

Developing and Testing a Patient Experience Survey for Cancer

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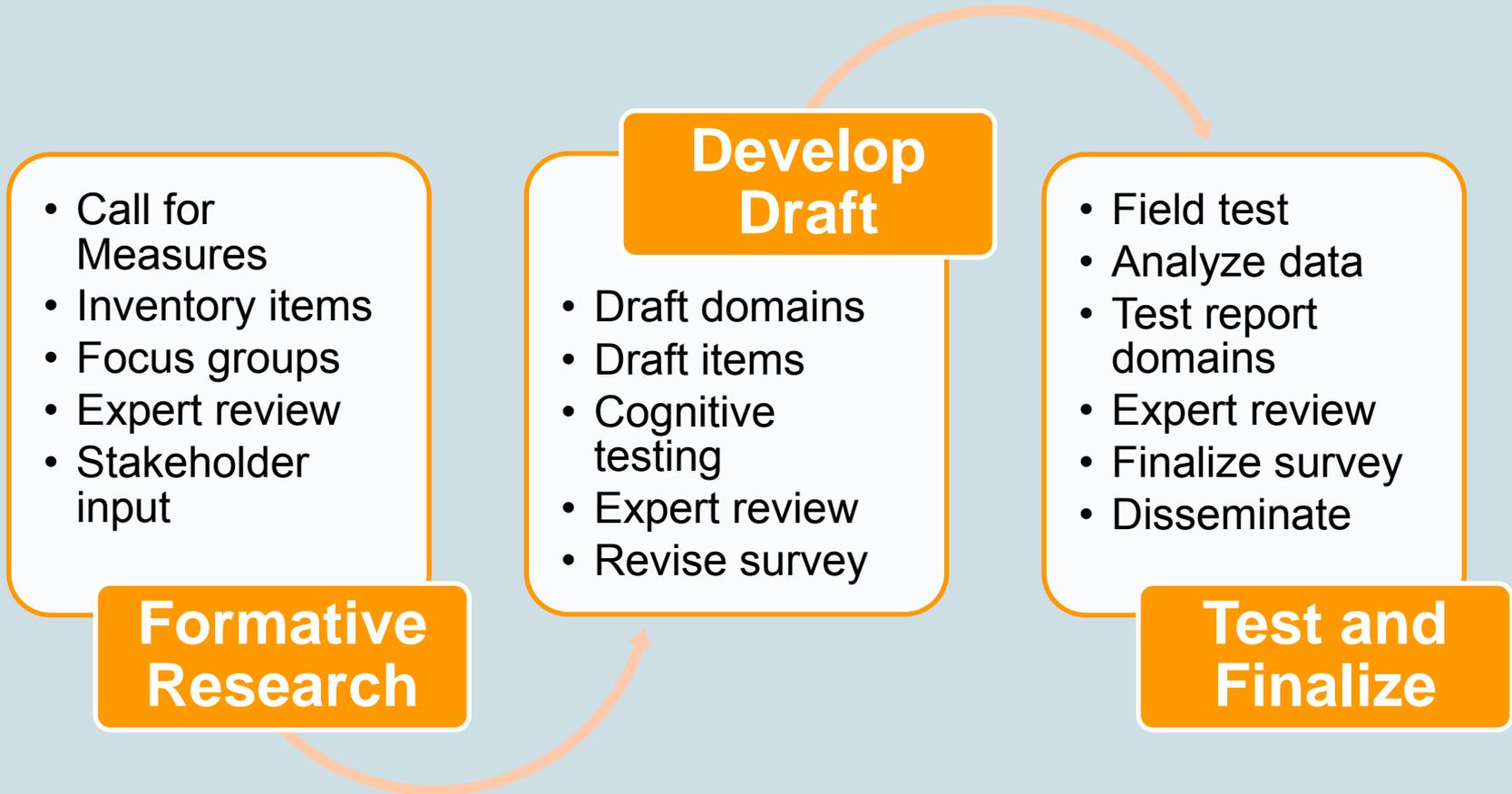
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Why Develop a Cancer CAHPS Survey?

- 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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