

About the CAHPS® Item Set for Addressing Health Literacy

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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' perspective, 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 to inform health care consumers and other stakeholders.

Why Is This Information Important?

Only 12 percent of U.S. adults have proficient health literacy. Over a third of U.S. adults—77 million people—would 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.

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. 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/PublicPolicy/health_literacy.htm.

The CAHPS Item Set for Addressing Health Literacy is intended to serve as both a measure of whether health care professional 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 Item Set for Addressing Health Literacy consists of 29¹ supplemental items designed for use with the CAHPS Clinician & Group Survey. The items address the following six topic areas:

- Communication with doctors.
- Communication about health problems and concerns.
- Communication about medicines.
- Communication about tests.

¹ The Spanish version of the item set contains 30 items.

- Communication about forms.
- Disease self-management.

A list of the items in the Item Set for Addressing Health Literacy (English version) can be found in Appendix A. Both the English and Spanish items are available in the supplemental item set for the Adult Primary Care Questionnaire in the CAHPS Clinician & Group Survey and Reporting Kit:

<https://www.cahps.ahrq.gov/cahpskit/CG/CGChooseQX.asp>.

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

To Improve Quality

The 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 for Addressing Health Literacy 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 for Addressing Health Literacy 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 B. 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, doctors can refer to the monograph at www.ama-assn.org/ama1/pub/upload/mm/367/hl_monograph.pdf.

To Inform Consumers and Others

Users of the 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 a composite measure: How Well Doctors Communicate About Medicines. This composite consists of the following six items:

How Well Doctors Communicate About Medicines	
HL19.	In the last 12 months, how often did this doctor give you easy to understand instructions about how to take your medicines?
HL20.	In the last 12 months, did this doctor explain the possible side effects of your medicines?
HL21.	In the last 12 months, how often did this doctor explain the possible side effects of your medicines in a way that was easy to understand?
HL22.	In the last 12 months, other than a prescription, did this doctor give you written information or write down information about how to take your medicines?
HL23.	In the last 12 months, how often was the written information you were given easy to understand?
HL24.	In the last 12 months, how often did this doctor suggest ways to help you remember to take your medicines?

For further information on calculating composite scores, review the analysis instructions in the CAHPS Clinician & Group Survey and Reporting Kit.

Development of the CAHPS Item Set for Addressing Health Literacy

AHRQ commissioned the CAHPS team, led by RAND, to create the Item Set for Addressing Health Literacy. The process followed the standard steps for developing CAHPS survey products, which include:

- 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.

Appendix A. Items in the Item Set for Addressing Health Literacy

The formatted items, complete with instructions on how to integrate them into the full CAHPS Clinician & Group Survey, are available in the Adult Primary Care Questionnaire in the Survey and Reporting Kit at <https://www.cahps.ahrq.gov/cahpskit/CG/CGChooseQX.asp>.

HL1.	In the last 12 months, how often were the explanations this doctor gave you hard to understand because of an accent or the way the doctor spoke English?
HL2.	In the last 12 months, how often did this doctor use medical words you did not understand?
HL3.	In the last 12 months, how often did this doctor talk too fast when talking with you?
HL4.	In the last 12 months, how often did this doctor use pictures, drawings, or models to explain things to you?
HL5.	In the last 12 months, how often did this doctor ignore what you told him or her?
HL6.	In the last 12 months, how often did this doctor interrupt you when you were talking?
HL7.	In the last 12 months, how often did this doctor show interest in your questions and concerns?
HL8.	In the last 12 months, how often did this doctor answer all your questions to your satisfaction?
HL9.	In the last 12 months, how often did this doctor give you all the information you wanted about your health?
HL10.	In the last 12 months, how often did this doctor encourage you to talk about all your health problems or concerns?
HL11.	In the last 12 months, did you see this doctor for a specific illness or for any health condition?
HL12.	In the last 12 months, how often did this doctor give you easy to understand instructions about what to do to take care of this illness or health condition?
HL13.	In the last 12 months, how often did this doctor ask you to describe how you were going to follow these instructions?
HL14.	Sometimes doctors give instructions that are hard to follow. In the last 12 months, how often did this doctor ask you whether you would have any problems doing what you need to do to take care of this illness or health condition?
HL15.	In the last 12 months, how often did this doctor explain what to do if this illness or health condition got worse or came back?
HL16.	In the last 12 months, how often did this doctor use a condescending, sarcastic, or rude tone or manner with you?
HL17.	In the last 12 months, how often did you feel this doctor really cared about you as a person?
HL18.	In the last 12 months, did this doctor prescribe any new medicines or change how much medicine you should take?

HL19.	In the last 12 months, how often did this doctor give you easy to understand instructions about how to take your medicines?
HL20.	In the last 12 months, did this doctor explain the possible side effects of your medicines?
HL21.	In the last 12 months, how often did this doctor explain the possible side effects of your medicines in a way that was easy to understand?
HL22.	In the last 12 months, other than a prescription, did this doctor give you written information or write down information about how to take your medicines?
HL23.	In the last 12 months, how often was the written information you were given easy to understand?
HL24.	In the last 12 months, how often did this doctor suggest ways to help you remember to take your medicines?
HL25.	In the last 12 months, how often were the results of your blood test, x-ray or other test easy to understand?
HL26.	In the last 12 months, did you have to fill out or sign any forms at this doctor's office?
HL27.	In the last 12 months, how often did someone explain the purpose of a form before you signed it?
HL28.	In the last 12 months, how often were you offered help in filling out a form at this doctor's office?
HL29.	In the last 12 months, how often were the forms that you got at this doctor's office easy to fill out?
HL30.	(Spanish version only) In the last 12 months, how often were the forms that you had to fill out available in Spanish?

Appendix B. 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 (AMA) 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 doctor gave you hard to understand because of an accent or the way the doctor spoke English?	Slow down. Use plain language and short statements. Ask for teach-back to ensure patient understanding of what the doctor has said.
HL2.	In the last 12 months, how often did this doctor use medical words you did not understand?	Use plain, non-medical language.
HL3.	In the last 12 months, how often did this doctor talk too fast when talking with you?	Slow down. Break information down.
HL4.	In the last 12 months, how often did this doctor use pictures, drawings, or models 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 doctor 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 doctor interrupt you when you were talking?	Listen rather than speak.
HL7.	In the last 12 months, how often did this doctor 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.”
HL8.	In the last 12 months, how often did this doctor 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.

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Item No.	Question	AMA Recommendation
HL9.	In the last 12 months, how often did this doctor 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 doctor encourage you to talk about all your health problems or concerns?	Ask if patients have any concerns that have not been addressed.
HL11.	In the last 12 months, did you see this doctor for a specific illness or for any health condition?	n/a – screener item
HL12.	In the last 12 months, how often did this doctor give you easy to understand instructions about what to do to take care of this illness or health condition?	Limit the amount of information given at each visit—and repeat it. Organize information into two or three concepts.
HL13.	In the last 12 months, how often did this doctor ask you to describe how you were going to follow these instructions?	Teach-back to confirm patient understanding.
HL14.	Sometimes doctors give instructions that are hard to follow. In the last 12 months, how often did this doctor 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.
HL15.	In the last 12 months, how often did this doctor explain what to do if this illness or health condition got worse or came back?	Schedule time for patient education and questions.
HL16.	In the last 12 months, how often did this doctor 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.
HL17.	In the last 12 months, how often did you feel this doctor really cared about you as a person?	Create a patient-centered visit in which the clinician focuses on addressing the patient's concerns. Exhibit a general attitude of helpfulness.
HL18.	In the last 12 months, did this doctor prescribe any new medicines or change how much medicine you should take?	n/a – screener item
HL19.	In the last 12 months, how often did this doctor give you easy to understand instructions about how to take your medicines?	Organize information into two or three concepts. Ensure medication review and/or reconciliation for all patients at all encounters.

Item No.	Question	AMA Recommendation
HL20.	In the last 12 months, did this doctor 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.
HL21.	In the last 12 months, how often did this doctor explain the possible side effects of your medicines in a way that was easy to understand?	Explain things to patients like you would explain them to your grandmother.
HL22.	In the last 12 months, other than a prescription, did this doctor give you written information or write down information about how to take your medicines?	n/a – screener item
HL23.	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
HL24.	In the last 12 months, how often did this doctor 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.
HL25.	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
HL26.	In the last 12 months, did you have to fill out or sign any forms at this doctor's office?	n/a – screener item
HL27.	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.
HL28.	In the last 12 months, how often were you offered help in filling out a form at this doctor's office?	Routinely offer all patients assistance in completing forms.
HL29.	In the last 12 months, how often were the forms that you got at this doctor's office easy to fill out?	Simplify paperwork demands. Only collect information that is essential.
HL30.	(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.