Why Develop a Nursing Home CAHPS for Family Members of Residents?

- CMS interested in family members as
  - (a) customer/decision maker, and
  - (b) though not a proxy, may be only representative for many long stay residents who are not able to respond to resident survey
Family Nursing Home CAHPS

• In 2003, CMS requested that AHRQ start work on a family survey to supplement and enhance the information obtained from the resident survey
• A literature review was conducted in late 2003 that included information on surveys currently administered to family members
• A Federal Register notice call for measures was published May 1, 2004 and closed August 5, 2004

Family Nursing Home CAHPS Survey Development

• NH CAHPS instrument team held first in person meeting in early October 2004 to cull items, determine critical topics within domains
• Created draft version for cognitive testing and cognitive testing protocol in late March 2005
• Cognitive testing conducted from May –July 2005
• Cognitive testing results summarized, August 2005
• Revisions to draft made in accordance with cognitive testing results, September-November 2005
• Draft discussed at TEP November 2005
• Revisions to draft made based on TEP feedback January-March 2006
Family Nursing Home CAHPS Survey Development – Next Steps

- Prepare for second round of cognitive testing—identify questions, create protocol, recruit target subject population
- Conduct cognitive testing April-June 2006
- Summarize findings and revise draft survey in accordance with findings, June-July 2006
- Design field test, including sampling strategy and data collection methods, recruitment of testing sites, etc., winter/spring 2006

Building on framework of established CAHPS survey conventions

- Write a survey consisting on items for which the respondent is the best or only source of information

- Ask respondents to report on actual experiences

- Include topics that stakeholders have identified as being important.
For the NHCAHPS- Family Instrument

1. Ask about what a Family Member knows

2. Ask questions about the Respondent’s own experiences (not resident's experiences, not experience of other family members)

3. Realize this is a complement to Resident NHCAHPS, not a replica of it

Original Domains

- Staffing
- Psycho-social
- Care Process
- Services
- Activities
- Food
- Environment
- Communication
- Safety
- Administration
Examples of Obvious Proxy Questions

- **Staffing:** Is there enough staff on weekends
- **Psycho-social:** Staff really cares about resident
- **Care Process:** Staff treats Resident gently
- **Activities:** Rate Resident’s enjoyment of activities
- **Food:** Rate Resident’s enjoyment of food

Ways to ask about what Respondent knows

Ask about what has R has seen or experienced

- **Staffing:** When you visit, do you see the same staff care for the Resident?
- **Psycho-social:** Does staff treat you with respect?
- **Care Process:** Do you see staff treat the Resident gently
- **Activities:** Do you participate in activities with Resident?
- **Environment:** When you visit, is the area around room quiet?
Can we make it “observable”

Hidden Proxy Questions

or......
The lure of adding “when you visited” and “did you see”

Example: How often did you see the nursing home staff try to be gentle with your family member when they provided help or care?

Problems with Hidden Proxies

- Often R did not experience what the question is asking about
- R sometimes relies on “feelings”
- R answers about what Resident told them
How do we know which questions work?

- Question experts
- Nursing Home experts
- Testing of questions

In-Depth (Cognitive) Interviews

- R completes survey
- Researcher uses verbal probes to investigate...
  - What R was thinking about?
  - How did R decide on answer?
  - How did R understand certain words and phrases

- Round 1
  - 27 interviews in 3 states
  - Family members of long-term, discharged, and deceased residents
1. Elimination of Questions

- **Proxy Questions**
  - How would you rate the food?
  - Does the Resident have enough to do in the facility?

- **Hidden Proxy Questions**
  - When you visited, how often did you see the nursing home staff tell your family member what to expect as they provided help or care?
  - How often did you see the nursing home staff help your family member when needed?

2. Modification of Questions

- **from Hidden Proxy to Observable**
  - Original: How often does the resident have enough privacy?
  - Test 1: When you visited, how often did you see the nursing home staff try to protect your family member’s modesty when delivering help or care?
  - Test 2: In the last 6 months, did you ever see the nurses and aides fail to protect any resident’s modesty?
2. Modification of Questions

- **from “R is Not Best Informer” to Observable**
  - Concept: Enough staff
  - Original: Is there enough staff to take care of Resident’s needs?
  KEEP CONCEPT-CHANGE FOCUS
  - **Test 1**: Did you have to help your family member with LIST OF ACTIVITIES because the nursing home staff either didn’t do it or they made him or her wait too long?
  - **Test 2**: Did you help your family member with LIST OF ACTIVITIES? (IF YES: Was it because the nurses or aides either didn’t help or made him or her wait too long?)

Other Overall Findings that led to changes for 2nd Round

- Need separate instruments for current and discharged residents
- Emphasize **self** reports by adding additional instructions
- Simplify time frame to ask about “the last 6 months”
- Some phrases (such as “homelike,” “nursing home staff, “power of attorney”) are not universally understood
- Use the phrase “nurses and aides”
- Phrase “Management” not understood so we added a separate section on interaction with Administrator
**Current Domains**

- About the resident (relationship, how often visited)
- Communication (get information)
- About Staff Behavior (treating family member kindly, checking on them, helping with dressing, etc.)
- About the Nursing Home (cleanliness of room, laundry services)
- About Care of Your Family Member (how nh provides care—protect privacy, encourage independence)
- Overall Ratings (availability of nurses and nurse aides, management)
- About Your Role (legal guardian, pay bills)
- About You (demographics of respondent)

**NH CAHPS Family Field Test**

**When?**
Summer / Fall 2006

**Why?**
1. Test Survey Operations
2. Identify a Subset of Questions that are best to Measure Quality
Requirements to Test Survey Operations

Survey Operations must be tested under conditions that mimic future use, so...

Need to answer the question: Who will field this survey in the future? And choose:

- NHs similar to those that will administer survey in the future
- Respondents similar to those that will answer survey in the future
- Operations that can be practicably implemented by future users

Requirements to Identify Subset of Questions that Precisely Measure Quality

- NHs that DIFFER in quality according to other measures
- Several (3+) NHs at 2+ levels of quality
- NHs that will provide contact information for potential respondents
- Potential to collect 30+ respondents per NH
Next Steps After Field Test

- Analyze results and revise draft survey, fall/winter 2006
- AHRQ Field Test Report to CMS with revised survey and protocol recommendations—early 2007
- Release survey to public domain after conducting internal review