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.
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. The framework defined six core PCC functions, as shown in Figure 1:

- **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 legitimation, 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. 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

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

**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

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

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

<table>
<thead>
<tr>
<th>Function</th>
<th>Number of Items</th>
<th>Reliability (Internal consistency)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall PCC</td>
<td>6</td>
<td>0.92</td>
</tr>
</tbody>
</table>

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


ACKNOWLEDGEMENTS

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
- **Richard Street Jr., PhD**, Professor and Head of Communication, Texas A&M University
- **Ronald Epstein, MD**, Professor of Family Medicine, Psychiatry and Oncology at the University of Rochester Medical Center, and board-certified in Family Medicine and Hospice and Palliative Medicine
- **Hanna Sanoff, MD, MPH**, Section Chief of GI Medical Oncology; Associate Professor, Department of Medicine, University of North Carolina at Chapel Hill; Cancer Prevention and Control, Gastrointestinal Oncology Programs
- **David Thissen, PhD**, Professor, University of North Carolina at Chapel Hill
- **Deborah Mayer, PhD, RN, AOCN, FAAN**, advanced practice oncology nurse, University of North Carolina at Chapel Hill School of Nursing
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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Lineberger Comprehensive Cancer
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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...

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Talk with you about your concerns and questions?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>b. Give you helpful information, even when you don’t ask for it?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>c. Make sure you have the information you need?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>d. Help you understand the information you need to know?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>e. Make sure your questions are answered?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

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 ... 

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Show they care about you?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>b. Remember details about you between visits?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>c. Have open and honest communication with you?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>d. Listen carefully to what you have to say?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

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 ...

<table>
<thead>
<tr>
<th>a. Explain the different choices you have?</th>
<th>Poorly</th>
<th>Not Very Well</th>
<th>Fairly Well</th>
<th>Very Well</th>
<th>Outstanding</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>b. Explain what they recommend?</th>
<th>○</th>
<th>○</th>
<th>○</th>
<th>○</th>
<th>○</th>
<th>○</th>
</tr>
</thead>
</table>

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

<table>
<thead>
<tr>
<th>a. Show interest in what you say about the decisions?</th>
<th>Not at All</th>
<th>Not Very Much</th>
<th>Somewhat</th>
<th>A Lot</th>
<th>A Great Deal</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>b. Give you information and resources to help you make decisions?</th>
<th>○</th>
<th>○</th>
<th>○</th>
<th>○</th>
<th>○</th>
<th>○</th>
</tr>
</thead>
</table>
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...

   a. Pay attention to how you are doing emotionally?
      - Not at All
      - Not Very Much
      - Somewhat
      - A Lot
      - A Great Deal
      - Does Not Apply

   b. Show concern for your feelings, not just your illness?
      - Not at All
      - Not Very Much
      - Somewhat
      - A Lot
      - A Great Deal
      - Does Not Apply

   c. Show concern for how your family is doing emotionally?
      - Not at All
      - Not Very Much
      - Somewhat
      - A Lot
      - A Great Deal
      - Does Not Apply

   d. Make you feel comfortable to talk about your fears, stress, and other feelings?
      - Not at All
      - Not Very Much
      - Somewhat
      - A Lot
      - A Great Deal
      - Does Not Apply

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...

<table>
<thead>
<tr>
<th></th>
<th>Not at All</th>
<th>Not Very Much</th>
<th>Somewhat</th>
<th>A Lot</th>
<th>A Great Deal</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. How cancer is affecting your everyday life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Ways you can manage any side effects or symptoms?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. How your family can help care for you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Any concerns you have about taking care of yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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 ...

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at All</th>
<th>Not Very Much</th>
<th>Somewhat</th>
<th>A Lot</th>
<th>A Great Deal</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. If you are getting better or worse?</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>b. The goal of your care?</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>c. What is likely to happen with your cancer?</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>d. How your symptoms may change?</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>

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.
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✔ Be sure to read all of the answer choices before marking your
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reserved. This work is licensed under a Creative Commons Attribution-No Derivatives 4.0 International
License (CC-BY-ND 4.0).
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