

Developing and Testing a Patient Experience Survey for Cancer

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**Co-sponsored by the National Cancer Institute and the Agency for Healthcare Research
and Quality under AHRQ Contract# HHSA290200600019I,
Task Order# HHSA29032003T TO#9**

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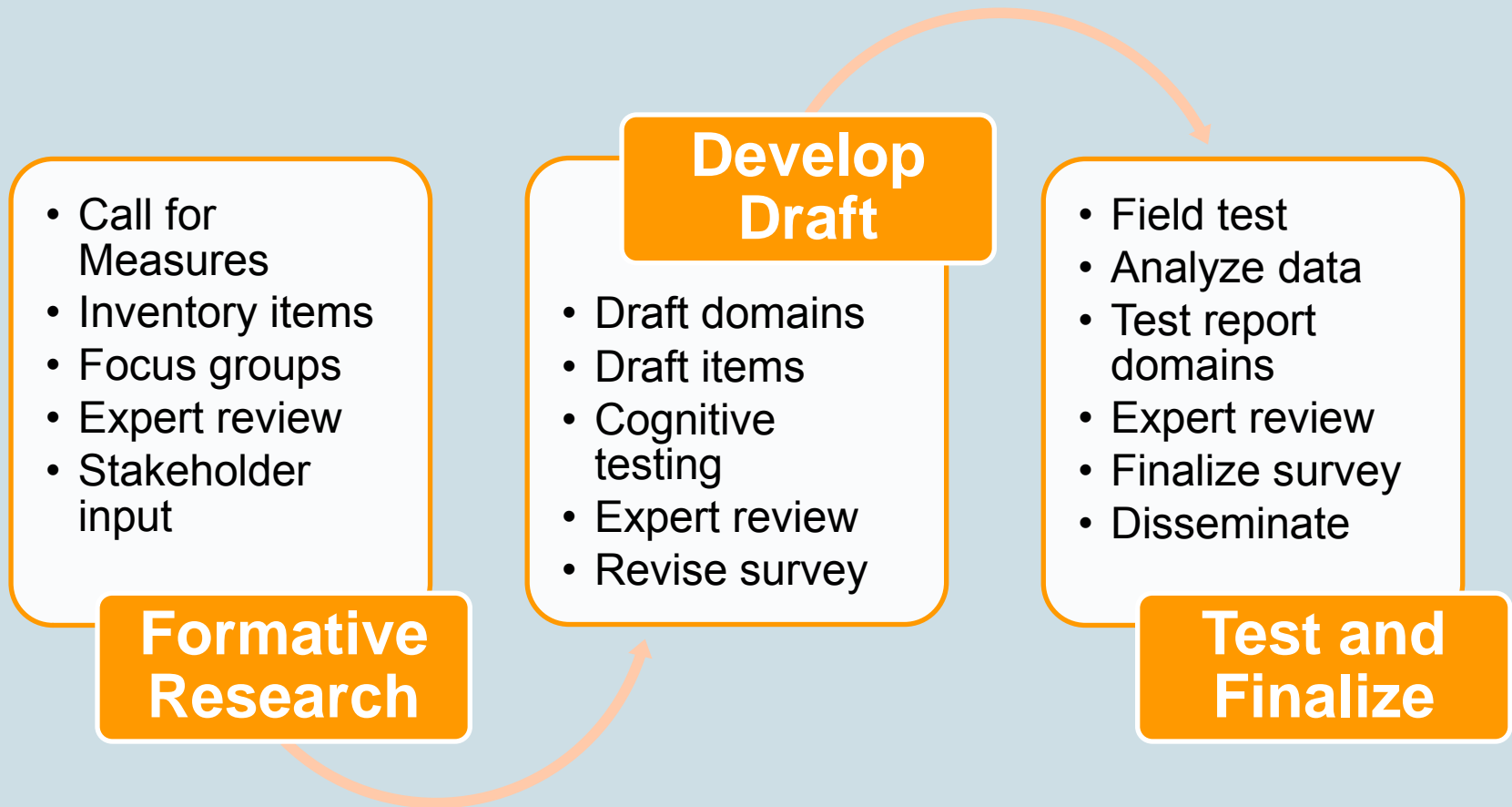
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Why Develop a Cancer CAHPS Survey?

- Uniformly measure cancer care by providers from a patient perspective
- Compare the care provided by different providers
- Expansion of CAHPS instruments

Survey Process



Item Inventory – Current Status

- 935 items (more arriving every day)
- All items coded into domains
- Three independent reviewers of initial domains and items

Draft Domains

1. Fostering Patient-Clinician Relationship
2. Exchanging Information
3. Responding to emotions
4. Managing uncertainty
5. Making decisions
6. Enabling patient self-management

Draft Domains *continued*

- 7. Shared decision-making
- 8. Quality of Care
- 9. Management of symptoms and side effects
- 10. Patient safety and adverse events
- 11. Coordination of care
- 12. Access to cancer care
- 13. Facilities

Typical CAHPS Surveys have
between 3-7 domains!

Patient-centered care

- Fostering Patient-Clinician Relationship
 - ◆ Importance of shared definitions of roles and responsibilities; trust; and rapport
- Exchanging Information
 - ◆ Provider-to-patient and patient-to-provider
 - ◆ Needs vary across the continuum of care

Patient-centered care *continued*

- Responding to emotions
 - ◆ Variety of patient emotions
 - ◆ Challenge—identifying key indicator behaviors
- Managing uncertainty
 - ◆ Inherent in cancer care, but providers can prepare patients for uncertainty

Patient-centered care *continued*

- Making decisions

- ◆ Information exchange, deliberation and making a final decision

- Enabling patient self-management

- ◆ Patient autonomy, patient activation, and patient navigation

Shared Decision-making

■ Shared decision-making

- ◆ Includes knowledge transfer, deliberating across the options, and making a plan to implement and revise the decision
- ◆ *“Were you involved in decisions about your care as much as you wanted?”*

Quality of care

- Patient judgments about how well or poorly provider imparted care
 - ◆ *“When you received any medical tests ordered by your follow-up care doctor, how often did you get the test results in a timely manner?”*

Management of symptoms and side effects

- Includes somatic and emotional side effects
- Potential aspects to include:
 - ◆ Extent to which patients are made aware of information to cope
 - ◆ Whether providers assist in identifying strategies

Patient safety and adverse events

- Avoiding injuries to patients from care that is intended to help them
 - ◆ *“Do you believe that anyone made a mistake that affected your care?”*

Coordination of care

- Ability for different providers (primary care physicians, nurses, oncologists, radiologists, etc) to coordinate information and care for the patient
 - ◆ Difficult to assess good coordination
 - ◆ *How often were your providers aware of changes in your treatment that other providers recommended?*

Access to Care and Facilities

■ Access to care

- ◆ Ability to obtain cancer care (access to hospitals, doctors, waiting time for appointment, etc.)

■ Facilities

- ◆ Cleanliness, adequate space, and privacy
- ◆ *“Overall, do the chemotherapy treatment rooms provide you with enough privacy?”*

Next Steps

■ Reviewing and reducing based on CAHPS principles:

- Is the patient the best source of information?
- Does the question ask about an experience or behavior?
- Do patients identify them as being important?

Next Steps: Excluding Items

- Is the patient the best source of information?
 - ◆ *“My doctors are very competent and well-trained”*

- Does the question ask about experiences or behaviors?
 - ◆ *“If my doctor tells me something is so, then it must be true”*

Next Steps: Focus Groups

- Do patients identify them as being important?
 - ◆ Conduct 16 focus groups to assess domains
 - Different stages of cancer
 - Different types of cancer
 - English vs. Spanish
 - Different treatment locations
 - Patients and caregivers



Focus Group Topics

- Who are the key providers that patients focus on?
 - ◆ Hospital care? Care from Primary Care Provider?
- What are key factors that patients use to determine quality of care?
 - ◆ Examples of “good” and “bad” visits.
 - ◆ Uses a modified Critical Incident Technique.

Focus Group Topics

- Are all domains developed by the team relevant to patients?
- Which constructs are most important?
- What type of information would have helped patients choose a cancer care provider?

The Future

- Meet with Technical Expert Panel and Stakeholder Group for input
 - ◆ 9 Technical Experts
 - ◆ 10+ stakeholders
- Develop draft survey
- Cognitively test
- Field test & analysis

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