



Update on Health Literacy Research

Developing and Testing the CAHPS® Clinician and Group Health Literacy Item Set

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Project team

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Health Literacy

- Healthy People 2010 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.”(HHS 2000 and Institute of Medicine 2004)
- According to the 2003 National Assessment of Adult Literacy (NAAL), only 12 percent of adults have the skills to proficiently manage their own medical care



Background

- Individuals with low health literacy are more prone to medication errors, have poorer adherence to recommended treatment, have poorer health status, worse health outcomes, and are more likely to be hospitalized.
- In addition, they are less likely than those with adequate health literacy to:
 - have knowledge of their disease,
 - possess disease self-management skills or
 - use preventive health care services



Purpose

- Develop a set of items that can be used to measure patients' perspective on how well health information is communicated to them by healthcare professionals
- Designed as a supplemental item set for the CAHPS Clinician and Group Survey



Instrument Development Process

- Environmental scan
- Call for measures through Federal Register
- Interviews with key informants
- Developed draft survey
- Stakeholder feedback
- Translation into Spanish
- Two rounds of cognitive testing
- Field test



Environmental Scan

- Reviewed published and unpublished literature (“gray literature”)
- Reviewed bibliographies/references to identify other relevant articles
- Purpose of environmental scan:
 - Identify health literacy domains of interest
 - Identify surveys or measures that collect information on health literacy issues from a patients’ perspective



Key Informant Interviews

- Conducted 11 interviews with key informants in the field of health literacy
- Interviews conducted by phone
- Informants included health literacy researchers, clinicians, health literacy advocates (including consumer advocate)
- Informants asked to provide feedback on domains/items, identify gaps, recommend existing measures, make suggestions for dissemination



Item Development

- Created matrix of health literacy domains and sub domains of interest
- Reviewed family of CAHPS surveys to identify existing items that address domains of interest
- Reviewed existing measures
- Adapted or modified measures in the public domain
- Wrote new items for domains/sub domains for which we were unable to identify existing measures



Overview of survey

Six composites and 29 items:

- Patient-Provider Communication (10 items)
- Communication about health problems or concerns (2 items)
- Disease self-management (5 items)
- Communication about medications (6 items)
- Communication about tests (2)
- Communication about forms (4)



Translation into Spanish

Used modified “translation by committee approach”

- Conducted 2 forward translations using ATA certified, professional translators
- Provided translators background info (purpose, characteristics of target audience, mode of data collection)
- Reviewed and reconciled translation differences and corrected errors by committee



Cognitive Testing: Goals

- Assess patients' understanding of draft survey items
- Assess whether patients' understand key concepts as intended
- Assess appropriateness of Spanish language translation/identify problems w/translation
- Identify terms, items, response options that are problematic
- Findings used to revise and refine survey items



Cognitive Testing: Overview

- Conducted two rounds of testing (20 interviews in 1st round and 10 in 2nd round)
- Tested concurrently in Spanish and English
- Aimed to get a mix of respondents in terms of age, race/ethnicity, gender
- Set targets for level of education (half of respondents had less than HS education)
- Set targets for Hispanic subgroups (aim for mix, no more than 4 of Mexican origin)
- Set targets for # of interviews in Spanish (8 1st round, and 5 2nd round)



Cognitive Testing Methods

To facilitate training of cognitive interviewers across sites and ensure comparability of information collected across sites and across languages, we used:

- Semi-structured interview with scripted probes
 - All 3 grantees used same recruitment and interview protocol (developed collaboratively)
- Defined measurement goal for each survey item
- Defined cognitive interview goal for each item



Cognitive Testing Methods

- Used interviewer administered and self - administered protocols
- Used concurrent, think aloud method to interview
- Interviewer coded R responses to survey items, recorded verbatim responses, and took notes using paper/pencil form
- Cognitive interviews were audio recorded



Cognitive Interview Findings

- Minor translation issues
- Double negatives problematic
- Some response options were problematic
- Need for simple syntax
- Problems reading
- Other than translation problems, did not find issues that were language specific
- Testing concurrently in English and Spanish allowed findings to inform revisions in both languages and facilitated “de-centering” of the English



Cognitive Interview Findings

- Respondents generally understood the survey items and were able to provide meaningful responses;
- Overall the survey covers issues and experiences that are relevant and important to the respondents;
- Used findings from cognitive interviews to refine survey items
- Dropped items that were redundant



Stakeholder meeting

- Invited key stakeholders to one day meeting
 - Researchers
 - Clinicians
 - Health Plans
 - Health Literacy Advocates (including consumer)
 - Representatives from government agencies, NCQA
- Purpose: present item set, review cognitive interview findings, obtain feedback on domains/item wording, how to prioritize items, how to disseminate
- Used feedback to further revise item set



Field Test

- Conducted by RAND and DataStat, Inc. in October and November 2008
- Two field test partners
 - Affinity Health Plan
 - University of Mississippi Medical Center
- Sample of 1200 patients
- Fielded in English and Spanish
- Mail with phone follow-up



Preliminary Field Test Results

- 601 completed interviews (473 English and 128 Spanish)
- 52% overall response rate
- 50% response rate among English speakers
- 57% response rate among Spanish speakers



Analysis of field test data (ongoing)

- Psychometric analysis focusing on the reliability and construct validity of the items (including by race/ethnicity and by language)
- Examination of item missing data
- Item distribution (including ceiling and floor effects)
- Internal consistency reliability of composites
- Correlations of composites with global rating items
- Reliability of global rating items and composites at the clinician level



Next Steps...

- Conduct analyses of field test data
- Revise item set based on findings from field test
- Submit survey items/documentation to AHRQ
- Make items publicly available (www.ahrq.gov)
- Expected release date: Spring 2009