

ATTACHMENT I – Rapid Feedback Patient Survey

The following survey is intended to obtain feedback from patients immediately following an informed consent discussion to provide evaluative or quality improvement information to hospitals to assess and improve their informed consent processes using strategies described in the AHRQ Informed Consent Training Modules.

Instructions on How to Administer the Survey

Aim: This survey can be used in a quality improvement or evaluation effort after improvements to the informed consent process are implemented to measure informed consent explanations and associated patient understanding. This survey can also be used to identify weaknesses in the informed consent to a test, procedure or treatment discussion, specifically if key components of informed consent are explained to patients and whether they understood the explanations.

Content: This survey can be given to patients or their family members who are asked to provide consent to procedures or treatments. This survey asks patients or surrogate decision makers to determine whether key components of a comprehensive informed consent discussion were explained and whether the explanations were easy for patients to understand. It also asks about unanswered questions, overall satisfaction with the consent discussion and the consent form.

IRB: If appropriate per hospital policy, the hospital IRB should approve use of this survey before administering it to patients.

Patients to exclude: Patients and surrogate decision makers should be excluded if completing the survey might present undue burden at a very stressful time in their hospital stay or if they decline to complete the survey, or for other reasons deemed appropriate.

Sampling: For pilot testing, we ask that you administer this survey to 50 patients before the hospital trains health care professionals and implements changes to informed consent practices. Then administer the survey to 50 patients after changes are implemented. We recommend using a systematic sampling approach to select patients (e.g., every patient in the unit that meets the selection criteria until you obtain at least 50 completed surveys or every other patient until you attain the 50 surveys).

Timing of administration: The baseline survey should be administered to patients before an intervention to improve informed consent discussions (e.g., training) is implemented in a hospital unit. The follow-up survey should be administered to patients after the improvements to the informed consent discussion have been systematically and consistently implemented across the unit. The survey should be given to patients immediately following an informed consent discussion whether or not consent was given.

Interpreters and readers: The survey is available in English and Spanish. Interpreters should be available to sight translate the survey into other languages spoken by patients and surrogate decision makers who do not speak English very well. Administrators should offer to read the survey to patients.

Patient Survey

We are asking you to answer the following questions based on the talk you just had with the doctor or nurse about having a test, treatment, or operation. Your answers will help the hospital understand what information patients get before giving consent for tests, treatments, or operations. That will let the hospital make improvements.

This survey does not collect any personal information about you. You do not have to complete this survey. Your medical care will not change in any way if you do not take this survey. If you decide to take this survey, you can stop answering the questions at any time.

Who Spoke with You

1. **Who was the main person who spoke with you about having a test, treatment, or operation?**

- ¹ My personal doctor
- ² A doctor from the hospital
- ³ A nurse from the hospital
- ⁴ I don't know
- ⁵ No one spoke to me about a test, treatment, or operation
- ⁶ Other: _____

2. **An interpreter is someone who helps you talk with others who do not speak your language. Did you use an interpreter to speak with that person?**

- ¹ No, I speak English very well
- ² No, we spoke in English although I do not speak English very well
- ³ No, that person spoke my language very well (for example, we both speak Spanish very well)
- ⁴ No, that person spoke my language a little
- ⁵ Yes, we spoke with the help of an interpreter provided by the hospital
- ⁶ Yes, we spoke with the help of my friend or family member

Explanations about the Main Test, Treatment or Operation

Think about the **main** test, treatment, or operation you talked about.

3. **Did the main person who spoke to you explain what would likely happen if you had the test, treatment or operation?**

- ¹ Yes
- ² No → If no, go to Question 6

Public reporting burden for this collection of information is estimated to average 20 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-XXXX) AHRQ, 540 Gaither Road, Room # 5036, Rockville, MD 20850.

4. Was the explanation about what would likely happen if you had the test, treatment, or operation easy to understand?
- ¹ Yes, definitely
 - ² Yes, somewhat
 - ³ No
5. Did that person ask you to describe your understanding of what would likely happen if you had the test, treatment, or operation?
- ¹ Yes
 - ² No
6. Did that person explain what might go wrong and how likely it was that something would go wrong?
- ¹ Yes
 - ² No → If no, go to Question 8
7. Was the explanation about what might go wrong and how likely it was easy to understand?
- ¹ Yes, definitely
 - ² Yes, somewhat
 - ³ No

Other Possible Tests, Treatments, or Operations

8. Did the main person who spoke to you describe your other options, such as having a different test, treatment, or operation or having *no* test, treatment, or operation?
- ¹ Yes
 - ² No → If no, go to Question 10
9. Was the description of your other options easy to understand?
- ¹ Yes, definitely
 - ² Yes, somewhat
 - ³ No
10. A decision aid provides information and helps you think about your options for tests, treatments, or operations. A decision aid can be on paper or be a video, audio tape, or computer program. Did anyone show you a decision aid or give you a decision aid to use?
- ¹ Yes
 - ² No → If no, go to Question 12
11. Did you find the decision aid helpful in deciding whether to have a test, treatment, or operation?
- ¹ Yes
 - ² No
 - ³ I didn't use it

About the Discussion

12. **Did the main person who spoke to you listen carefully to you?**
¹ Yes
² No
13. **Did that person spend enough time with you?**
¹ Yes
² No
14. **Did that person ask you what matters most to you in choosing what to do?**
¹ Yes
² No
15. **Did that person encourage you to ask questions?**
¹ Yes
² No
16. **After the discussion, did you have any questions that were not answered?**
¹ Yes
² No → If no, go to Question 18
17. **Why were your questions not answered?**
¹ I asked, but I didn't get an answer
² I asked, but the response didn't answer my questions
³ I asked, but the response was hard to understand
⁴ There wasn't enough time to ask questions
⁵ I didn't feel that I could ask questions
⁶ Other: _____
18. **Did you feel like you had enough information about all the options to make a decision?**
¹ Yes
² No
19. **Did you feel free to choose any of the options, including the choice of *not* having any test, treatment, or operation?**
¹ Yes
² No
20. **Overall, how satisfied are you with the experience you had discussing the options for tests, treatments, or operations and making a decision?**
¹ Very unsatisfied
² Somewhat unsatisfied
³ Somewhat satisfied
⁴ Very satisfied

The Consent Form

21. Was the consent form you were asked to sign for the test, treatment, or operation in a language you read very well?

- ¹ Yes, it was in English and I read English very well
- ² Yes, it was in my language (not English) and I read my language very well
- ³ No, it was in English and I do not read English very well
- ⁴ No, it was in my language (not English) and I do not read my language very well
- ⁵ I did not look at the form → Go to Question 24
- ⁶ I was not asked to sign a form → Go to Question 24

22. Did anyone help you read the form?

- 23. ¹ Yes, someone from the hospital read it to me in English
- 24. ² Yes, someone from the hospital read it to me in my language (not English)
- 25. ³ Yes, a friend or family member read it to me in English
- 26. ³ Yes, a friend or family member read it to me in my language (not English)
- ⁴ No, I read it myself
- 27. ⁵ No, no one helped me read the form and I did not read it → Go to Question 24

28. How easy was the form to understand?

- ¹ Very hard to understand
- ² Somewhat hard to understand
- ³ Somewhat easy to understand
- ⁴ Very easy to understand

Person who Completed Survey

29. Please select the option that best describes the person who answered these questions.

- ¹ I am the patient
- ² I am the parent, legal guardian, or health care proxy of the patient
- ³ I am a family member or friend of the patient
- ⁴ Other