

## Treating Prostate Cancer Decision Quality Instrument User Guide

### I. Purpose:

To measure the extent to which patients are informed, involved in the decision making process and receive treatments that match their goals and preferences.

### II. Versions:

Prostate Cancer Treatment Decision Quality Instrument v1.0, ©2010, updated 2013  
Decision Quality Worksheet: For Treating Prostate Cancer v1.0, ©2010, last reviewed 2013

### III. Timing

The decision quality instrument version is designed to be administered after a decision has been made. Modifications are required (e.g. to instructions and tenses of items) if it is to be used before a decision has been made.

The shorter worksheet version is worded to be used during the decision making process. The knowledge items and goals can be administered at any time, e.g. before or after a visit, before or after a decision aid. The decision process items need to be administered after a provider consult.

### IV. Scoring:

The survey contains three sets of items and results in three scores, a total knowledge score, a concordance score and a decision process score.

**1. Knowledge Score:** The items are located in “Section 1: Facts About Treatment For Prostate Cancer.” For each fact, a correct response receives one point (see Table 1). Missing responses receive 0 points. A total score is calculated for all patients who complete at least half of the items. Total scores are scaled from 0-100%.

**Table 1: Facts** (# indicates items in the brief version)

Question	Correct response
#1. <u>With</u> treatment, about how many men diagnosed with early stage prostate cancer will eventually die of prostate cancer?	Most will die of something else
2. <u>Without</u> treatment, about how many men diagnosed with early stage prostate cancer will eventually die of prostate cancer?	Most will die of something else
#3. For most men with early stage prostate cancer, how much would <u>waiting a few months</u> to make a treatment decision hurt their chances of survival?	A little or not at all
4. For most men, what is the <u>best plan</u> for managing early stage prostate cancer?	Any of the above (surgery, radiation, no immediate treatment of the cancer, with

Question	Correct response
	watchful waiting or active surveillance), based on what the man wants
5. Has <b>prostate surgery</b> been shown to help men with early stage prostate cancer live longer than they would have if they had no treatment?	Yes, possibly for men with higher risk cancers
6. Has <b>radiation therapy</b> been shown to help men with early stage prostate cancer live longer than they would have if they had no treatment?	No
#7. In the first few years after treatment for prostate cancer, which is <b>more</b> likely to cause bowel problems?	Radiation
8. Which treatment(s) for prostate cancer <b>can cause sexual problems</b> , such as problems with erections?	Both surgery and radiation cause sexual problems
#9. In the first few years after treatment for prostate cancer, which is <b>more</b> likely to cause sexual problems with erections?	Surgery
#10. In the first few years after treatment for prostate cancer, which is more likely to cause <b>dripping or leaking urine</b> ?	Surgery
11. Which treatment takes the <b>longest to complete</b> ?	Radiation delivered by a beam outside the body

**2. Concordance score:** In "Section 1: What Matters Most To You," patients rate their goals and concerns on an 11-point importance scale from 0 (not important at all) to 10 (extremely important). These questions and one question about patient's treatment preference can be used to calculate a concordance score. There are multiple approaches to calculate a concordance score, we describe two below. Note for those who use the worksheet version, there must be some way to track the treatment that patients received to complete this calculation.

The first is a simple match, and in this direct approach, we use patients' preferred treatment (assessed with a single item, "Which treatment do you want to do to treat your prostate cancer?") and then compare with treatment received to determine whether they match. Patients who are unsure are not considered to have treatment that matches. A summary score (0-100%) indicating the percentage of patients who received treatment that matched their stated preference can be generated.

The second approach uses patients' ratings of the importance of salient goals and concerns on a 0 to 10 scale in a multiple logistic regression model to generate a predicted probability of treatment. The dependent variable is often collapsed to: Treatment versus No Treatment (e.g. Active Surveillance) or Radiation versus Surgery and the independent variables are the

individual goals. Patients with a predicted probability  $>0.5$  and who had treatment for prostate cancer or those with a predicted probability  $\leq 0.5$  and who did not have treatment for prostate cancer, were classified as having treatments matching their goals. A summary score (0-100%) can be generated to reflect the percentage of patients in the sample who received treatments that matched their goals.

**3. Decision Process Score:** These questions are located in the Decision Quality Instrument in "Section 3: Talking with your Health Care Providers" and in the Decision Quality Worksheet in "Section 3: Making Choices." Patients are asked about whether they were offered a choice, how much the pros and cons were discussed, and whether the health care provider asked for their preferences. Participants receive 1 point for a response of "yes" or "a lot/some." The total points are summed and then divided by the total number of items to result in scores from 0-100%, with higher scores indicated a more shared decision making process.

#### **V. Development Process:**

This has been described in detail in Sepucha et al (2008), briefly to generate the survey we:

- Conducted a review of the clinical evidence & of focus groups and interviews with patients to generate a candidate set of facts and goals salient to the decision
- Surveyed a convenience sample of male patients (n=17) and a multidisciplinary group of clinical experts (n=18) to rate the facts and goals for importance, completeness, and accuracy.
- Drafted the instrument and conducted cognitive interviews with male patients who were recent survivors (within 3 years) of prostate cancer (n=6) to evaluate items for acceptability and comprehension

#### **VI. Psychometric Properties:**

To date there have been no formal studies that have used this instrument to evaluate the psychometric properties. Other instruments that have followed the same development process have been shown to be acceptable and feasible, with good reliability and validity.

#### **VII. Appropriate Use**

The DQIs are protected by copyright. They are available to use at no cost, provided that you:

- Cite the reference in any questionnaires or publications
- Do not charge for or profit from them
- Do not alter them except for customization for a specific condition and reformatting

#### **Suggested Citations for the DQIs:**

Sepucha KR. Prostate Cancer Decision Quality Instrument v.1.0. ©Massachusetts General Hospital, 2010, updated 2013.

Sepucha KR. Decision Quality Worksheet: For Treating Prostate Cancer v.1.0. ©Massachusetts General Hospital, 2010, last reviewed 2013. Downloaded from:

[http://www.massgeneral.org/decisionsciences/research/DQ\\_Instrument\\_List.aspx](http://www.massgeneral.org/decisionsciences/research/DQ_Instrument_List.aspx).

### **Suggested Citation of the User Guide:**

Sepucha KR and Feibelman S. Treating Prostate Cancer Decision Quality Instrument User Guide. © 2013. Available from: <http://www.massgeneral.org/decisionsciences/research/>

### **VIII. Selected References**

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Sepucha K, Stacey D, Clay C, Chang Y, Cosenza C, Dervin G, Dorrwachter J, Feibelman S, Katz JN, Kearing S, Malchau H, Taljaard M, Tomek I, Tugwell P, Levin C. Decision quality instrument for treatment of hip and knee osteoarthritis: a psychometric evaluation. *BMC Musculoskeletal Disord.* 2011; 12(1):149.

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**IX. Questions or comments?** Please contact us at [decisions@partners.org](mailto:decisions@partners.org) or visit our website at <http://www.massgeneral.org/decisionsciences/research/>.