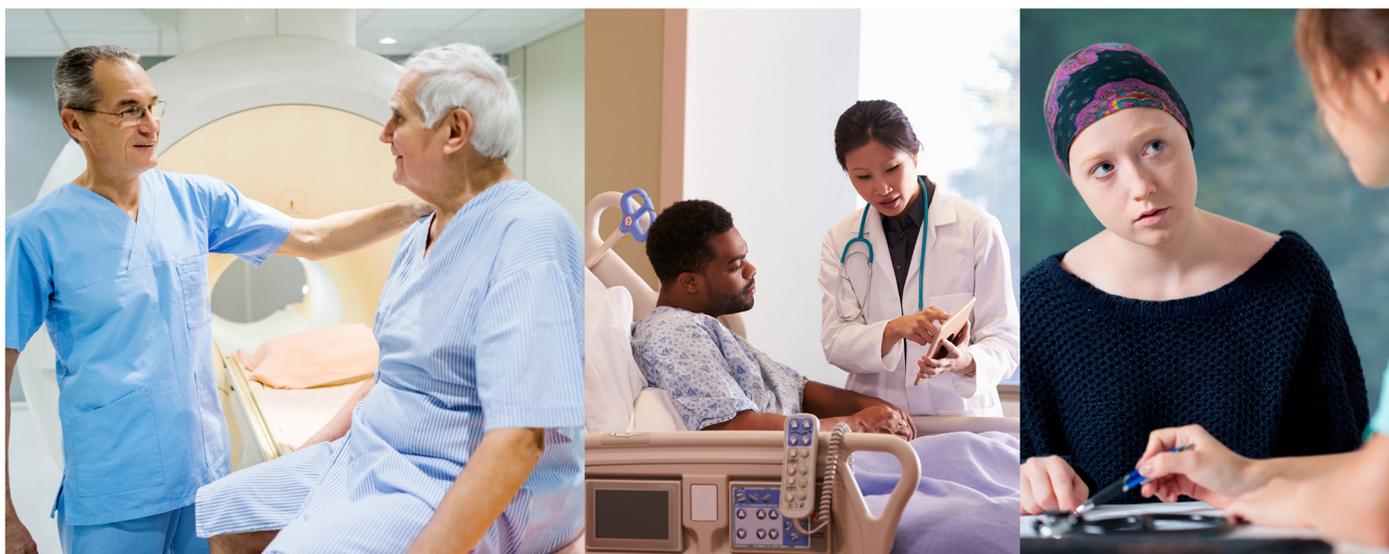


Patient-Centered Communication in Cancer Care

Instrument User Guide



Version 1.0 | September 1, 2016

36-Item Instrument (PCC-Ca-36) and 6-Item Instrument (PCC-Ca-6)

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SUMMARY

Patient-centered communication (PCC) is essential to providing high-quality, patient-centered care. Standard measures are needed to be able to consistently and accurately measure how well health professionals communicate with their patients.

To address this need, RTI International and the University of North Carolina at Chapel Hill developed a comprehensive, publicly available instrument: Patient-Centered Communication in Cancer Care (PCC-Ca). The instrument is available in both a long form (36 items) and a short form (6 items) and is easy to score. The PCC-Ca was validated with a colorectal cancer patient population.

The purpose of the measure is to assess PCC in six core domains: (1) exchanging information, (2) making decisions, (3) fostering healing relationships, (4) enabling patient self-management, (5) managing uncertainty, and (6) responding to emotions.

Researchers and practitioners can use the PCC-Ca for surveillance, quality monitoring, assessment, and intervention evaluation.

To contact us regarding the PCC-Ca, please e-mail pcc-ca@rti.org.

BACKGROUND

Patient-centered communication is an essential component of high-quality medical care. By providing trustworthy information that is attentive, responsive, and tailored to a patient's needs, clinicians can improve patient satisfaction, health-related quality of life, and other important health outcomes.^{1,2}

PCC encompasses three core values:

- considering patients' needs, perspectives, and experiences,
- providing opportunities for patients to take part in their care, and
- strengthening the patient-clinician relationship.

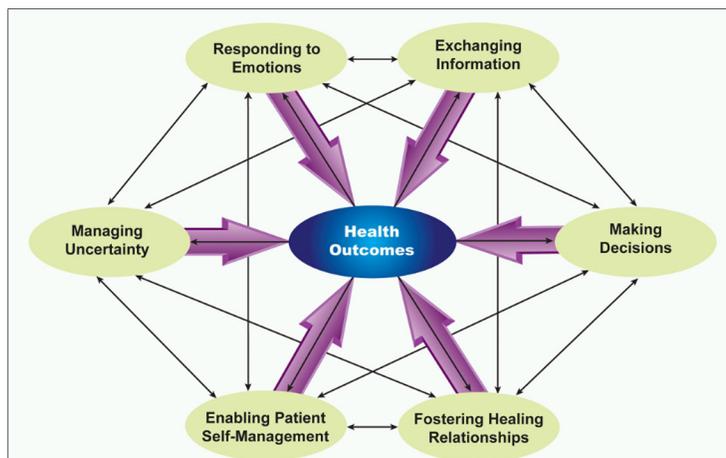
In the cancer care setting, a PCC approach can help patients:

- improve how they deal with difficult news,
- handle the emotional impact of a serious illness,
- understand complex medical information,
- communicate with multiple clinicians,
- manage uncertainty,
- make decisions about their care, and
- adopt healthy behaviors.

Patient-Centered Communication in Cancer Care: Instrument User Guide

In 2007, the National Cancer Institute (NCI) commissioned a white paper that outlined a conceptual framework of PCC based on the literature and expert input.¹ The framework defined six core PCC functions, as shown in Figure 1:

Figure 1. Patient Centered Communication model, from Epstein and Street, 2007



- **Exchanging Information** is communication to assess and understand patients' information needs, to facilitate reciprocal sharing of information, and to achieve a shared understanding.
- **Making Decisions** is communication to understand patient's preferences for involvement in decision-making, to let patients know when there is a decision to be made, and to engage patients so that decisions are based on the best scientific evidence and reflect the patient's values and preferences.
- **Fostering Healing Relationships** is communication that builds trust, rapport, commitment, and mutual understanding about roles and responsibilities.
- **Enabling Patient Self-Management** is communication to help patients manage their symptoms and side effects and to navigate the healthcare system.
- **Managing Uncertainty** is communication that acknowledges uncertainties and recognizes that some uncertainties are not reducible and that helps patients manage uncertainty by providing information, support, and strategies.
- **Responding to Emotions** is communication to elicit, acknowledge, and understand patients' emotions and to respond with legitimization, validation, empathy, and support.

VERSIONS

The 36-item version, the PCC-Ca-36 (see Appendix A), uses 36 questionnaire items and provides scores for each of the six core PCC functions and overall PCC.

The 6-item version, the PCC-Ca-6 (see Appendix B), uses six questionnaire items, one item from each PCC function, and provides a score for overall PCC only. All items on the PCC-Ca-6 are included in the PCC-Ca-36.

ITEM DEVELOPMENT

To develop the survey items, we conducted a literature review, engaged in formative research with colorectal cancer patients and clinicians, and identified existing survey items that could be used or adapted.³ We adapted one item on the PCC-Ca-36 from a previously published instrument:

- Item 10 is adapted from an item on the Health Information National Trends Survey (HINTS) 2007.⁴

We conducted two rounds of cognitive interviewing to evaluate colorectal cancer patients' ability to understand and provide valid answers to the PCC questions. We involved a patient advocacy group, Fight Colorectal Cancer, and a multidisciplinary panel of stakeholders throughout the measurement development process to ensure that the survey questions captured aspects of PCC that are important to patients and that meet the needs of potential end users, including researchers, healthcare organizations, and health professionals.⁵

To establish the reliability and validity of the PCC-Ca, we pilot tested the instrument in English using a sample of 501 adult colorectal cancer patients from North Carolina. The sample was by gender, 47% male and 48% female; by race, 80% white, 13% Black/African-American, and 3% other; and by age, ranged from 27 to 96 years old, with an average of 67 years.

We conducted a psychometric evaluation of the PCC items to design the final versions of the PCC-Ca-36 and PCC-Ca-6 measures. We used a single-time-point assessment of the psychometric properties, including reliability (internal consistency) and construct validity. A full discussion of the study methods, sample, and results will be published in the future.

ADMINISTRATION

We designed both the PCC-Ca-36 and the PCC-Ca-6 measures to be administered as a paper-and-pencil survey or web-based survey. Some questionnaire items could potentially be administered in a telephone survey. However, the instrument was not validated using that mode of administration.

SCORING

Each item included in the PCC-Ca instrument consists of a question stem and five response options. The response options are scored from 1 to 5, with higher scores representing better communication; for example, where 1 = Never and 5 = Always. There are no reverse scored items. Some items have a sixth "does not apply" option. This response is not scored.

The PCC-Ca-36 measure provides scores for each of the six PCC core functions and overall PCC. The PCC-Ca-6 measure provides a single score for overall PCC only. On the PCC-Ca-36 measure, scores for each PCC function are an average of the item responses within each function. Scores across the entire PCC-Ca-36 measure for the overall PCC score are an average of all of the items. Scores are averaged, not summed, across items and functions so that missing data do not result in an artificially low score. Table 1 presents scoring instructions for both measures.

Table 1. Scoring Instructions for the PCC-Ca-36 and PCC-Ca-6 Measures

Function	Scoring for PCC-Ca-36	Scoring for PCC-Ca-6
Exchanging Information	Mean of “Sharing Information” item responses (1a, 1b, 1c, 1d, 1e, and 2)	Not applicable
Fostering Healing Relationships	Mean of “Relationships with Doctors and Other Health Professionals” item responses (3, 4a, 4b, 4c, 4d, 5, and 6)	
Making Decisions	Mean of “Making Decisions” item responses (7, 8a, 8b, 9a, and 9b)	
Responding to Emotions	Mean of “Attention to Your Emotions” item responses (10, 11a, 11b, 11c, 11d, and 12)	
Enabling Patient Self-Management	Mean of “Taking Care of Yourself” item responses (13, 14a, 14b, 14c, 14d, and 15)	
Managing Uncertainty	Mean of “Dealing with Uncertainty” item responses (16, 17a, 17b, 17c, 17d, and 18)	
Overall PCC	Mean of all 36 item responses	Mean of all 6 item responses

SUGGESTED ANALYSES

The PCC-Ca can be used as an independent or a dependent variable. Some suggested analyses include:

- examining the variation in sociodemographic and cancer characteristics according to the PCC-Ca,
- assessing the relationship between PCC and other experiences with cancer care, and
- conducting path analyses to determine the relationship between PCC and health outcomes, and whether variables such as health literacy and attitudes toward the healthcare system mediate that relationship.

Some suggested opportunities for further validation include:

- extension of the PCC-Ca for use by telephone or other formats,
- use of the PCC-Ca in other patient populations (e.g., other cancer types), and
- translation of the PCC-Ca into other languages.

If you wish to make translations or modifications—such as modifying the instrument for use with non-cancer patient populations—you must first contact us for permission. Contact information is listed on page 7 of the User Guide.

SUGGESTED USES

The PCC-Ca-36 and the PCC-Ca-6 measures were designed to be used for national and regional surveillance of PCC and to assess interventions designed to increase PCC. Although the PCC-Ca was designed for use with patients with range of cancer types, the measures were validated with a colorectal cancer patient population. The validity of the measure with other cancers has not been established and may differ.

PROPERTIES OF THE PCC-CA-36 AND PCC-CA-6 MEASURES

The properties of the PCC-Ca-36 and PCC-Ca-6 measures are shown in Tables 2 and 3, respectively.

Table 2. Properties of the PCC-Ca-36 Measure

Function	Number of Items	Reliability (Internal consistency)
Exchanging Information	6	0.94
Fostering Health Relationships	7	0.92
Making Decisions	5	0.90
Responding to Emotions	6	0.96
Enabling Patient Self-Management	6	0.94
Managing Uncertainty	6	0.94
Overall PCC	36	0.94

Table 3. Properties of the PCC-Ca-6 Measure

Function	Number of Items	Reliability (Internal consistency)
Overall PCC	6	0.92

MODIFICATIONS AND ADAPTATIONS

No modifications are allowed to the PCC-Ca-36 or PCC-Ca-6 measures without the permission of the licensor. Any changes may have an impact on the validity and reliability of the measures.

REFERENCES

1. Epstein RM, Street RL, Jr. Patient-centered communication in cancer care: promoting healing and reducing suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD, 2007. http://appliedresearch.cancer.gov/areas/pcc/communication/pcc_monograph.pdf
2. Institute of Medicine, Committee on Quality of Health Care in America. Crossing the quality chasm: a new health system for the 21st Century. Washington, DC: National Academy Press; 2001. <http://www.ncbi.nlm.nih.gov/books/NBK222274/>
3. McCormack LA, Treiman K, Rupert D, et al. Measuring patient-centered communication in cancer care: a literature review and the development of a systematic approach. *Soc Sci Med*. 2011;72(7):1085-1095. DOI: [10.1016/j.socscimed.2011.01.020](https://doi.org/10.1016/j.socscimed.2011.01.020)
4. National Cancer Institute. Health Information National Trends Survey 2007 (HINTS 2007) English Extended Interview Instrument – Final Version. September 2008. [http://hints.cancer.gov/docs/Instruments/HINTS%202007%20CATI%20Instrument%20\(English\).pdf](http://hints.cancer.gov/docs/Instruments/HINTS%202007%20CATI%20Instrument%20(English).pdf)
5. Treiman K, McCormack LA, Olmsted M, et al. Engaging patient advocates and other stakeholders to design measures of patient-centered communication in cancer care. *The Patient: Patient-Centered Outcomes Research*. In press.

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Stakeholder Panel Members

- **Nancy Roach**, Founder and Chair, Board of Directors, Fight Colorectal Cancer
- **Anjee Davis**, President, Fight Colorectal Cancer
- **Andrea Dwyer**, Director of Health Promotion, Fight Colorectal Cancer
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DISCLAIMER

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The statements in this work are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors, its Methodology Committee, the Agency for Healthcare Research and Quality, the National Cancer Institute, or the U.S. Department of Health and Human Services.

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APPENDIX A: PATIENT-CENTERED COMMUNICATION-CANCER-36 ITEMS (PCC-CA-36)

Patient-Centered Communication-Cancer-36 Items (PCC-Ca-36)

Thank you for taking the time to fill out this survey.

This survey asks about your experiences with doctors and other health professionals such as nurses and physician assistants. This is not a test, and there are no right and wrong answers.

Instructions:

- ✓ Please share your honest opinions. All of your answers will be kept private. The information will not be reported back to your doctors, nurses, or anyone else who provides care.
- ✓ Please use a **BLACK** or **DARK BLUE** ink pen to mark your answers.
- ✓ Be sure to read all of the answer choices before marking your answer.

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Sharing Information

1. How often do your doctors and other health professionals...

	Never	Rarely	Some- times	Often	Always
a. Talk with you about your concerns and questions?	<input type="radio"/>				
b. Give you helpful information, even when you don't ask for it?	<input type="radio"/>				
c. Make sure you have the information you need?	<input type="radio"/>				
d. Help you understand the information you need to know?	<input type="radio"/>				
e. Make sure your questions are answered?	<input type="radio"/>				

2. How much do your doctors and other health professionals make you feel comfortable asking questions?

- Not At All
- Not Very Much
- Somewhat
- A Lot
- A Great Deal

Relationships with Doctors and Other Health Professionals

3. How much can you depend on your doctors and other health professionals to give you the care you need?

- Not at all
- Not very much
- Somewhat
- A lot
- A great deal

4. How often do your doctors and other health professionals ...

	Never	Rarely	Some- times	Often	Always
a. Show they care about you?	<input type="radio"/>				
b. Remember details about you between visits?	<input type="radio"/>				
c. Have open and honest communication with you?	<input type="radio"/>				
d. Listen carefully to what you have to say?	<input type="radio"/>				

5. How much do your doctors and other health professionals seem well informed about your type of cancer?

- Not at all
- Not very much
- Somewhat
- A lot
- A great deal

6. Different doctors and health professionals are often involved in a patient's care. How well do your doctors and other health professionals explain what they each do?

- Poorly
- Not Very Well
- Fairly Well
- Very Well
- Outstanding

Making Decisions

Many decisions need to be made in cancer care, such as decisions about treatment choices, where to go for care, or how to manage side effects. Please think about all of the decisions there have been in your care.

7. How often do your doctors and other health professionals involve you in making decisions about your care?

- Never
- Rarely
- Sometimes
- Often
- Always
- Does not apply/there have not been any decisions

8. How well do your doctors and other health professionals ...

	Poorly	Not Very Well	Fairly Well	Very Well	Out-standing	Does Not Apply
a. Explain the different choices you have?	<input type="radio"/>					
b. Explain what they recommend?	<input type="radio"/>					

9. How much do your doctors and other health professionals...

	Not at All	Not Very Much	Some-what	A Lot	A Great Deal	Does Not Apply
a. Show interest in what you say about the decisions?	<input type="radio"/>					
b. Give you information and resources to help you make decisions?	<input type="radio"/>					

Attention to Your Emotions

10. How often do your doctors and other health professionals give the attention you need to your feelings and emotions?

- Never
- Rarely
- Sometimes
- Often
- Always
- Does not apply/I do not want attention to my feelings and emotions

11. How much do your doctors and other health professionals...

	Not at All	Not Very Much	Some-what	A Lot	A Great Deal	Does Not Apply
a. Pay attention to how you are doing emotionally?	<input type="radio"/>					
b. Show concern for your feelings, not just your illness?	<input type="radio"/>					
c. Show concern for how you family is doing emotionally?	<input type="radio"/>					
d. Make you feel comfortable to talk about your fears, stress, and other feelings?	<input type="radio"/>					

12. How well do your doctors and other health professionals talk with you about how to cope with any fears, stress, and other feelings?

- Poorly
- Not very well
- Fairly well
- Very well
- Outstanding
- Does not apply

Taking Care of Yourself

13. How well do your doctors and other health professionals help you understand ways you can take care of your health?

- Poorly
- Not very well
- Fairly well
- Very well
- Outstanding

14. How much do your doctors and other health professionals talk with you about...

	Not at All	Not Very Much	Some-what	A Lot	A Great Deal	Does Not Apply
a. How cancer is affecting your everyday life?	<input type="radio"/>					
b. Ways you can manage any side effects or symptoms?	<input type="radio"/>					
c. How your family can help care for you?	<input type="radio"/>					
d. Any concerns you have about taking care of yourself?	<input type="radio"/>					

15. How often do your doctors and other health professionals make sure you understand the steps in your care?

- Never
- Rarely
- Sometimes
- Often
- Always

Dealing with Uncertainty

16. Cancer patients often face uncertainties about their cancer. For example, patients may not know what will happen, how treatment is working, and how to make sense of different information and opinions.

How well do your doctors and other health professionals help you deal with the uncertainties about your cancer?

- Poorly
- Not very well
- Fairly well
- Very well
- Outstanding
- Does not apply/have not been any uncertainties

17. How much do your doctors and other health professionals help you understand ...

	Not at All	Not Very Much	Some-what	A Lot	A Great Deal	Does Not Apply
a. If you are getting better or worse?	<input type="radio"/>					
b. The goal of your care?	<input type="radio"/>					
c. What is likely to happen with your cancer?	<input type="radio"/>					
d. How your symptoms may change?	<input type="radio"/>					

18. Patients often get information from different places. How well do your doctors and other health professionals help you understand what information is most important?

- Poorly
- Not very well
- Fairly well
- Very well
- Outstanding
- Does not apply/I have not gotten information from different places

APPENDIX B: PATIENT-CENTERED COMMUNICATION-CANCER-6 ITEMS (PCC-CA-6)

Patient-Centered Communication-Cancer-6 Items (PCC-Ca-6)

Thank you for taking the time to fill out this survey.

This survey asks about your experiences with doctors and other health professionals such as nurses and physician assistants. This is not a test, and there are no right and wrong answers.

Instructions:

- ✓ Please share your honest opinions. All of your answers will be kept private. The information will not be reported back to your doctors, nurses, or anyone else who provides care.
- ✓ Please use a **BLACK** or **DARK BLUE** ink pen to mark your answers.
- ✓ Be sure to read all of the answer choices before marking your answer.

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1. How much do your doctors and other health professionals make you feel comfortable asking questions?

- Not at all
- Not Very Much
- Somewhat
- A Lot
- A Great Deal

2. How often do your doctors and other health professionals have open and honest communication with you?

- Never
- Rarely
- Sometimes
- Often
- Always

3. Many decisions need to be made in cancer care, such as decisions about treatment choices, where to go for care, or how to manage side effects. Please think about all of the decisions there have been in your care.

How much do your doctors and other health professionals give you information and resources to help you make decisions?

- Not at All
- Not Very Much
- Somewhat
- A Lot
- A Great Deal
- Does Not Apply

4. How well do your doctors and other health professionals talk with you about how to cope with any fears, stress, and other feelings?

- Poorly
- Not Very Well
- Fairly Well
- Very Well
- Outstanding
- Does Not Apply

5. How often do your doctors and other health professionals make sure you understand the steps in your care?

- Never
- Rarely
- Sometimes
- Often
- Always

6. Cancer patients often face uncertainties about their cancer. For example, patients may not know what will happen, how treatment is working, and how to make sense of different information and opinions.

How well do your doctors and other health professionals help you deal with the uncertainties about your cancer?

- Poorly
- Not very well
- Fairly well
- Very well
- Outstanding
- Does not apply/have not been any uncertainties