

# About the CAHPS® Item Set for Addressing Health Literacy

<b>Introduction .....</b>	<b>1</b>
<b>Why Is This Information Important? .....</b>	<b>1</b>
<b>Contents of the CAHPS Item Set for Addressing Health Literacy .....</b>	<b>1</b>
<b>Using the Results of the CAHPS Item Set for Addressing Health Literacy .....</b>	<b>2</b>
To Improve Quality .....	2
To Inform Consumers and Others .....	3
<b>Development of the CAHPS Item Set for Addressing Health Literacy.....</b>	<b>3</b>
<b>Appendixes</b>	
Appendix A. Items in the CAHPS Item Set for Addressing Health Literacy (updated May 2012) .....	4
Appendix B. Guidance on Selecting a Subset of the Health Literacy Items .....	7
Appendix C. Health Literacy Quality Improvement Crosswalk .....	8

## Introduction

*Healthy People 2010*, a national health promotion and disease prevention initiative, defines health literacy as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. While health literacy depends in part on individuals' skills, it also depends on the complexity of health information and how it is communicated. The primary goal of the CAHPS Item Set for Addressing Health Literacy is to measure, from the patients' perspectives, how well health information is communicated to them by health care professionals.

This document explains why this information is important, what is included in this set of items, and how the survey results can be used to improve quality of care and inform health care consumers and other stakeholders.

## Why Is This Information Important?

Only 12 percent of U.S. adults have proficient health literacy. More than a third of U.S. adults—77 million people—have difficulty with common health tasks, such as following directions on a prescription drug label or adhering to a childhood immunization schedule using a standard chart.<sup>1</sup> Moreover, complex health information can overwhelm even individuals with proficient health literacy skills. Research has shown that health information often exceeds individuals' health literacy capabilities.

Recent years have seen an increased awareness of the mismatch between patients' skills and the health literacy demands that are placed on them. There is also a growing recognition that health care professionals have a responsibility to improve patients' understanding of what they are being told and what they need to do to care for themselves. The Joint Commission, for example, issued a call to action in its 2007 white paper, "*What Did the Doctor Say?*" *Improving Health Literacy to Protect Patient Safety*, available at [http://www.jointcommission.org/What\\_Did\\_the\\_Doctor\\_Say/](http://www.jointcommission.org/What_Did_the_Doctor_Say/).

The CAHPS Item Set for Addressing Health Literacy is intended to serve as both a measure of whether health care professionals have succeeded in reducing the health literacy demands they place on patients, and as a tool for quality improvement.

## Contents of the CAHPS Item Set for Addressing Health Literacy

The CAHPS Item Set for Addressing Health Literacy consists of 31 supplemental items designed for use with the CAHPS Clinician & Group Surveys.<sup>2</sup> The items address the following five topic areas:

- Communication with providers
- Disease self-management
- Communication about medicines

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<sup>1</sup> Kutner M, Greenberg E, Jin Y, Paulsen C. *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy* (NCES 2006-483). Washington, DC: U.S. Department of Education, National Center for Education Statistics; 2006.

<sup>2</sup> The Spanish version of the item set contains 32 items.

- Communication about tests
- Communication about forms

Appendix A lists the items in the CAHPS Item Set for Addressing Health Literacy. The formatted items are available in English in the **Supplemental Items for Adults** in the *CAHPS Clinician & Group Surveys and Instructions*:

<https://www.cahps.ahrq.gov/Surveys-Guidance/CG/Get-CG-Surveys-and-Instructions.aspx>. A Spanish version is in development.

Appendix B offers guidance on selecting a subset of the items if users are unable to include the entire item set in the survey.

## Using the Results of the CAHPS Item Set for Addressing Health Literacy

### To Improve Quality

The CAHPS Item Set for Addressing Health Literacy was developed to provide health care providers with data that could help them improve their health literacy practices. The survey can be used to—

- Identify specific topic areas for quality improvement (e.g., communication about test results, medications, and forms).
- Recognize particular behaviors that inhibit effective communication (e.g., talking too fast, using medical jargon).
- Assist in designing a safer, shame-free environment where patients feel comfortable discussing their health care concerns (e.g., showing interest in questions, explaining forms).
- Measure the effect of behaviors that promote effective communication (e.g., confirming understanding through teach-back, using visual aids).

For example, providers could administer the item set as an assessment tool to identify their health literacy strengths and weaknesses. Having identified opportunities for improvement and embarked on quality improvement activities, the providers could use the item set again to evaluate the success of its improvement activities.

To assist providers in determining how to address an area needing improvement, the Agency for Healthcare Research and Quality (AHRQ) has mapped each item in the Item Set for Addressing Health Literacy to a health literacy practice recommended by the American Medical Association (AMA) Foundation and the AMA in their 2007 monograph *Health Literacy and Patient Safety: Help Patients Understand*. This Health Literacy Quality Improvement Crosswalk is available in Appendix C. You can also use this crosswalk to identify items to evaluate the implementation of particular AMA recommendations. For specific techniques and strategies to facilitate AMA recommendations, please refer to the monograph at [http://www.ama-assn.org/ama1/pub/upload/mm/367/hl\\_monograph.pdf](http://www.ama-assn.org/ama1/pub/upload/mm/367/hl_monograph.pdf).

## To Inform Consumers and Others

Users of the CAHPS Item Set for Addressing Health Literacy can report results for individual clinicians, as well as aggregated at the group (medical practice or clinic) level. In addition to the individual items in the item set, users can calculate and report one composite measure, How Well Providers Communicate About Medicines, that consists of four items:

- Provider gave easy-to-understand instructions about taking medicines.
- Provider gave easy-to-understand explanations about possible side effects of medicines.
- Provider gave easy-to-understand written information about medicines.
- Provider suggested ways to help patient remember to take medicines.

The remaining questions in the item set cannot be rolled up into composite measures for public reporting.

For further information on calculating composite scores, review the analysis instructions in the *CAHPS Clinician & Group Surveys and Instructions*: <https://www.cahps.ahrq.gov/Surveys-Guidance/CG/Get-CG-Surveys-and-Instructions.aspx>.

## Development of the CAHPS Item Set for Addressing Health Literacy

AHRQ commissioned members of the CAHPS team from the RAND Corporation to create the Item Set for Addressing Health Literacy. The process followed the standard steps for developing CAHPS survey products, which include the following:

- Stakeholder interviews with health literacy experts
- Literature review and environmental scan
- A Call for Measures in the *Federal Register*
- The development of domains and an initial set of items
- Cognitive testing of items in English and Spanish
- A stakeholder meeting to obtain feedback
- A second round of cognitive testing
- Field testing at two sites
- The construction of composite measures

The Item Set for Addressing Health Literacy was revised slightly in May 2012 to align the questions and placement instructions with the 2.0 version of the Clinician & Group Surveys.

## Appendix A. Items in the CAHPS Item Set for Addressing Health Literacy (updated May 2012)

The table below lists the items in the Health Literacy Item Set by domain. The formatted items, complete with instructions on how to integrate them into the full CAHPS Clinician & Group Surveys, are available in the **Supplemental Items for Adults** in the *Clinician & Group Surveys and Instructions*: <https://www.cahps.ahrq.gov/Surveys-Guidance/CG/Get-CG-Surveys-and-Instructions.aspx>.

Several of the items listed below are also in the CAHPS Cultural Competence Item Set.<sup>3</sup> The numbering of these supplemental items is provided below for cross reference.

Number in the Health Literacy Item Set	Item Wording	Number of corresponding items in the Cultural Competence Item Set
Communication with provider		
HL1.	In the last 12 months, how often were the explanations this provider gave you hard to understand because of an accent or the way the provider spoke English?	CU1
HL2.	In the last 12 months, how often did this provider use medical words you did not understand?	CU2
HL3.	In the last 12 months, how often did this provider talk too fast when talking with you?	CU3
HL4.	In the last 12 months, how often did this provider use pictures, drawings, models, or videos to explain things to you?	
HL5.	In the last 12 months, how often did this provider ignore what you told him or her?	CU4
HL6.	In the last 12 months, how often did this provider interrupt you when you were talking?	CU5
HL7.	In the last 12 months, how often did this provider show interest in your questions and concerns?	CU6
HL8.	In the last 12 months, how often did this provider answer all your questions to your satisfaction?	CU7
HL9.	In the last 12 months, how often did this provider give you all the information you wanted about your health?	

<sup>3</sup> Read about the CAHPS Cultural Competence Item Set: <https://www.cahps.ahrq.gov/Surveys-Guidance/Item-Sets/Cultural-Competence.aspx>

Number in the Health Literacy Item Set	Item Wording	Number of corresponding items in the Cultural Competence Item Set
HL10.	In the last 12 months, how often did this provider encourage you to talk about all your health questions or concerns?	
HL17.	In the last 12 months, how often did this provider use a condescending, sarcastic, or rude tone or manner with you?	CU8
<b>Disease self-management</b>		
HL11.	In the last 12 months, did you see this provider for a specific illness or for any health condition?	
HL12.	In the last 12 months, did this provider give you instructions about what to do to take care of this illness or health condition?	
HL13.	In the last 12 months, how often were these instructions easy to understand?	
HL14.	In the last 12 months, how often did this provider ask you to describe how you were going to follow these instructions?	
HL15.	Sometimes providers give instructions that are hard to follow. In the last 12 months, how often did this provider ask you whether you would have any problems doing what you need to do to take care of this illness or health condition?	
HL16.	In the last 12 months, how often did this provider explain what to do if this illness or health condition got worse or came back?	
<b>Communication about medicines</b>		
HL19.	In the last 12 months, did this provider prescribe any new medicines or change how much medicine you should take?	
HL20.	In the last 12 months, did this provider give you instructions about how to take your medicines?	
HL21.	In the last 12 months, how often were these instructions about how to take your medicines easy to understand?	
HL22.	In the last 12 months, did this provider explain the possible side effects of your medicines?	
HL23.	In the last 12 months, how often were these explanations easy to understand?	

Number in the Health Literacy Item Set	Item Wording	Number of corresponding items in the Cultural Competence Item Set
HL24.	In the last 12 months, other than a prescription, did this provider give you written information or write down information about how to take your medicines?	
HL25.	In the last 12 months, how often was the written information you were given easy to understand?	
HL26.	In the last 12 months, how often did this provider suggest ways to help you remember to take your medicines?	
Communication about test results		
HL18.	In the last 12 months, how often were the results of your blood test, x-ray, or other test easy to understand?	
Communication about forms		
HL27.	In the last 12 months, did you sign any forms at this provider's office?	
HL28.	In the last 12 months, how often did someone explain the purpose of a form before you signed it?	
HL29.	In the last 12 months, did you fill out any forms at this provider's office?	
HL30.	In the last 12 months, how often were you offered help to fill out a form at this provider's office?	
HL31.	In the last 12 months, how often were the forms from this provider's office easy to fill out?	
HL32.	(Spanish version only) In the last 12 months, how often were the forms that you had to fill out available in Spanish?	

## Appendix B. Guidance on Selecting a Subset of the Health Literacy Items

Users who need to limit the number of items to include in their survey may consider including the five items listed below. These five items are closely associated with the global rating of the provider and provide feedback on various health literacy practices.

HL9.	In the last 12 months, how often did this provider give you all the information you wanted about your health?
HL10.	In the last 12 months, how often did this provider encourage you to talk about all your health questions or concerns?
HL14.	In the last 12 months, how often did this provider ask you to describe how you were going to follow these instructions?
HL18.	In the last 12 months, how often were the results of your blood test, x-ray, or other test easy to understand?
HL21.	In the last 12 months, how often were these instructions about how to take your medicines easy to understand?



## Appendix C. Health Literacy Quality Improvement Crosswalk

The questions in the Item Set for Addressing Health Literacy correspond to recommendations made in the American Medical Association's *Health Literacy Educational Toolkit 2nd Edition*. This toolkit contains educational information on how clinicians can improve the quality and safety of health care for their patients with low health literacy.

Item No.	Question	AMA Recommendation
HL1.	In the last 12 months, were any of the explanations this provider gave you hard to understand because of an accent or the way the provider spoke English?	Slow down. Use plain language and short statements. Ask patients to “teach-back” what they learned.
HL2.	In the last 12 months, how often did this provider use medical words you did not understand?	Use plain, nonmedical language.
HL3.	In the last 12 months, how often did this provider talk too fast when talking with you?	Slow down. Break information down.
HL4.	In the last 12 months, how often did this provider use pictures, drawings, models, or videos to explain things to you?	Use visual aids to help understand medical information. Images should be age- and culturally-appropriate.
HL5.	In the last 12 months, how often did this provider ignore what you told him or her?	Listen rather than speak. Elicit understanding, identify information gaps, and assist patient management of care.
HL6.	In the last 12 months, how often did this provider interrupt you when you were talking?	Listen rather than speak.
HL7.	In the last 12 months, how often did this provider show interest in your questions and concerns?	Encourage patients to ask questions. Create a patient-centered visit in which the clinician focuses on addressing the patient's concerns. Wear a button that states, “Ask Me. I Can Help.”

Item No.	Question	AMA Recommendation
HL8.	In the last 12 months, how often did this provider answer all your questions to your satisfaction?	Schedule time for patient education. Ask patients if all their questions were answered before they leave. Enlist the aid of others (patient's family or friends) to promote understanding.
HL9.	In the last 12 months, how often did this provider give you all the information you wanted about your health?	Schedule time for patient education. Plan for health literacy help.
HL10.	In the last 12 months, how often did this provider encourage you to talk about all your health questions or concerns?	Ask if patients have any concerns that have not been addressed.
HL11.	In the last 12 months, did you see this provider for a specific illness or for any health condition?	n/a – screener item
HL12.	In the last 12 months, did this provider give you instructions about what to do to take care of this illness or health condition?	n/a – screener item
HL13.	In the last 12 months, how often were these instructions easy to understand?	Limit the amount of information given at each visit—and repeat it. Organize information into two or three concepts.
HL14.	In the last 12 months, how often did this provider ask you to describe how you were going to follow these instructions?	Ask patients to “teach-back” what they learned.
HL15.	Sometimes providers give instructions that are hard to follow. In the last 12 months, how often did this provider ask you whether you would have any problems doing what you need to do to take care of this illness or health condition?	Use plain, nonmedical language. Elicit understanding, identify information gaps, and assist patient management of care.
HL16.	In the last 12 months, how often did this provider explain what to do if this illness or health condition got worse or came back?	Schedule time for patient education and questions.

Item No.	Question	AMA Recommendation
HL17.	In the last 12 months, how often did this provider use a condescending, sarcastic, or rude tone or manner with you?	Design a safer, shame-free environment. Create a patient-centered visit focusing on patient's concerns. Exhibit a general attitude of helpfulness.
HL18.	In the last 12 months, how often were the results of your blood test, x-ray, or other test easy to understand?	Aim for fifth- to sixth-grade reading level on all written information.
HL19.	In the last 12 months, did this provider prescribe any new medicines or change how much medicine you should take?	n/a – screener item
HL20.	In the last 12 months, did this provider give you instructions about how to take your medicines?	n/a – screener item
HL21.	In the last 12 months, how often were these instructions about how to take your medicines easy to understand?	Organize information into two or three concepts. Ensure medication review and/or medication reconciliation for all patients at all encounters.
HL22.	In the last 12 months, did this provider explain the possible side effects of your medicines?	For medication management, elicit understanding, identify information gaps, and assist patient management of care. Ensure medication review and/or medication reconciliation for all patients at all encounters.
HL23.	In the last 12 months, how often were these explanations easy to understand?	Explain things to patients as you would explain them to your grandmother.
HL24.	In the last 12 months, other than a prescription, did this provider give you written information or write down information about how to take your medicines?	n/a – screener item

Item No.	Question	AMA Recommendation
HL25.	In the last 12 months, how often was the written information you were given easy to understand?	Provide handouts in an easy-to-read format.
HL26.	In the last 12 months, how often did this provider suggest ways to help you remember to take your medicines?	Read aloud and highlight, underline, circle, or number key points for the patient to remember.  Draw supplemental pictures and write out steps and directions.
HL27.	In the last 12 months, did you sign any forms at this provider's office?	n/a – screener item
HL28.	In the last 12 months, how often did someone explain the purpose of a form before you signed it?	Offer to read aloud and explain.
HL29.	In the last 12 months, did you fill out any forms at this provider's office?	n/a – screener item
HL30.	In the last 12 months, how often were you offered help to fill out a form at this provider's office?	Routinely offer all patients assistance in completing forms.
HL31.	In the last 12 months, how often were the forms from this provider's office easy to fill out?	Simplify paperwork demands.  Collect only information that is essential.
HL32.	(Spanish version only) In the last 12 months, how often were the forms that you had to fill out available in Spanish?	Provide forms in patients' languages.