

Preparing a Questionnaire Using the CAHPS® Cancer Care Survey

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Documents Available for the CAHPS Cancer Care Survey

This document is part of a set of instructional materials that address implementing the Cancer Care Survey, analyzing the data, and reporting the results. All documents are available on the [Agency for Healthcare Research and Quality's 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 CAHPS Cancer Care Survey*.

Available for the Cancer Care Survey:

Questionnaires

- *CAHPS Cancer Care Survey* (English and Spanish)
 - *Radiation Therapy Survey*
 - *Drug Therapy Survey*
 - *Cancer Surgery Survey*

Supplemental Items

- *Supplemental Items for the CAHPS Cancer Care Survey*

Survey Administration Guidelines

- *Preparing a Questionnaire Using the CAHPS Cancer Care Survey*
- *Fielding the CAHPS Cancer Care Survey*
- *Sample Notification Letters and Emails for the CAHPS Cancer Care Survey*

Reporting Measures and Guidelines

- *Patient Experience Measures from the CAHPS Cancer Care Survey*

Available for all CAHPS surveys:

- [Analyzing CAHPS Survey Data](#): Free programs for analyzing the data, guidance on preparing survey results for analysis, and instructions for using the CAHPS Analysis Program.
- [Translating Surveys and Other Materials](#): Guidelines for translating surveys and selecting translators and translation reviewers.

Introduction

The CAHPS Cancer Care Survey asks adult patients (age 18 and older) to report on their experiences with the care team that delivered the cancer treatment and the cancer center's office staff. It includes three standardized questionnaires and optional supplemental items to assess patients' experiences with the three most common treatment modalities: radiation therapy, drug therapy, and cancer surgery.

This document explains how to use the core and supplemental items from the CAHPS Cancer Care Survey to construct a questionnaire that meets your needs. It focuses on steps you can take when preparing a questionnaire to ensure that it is consistent with your project's objectives and will generate useful information. These steps include—

- Incorporating supplemental questions
- Translating the questionnaire
- Formatting the questionnaire

Incorporating Supplemental Questions

Like most CAHPS surveys, the Cancer Care Survey includes core items and supplemental items.

Core items are questions that are included in every questionnaire to ensure standardization and comparability across survey users. They are applicable across different cancer care providers, treatment modalities, and patient populations.

Appendix A presents the core items in the survey by topic.

Supplemental items are optional questions that may be added to the core items to customize the questionnaire to meet users' specific needs.

A list of the topics covered by the core and supplemental items is provided at right.

Users of the CAHPS Cancer Care Survey are free to incorporate supplemental items to meet the needs of their organizations, local markets, and/or audiences. It may be helpful to add items to help providers and care teams better understand what is driving their performance on core composite measures. For example, patients' reports on their experiences with getting information from

Topic Covered by Core Items

- Availability of care team
- Involvement of family members and friends
- Access to care
- Communication between patients and the care team
- Coordination of care
- Support in managing effects of care and treatment
- Availability of interpreters
- Customer service
- Rating of care team
- Rating of overall care

Topic Covered by Supplemental Items

- Shared decision making
- Information from providers
- Access to care

providers can pinpoint specific issues that may be undermining communication between the care team and their patients.

Some items cover events that occur with low frequency in the general population. You should include them only if your sample design is likely to yield enough responses to those questions for statistical analysis and reporting. To learn more about the minimum number of responses needed and the implications for sample size, refer to *Fielding the CAHPS Cancer Care Survey*.

You also have the option of adding your own items to the core questionnaire. Please follow the instructions provided in the next section for placement of these items in your survey.

Tailoring of Supplemental Items for Treatment Modality

The supplemental items can be inserted into any of the three versions of the Cancer Care Survey. To make the wording of the items consistent with the core items, please replace the bracketed references to [CANCER TREATMENT MODALITY] with the appropriate term: radiation therapy, drug therapy, or cancer surgery.

Placement of Supplemental Items

The list of supplemental items includes instructions for placing items in the Cancer Care Survey. These instructions were designed to ensure consistency across surveys in the location and order of items and to support survey users in creating questionnaires that flow in a fashion that is consistent with how respondents think about the topics.

Whenever you add items, be sure to—

- **Renumber** the supplemental item and **ALL** subsequent items so that they are consecutive. Each questionnaire should start with question #1 and continue sequentially. Do not start renumbering within sections or any other place in the survey. Use integers only and not letters (e.g., 5a, 5b, SDM1).
- **Revise ALL skip instructions** in the questionnaire to make sure they point respondents to the correct item number. Make sure you have already renumbered the survey items consecutively, then update the skip instructions to match the new survey item numbering.
 - Skip instructions should be formatted consistently.
 - Skip instructions in the formatted items often refer to “[core question] #x” where x represents an item number from the core survey. Be sure to delete “core question” and make sure the item number in the skip instructions is correct after renumbering.
- **Format the items** as needed to fit into the two-column format (if you are preparing the survey to be mailed).

Original supplemental item:

26. In the last 6 months, did you take any prescription medicine?

¹ ☐ Yes

² ☐ No → **If No, go to #28**

27. In the last 6 months, how often did you and your drug therapy team talk about all the prescription medicines you were taking?

¹ ☐ Never

² ☐ Sometimes

³ ☐ Usually

⁴ ☐ Always

INF4. In the last 6 months, did your [CANCER CARE MODALITY] team prescribe medicine that you had not taken before?

¹ ☐ Yes

² ☐ No → **If No, go to #28 in core survey**

28. In the last 6 months, did you and your drug therapy team talk about pain related to your cancer or drug therapy?

¹ ☐ Yes

² ☐ No

Same question when added to the core survey:

26. In the last 6 months, did you take any prescription medicine?

¹ ☐ Yes

² ☐ No → **If No, go to #29**

27. In the last 6 months, how often did you and your drug therapy team talk about all the prescription medicines you were taking?

¹ ☐ Never

² ☐ Sometimes

³ ☐ Usually

⁴ ☐ Always

28. In the last 6 months, did your drug therapy team prescribe medicine that you had not taken before?

¹ ☐ Yes

² ☐ No → **If No, go to #29**

29. In the last 6 months, did you and your drug therapy team talk about pain related to your cancer or drug therapy?

¹ ☐ Yes

² ☐ No

If you plan to add your own questions, append them in a new section **before** the “About You” section. Adding new items prior to core items is strongly discouraged as it creates a different context around the core items and may influence responses to the core items.

Concerns About Questionnaire Length

If you choose to add either supplemental items or your own items, pay attention to the length of the questionnaire. The longer the questionnaire, the greater the burden on the respondent. That said, research by the CAHPS grantees indicates that, up to a point, survey length has little impact on response rates.¹

Translating CAHPS Surveys Into Other Languages

To help identify and reduce ethnic and racial disparities in health care, survey users may want to field translations of the survey that assess the experiences of individuals who are not fluent in English. Spanish translations of the core and supplemental items are available from AHRQ; translations in other languages would have to be developed by survey users and/or their vendors.

The AHRQ Web site offers guidance on [translating surveys and other materials](#) into a language other than English or Spanish. To translate CAHPS surveys into another language, the recommended approach is for two translators to each produce a forward translation. Another bilingual reviewer then reviews the two forward translations against each other and compare them to the original English survey to develop the final Spanish survey.

Formatting CAHPS Surveys

To ensure consistency across surveys, please observe the following guidelines when formatting your survey to be administered by mail, telephone, or the Web. Survey users should carefully consider which mode would be the most desirable and appropriate for their patient population. For guidance on survey modes, please refer to *Fielding the CAHPS Cancer Care Survey*.

Formatting the Questionnaire for Mail Surveys

The CAHPS Team strongly recommends taking steps to maximize the visual appeal and readability of mailed questionnaires. A well-formatted questionnaire contributes to response rates, completion rates, and the accuracy of responses.

The surveys available from the AHRQ Web site are formatted to be self-administered mail questionnaires that are explicitly designed to be easy to read. Important elements

¹ To learn more, see: Gallagher PM, Fowler FJ. Notes from the Field: Experiments in Influencing Response Rates from Medicaid Enrollees. 2000 Proceedings, Data Quality Section. American Statistical Association; Alexandria, VA; 971-976.

include the two-column format, the use of white space, and the font size and type (12-point Times New Roman). Please retain these elements if you add supplemental items to your questionnaire. The table below provides detailed recommendations for formatting the survey.

To minimize the number of pages required to print the questionnaire, survey users are often tempted to orient response options horizontally instead of vertically, especially for the 0-10 ratings items. However, research has shown that respondents are often confused by the horizontal orientation, which can lead to invalid responses. Therefore, the CAHPS Team strongly recommends maintaining the vertical orientation that is shown in the formatted questionnaires.

Guidelines for Questionnaire Formatting

Element	General recommendation	Rationale
General		
Layout	2 columns with line separating columns	Makes survey navigation easier for respondents
Margins	Top & Bottom = 1 inch; Left & Right = 0.75 inch; Header = 0.5 inch; Footer = 0.4 inch	Makes navigation easier for respondents
Orientation	Vertical	Avoids the confusion cause by the horizontal orientation of response options
Section Headings		
Font Size	Should appear slightly larger than item text. Use 13 pt. as a guide (although font sizes can vary in actual size)	Minimum size necessary to ensure readability.
Font style	Any sans serif font (e.g., Arial), title case, bold, with line above and line below to separate heading from item text	Provides contrast to serif font and style used for text
Spacing	Double space before box and single space after box	Provides white space around heading
Item Text		
Font size	Minimum 12 pt.	Minimum size necessary to ensure readability
Font style	Any serif font (e.g., Times New Roman)	Improves readability

Element	General recommendation	Rationale
Visual emphasis	Item number bold, item text not bold; bold to emphasize individual words (instead of underlining)	Improves readability, facilitates identification of key words in item
Spacing	Single space (plus 6 pts. at end of item)	Improves readability
Hanging indent and tab after item number	0.4 inch	Improves readability
Response Options		
Font size	Minimum 12 pt. (Can use 12 pt. as a rough guide since size varies with style)	Minimum size required for readability
Font style	Any serif font (same as item font)	Improves readability
Spacing	Half line between item text and responses	Improves readability
Skip instructions	Bold	Emphasizes instruction to go to an item that is not sequential
Spacing between response and new item	Single plus additional 6 pts.	Improves readability
Indentation	Use vertical alignment of response options	Creates white space and improves readability
Precodes		
Use of precodes	Optional	Facilitates data entry
Location and style	Left of check box as superscript	De-emphasizes code for respondent
0-10 responses	Do not use precodes on 0-10 responses	Redundant with response options
Responses that are numbers	Do not use precodes on responses that are numbers	Minimizes possibility that respondents confuse precodes for response options

Formatting the Front Cover

The front cover of the formatted questionnaires is designed to identify the questionnaire for survey users and vendors; it is not intended for distribution to patients. The CAHPS Team recommends developing a customized cover that explains the purpose of the survey and identifies its sponsor. Be sure to include—

- The name of the survey sponsor.
- The sponsor's logo, if appropriate.
- A statement about the voluntary nature of the survey and the confidentiality of all responses. Please use or adapt the statement provided with the questionnaires.

Respondents may not recognize the names of some survey sponsors, such as community alliances or collaboratives. In those cases, consider including the name of an entity that is more familiar to respondents, such as the cancer center. This tactic increases the likelihood that the respondent will complete the survey.

Because appearances are important, use color as well as artwork to make the front cover of the questionnaire booklet attractive. You can also use photographs to liven up the cover. However, pay attention to the photos you choose: Are the people in the photo representative of your survey population? Are the photos in the public domain? While these issues should be addressed, remember that efforts to make a questionnaire attractive and appealing to respondents should not overshadow the questions and instructions in the survey. It is important to strike a balance between appearance and utility.

Formatting the Scripts for Telephone Surveys

If you are planning to implement telephone surveys, please keep the following guidelines in mind:

- Include text in your introduction to ask for informed content. This text typically includes—
 - a description of the survey,
 - the estimated time to complete the survey,
 - uses of the survey data, and
 - an indication that participation is voluntary.

Please consult your Institutional Review Board or any other board that addresses protection of human subjects regarding consent language. Sample language is provided below:

We recently sent you a package of material about this survey, but just in case you didn't receive it, let me tell you a little about the survey before we continue. We have randomly selected you and other people to represent

all the people who get health care from {CANCER CENTER}. Your answers are very important.

You may choose to do this interview or not – it is entirely optional. Whether you decide to be interviewed or not, the health care you receive will not be affected. If you do choose to participate, your responses will be kept private. Your provider will never know how you answered. The questions should take about {TIME} to answer.

I will ask about the health care you received from {CANCER CENTER} and how you feel about it. Other people who get care from {CANCER CENTER} will be asked the same questions. {CANCER CENTER} will use this information to learn how well they have been doing in serving their patients, and how they can improve their care and services.

I'd like to begin the interview now. Before we begin, do you have any questions about the survey?

- Include a “DON’T KNOW” (DK) and “REFUSED” (REF) response option, either in a Computer Assisted Telephone Interview (CATI) program or on the interviewer’s manual notation sheet. “DON’T KNOW” and “REFUSED” responses should not be read aloud on the telephone. Unless otherwise noted, “DON’T KNOW” and “REFUSED” responses should follow the same skip pattern as the “NO” response option.
- Emphasize survey text that is shown in **bold**.
- Omit the last two questions of the core questionnaires that ask about receiving assistance in completing the questionnaire. These are not included in telephone scripts because interviews should not be conducted with proxy respondents.

Formatting Web-Based Surveys

As access to the Internet continues to rise, Web-based surveys are becoming more prevalent. Web-based surveys can offer convenience to respondents and cost-effectiveness to survey users. However, it is important to keep in mind that not all patients with email addresses have sufficient knowledge or literacy to navigate a Web-based survey. Survey users need to carefully consider whether the Web is an appropriate mode for their patient population. Web surveys may be more appropriate for populations that use a patient portal, routinely communicate with their health care provider via email, or are known to use the Internet.

If you determine that Web-based surveys are appropriate for you, please consider the following guidelines:

- Keep screen design simple so that the survey experience is similar across a range of Internet browsers, e.g., Chrome, Firefox, Safari, and platforms, including personal computers, Macs, tablets, and smart phones.

- Work with your vendor or in-house survey team to test the survey on multiple browsers and platforms. When testing the survey in different browsers and platforms, check for consistency in:
 - The presentation of images, colors, and fonts.
 - Functionality (i.e., all features operate as intended).
 - Usability, particularly on mobile devices.
- Avoid designs that require the user to scroll to see all of the content. Avoid large logos or design elements at the top of the page as this increases the need for scrolling.
- Use a font type that promotes readability on a Web page, such as Verdana or Arial.
- Provide a welcome screen that emphasizes the ease of response, is motivational, and instructs the user on how to proceed to the survey.²
- Use a single column and display one or two questions per screen to make it easier for respondents to follow skip patterns and to complete the survey on mobile devices.
- Follow the general formatting guidelines provided for the print version (with respect to spacing, vertical response options, etc.). If using both mail and Web versions of the survey, keep the survey formats as consistent as possible to reduce the potential for differences between modes due to formatting.²

² Dillman DA. Mail and Internet surveys—The tailored design method. New York: John Wiley & Sons, Inc.; 2000.

Appendix A: Topics Covered by the CAHPS Cancer Care Survey (Core Items Only)

Topic	Short Item	Item #
Confirmation of eligibility	Patient received care from facility named below	1
	Patient has been diagnosed with cancer	2
	Patient received specified type of treatment	3
	How long it has been since this patient was diagnosed with cancer	6
	Patient received care from cancer center within the last 6 months	11
Facility identification	Patient usually goes to this facility for care	4
Length of relationship	How long this patient has been going to this facility	5
Availability of care team	Cancer care team encouraged questions between visits	7
	Cancer care team said to call immediately if patient has certain symptoms or side effects	8
	Cancer care team gave instructions on how to contact them after hours	9
Involvement of family members and friends	Cancer care team involved family members or friends in discussions	10
Utilization	Number of times this patient visited this cancer center for care	12
Access to care	Patient got appointment for urgent care as soon as needed	14
	Patient got appointment for non-urgent care as soon as needed	16
	Patient got answer to medical question the same day he/she contacted provider's office	18

Topic	Short Item	Item #
Communication between patient and the care team	Cancer care team explained things in a way that was easy to understand	19
	Cancer care team listened carefully to patient	20
	Cancer care team showed respect for what patient had to say	22
	Cancer care team spent enough time with patient	23
Coordination of care	Cancer care team knew important information about patient's medical history	21
	Someone from cancer center followed up with patient to give results of blood test, x-ray, or other test	25
	Patient and cancer care team talked about all prescription medications the patient was taking	27
Support in managing effects of care and treatment	Patient and cancer care team talked about cancer-related pain	28
	Cancer care team advised patient or helped patient deal with pain	30
	Patient and cancer care team talked about changes in patient's energy levels	31
	Cancer care team advised patient or helped patient deal with changes in energy levels	33
	Patient and cancer care team talked about emotional problems	34
	Cancer care team advised patient or helped patient deal with emotional problems	36
	Patient and cancer care team talked about additional services to manage care at home	37
	Patient and cancer care team talked about things patient could do to maintain health	38
Availability of interpreters	Patient got interpreter when needed	41
Cancer center staff	Clerks and receptionists were helpful	43
	Clerks and receptionists were courteous and respectful	44

Topic	Short Item	Item #
Ratings	Rating of cancer care team	39
	Rating of overall cancer care	42
Decision making	Patient's preferences for decision making	46
Health status	Cancer treatments received	45
	Hospital stay for cancer	47
	Rating of overall health	48
	Rating of mental or emotional health	49
Demographic items	Age of patient	50
	Male or female	51
	Highest grade level completed	52
	Hispanic or Latino origin	53
	Race	54
Proxy respondent items	Someone helped respondent complete survey	55
	How that person helped	56