APÊNDICE 1

Questionário Patient Assessment of Cancer Communication Experiences

Core Item Set

- 1. I was treated with sensitivity and respect. a
- 2. I felt known as a person. a
- 3. I felt listened to. a
- 4. I felt comfortable asking questions and voicing my concerns. a
- 5. I felt that everyone worked together as a team in taking care of me. a
- 6. My wishes were respected. a
- 7. I got the information I needed, when I needed it. a
- 8. I got clear, understandable information. a
- 9. I knew who to contact if I had a question or concern. a
- 10. I felt comfortable bringing up anything that was on my mind. a
- 11. I got consistent information from all my doctors and nurses; everyone was on the same page. a
- 12. My cancer care team helped me cope with any uncertainty or unknowns. a
- 13. My cancer care team helped me cope with difficult feelings, like fear, anxiety, and feeling down. a
- 14. I felt optimism and hope from my doctors and nurses. a
- 15. I was involved in making decisions as much as I wanted. a
- 16. I knew who in the healthcare system I could reach out to if I was worried that something had gone wrong with my care. a
- 17. Overall, how would you rate your experiences with communication related to your cancer care, from the time there was a suspicion that you might have cancer, through the present? b

Diagnosis Item Set

- 18. I was told I had cancer in a way that was sensitive and caring. c
- 19. The person who told me I had cancer was the right person to tell me. c
- 20. My cancer care team helped me cope with the uncertainty or unknowns about my diagnosis. c
- 21. Soon after I was told I had cancer, someone was available to answer my questions about my diagnosis and next steps.c
- 22. Soon after I was told I had cancer, I knew what would happen next, and what decisions I would face. o
- 23. Overall, how would you rate your experiences with communication when you were diagnosed with cancer? b

Treatment Decision Making Item Set

- 24. I got clear, understandable information about treatments we were considering. ^a
- 25. I knew who to contact if I had a question or concern. a
- 26. I felt comfortable bringing up anything that was on my mind. a
- 27. I got consistent information from all my doctors and nurses; everyone was on the same page. a
- 28. My cancer care team helped me cope with the uncertainty or unknowns about my treatment decisions. a
- 29. I was given the right amount of information, at the right time, on my treatment choices. a
- 30. I understood what treatment choices were available to me. a
- 31. I understood the risks of my different treatment choices. a
- 32. I understood the likely benefits of different treatment choices. a
- 33. I got a clear recommendation about what treatment approach would be best for me. a
- 34. I understood why my doctor recommended a certain treatment approach. a
- 35. I was involved in making decisions as much as I wanted. a
- 36. I felt comfortable telling my doctor my thoughts and feelings about my treatment choices. a
- 37. I was encouraged to ask questions about my treatment choices. a
- 38. I was encouraged to give my opinion about what treatment choices I would prefer. a
- 39. I felt my doctor understood what was important to me, and considered that in recommending a treatment. a
- 40. I understood why we made the decisions we did. a
- 41. I got the treatment that was best for me. a
- 42. I was told clearly whether the treatment(s) we chose would be likely to cure my cancer. a
- 43. Overall, how would you rate your experiences with communication as you decided about your treatment? b

Surgery Item Set

- 44. I was given enough information, at the right time, on how to avoid or deal with any possible complications of my surgery. a
- 45. I was given enough information, at the right time, on what to expect from my surgery. a
- 46. I was given enough information, at the right time, on how to take care of myself after surgery. a
- 47 I knew who to contact if I had a question or concern. a
- 48. I got consistent information from all my doctors and nurses. a
- 49. My surgery team helped me cope with difficult feelings, like fear, anxiety, and feeling down. a
- 50. I felt optimism and hope from my doctors and nurses. a
- 51. The doctors and nurses listened to what I had to say about how I was recovering from the surgery. a
- 52. My doctors respected my wishes about trying additional treatments. a
- 53. Overall, how would you rate your experiences with communication related to your surgery? b

Chemotherapy Item Set

- 54. I was given enough information, at the right time, on how to avoid or deal with the side effects of chemotherapy. a
- 55. I was given enough information, at the right time, on what to expect during chemotherapy. a
- 56. I was given enough information, at the right time, on how to take care of myself during chemotherapy. a
- 57. I felt that the doctors and nurses worked together as a team in taking care of me. a
- 58. I knew who to contact if I had a question or concern.a
- 59. I got consistent information from all my doctors and nurses. a
- 60. My cancer care team helped me cope with difficult feelings, like fear, anxiety, and feeling down. a
- 61. I felt optimism and hope from my doctors and nurses. a
- 62. The doctors and nurses listened to what I had to say about how the chemotherapy was affecting me. a
- 63. My doctors respected my wishes about trying additional treatments. a
- 64. Overall, how would you rate your experiences with communication during the period you were receiving chemotherapy? b

Radiation Item Set

- 65. I was given enough information, at the right time, on how to avoid or deal with side effects of radiation. a
- 66. I was given enough information, at the right time, on what to expect during my radiation treatment. a
- 67. I was given enough information, at the right time, on how to take care of myself during radiation. a
- 68. I felt that the doctors and nurses worked together as a team in taking care of me. a
- 69. I knew who to contact if I had a question or concern. a
- 70. I got consistent information from all my doctors and nurses. a
- 71. My cancer care team helped me cope with difficult feelings, like fear, anxiety, and feeling down. a
- 72. I felt optimism and hope from my doctors and nurses. a
- 73. The doctors and nurses listened to what I had to say about how the radiation treatments were affecting me. a
- 74. My doctors respected my wishes about trying additional treatments. a
- 75. Overall, how would you rate your experiences with communication during the period when you were receiving radiation treatment? b

Once Treatment was Completed Item Set

- 76. I had help with difficult feelings, like fear, anxiety, and feeling down. a
- 77. I was given enough information on possible long-term side effects of my cancer treatment(s). a
- 78. I felt that my doctors and nurses listened to my concerns about whether my cancer treatment(s) worked. a
- 79. I knew where to go for my different health care needs.a
- 80. I knew what sort of follow up care I should have, and when to get it. a
- 81. Overall, how would you rate your experiences with communication after you completed treatment? b

Response options: aNever, Sometimes, Usually, Always, Does not apply; bExcellent, Very Good, Good, Fair, Poor; Strongly Disagree, Disagree, Agree, Strongly Agree, Does not apply