

# Survey Development for Assessment of Patient-Centered Communication in Cancer Care

Katherine Treiman, PhD, MPH  
CAHPS-SOPS User Group Meeting

April 20, 2010  
Baltimore, MD

**Track:** The Evolution of CAHPS Surveys  
**Session:** Assessment of Patient Perspectives on Cancer  
Care in Multiple Health Care Settings  
**Date & Time:** April 21, 2010, 9:30 am  
**Track Number:** CAHPS T1 – S5

# Project Team

## **NCI**

Neeraj Arora, PhD

## **AHRQ**

William Lawrence, MD, MS

## **RTI**

Lauren McCormack, PhD, MSPH

Katherine Treiman, PhD, MPH

Murrey Olmsted, PhD

Pamela Williams-Piehota, PhD

Douglas Rupert, MPH

Samruddhi Thaker, PhD, MHA, MBBS

Rebecca Moultrie

## **Consultants**

Richard Street, PhD

Eric Nadler, MD, MPP

## **Project sponsored by:**

- National Cancer Institute
- Agency for Healthcare Research and Quality (AHRQ), through the DEcIDE program

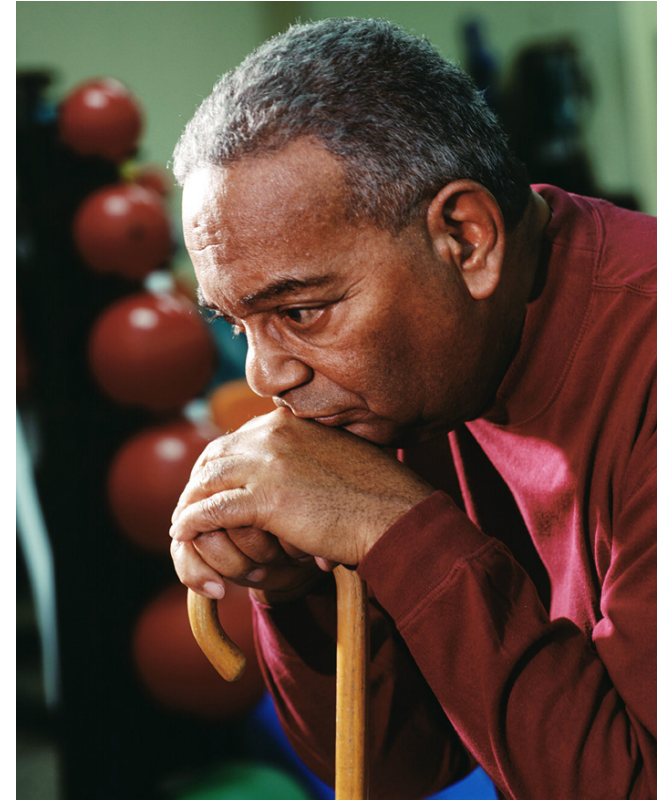
# Presentation Overview

- Role of patient-centered communication (PCC) in the context of cancer care
- PCC conceptual framework
- Importance of measuring PCC
- Current AHRQ and NCI-supported project to develop PCC measurement tools



# The Cancer Care Context

- Patients and family members dealing with potentially life-threatening illness
- Care involves numerous clinicians
- Health care team can change over time
- Care can be complex, involve multiple treatment modalities
- Patients and family members dealing with uncertainty (e.g., about prognosis, treatment effectiveness)



# Why Is Patient-Centered Communication Important?

Effective communication can help patients and family members

- Receive bad news
- Handle the emotional impact of a cancer diagnosis
- Understand complex information
- Make informed decisions
- Manage uncertainties
- Communicate with multiple providers
- Build trust that will sustain long-term therapeutic relationships





Patient-centered care is  
*“respectful and responsive  
to individual patient  
preferences, needs and  
values and ensures that  
patient values guide all  
clinical decisions.”*

(Institute of Medicine, 2001)

Patient-centered communication considers patients' needs, perspectives, and individual experiences; provides opportunities to patients to participate in their care; and enhances the patient-clinician relationship.

(Epstein et al., 2005)



# What Is Patient-Centered Communication?

## PCC involves

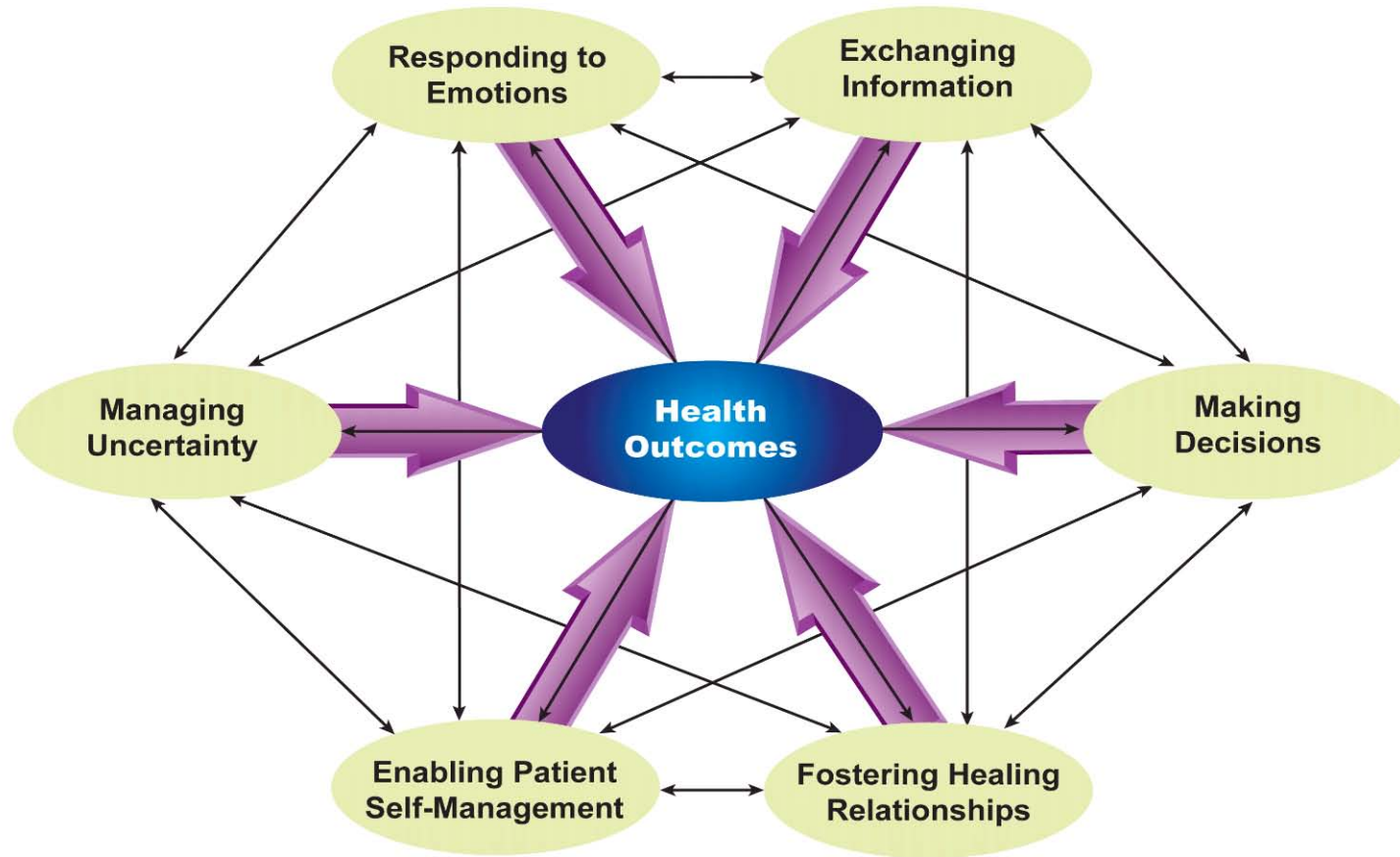
- Eliciting, understanding, and validating the patient's perspective
- Understanding the patient within his or her own psychological and social context
- Reaching a shared understanding of the patient's problem and treatment
- Helping the patient share power by offering meaningful choices related to his or her health

(Epstein & Street, 2007)



# The National Cancer Institute's Conceptual Model of Patient-Centered Communication

Figure 2.1: Six domains of communication and health outcomes



# Six Functions of Patient-Centered Communication

## **1. Exchanging information**

Communication to assess and understand patient's information needs, facilitate reciprocal sharing of information, and achieve a shared understanding

## **2. Fostering healing relationships**

Communication that builds trust, rapport, commitment, and mutual understanding about roles and responsibilities

## **3. Recognizing and responding to emotions**

Communication to elicit, acknowledge, and understand patients' emotions and to respond with legitimation, validation, empathy, and support

# Functions (cont.)

## **4. Managing uncertainty**

Communication that acknowledges uncertainty to allow space for hope, recognizes that uncertainty often cannot be eliminated, and helps manage uncertainty by providing information, support, and cognitive strategies

## **5. Making decisions**

Communication to understand patients' preferences for involvement in decision making, engage patients in decision making, and help patients make informed decisions

## **6. Enabling patient self-management**

Communication to help patients self-manage their illness (e.g., cope with side effects, manage self-care) and to navigate the health care system

# In the Words of Patients and Family Members

*“He said to her, ‘tell me about you.’ He wanted to hear what made her tick, what her support system was like, and about her family and her church. She has been a person to him, not a name on a piece of paper. That cemented the relationship.” (husband)*

*“The doctor would hug you or hold your hand if you needed it. He made you feel like you were the most important person in his day.” (patient)*

# In the Words of Patients and Family Members (cont.)

*“You know the sheet of paper that goes over the examining table? He drew on that sheet of paper a timeline of treatments and he let me see a picture. That was very helpful.” (patient)*

*“Dr. X was a general practitioner who was there for him since the beginning. He told him people to go to, making referrals, giving names, looking for second opinions. He helped to decipher all the confusing information we were getting.” (wife)*



# Importance of Developing Measures of Patient-Centered Communication



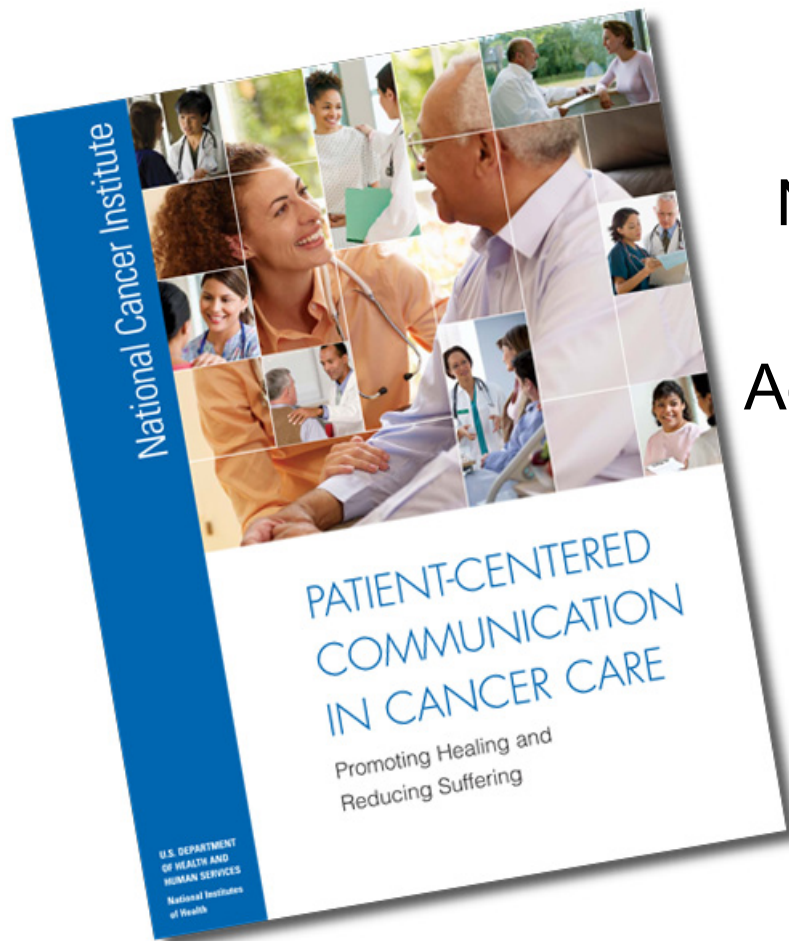
- Lack of common measures
- Measurement tools to assess patient-centered communication at the organizational level
  - quality monitoring
  - inform and evaluate quality improvement efforts
- Measurement tools for surveillance at the population level
- Facilitate research to better understand the role of communication

# Approach to Measuring Patient-Centered Communication

Grounded in the conceptual framework in NCI's recent monograph, *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering* (Epstein & Street, 2007)

Reasons we take a functional approach to assessing PCC:

- It taps into the “work” that communication does, an appropriate metaphor given that communication in medical care aims to accomplish certain tasks and activities (e.g., reach a diagnosis, make treatment decisions, build the relationship).
- It extends beyond what patients and clinicians do as individuals and addresses characteristics of the interaction itself (e.g., exchanging information, deliberating, negotiating).

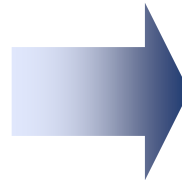


## National Cancer Institute Initiative

### Advancing Measurement of Patient-Centered Communication in Cancer Care

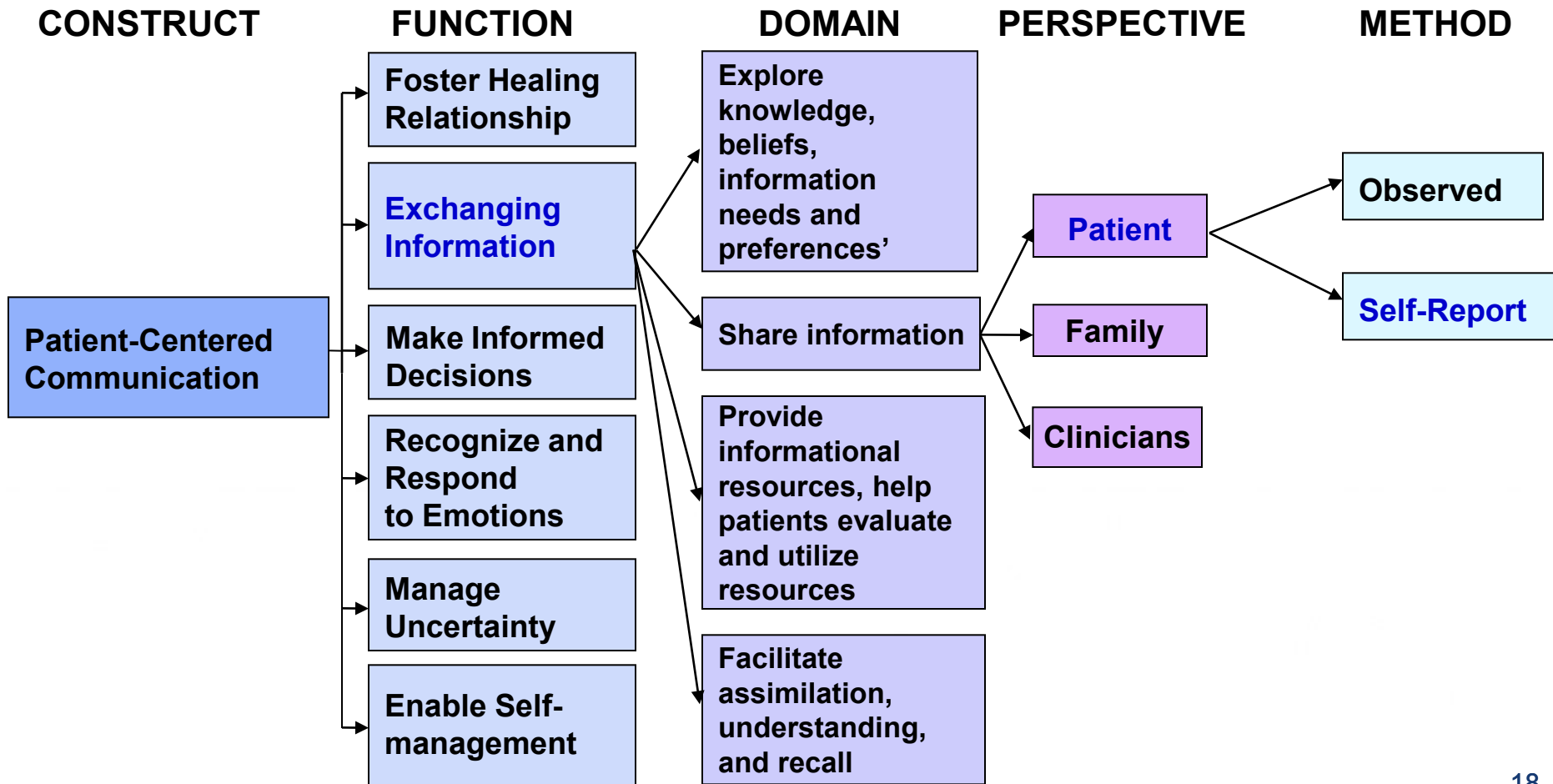
# Project Activities—Phase I

1. Updated literature review
2. Conducted primary data collection (observations of medical encounters, patient/family interviews)
3. Held scientific symposium with content experts



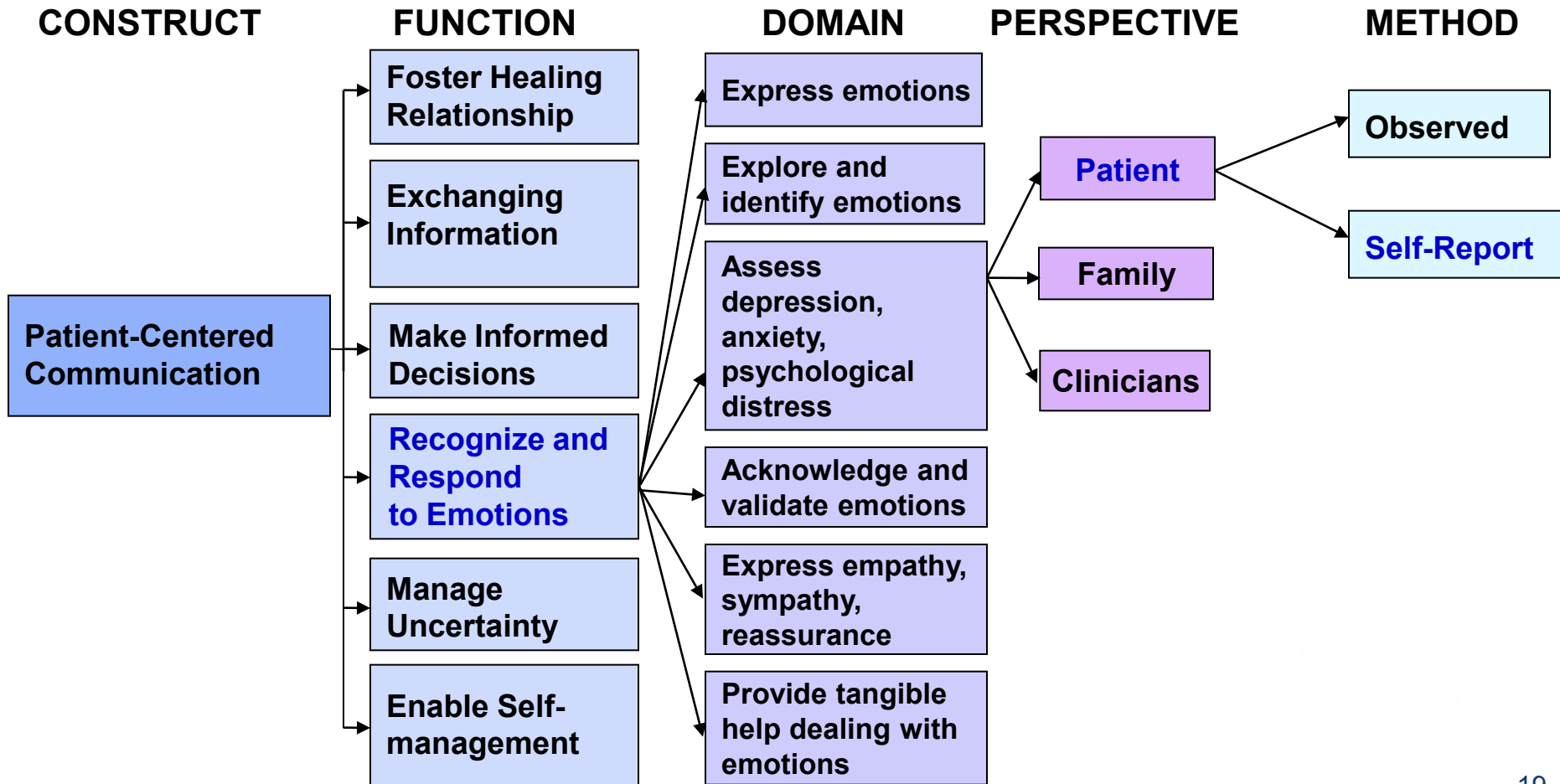
Developed inventory of measurement domains and subdomains

# PCC Domain Framework



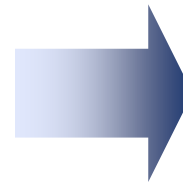


# PCC Domain Framework



# Project Activities—Phase II

- Stakeholder input
- Inventory of existing PCC measures
- Identify strengths/weaknesses of existing measures
- Identify gaps in existing measures
- Measurement development
- Cognitive testing



Tested, validated  
item pool

## Sources:

- ## Types of measures:

- Focus on self-report instruments; also some observational tools included



# Inventory of Existing Measures

- Mapped items to functions and domains
- Most existing items relate to three functions
  - Exchanging Information
  - Fostering Healing Relationships
  - Making Decisions
- Many items focused on customer satisfaction-type issues
- Many items used in limited number of studies, little published psychometric information available

# Considerations in Developing Measures

Measures should be “*parsimonious, reliable, robust, practicable, and theoretically-based. Measurements should also generalize across disease, continuum of care and setting.*”

(Brad Hesse, NCI, 2007)



# Considerations in Developing Measures

- Reliability
- Validity
- Literacy level
- Avoid ceiling effects—framing items, response options
- Suitable for multiple data collection modalities

# Measurement Issues and Challenges

- Balancing need for parsimony and need for comprehensive PCC measures
- Assessing PCC in context of multiple providers (pros/cons of measuring communication experience with “team” vs. individual providers)
- Challenges of measuring PCC longitudinally over the course of care



# Future Activities

- Field testing in different settings, with diverse populations
- Revise conceptual model based on empirical findings
- Possible development of specialized survey modules (e.g., for patients at different stages in care, different cancer types or care settings)
- Dissemination

# Quality Improvement

