

About the CAHPS® Health Literacy Item Set for Hospitals

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Introduction

The CAHPS Hospital Survey (HCAHPS) and other CAHPS surveys are designed to gather information about patients' experiences with their health care, including their experiences understanding and using the information they receive from health care providers. The nature of these experiences may be influenced by the patients' health literacy, defined 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.¹ While health literacy depends in part on individuals' skills, it also depends on the complexity of health information and how it is communicated.

There are many ways in which health care professionals in the inpatient setting can address the communication challenges posed by low health literacy in their patients. The purpose of the CAHPS Health Literacy Item Set for Hospitals is to enhance the capacity of the CAHPS Hospital Survey to:

- Assess from the patients' perspective whether these professionals are reducing the health literacy demands they place on patients and
- Identify potential areas in which hospitals could improve.

Note: The CAHPS Hospital Survey is implemented and supported by the Centers for Medicare & Medicaid Services (CMS). For information or help with this survey, please visit www.hcahpsonline.org.

Similar item sets are available to supplement the CAHPS Clinician & Group Survey and the CAHPS Health Plan Survey.

This document discusses the topics covered by the CAHPS Health Literacy Item Set for Hospitals and the ways in which the survey results could be used to inform health care providers, consumers, and other stakeholders.

¹ Nielsen-Bohlman L. *Health Literacy: A Prescription to End Confusion*. Washington, D.C.: National Academies Press, 2004.

Background: Health Literacy Is a Major Concern

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-related tasks, such as following directions on a prescription drug label or adhering to a childhood immunization schedule using a standard chart.² 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 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. In May 2010, the U.S. Department of Health and Human Services published the *National Action Plan to Improve Health Literacy*: http://www.health.gov/communication/hlactionplan/pdf/Health_Literacy_Action_Plan.pdf

Topics Covered by the CAHPS Health Literacy Item Set for Hospitals

The CAHPS Health Literacy Item Set for Hospitals consists of 42 supplemental items designed for use with the Adult version of the CAHPS Hospital Survey (HCAHPS). The items address the following six topic areas:

- Information about medications
- Communication between nurses and patients
- Communication between doctors and patients
- Communication about tests
- Communication about forms
- Information about how to care for yourself at home

² 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.

In developing these items, the CAHPS team focused on aspects of health literacy for which patients are the best or only source of information. A complete list of the items is provided in Appendix A.

Note: For supplemental items that ask about patient experience with interpreter services, a topic closely related to health literacy, please refer to a document called *CAHPS Hospital Survey: Supplemental Items for the Adult Survey* (available at <https://cahps.ahrq.gov/surveys-guidance/hospital/instructions/hospinstructions.html>).

Where to Find Information About Using These Items

Where do I find information about the CAHPS Hospital Survey (HCAHPS)? The Centers for Medicare & Medicaid Services (CMS) is responsible for the implementation of the Adult HCAHPS Survey and uses it for both public reporting as well as value-based purchasing. The survey and all supporting documentation for survey administration are available from CMS at www.hcahpsonline.org.

Where are the formatted supplemental items? Formatted items with response options are available in English and Spanish in a document called *CAHPS Hospital Survey: Supplemental Items for the Adult Survey*, available at <https://cahps.ahrq.gov/surveys-guidance/hospital/instructions/hospinstructions.html>. In contrast to the Adult Hospital Survey, which is supported by CMS, this supplemental item set is fully supported by AHRQ's CAHPS User Network.

How do I administer these survey items? The CAHPS Health Literacy Item Set for Hospitals is designed to be administered as part of an Adult HCAHPS Survey, not on its own. Users must follow the administration guidelines for the Adult HCAHPS Survey issued by CMS at www.hcahpsonline.org. These guidelines also have instructions for placing these supplemental items at the end of the Adult HCAHPS Survey.

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

Organizations that field the Adult HCAHPS Survey may want to use data from the supplemental questions in this item set to spur improvements in patients' experiences with care and to inform consumers and other stakeholders.

Improving Quality

The CAHPS Health Literacy Item Set for Hospitals was developed to provide a source of standardized information that can help organizations identify their health literacy strengths and weaknesses. After administering this item set as part of the HCAHPS Survey, hospital administrators, providers, and staff can use the survey results 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., by 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).

Having identified opportunities for improvement and embarked on quality improvement activities, the hospital could administer the item set again to evaluate the effectiveness of its improvement activities.

Informing Consumers and Others

Unlike the Adult HCAHPS Survey, results from these supplemental items will not be reported on the Hospital Compare Web site. However, organizations that have access to the survey results across multiple hospitals could report a few scores from this item set at the hospital level to consumers and other stakeholders.

Specifically, users can calculate and report two composite measures that summarize performance across two topics that are not addressed by the HCAHPS Survey:

- How well hospital staff explain tests and test results (4 items)
- Ease of filling out forms (4 items)

The items included in each of these composite measures are listed in Appendix B.

The CAHPS team does not recommend including scores for individual questions in the item set outside of internal reports. One reason is to avoid overwhelming external audiences with data. Another is that many of the questions in this item set are designed to help hospitals identify the drivers of performance on core measures in the HCAHPS Survey, such as communication with nurses. Reporting the results of these individual items is more likely to confuse than enlighten external audiences.

Choosing a Subset of Health Literacy Items

Survey users may not be able to include all of the Health Literacy items in their survey. To figure out which subset of items to use, you will need to first consider how you intend to use the survey results.

Are you planning to include a composite measure in internal or public reports of the survey results?

If you intend to report a composite measure, make sure you include all the items in the measure as well as any screener items that are associated with those items. Composite measures can only be calculated if all of the items in the measure are included.

Do you have a specific target area for QI?

The Health Literacy items can help you explore performance issues raised by the core survey measures and items or probe specific areas that are a focus for your organization. For example, you may want to better understand what is influencing patients' experiences with communication with nurses, which is one of the composite measures in the Adult HCAHPS Survey. In that case, you may choose to include some or all of the supplemental items about communicating with nurses.

Development of the CAHPS Health Literacy Item Set for Hospitals

AHRQ commissioned members of the CAHPS team, led by RAND Corporation, to create the CAHPS Health Literacy Item Sets. The first of these items sets was designed to supplement the CAHPS Clinician & Group Survey. More recently, the team developed item sets to supplement the CAHPS Hospital Survey and the CAHPS Health Plan Survey.

The development process for each of these items sets followed the standard steps for developing CAHPS survey products, which include the following:

- Stakeholder interviews with health literacy experts
- Literature review and environmental scan
- Call for Measures in the *Federal Register*
- Stakeholder meeting to obtain feedback
- Development of domains and an initial set of items
- Cognitive testing of items in English and Spanish
- Field testing
- Construction of composite measures

Appendix A. Items in the CAHPS Health Literacy Item Set for Hospitals

The table below lists the individual questions in the item set. Formatted items—with complete wording and response categories—are available in the document called *CAHPS Hospital Survey: Supplemental Items for the Adult Survey*, available at <https://cahps.ahrq.gov/surveys-guidance/hospital/instructions/hospinstructions.html>. You will also find guidelines on placing these items at the end of the Adult HCAHPS Survey (before the “About You” section). For addition guidance, please visit www.hcahponline.org.

Number in the Health Literacy Item Set for Hospitals	Survey Item
Topic: Information about medications <i>Note: These individual items cannot be combined into a composite measure.</i>	
H-HL1	Staff asked patient to describe how patient would take medications at home
H-HL2	Staff told patient who to call if patient had questions about medications
Topic: Communication between nurses and patients <i>Note: These individual items cannot be combined into a composite measure.</i>	
H-HL3	Nurses hard to understand because of the way they spoke patient’s language
H-HL4	Nurses used medical words patient did not understand
H-HL5	Nurses talked too fast
H-HL6	Nurses interrupted patient
H-HL7	Nurses answered all questions to patient’s satisfaction
H-HL8	Nurses used condescending, sarcastic, or rude tone or manner with patient
H-HL9	Nurses cared about patient as a person
Topic: Communication between doctors and patients <i>Note: These individual items cannot be combined into a composite measure.</i>	
H-HL10	Doctors hard to understand because of the way they spoke patient’s language
H-HL11	Doctors used medical words patient did not understand
H-HL12	Doctors talked too fast

Number in the Health Literacy Item Set for Hospitals	Survey Item
H-HL13	Doctors used pictures, drawings models, or videos to explain things
H-HL14	Doctors interrupted patient
H-HL15	Doctors answered all questions to patient's satisfaction
H-HL16	Doctors made sure patient understood all information
H-HL17	Doctors used condescending, sarcastic, or rude tone or manner with patient
H-HL18	Doctors cared about patient as a person
<p>Topic: Communication about tests <i>Items H-HL20 – H-HL23 can be combined into a composite measure.</i> <i>Recommended label for reporting: How Well Hospital Staff Explain Tests and Test Results</i></p>	
H-HL19	Patient had a blood test, x-ray, or other test
H-HL20	Hospital staff explained what a blood test, x-ray, or other test was for
H-HL21	Explanation of blood test, x-ray, or other test was easy to understand
H-HL22	Hospital staff explained blood test, x-ray, or other test results to patient
H-HL23	Blood test, x-ray, or other test results were easy to understand
<p>Topic: Communication about forms <i>Items H-HL25, H-HL27, H-HL28, and H-HL29 below can be combined into a composite measure.</i> <i>Recommended label for reporting: Ease of filling out forms</i></p>	
H-HL24	Patient had to sign forms
H-HL25	Staff explained the purpose of a form before patient signed it
H-HL26	Patient had to fill out forms
H-HL27	Staff offered patient help in filling out a form
H-HL28	Forms were easy for patient to fill out
H-HL29	Patient was given enough time to fill out forms
H-HL30	Patient needed forms in a language other than English
H-HL31	Forms were available in patient's language

Number in the Health Literacy Item Set for Hospitals	Survey Item
<p>Topic: Information about how to care for yourself at home <i>Note: These individual items cannot be combined into a composite measure.</i></p>	
H-HL32	Patient went to own home, someone else's home, or another health facility
H-HL33	Staff give patient a telephone number to call if patient had problems after leaving hospital
H-HL34	Staff told patient how to take care of self at home
H-HL35	Information from hospital staff about taking care of self at home was easy to understand
H-HL36	Patient received instructions in writing about how to take care of self at home
H-HL37	Written instructions about how to take care of self at home were easy to understand
H-HL38	Patient needed instructions about how to take care of self at home in a language other than English
H-HL39	Instructions about how to take care of self at home were available in patient's language

Appendix B. Health Literacy Composite Measures

The following table lists the items in the two composite measures for this item set.

How Well Hospital Staff Explain Tests and Test Results	
H-HL20	Hospital staff explained what a blood test, x-ray, or other test was for
H-HL21	Explanation of blood test, x-ray, or other test was easy to understand
H-HL22	Hospital staff explained blood test, x-ray, or other test results to patient
H-HL23	Blood test, x-ray, or other test results were easy to understand
Ease of Filling Out Forms	
H-HL25	Staff explained the purpose of a form before patient signed it
H-HL27	Staff offered patient help in filling out a form
H-HL28	Forms were easy for patient to fill out
H-HL29	Patient was given enough time to fill out forms