Tools Demonstration on the HCBS CAHPS Survey page on Medicaid.gov or the page “Hiring A Vendor for a CAHPS Survey” on AHRQ.gov.

MODIFICATIONS, CHANGES, AND SUPPLEMENTAL ITEMS

Is there a way to align or combine different CAHPS Surveys? For example, if we already administer the Health Plan CAHPS, is there a way to combine that with the HCBS CAHPS?

Two separate CAHPS Surveys should not be combined because they have been tested and validated as singular surveys. While there may be similarities, each is distinct and will provide you with different data. If your state administers both, it is possible that some individuals will be eligible to take both the Health Plan CAHPS Survey and the HCBS CAHPS Survey if they are participants in an HCBS program that is delivered by an MCP. To avoid over-burdening these HCBS program participants, you should draw samples for both surveys and then compare the lists to make sure no individual is asked to respond to both surveys. If this is not possible, you should stagger the timing of when the two surveys are administered. It is recommended that you avoid administering any other survey with program participants for four weeks leading up to and then during the administration of the HCBS CAHPS Survey.

Can HCBS CAHPS be modified (i.e., can the user remove and/or add questions from HCBS CAHPS)?

Survey users should be very cautious about making any modifications to the HCBS CAHPS Survey. The survey can only be modified in very specific ways and still be eligible to maintain the CAHPS trademark and participate in the AHRQ HCBS CAHPS Database. Users can send their survey with proposed supplemental items to the AHRQ/Westat team prior to administering the survey to make sure the survey is still eligible for use of the CAHPS trademark and inclusion in the HCBS CAHPS Database. You can write to them at HCBSCAHPSDatabase@westat.com.

For the AHRQ rules that apply to using the CAHPS trademark see https://www.ahrq.gov/CAHPS/surveys-guidance/helpful-resources/modifying/index.html.

Programs are encouraged to modify the program and service terminology used in the survey before it is administered to match the state-specific terms participants will recognize. Then interviewers will use the terms the participant uses to refer to specific service providers. Other than these terminology modifications, the core of the survey must remain almost entirely unchanged to retain use of the CAHPS trademark in the survey name, its validity and comparability as a survey instrument, and the endorsement of the National Quality Forum. Furthermore, altering the survey may remove one of the major advantages of using it - comparability across programs and states. Questions should not be asked out of order and question text and answer options should not be deleted or altered. Survey users can tailor the survey by adding questions immediately before the “About You” demographic section only. Please contact the CMS HCBS Measures team to discuss specific modifications you are considering (HCBSmeasures@lewin.com).

Does a sponsor need approval to add supplemental items that are not already on the supplemental questions document?

No approval is needed to add supplemental items in the right place on the survey, which is immediately before the "About You" demographic section of the survey. If you are considering adding supplemental questions, it is advisable that you select and use questions that have been tested and validated with the populations you will survey. You should also consider that additional questions will require additional time to ask. Please contact the CMS HCBS Measures team if you would like to discuss adding supplemental questions (HCBSmeasures@lewin.com).

What are the rules about modifications that can be made to the HCBS CAHPS Survey or its name when using it?

To ensure that CAHPS Surveys retain their high standard and maintain comparability and consistency across the family of surveys with the CAHPS trademark, AHRQ provides guidelines about what changes can be made to a CAHPS Survey while retaining the ability to refer to it as such, as well as how to give proper attribution to the CAHPS program. See http://www.ahrq.gov/CAHPS/surveys-guidance/helpful-resources/modifying/index.html for the most up-to-date information about modifying and naming the HCBS CAHPS Survey.

Does CMS have plans to make changes to the HCBS CAHPS Survey?

There are no changes to the HCBS CAHPS Survey currently planned. However, as the survey's developer and sponsor, CMS will continue to monitor its use and gather feedback from users and stakeholders to inform future revisions and improvements. Please contact the CMS HCBS Measures team if you would like to discuss potential revisions and improvements to the survey (HCBSmeasures@lewin.com).
SURVEY RESULTS

Is there any publicly reported comparative data available? When will benchmark data be available publicly (e.g., for research)?

AHRQ/Westat maintain the HCBS CAHPS Database. 2020 was the first year states and MCPs submitted data to the HCBS CAHPS Database. At this time, data are not publicly available but may be available in the future. For more information on the HCBS CAHPS Database, see: https://cahpsdatabase.ahrq.gov/HCBSSurveyGuidance.aspx.

What if a state with MLTSS wants to compare their plans to each other? Can they get plan specific results?

If the state requires their MLTSS plans to administer the HCBS CAHPS Survey and provide the state with the raw survey data, then the state can conduct its own analysis and compare experience of care across plans. States and other survey users who elect to participate in AHRQ’s HCBS CAHPS Database will also receive a private, customized feedback report that compares their state and individual program type results to overall findings. The HCBS CAHPS Database also produces an Online Reporting System that allows users to view, download, and print custom reports of survey results and de-identified data available in research datasets for approved research purposes. For more information about the HCBS CAHPS Database, see: https://cahpsdatabase.ahrq.gov/HCBSSurveyGuidance.aspx.

Can CAHPS Survey data be linked with Medicaid and Medicare claims data at the individual level to evaluate how the individual's experience of care impacts outcomes?

The HCBS CAHPS Database only accepts and analyzes de-identified data submissions and cannot link individually identifiable data to claims data. Because the HCBS CAHPS Database utilizes de-identified data, it is not possible to evaluate the relationship between experience of care and outcomes on an individual level.

AVAILABLE TECHNICAL ASSISTANCE

Who can I contact for technical assistance with using the HCBS CAHPS Survey?

If you have questions or would like to request technical assistance about the HCBS CAHPS Survey, you can write to the CMS/Lewin team at: HCBSmeasures@lewin.com.

More information about the HCBS CAHPS Survey can be found on Medicaid.gov.

If you have questions or would like technical assistance about the HCBS CAHPS Database or the broader CAHPS family of surveys, you can write to AHRQ/Westat team at: HCBSCAHPSDatabase@Westat.com.

Finally, if you have questions for CMS about the HCBS CAHPS Survey or CMS’s other HCBS quality measurement initiatives, you can write to: HCBS-CAHPS@cms.hhs.gov.

Appendix G. Frequently asked questions about the HCBS CAHPS Survey