



PATIENT-CENTERED COMMUNICATION IN CANCER CARE

Instrument User Guide

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

English and Spanish Versions



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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
- ♦ **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

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CONTACT INFORMATION

E-mail: pcc-ca@rti.org

Address correspondence to:

Lauren McCormack, PhD, MSPH

Vice President, Public Health Research Division
RTI International

Bryce Reeve, PhD

Director, Center for Health Measurement
Duke University School of Medicine

Katherine Treiman, PhD, MPH

Senior Research Scientist, Center for Communication Science
RTI International



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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 English and Spanish 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.

The PCC-Ca team is interested in learning about how researchers and practitioners are using the PCC-Ca. We encourage you to share information about how you are using the instrument, including study plans, findings, publications and presentations.

To contact us about your research or regarding any questions about 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.

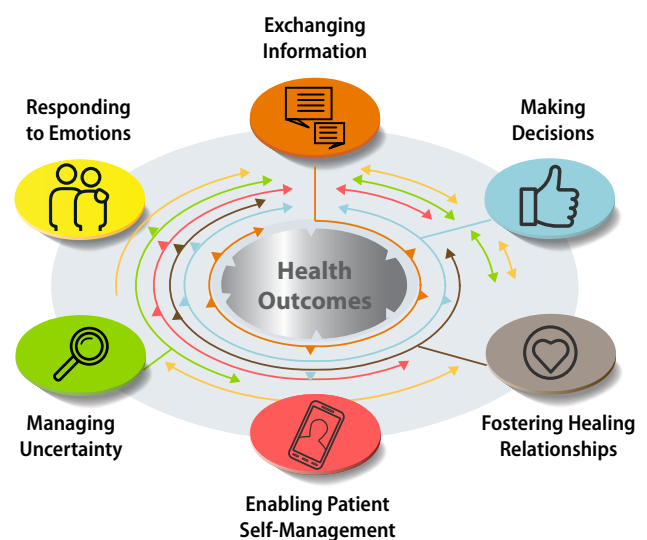
In the cancer care setting, a PCC approach can help patients:

- ♦ 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.¹ The framework defined six core PCC functions, as shown in **Figure 1**.

Figure 1. Patient-Care 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 instrument is available in English and Spanish and in both a long form (36 items) and a short form (6 items).

The 36-item version, the PCC-Ca-36 (see Appendix A for English, Appendix C for Spanish), 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 for English, Appendix D for Spanish), 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 are presented in several publications.^{5,6,7}

Spanish-language Version

We performed a three-step process to develop the Spanish-language version of the instrument. A professional language methodologist conducted a forward translation designed to convey the meaning of the original source language (English) into Spanish, using standard language that is understood by the majority of Spanish-speaking adults.

Then we conducted six cognitive interviews with native Spanish speakers who were patients or caregivers of individuals with colorectal cancer to assess how respondents interpreted the translation of key questions and terms to determine whether respondents' interpretations were consistent with the English instrument.

Next, following minor wording adjustments as result of the interviews, a second certified professional translator proofread and edited the instrument. Any discrepancies or questions that arose were reconciled between the two language methodologists and the Spanish version was finalized.

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)	Not applicable
Making Decisions	Mean of “Making Decisions” item responses (7, 8a, 8b, 9a, and 9b)	Not applicable
Responding to Emotions	Mean of “Attention to Your Emotions” item responses (10, 11a, 11b, 11c, 11d, and 12)	Not applicable
Enabling Patient Self-Management	Mean of “Taking Care of Yourself” item responses (13, 14a, 14b, 14c, 14d, and 15)	Not applicable
Managing Uncertainty	Mean of “Dealing with Uncertainty” item responses (16, 17a, 17b, 17c, 17d, and 18)	Not applicable
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 **Table 3**, respectively. Detailed information on the psychometric properties of the measures can be found in Reeve et al., 2017.

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.

Language Translation

The PCC-Ca-36 and PCC-Ca-6 instruments have been validated in English and the Spanish-language versions were developed and tested by RTI language methodologists. RTI hereby grants you a license to translate any of the instruments into other languages only under the following conditions:

1. The following statement (in both English and the language of translation) must be prominently included in any translation, resulting publications or dissemination of research findings: "RTI has validated the PCC-Ca-36 and PCC-Ca-6 instruments in English and has created a Spanish-language version of each. RTI has not validated and does not endorse this translated version."
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For clarity, this license to translate granted by RTI will be automatically void if these terms are not followed

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/NBK22274/>
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
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. 2017;10 (1): 93-103. <https://link.springer.com/article/10.1007%2Fs40271-016-0188-6>
6. Reeve, BB, Thissen, DM, Bann CM, et al. Psychometric evaluation and design of patient-centered communication measures for cancer care settings. Patient Education and Counseling. 2017; 100: 1322-1328. <https://www.sciencedirect.com/science/article/pii/S0738399117300757?via%3Dihub>
7. Treiman K, McCormack L, Wagner L, et al. Factors affecting the communication experiences of newly diagnosed colorectal cancer patients. Patient Education and Counseling. 2018; 101 (9): 1585-1593. <https://www.sciencedirect.com/science/article/abs/pii/S0738399118301964?via%3Dihub>



APPENDIX A:

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.

Sharing Information

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

	Never	Rarely	Sometimes	Often	Always
a. Talk with you about your concerns and questions?					
b. Give you helpful information, even when you don't ask for it?					
c. Make sure you have the information you need?					
d. Help you understand the information you need to know?					
e. Make sure your questions are answered?					

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 Sometimes Often Always

a. Show they care about you?

b. Remember details about you between visits?

c. Have open and honest communication with you?

d. Listen carefully to what you have to say?

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	Outstanding	Does Not Apply
a. Explain the different choices you have?						
b. Explain what they recommend?						

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

	Not at All	Not Very Much	Somewhat	A Lot	A Great Deal	Does Not Apply
a. Show interest in what you say about the decisions?						
b. Give you information and resources to help you make decisions?						

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/there have not been any decisions

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

	Not at All	Not Very Much	Somewhat	A Lot	A Great Deal	Does Not Apply
a. Pay attention to how you are doing emotionally?						
b. Show concern for your feelings, not just your illness?						
c. Show concern for how your family is doing emotionally?						
d. Make you feel comfortable to talk about your fears, stress, and other feelings?						

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	Somewhat	A Lot	A Great Deal	Does Not Apply
a. How cancer is affecting your everyday life?						
b. Ways you can manage any side effects or symptoms?						
c. How your family can help care for you?						
d. Any concerns you have about taking care of yourself?						

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

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

	Not at All	Not Very Much	Somewhat	A Lot	A Great Deal	Does Not Apply
a. If you are getting better or worse?						
b. The goal of your care?						
c. What is likely to happen with your cancer?						
d. How your symptoms may change?						

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)

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.

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



APPENDIX C:

COMUNICACIÓN SOBRE EL CÁNCER CENTRADA EN EL PACIENTE-36 PREGUNTAS (PCC-CA-36, POR SUS SIGLAS EN INGLÉS)

Gracias por su tiempo en contestar esta encuesta.

Esta encuesta le hace preguntas sobre sus experiencias con los doctores y otros profesionales de la salud, como enfermeras y asistentes médicos. Esto no es un examen y no hay respuestas correctas ni incorrectas.

Instrucciones:

- ♦ Por favor, comparta sus opiniones honestas. Todas sus respuestas se mantendrán privadas. La información no se reportará a sus doctores, las enfermeras o cualquier otra persona que brinde atención médica.
- ♦ Por favor, utilice un bolígrafo de tinta **NEGRA** o **AZUL OSCURO** para marcar sus respuestas.
- ♦ Asegúrese de leer todas las opciones de respuestas antes de marcar su respuesta.

Compartir la información

1. ¿Con qué frecuencia sus doctores y otros profesionales de la salud ...

	Nunca	Rara vez	A veces	Con frecuencia	Siempre
a. Hablan con usted sobre sus preocupaciones y preguntas?					
b. Le dan información útil, incluso cuando usted no la solicita?					
c. Se aseguran de que usted tenga la información que necesita?					
d. Le ayudan a entender la información que necesita?					
e. Se aseguran de contestar sus preguntas?					

2. ¿Qué tan cómodo(a) le hacen sentir sus doctores y otros profesionales de la salud cuando usted les hace preguntas?

- Nunca
- No mucho
- Algo
- Mucho
- Muchísimo

Relaciones con los doctores y otros profesionales de la salud

3. ¿Cuánto puede depender de sus doctores y otros profesionales de la salud para que le brinden la atención que necesita?

- Nunca
- No mucho
- Algo
- Mucho
- Muchísimo

4. **¿Con qué frecuencia sus doctores y otros profesionales de la salud ...**

	Nunca	Rara vez	A veces	Con frecuencia	Siempre
a. Demuestran que se preocupan por usted?					
b. Recuerdan detalles sobre usted entre visitas?					
c. Tienen una comunicación abierta y honesta con usted?					
d. Escuchan con atención lo que usted tiene que decir?					

5. **¿Qué tan bien informados parecen estar sus doctores y otros profesionales de la salud sobre su tipo de cáncer?**

- Nada
- No mucho
- Algo
- Mucho
- Muchísimo

6. **Con frecuencia, diferentes doctores y profesionales de la salud participan en la atención del paciente. ¿Qué tan bien le explican sus doctores y otros profesionales de la salud lo que hace cada uno de ellos?**

- Mal
- No muy bien
- Más o menos bien
- Muy bien
- Excelente

Tomar Decisiones

Se deben tomar muchas decisiones sobre la atención del cáncer, como las decisiones sobre opciones de tratamiento, a dónde ir para recibir atención o cómo controlar los efectos secundarios. Por favor, piense en todas las decisiones que se han tomado durante su atención médica.

7. **¿Con qué frecuencia sus doctores y otros profesionales de la salud lo(a) incluyen a usted al tomar decisiones sobre su atención médica?**

- Nunca
- Rara vez
- A veces
- Con frecuencia
- Siempre
- No corresponde/no se han tomado decisiones

8. ¿Qué tan bien sus doctores y otros profesionales de la salud ...

	Mal	No muy bien	Más o menos bien	Muy bien	Excelente	No corresponde
a. Le explican las diferentes opciones que tiene usted?						
b. Le explican lo que le recomiendan?						

9. ¿Hasta qué punto sus doctores y otros profesionales de la salud...

	Mal	No muy bien	Más o menos bien	Muy bien	Excelente	No corresponde
a. Muestran interés en lo que usted dice acerca de las decisiones?						
b. Le dan información y recursos para ayudarle a tomar decisiones?						

Atención a sus emociones

10. ¿Con qué frecuencia sus doctores y otros profesionales de la salud le prestan la atención que necesita a sus sentimientos y emociones?

Nunca

Rara vez

A veces

Con frecuencia

Siempre

No corresponde/no deseo atención a mis sentimientos y emociones

11. ¿Hasta qué punto sus doctores y otros profesionales de la salud ...

	Nunca	No mucho	Algo	Mucho	Muchísimo	No corresponde
a. Prestan atención sobre cómo se siente usted emocionalmente?						
b. Muestran preocupación por sus sentimientos, no solo por su enfermedad?						
c. Muestran preocupación sobre cómo se siente su familia emocionalmente?						
d. Le hacen sentirse cómodo(a) para que usted hable sobre sus temores, su estrés y otros sentimientos?						

12. ¿Qué tan bien hablan con usted sus doctores y otros profesionales de la salud sobre cómo enfrentar los temores, el estrés y otros sentimientos?

- Mal
- No muy bien
- Más o menos bien
- Muy bien
- Excelente
- No corresponde

Cuidado de sí mismo(a)

13. ¿Qué tan bien le ayudan sus doctores y otros profesionales de la salud a entender las maneras en que pueda cuidar de su salud?

- Mal
- No muy bien
- Más o menos bien
- Muy bien
- Excelente

14. ¿Cuánto hablan con usted sus doctores y otros profesionales de la salud acerca de ...

	Nunca	No mucho	Algo	Mucho	Muchísimo	No corresponde
a. ¿Cómo el cáncer le afecta su vida diaria?						
b. Las maneras en que puede controlar los efectos secundarios o los síntomas?						
c. Cómo puede cuidarlo(a) su familia?						
d. Cualquier inquietud que usted tenga sobre cómo cuidarse a sí mismo(a)?						

15. ¿Con qué frecuencia se aseguran sus doctores y otros profesionales de la salud que usted entiende los pasos a seguir en su cuidado?

- Nunca
- Rara vez
- A veces
- Con frecuencia
- Siempre

Enfrentando la inseguridad

16. Los pacientes con cáncer enfrentan con frecuencia inseguridad acerca de su cáncer. Por ejemplo, los pacientes pueden no saber qué sucederá, si es que el tratamiento está dando resultado y cómo interpretar la información y las diferentes opiniones recibidas.
- ¿Qué tan bien le ayudan sus doctores y otros profesionales de la salud en enfrentarse a la inseguridad sobre su cáncer?
- Mal
 - No muy bien
 - Más o menos bien
 - Muy bien
 - Excelente
 - No corresponde/no ha existido inseguridad

17. ¿Hasta qué punto le ayudan sus doctores y otros profesionales de la salud a entender ...

	Nunca	No mucho	Algo	Mucho	Muchísimo	No corresponde
a. Si usted está mejorando o empeorando?						
b. El objetivo de su atención médica?						
c. Lo que es posible que ocurra con su cáncer?						
d. Cómo pueden cambiar sus síntomas?						

18. Con frecuencia, los pacientes obtienen información de diferentes fuentes. ¿Qué tan bien le ayudan sus doctores y otros profesionales de la salud a entender qué información es más importante?
- Mal
 - No muy bien
 - Más o menos bien
 - Muy bien
 - Excelente
 - No corresponde/No he recibido información de diferentes fuentes



APPENDIX D:

COMUNICACIÓN SOBRE EL CÁNCER CENTRADA EN EL PACIENTE-6 PREGUNTAS (PCC-CA-6, POR SUS SIGLAS EN INGLÉS)

Gracias por su tiempo en contestar esta encuesta.

Esta encuesta le hace preguntas sobre sus experiencias con los doctores y otros profesionales de la salud, como enfermeras y asistentes médicos. Esto no es un examen y no hay respuestas correctas ni incorrectas.

Instrucciones:

- ♦ Por favor, comparta sus opiniones honestas. Todas sus respuestas se mantendrán privadas. La información no se reportará a sus doctores, las enfermeras o cualquier otra persona que brinde atención médica.
- ♦ Por favor, utilice un bolígrafo de tinta **NEGRA** o **AZUL OSCURO** para marcar sus respuestas.
- ♦ Asegúrese de leer todas las opciones de respuestas antes de marcar su respuesta.

1. ¿Qué tan cómodo(a) le hacen sentir sus doctores y otros profesionales de la salud cuando usted les hace preguntas?

- Nunca
- No mucho
- Algo
- Mucho
- Muchísimo

2. ¿Con qué frecuencia sus doctores y otros profesionales de la salud tienen una comunicación abierta y honesta con usted?

- Nunca
- Rara vez
- A veces
- Con frecuencia
- Siempre

3. Se deben tomar muchas decisiones sobre la atención del cáncer, como las decisiones sobre opciones de tratamiento, a dónde ir para recibir atención o cómo controlar los efectos secundarios. Por favor, piense en todas las decisiones que se han tomado durante su atención médica.

¿Hasta qué punto sus doctores y otros profesionales de la salud le dan información y recursos para ayudarle a tomar decisiones?

- Nada
- No mucho
- Algo
- Mucho
- Muchísimo
- No corresponde

4. ¿Qué tan bien hablan con usted sus doctores y otros profesionales de la salud sobre cómo enfrentar los temores, el estrés y otros sentimientos?

- Mal
- No muy bien
- Más o menos bien
- Muy bien
- Excelente
- No corresponde

- 
5. **¿Con qué frecuencia se aseguran sus doctores y otros profesionales de la salud que usted entiende los pasos a seguir en su cuidado?**

Nunca

Rara vez

A veces

Con frecuencia

Siempre

6. **Los pacientes con cáncer enfrentan con frecuencia inseguridad acerca de su cáncer. Por ejemplo, los pacientes pueden no saber qué sucederá, si es que el tratamiento está dando resultado y cómo interpretar la información y las diferentes opiniones recibidas.**

¿Qué tan bien le ayudan sus doctores y otros profesionales de la salud en enfrentarse a la inseguridad sobre su cáncer?

Mal

No muy bien

Más o menos bien

Muy bien

Excelente

No corresponde/no ha existido inseguridad