

About the CAHPS® Patient Narrative Elicitation Protocol

Introduction.....	1
Why Elicit Patient Narratives?	2
Questions in the CAHPS Patient Narrative Elicitation Protocol.....	3
Administering the CAHPS Patient Narrative Elicitation Protocol.....	4
Administration with the Clinician & Group Survey	4
Administration of the Elicitation Protocol on its own.....	7
Processing Patient Narratives.....	8
Using Patient Narratives to Inform Providers and Patients.....	9
Informing Providers	9
Informing Consumers.....	9
Development of the CAHPS Patient Narrative Elicitation Protocol.....	10
Relevant Literature by the Research Team	11
 Appendixes	
Appendix A. Items in the Adult Version of the Patient Narrative Elicitation Protocol (beta)	12
Appendix B. Items in the Child Version of the Patient Narrative Elicitation Protocol (beta)	14
Appendix C. Sample Language to Add to Survey Invitation.....	16

Documents Available for the CAHPS Clinician & Group Survey

This document is part of a comprehensive set of instructional materials that address implementing the Clinician & Group Survey, analyzing the data, and reporting the results. All documents are available on the [Agency for Healthcare Research and Quality's CAHPS Web site](#). For assistance in accessing these documents, please contact the CAHPS Help Line at 800-492-9261 or cahps1@westat.com.

For descriptions of these documents, refer to: *What's Available for the Clinician & Group Survey 3.0*.

Questionnaires

- *CAHPS Clinician & Group Survey: Overview of the Questionnaires*
- *Clinician & Group Survey 3.0* (Adult and Child, English and Spanish)
- *Clinician & Group Survey 2.0* (Adult and Child, English and Spanish)
 - *12-Month Survey 2.0*
 - *Patient-Centered Medical Home Survey 2.0*
 - *Visit Survey 2.0*

Supplemental Items

The CAHPS team is currently reviewing all supplemental items for the 3.0 version of the Clinician & Group Plan Survey. As the items are finalized, they are posted on the AHRQ CAHPS Web site as [supplemental items](#) for this survey.

- *About the Patient Narrative Elicitation Protocol*
- *About the Patient-Centered Medical Home (PCMH) Item Set*
- *About the Health Literacy Item Set for Clinicians & Groups*
- *About the Cultural Competence Item Set*
- *About the Health Information Technology Item Set*
- *Supplemental Items for the Adult Survey (for 2.0 version)*
- *Supplemental Items for the Child Survey (for 2.0 version)*

Survey Administration Guidelines

- *Preparing a Questionnaire Using the CAHPS Clinician & Group Survey*
- *Fielding the CAHPS Clinician & Group Survey*
- *Sample Notification Letters and Emails for the CAHPS Clinician & Group Survey*
- *Sample Telephone Script for the CAHPS Clinician & Group Survey*
- *Translating CAHPS Surveys*

Data Analysis Program and Guidelines

- *CAHPS Analysis Program (SAS)*
- *Preparing and Analyzing Data from the CAHPS Clinician & Group Survey*
- *Instructions for Analyzing Data from CAHPS Surveys*

Reporting Measures and Guidelines

- *Patient Experience Measures from the CAHPS Clinician & Group Survey*

Introduction

Patients' stories about their experiences with health care are an important complement to the information derived from close-ended questions in the CAHPS Clinician & Group Survey and other CAHPS surveys. Reading what patients say can help doctors and their staff better understand what is happening when their patients seek and receive care and what they can do to provide a better experience. It can also help health care consumers identify the providers whose care appears to be consistent with their needs and values and learn how other patients and providers deal with various issues that arise.

To date, the vast majority of patient comments have been gathered in two ways: either volunteered on a Web site or solicited through one or more open-ended questions from a health care organization, often as part of a more extensive survey. These approaches have helped to make patient comments one of the most common and familiar forms of information about provider quality available today. At the same time, concerns about the accuracy and representativeness of current patient comments have grown.

To support health care organizations in collecting patients' comments in a systematic and structured way, the Agency for Healthcare Research and Quality (AHRQ) has funded the development and testing of the CAHPS Patient Narrative Elicitation Protocol, a supplemental set of five open-ended questions that can be added to the CAHPS Clinician & Group Survey.

This document introduces the **beta version** of this new supplemental item set and discusses:

- The impetus for a scientifically rigorous approach to gathering patient narratives.
- The structure and flow of the questions.
- How use of these items affects the administration of the survey.
- Possible approaches to processing the narrative content.
- Use of patient narratives with health care providers and consumers.
- How these questions were developed.

The development of the CAHPS Patient Narrative Elicitation Protocol is an ongoing process. The questions have been tested in an experimental setting as well as in real-world data collection projects with field partners. While the wording of the questions and the guidance in this document reflect what we have learned to date, both will be refined as we learn more. The CAHPS team will also continue to explore ways to manage, collate, and display large amounts of narrative content so that it is usable and actionable for health care providers and consumers.

Why Elicit Patient Narratives?

Thanks to the tremendous growth of user-generated content and the popularity of review sites such as Yelp, TripAdvisor, and Amazon, Americans have become accustomed to seeking out each other's opinions on goods and services on the Internet. Not surprisingly, health care services are a part of this trend. Since Yelp and RateMDs were launched in 2004, the number of patients' comments about their doctors and other providers on the Internet has grown from a couple hundred into the millions. As of 2016, patients' comments can be found on several dozen public sites hosted by commercial companies, as well as on sites hosted by health systems, health plans, and other organizations.^{1,2,3}

Surveys of American adults indicate that they are increasingly seeking out online reviews of health care services. The Pew Internet and American Life Project found that about 20 percent of Internet users were looking for health-related reviews in 2012, with about 17 percent consulting reviews or rankings of doctors or other providers.⁴ Based on its own survey of a cross-section of American adults who reported recent contact with a health care provider, the CAHPS team found a similar level of exposure to comparative quality information for physicians, hospitals, and health plans among Internet users at that time. Moreover, the team's analyses suggest that consumers' awareness of quality information for physicians has been growing steadily, to the extent that it now exceeds their awareness of hospital information. Moreover, patients' comments have become the form of physician quality information that Americans are most likely to see online. When the team conducted the survey in 2015, roughly a third of respondents who saw any kind of comparative quality information about physicians indicated that they saw patients' comments, and about a quarter of those people saw *only* comments.

While patient comments offer a valuable perspective on patient experience with care, most of the information available from comments today is flawed. The primary problem is that even though there are millions of comments, only a handful of comments are available for most individual providers. As a result, providers, consumers, and policymakers share concerns about the representativeness of comments. Moreover, because most of the comments are volunteered anonymously on the Internet, providers are at risk of fraudulent claims, comments from people misrepresenting themselves as patients, and comments from a small number of patients who do not adequately represent their patient population. Thus, while those

¹ Personal communication with Tara Lagu, MD, MPH, Research Scientist, Center for Quality of Care Research Baystate Medical Center Associate, and Professor, Tufts University School of Medicine. October 3, 2016.

² Findlay SD. Consumers' interest in provider ratings grows, and improved report cards and other steps could accelerate their use Health Aff 2016; 35(4):688-696.

³ Health Research Institute. Scoring healthcare: Navigating customer experience ratings. Delaware; Pricewaterhouse Coopers, 2012.

⁴ Fox S, Duggan M. Health Online 2013. Pew Internet & American Life Project. January 15, 2013. Accessed at <http://pewinternet.org/Reports/2013/Health-online.aspx>.

who read comments may value them, the information they are getting is not necessarily representative or valid.

Collecting comments as part of a standardized patient experience survey is one way to address some of these concerns because the comments, like the survey data, are collected from a random sample of confirmed patients. Users of the CAHPS Clinician & Group Survey and other CAHPS patient experience surveys have always been free to add one or more open-ended questions at the end of the standardized closed-ended survey items to enable respondents to comment on their experience in their own words. The use of open-ended questions in the CAHPS Hospital Survey (HCAHPS), for example, has generated information useful for identifying problems with inpatient care.⁵ However, a generic invitation to comment on one's experience with care does not represent a scientific approach to inviting consumers to provide complete and meaningful qualitative information.

The CAHPS team took on the challenge of developing and testing open-ended questions with the same scientific rigor that goes into the development of CAHPS surveys. The goal was to create questions that could be added to CAHPS surveys to generate insights into the topics addressed by the survey's measures as well as other important aspects of patient experience that may not be captured by closed-ended questions.

The beta version of these questions, referred to as the CAHPS Patient Narrative Elicitation Protocol (or Elicitation Protocol), is intended to be used with the CAHPS Clinician & Group Survey only. In addition to ongoing refinement of the beta version of this Elicitation Protocol, research is needed to determine how best to adapt this item set to other settings and contexts so that it can be incorporated into other CAHPS surveys.

Questions in the CAHPS Patient Narrative Elicitation Protocol

The CAHPS Narrative Elicitation Protocol (beta version) is a set of supplemental items developed for use with the CAHPS Clinician & Group Survey (5 items for the Adult version; 6 items for the Child version). The questions are purposely designed to lead the respondent through the telling of his or her "story" in a structured sequence in order to elicit a clear and comprehensive portrayal of the experience. Because of the sequential design of the questions, they are meant to be used together in the order specified. For example, the first question is designed to prompt respondents to state the most important things they look for in a health care provider so that they have them in mind when answering the subsequent questions. The CAHPS team strongly recommends against selecting a subset of the questions for partial use or reordering the questions.

⁵ Huppertz JW, Smith R. The Value of Patients' Handwritten Comments on HCAHPS Surveys. *Journal of Healthcare Management/American College of Healthcare Executives*. 2013;59(1): 31–47.

The questions in the Adult version of the Patient Narrative Elicitation Protocol are listed below. **Appendix A** provides the Adult Protocol in English and Spanish. **Appendix B** provides the Child Protocol in English and Spanish.

- PN-1.** What are the most important things that you look for in a healthcare provider and the staff in his or her office?
- PN-2.** When you think about the things that are most important to you, how do your provider and the staff in his or her office measure up?
- PN-3.** Now we'd like to focus on anything that has gone well in your experiences in the last 6 months with your provider and the staff in his or her office. Please explain what happened, how it happened, and how it felt to you.
- PN-4.** Next we'd like to focus on any experiences in the last 6 months with your provider and the staff in his or her office that you wish had gone differently. Please explain what happened, how it happened, and how it felt to you.
- PN-5.** Please describe how you and your provider relate to and interact with each other.

The Child version of the Elicitation Protocol adds a sixth question that asks how the child and provider relate to each other.

Administering the CAHPS Patient Narrative Elicitation Protocol

The Patient Narrative Elicitation Protocol (beta version) can be administered in two ways: as a supplement to the CAHPS Clinician & Group Survey or on its own. The CAHPS team recommends that the Elicitation Protocol be used in conjunction with the Clinician & Group Survey for two reasons: (1) to take advantage of the sampling frame drawn for the survey questions and (2) to facilitate the linking of narrative responses to the responses on the closed-ended survey questions. However, as discussed below, using the complete Elicitation Protocol separately from the survey may provide an opportunity to collect additional narrative information outside of routine survey fielding periods.

Administration with the Clinician & Group Survey

When using these items as part of the Clinician & Group Survey 3.0, please follow the [guidelines provided on the AHRQ site](#). All guidance documents are available at no charge.

Use of the Elicitation Protocol has a few implications for the survey administration process, as discussed below:

Placement of the items: Add the Elicitation Protocol at the end of the survey, just before the “About You” section. To signal that this is a new section of the survey, use the subheading (“In your own words”) and the following introductory sentences:

In Your Own Words

In your own words, please describe your experiences with this provider and his or her office staff, such as nurses and receptionists.

If you need medical advice or care, please contact your provider’s office.

The purpose of these sentences is to emphasize that the open-ended questions are an opportunity to share one’s personal experience and to remind respondents not to use the comments to seek medical advice.

Time for administration: In testing, the Elicitation Protocol added 5-7 minutes on average to the response time for the closed-ended questions (which is estimated at 12-15 minutes). However, the additional time for answering the questions in experimental testing ranged widely, from a few minutes to 30 minutes. The CAHPS team recommends that users of the Elicitation Protocol not impose limits on the amount of time that respondents have to answer these questions.

Anticipated length of comments: The CAHPS team suggests providing respondents with ample space to write their responses. In pilot tests of the Elicitation Protocol, the average response to each question was a few sentences (16-28 words), but some responses exceeded 300 words (about two paragraphs).

Sampling: Guidelines for pulling a representative sample of patients for the Clinician & Group Survey are available in *Fielding the CAHPS Clinician & Group Survey*. Use of the Elicitation Protocol does not require any changes to the sampling strategy for this survey.

Data collection: The CAHPS Clinician & Group Survey is typically administered with a mixed-mode method of mail/telephone, email/telephone, or email/mail.⁶ To date, the Elicitation Protocol has been administered by telephone and on the Web (also referred to as email administration); based on its performance in those modes, the CAHPS team recommends the use of email followed by telephone.

One of the biggest challenges to this approach is obtaining email addresses, which may not be available for a representative sample of the patient population. The CAHPS approach for email administration emphasizes the importance of following the email with telephone administration for non-respondents.

Another option is to include a link to the online survey as part of the mail data collection method. However, the use of mailed/paper invitations to the online survey does not appear to be an effective strategy. In testing of this approach, there was little uptake when respondents were invited by mail to respond online; this finding is

⁶ In the email protocol, a link to a Web-based survey is provided in the email.

consistent with other research on the use of mailed/paper invitations with the CAHPS Clinician & Group Survey.^{7,8}

For descriptions of recommended data collection methods, go to *Fielding the CAHPS Clinician & Group Survey*.

Invitation and reminder letters and emails: To support users of the Clinician & Group Survey in motivating people to respond, the guidance documents for the survey include sample language for emails, reminders, and an advance letter for the telephone survey. The Elicitation Protocol represents an opportunity to encourage more patients to respond to the Clinician & Group Survey because it invites them to give feedback on issues of importance to them, using their own words. If you are including the Elicitation Protocol, consider revising the sample language to encourage thoughtful responses and address a few issues raised by open-ended responses:

- Let respondents know how their comments are likely to be used (for example, whether the responses will be shared with providers or posted on a public site).
- Reassure respondents that their comments will be screened to eliminate any information that is potentially identifiable.

Appendix C provides sample language that can be adapted for this purpose. The impact of specific invitation language on participation rates and data quality has not yet been evaluated. For additional examples of language you can use in an invitation, refer to *Sample Notification Letters and Emails for the CAHPS Clinician & Group Survey*.

Instructions to vendors: The guidelines for administering CAHPS surveys emphasize the importance of maintaining the confidentiality of respondents. When using the Elicitation Protocol (or any other open-ended questions), it is especially important for the vendor to review and redact any potentially identifiable information (including names, phone numbers, and email addresses) from the comments before distributing them to clinicians or including them in a public Web site. Vendors should also have systems in place to flag any comments that require an immediate response from health care providers.

⁷ Elliott MN, Brown JA, Lehrman WG, Beckett MK, Hambarsoomian K, Giordano LA, Goldstein EH. A randomized experiment investigating the suitability of speech-enabled IVR and Web modes for publicly reported surveys of patients' experience of hospital care. *Medical Care Research and Review* 2012;70(2):165-184.

⁸ Medway RL, Fulton J. When more gets you less: A meta-analysis of the effect of concurrent Web options on mail survey response rates. *Public Opinion Quarterly* 2012;76(4):733-746.

Administration of the Elicitation Protocol on its own

The CAHPS Patient Narrative Elicitation Protocol (beta version) can also be administered by itself, i.e., not as part of the CAHPS Clinician & Group Survey. Use of the Elicitation Protocol on its own could be especially useful for two purposes:

- To hear directly from a subsample of patients who may be of particular interest (e.g., high utilizers, patients with chronic conditions, specific demographic groups).
- To obtain ongoing feedback during periods when the CAHPS survey is not being administered (e.g., when the survey is fielded only once a year or every two years).

Please note that the Elicitation Protocol was not tested on its own. However, as part of the testing process, the open-ended items were administered both before and after the core Clinician & Group Survey. When administered before the closed-ended questions, the Elicitation Protocol functioned in a way that is similar to when it is administered independently because the respondents were not primed to consider specific aspects of their care. This testing indicated that the Elicitation Protocol performed virtually the same whether placed before or after the closed-ended questions, in terms of the evaluation criteria used (namely, the completeness, balance, meaningfulness, and representativeness of narratives; refer to page 10 to learn more about these criteria).

Sampling: The CAHPS team recommends a random sampling approach similar to the one used for the Clinician & Group Survey. Even if you are seeking feedback from a specific segment of the patient population, please follow the basic sampling guidelines:

- Include only patients who have had at least one visit to the selected provider/practice in the target time frame.
- If seeking feedback from adults, include adults 18 years or older. If seeking feedback from parents or guardians of children, include children 17 years or younger.
- Include all patients who meet the sampling criteria even if they are no longer currently receiving care from the practice site/clinic or provider.
- Allow the sample frame to include multiple individuals from the same household, but do not include more than one person (adult or child) per household in the final sample for which the survey will be administered.

Data collection: Based on testing of the Elicitation Protocol as part of the Clinician & Group Survey, the CAHPS team recommends administering these items by Web and telephone. For descriptions of these recommended data collection methods, go to *Fielding the CAHPS Clinician & Group Survey*.

The CAHPS guidelines are designed to preserve the anonymity of respondents. If you use different sampling and/or data collection processes for the Elicitation Protocol, please take steps to ensure that respondents cannot be identified.

Invitation and reminder letters and emails: When fielding the Elicitation Protocol on its own, consider using the invitation and reminders to explain how the responses will be used and to reassure patients that their identities will not be revealed. For further guidance and suggested language, refer to the sample language in **Appendix C** and the *Sample Notification Letters and Emails for the CAHPS Clinician & Group Survey*.

Use of responses to the protocol: Unless the Elicitation Protocol is fielded to a representative sample of patients (as required for the Clinician & Group Survey), the respondents will not mirror the patient population. In that case, the responses should not be publicly posted. The feedback can be shared with health care providers, but it will be important to acknowledge that the information did not come from a representative sample.

Acknowledging CAHPS: If you are using the Elicitation Protocol on its own, please [acknowledge AHRQ's CAHPS program](#) as the source of the items.

Processing Patient Narratives

While responses to the Patient Narrative Elicitation Protocol will likely have great value in being read verbatim, the collection of large volumes of narrative responses may require some type of processing in order to more efficiently extract the core meaning of the information. Two basic types of processing can be used:

(1) qualitative analysis methods using human coders, and (2) methods using computerized, automated analyses such as natural language processing (NLP).

In testing the Elicitation Protocol, the CAHPS team used a relatively labor-intensive qualitative method to analyze the narrative data collected. This method involved the development of a coding scheme for identifying key content domains. (The coding scheme used in testing is available upon request to the CAHPS Help Line at cahps1@westat.com.) Responses to the five narrative questions were aggregated to create a single narrative. Trained researchers then coded the single narrative on several dimensions, including the overall valence of the narrative and the number of times certain aspects of care were mentioned, as well as the number of words used. Reliability was established through agreement among the trained coders. This method worked well for initial testing, and a number of health systems have used a similar approach to coding and labeling themes in their comments. However, at a large scale, this method may prove too costly or cumbersome to administer in a way that ensures consistent coding.

NLP represents another approach to the analysis of narrative comments. NLP methods are increasingly being used to analyze clinical notes in medical records, and several organizations have developed NLP programs specifically designed to analyze the content of patient narratives. To date, the CAHPS team has not tested or evaluated

NLP approaches and can therefore not yet make any recommendations regarding their use. This is an area requiring further research and development.

Using Patient Narratives to Inform Providers and Patients

As noted earlier, patient narratives can provide valuable information for both provider improvement as well as consumer choice. For providers, narratives can reveal what is driving CAHPS survey scores and what specific processes and behaviors can be addressed to improve patient experience. For consumers, narratives can communicate information beyond CAHPS scores regarding what a patient's experience with a clinician and his or her office staff is like, and how that compares to the patient's own values and preferences.

Informing Providers

Strategies for providing narrative feedback to providers will depend in part on how the narrative data are processed. Many health systems that are currently collecting open-ended responses as part of their patient survey disseminate the verbatim comments to medical practice leaders and individual clinicians along with their survey scores. In addition, a growing number of health systems are publishing patient comments along with the survey scores of individual physicians on their Web sites. Some medical leaders believe that publishing this information online is an effective strategy for driving improvements in patient experience survey scores. For example, following the online publication of survey scores and patient comments about their physicians, the University of Utah Health System saw its physician communication scores increase from the 35th percentile in 2010 to the 90th percentile in 2014 and experienced a two-fold increase in Web site traffic.⁹ Further research is needed to identify the most useful way of relaying patient narrative information to clinicians.

General guidance on developing effective physician feedback reports is available in [Confidential Feedback Reports: Designing for Optimal Impact on Performance](#).

[The CAHPS Ambulatory Care Improvement Guide](#) offers insights into quantitative and qualitative analyses useful for identifying improvement opportunities as well as strategies for improving patients' experiences.

Informing Consumers

Strategies for reporting narrative information to consumers are also evolving. While patient comments are available on a growing number of standalone Web sites, there is increasing interest in incorporating narrative information into consumer reports that also contain standardized measures of health care quality, including CAHPS survey measures.

⁹ Schlesinger M, Grob R, Shaller D. Using Patient-Reported Information to Improve Clinical Practice. *Health Services Research* 2015 December; 50:Suppl 2:2116-2154.

The CAHPS team is exploring ways of integrating patient narratives into consumer reports to enhance consumers' understanding of standardized measures of quality, better engage consumers in health care decision-making, and more effectively convey patient-reported experiences. Findings from this research suggest that narratives have the potential to increase consumers' attention to and engagement with reports on physician quality, but can also reduce consumers' attention to standardized measures and lead to suboptimal doctor choices based on those measures alone,¹⁰ even among those who judged the standardized measures to be important indicators of quality. The CAHPS team is currently analyzing data from a second round of experiments to determine ways to better integrate patient narratives with standardized measures in order to help augment consumers' understanding of each and make it easier to synthesize the two when making good decisions about doctors.

Development of the CAHPS Patient Narrative Elicitation Protocol

AHRQ funded the development of the Patient Narrative Elicitation Protocol by researchers affiliated with the Yale School of Public Health, RAND, and the University of Wisconsin-Madison. The goal of this work has been to develop and test a scientifically rigorous design for open-ended survey items that could be administered as part of the CAHPS Clinician & Group Survey to elicit short, salient narratives from patients about their experiences with clinicians.

The research team began by specifying a set of characteristics for a “high-quality” patient narrative and developing strategies for measuring those characteristics. Drawing on previous research with patient narratives, the team then developed and tested an initial version of the Elicitation Protocol. This first draft went through both cognitive testing as well as testing with several hundred respondents who answered the open-ended questions as part of an experiment with the CAHPS Clinician & Group Survey. To assess the qualities of the responses to the open-ended questions, the research team compared them to the results of detailed interviews with 50 of the respondents.

Based on the findings from these tests, the team revised the Elicitation Protocol and conducted a second test using the same approach of comparing survey responses to the results of interviews with respondents. An analysis of this comparison indicated that the revisions to the Elicitation Protocol increased the completeness of elicitations from roughly 40 percent to approximately 60 percent of the content gleaned from the hour-long interviews.

To assess how well this version of the Elicitation Protocol would perform in a real-world environment, the team also field-tested the protocol as part of a pilot project conducted by the California Healthcare Performance Information System (CHPI) and Massachusetts Health Quality Partners (MHQP). Following a final internal review

¹⁰ Kanouse DE, Schlesinger M, Shaller D, Martino SC, Rybowski L. How patient comments affect consumers' use of physician performance measures. *Medical Care* 2016 January; 54(1):24-31.

process, AHRQ released the beta version of the Elicitation Protocol in December 2016.

More information on the development of the Elicitation Protocol is available on the [AHRQ CAHPS Web site](#) and in Grob R, Schlesinger M, Parker AM, et al. Breaking Narrative Ground: Innovative Methods for Rigorously Eliciting and Assessing Patient Narratives. *Health Serv Res* 2016 April; 51:1475-6773.

For more information about the Elicitation Protocol, please contact the CAHPS Help Line at cahps1@westat.com or 1-800-492-9261.

Relevant Literature by the Research Team

Grob R, Schlesinger M, Parker AM, et al. Breaking Narrative Ground: Innovative Methods for Rigorously Eliciting and Assessing Patient Narratives. *Health Serv Res* 2016 April; 51:1475-6773.

Kanouse DE, Schlesinger, M, Shaller D, et al. How patient comments affect consumers' use of physician performance measures. *Med Care* 2016 Jan;54(1):24-31.

Schlesinger M, Grob R, Shaller D. Using Patient-Reported Information to Improve Clinical Practice. *Health Serv Res* 2015 Dec;50(S2):2116-2154.

Schlesinger M, Grob R, Shaller D, et al. Taking Patients' Narratives about Clinicians from Anecdote to Science. *N Engl J Med* 2015 August;373(7):675-679.

Schlesinger M, Kanouse DE, Martino SC, et al. Complexity, public reporting, and choice of doctors: a look inside the blackest box of consumer behavior. *Med Care Res Rev* 2014;71:Suppl:38S-64S.

Schlesinger M, Kanouse DE, Rybowski L, et al. Consumer response to patient experience measures in complex information environments. *Med Care* 2012;50:S56-S64.

Appendix A. Items in the Adult Version of the Patient Narrative Elicitation Protocol (beta)

The following items should be placed before the “About You” section of the survey.

English Version

In Your Own Words

In your own words, please describe your experiences with this provider and his or her office staff, such as nurses and receptionists.

If you need medical advice or care, please contact your provider’s office.

- PN-1. What are the most important things that you look for in a healthcare provider and the staff in his or her office?
- PN-2. When you think about the things that are most important to you, how do your provider and the staff in his or her office measure up?
- PN-3. Now we’d like to focus on anything that has gone well in your experiences in the last 6 months with your provider and the staff in his or her office. Please explain what happened, how it happened, and how it felt to you.
- PN-4. Next we’d like to focus on any experiences in the last 6 months with your provider and the staff in his or her office that you wish had gone differently. Please explain what happened, how it happened, and how it felt to you.
- PN-5. Please describe how you and your provider relate to and interact with each other.

Spanish Version

En Sus Propias Palabras

En sus propias palabras, por favor describa sus experiencias con este profesional médico y el personal del consultorio de ese profesional médico, por ejemplo, enfermeras o recepcionistas.

Si usted necesita consejos médicos o atención médica, comuníquese con el consultorio de su profesional médico.

- PN-1. ¿Cuáles son las cosas más importantes que busca en un profesional médico y el personal del consultorio de ese profesional médico?
- PN-2. Respecto a las cosas que son más importantes para usted, ¿cómo evalúa a su profesional médico y al personal del consultorio de ese profesional médico?
- PN-3. Ahora quisiéramos concentrarnos en todas las experiencias buenas que ha tenido con su profesional médico y el personal del consultorio de ese profesional médico en los últimos 6 meses. Por favor explique qué sucedió, cómo sucedió y cómo lo sintió usted.
- PN-4. Ahora quisiéramos concentrarnos en todas las experiencias con su profesional médico y el personal del consultorio de ese profesional médico que usted desearía que hubieran

sido diferentes en los últimos 6 meses. Por favor explique qué sucedió, cómo sucedió y cómo lo sintió usted.

PN-5. Por favor describa cómo se relacionan e interactúan usted y su profesional médico.

Appendix B. Items in the Child Version of the Patient Narrative Elicitation Protocol (beta)

The following items should be placed before the “About Your Child and You” section of the survey.

Please note that this Child version of the Protocol was not field tested and validated.

English Version

In Your Own Words

In your own words, please describe your experiences with this provider and his or her office staff, such as nurses and receptionists.

If you need medical advice or care for your child, please contact your provider’s office.

- PN-1. What are the most important things that you look for in your child’s healthcare provider and the staff in his or her office?
- PN-2. When you think about the things that are most important to you, how do your child’s provider and the staff in his or her office measure up?
- PN-3. Now we’d like to focus on anything that has gone well in your experiences in the last 6 months with your child’s provider and the staff in his or her office. Please explain what happened, how it happened, and how it felt to you.
- PN-4. Next we’d like to focus on any experiences in the last 6 months with your child’s provider and the staff in his or her office that you wish had gone differently. Please explain what happened, how it happened, and how it felt to you.
- PN-5. Please describe how you and your child’s provider relate to and interact with each other.
- PN-6. Please describe how **your child** and his or her provider relate to and interact with each other.

Spanish Version

En Sus Propias Palabras

En sus propias palabras, por favor describa sus experiencias con este profesional médico y el personal del consultorio de ese profesional médico, por ejemplo, enfermeras o recepcionistas.

Si usted necesita consejos médicos o atención médica para su niño/a, comuníquese con el consultorio de su profesional médico.

- PN-1. ¿Cuáles son las cosas más importantes que busca en el profesional médico de su niño/a y el personal del consultorio de ese profesional médico?
- PN-2. Respecto a las cosas que son más importantes para usted, ¿cómo evalúa al profesional médico de su niño/a y al personal del consultorio de ese profesional médico?
- PN-3. Ahora quisiéramos concentrarnos en todas las experiencias buenas que ha tenido con el profesional médico de su niño/a y el personal del consultorio de ese profesional médico

en los últimos 6 meses. Por favor explique qué sucedió, cómo sucedió y cómo lo sintió usted.

- PN-4.** Ahora quisiéramos concentrarnos en todas las experiencias con el profesional médico de su niño/a y el personal del consultorio de ese profesional médico que usted desearía que hubieran sido diferentes en los últimos 6 meses. Por favor explique qué sucedió, cómo sucedió y cómo lo sintió usted.
- PN-5.** Por favor describa cómo se comunican e interactúan usted y el profesional médico de su niño/a.
- PN-6.** Por favor describa cómo se comunican e interactúan **su niño/a** y su profesional médico.

Appendix C. Sample Language to Add to Survey Invitation

The text below comes from one of the sample letters for the CAHPS Clinician & Group Survey. If you are fielding the Patient Narrative Elicitation Protocol as part of that survey, consider adding the second paragraph shown below and revising the third paragraph as indicated.

DATE

FIRST AND LAST NAME
 LINE ONE OF ADDRESS
 LINE TWO OF ADDRESS (IF ANY)
 CITY, STATE ZIP

Dear {Mr./Ms.} [LAST NAME]

We at [NAME OF PROVIDER ORGANIZATION] need your help. Our records indicate that you have visited [PROVIDER'S NAME] in the last 6 months, and we would like you to tell us about your care. We are committed to providing you with the best quality health care available, and your input will help us to achieve this goal. This brief survey should only take about [TIME] minutes or less of your time.

(Insert this paragraph:) Our survey includes some questions that ask you to describe, in your own words, your care and your relationship with [PROVIDER'S NAME] and his or her staff. Please describe your experiences as if you were explaining them to your family and friends.

(Delete the text in this paragraph that appears with a strikethrough:) The information that you provide will be kept **completely private and confidential**. Your answers will never be matched with your name. ~~No one involved in your care will see your individual answers.~~ We have hired [NAME OF SURVEY VENDOR], an independent professional survey organization, to conduct the survey. [VENDOR] will combine your answers with those of other people who complete the survey to create a summary report that tells us about our patients' experiences with our providers and medical offices. *(Add this sentence:)* [VENDOR] will also ensure that your responses do not contain any personal information or descriptions of your care that could reveal your identity.

We hope you will take this chance to tell us about your experiences with health care. Please return the completed survey in the enclosed postage-paid envelope by [MONTH/DAY/YEAR]. You may choose to participate or not, but the more people who respond, the greater our ability to improve the quality of care you receive. **If you choose not to participate, this will not affect the health care you get from your providers.**

If you have any questions about this survey, please call [CONTACT NAME] at (XXX) [XXX-XXXX]. All calls to this number are free. Thank you for helping to make health care at [NAME OF PROVIDER ORGANIZATION] better for everyone!

Sincerely,

[NAME OF PERSON REPRESENTING PROVIDER ORGANIZATION]

Nota: Si quiere un cuestionario en español, por favor llame al (XXX) [XXX-XXXX].