

Benign Prostatic Hyperplasia 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:

Benign Prostatic Hyperplasia Decision Quality Instrument v1.0, ©2010

Decision Quality Worksheet: Treatments for Benign Prostatic Hyperplasia v1.0, ©2010

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 2: Facts About Benign Prostatic Hyperplasia (BPH). "For each fact, a correct response receives one point (see Table 1). Questions with multiple parts (e.g. items 2, 7 and 12 in Table 1) are scaled to total 1 point per item. 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, BPH=benign prostatic hyperplasia)

Question	Correct response
1. What is the common name for BPH?	Enlarged prostate
2a. Is a bladder that feels like it does not empty a symptom of BPH?	Yes
2b. Is frequent urination a symptom of BPH?	Yes
2c. Are problems with erections a symptom of BPH?	No
2d. Is stopping and starting when urinating a symptom of BPH?	Yes
2e. Is having to push or strain when urinating a symptom of BPH?	Yes
#3. What happens if BPH is <u>left untreated</u> ?	Most men stay about the same or get slowly worse over time
# 4. In general, <u>when</u> is treatment for BPH needed?	When symptoms are

Question	Correct response
	bothersome
# 5. For most men, which treatment has been shown to be most effective for treating BPH symptoms?	Surgery
# 6. For most men, which treatment is least effective for treating BPH symptoms?	Medicine
7a. Is acute retention of urine a possible risk of no active treatment?	Yes
7b. Are kidney stones a possible risk of no active treatment?	No
7c. Is prostate cancer a possible risk of no active treatment?	No
7d. Is a bladder infection a possible risk of no active treatment?	Yes
8. For most men, what is the best plan for managing BPH?	Any of the above, based on what the man wants
# 9. Which is the single most common side effect of surgery for BPH?	Problems with ejaculation of semen
10. Lifestyle changes can include things such as change to diet and drinking fewer beverages after dinner. Can making lifestyle changes help with BPH symptoms?	Yes, lifestyle changes can help with symptoms
11a. Is dizziness a common side effect of alpha-blocker medicine for BPH?	Yes
11b. Are sexual problems a common side effect of alpha-blocker medicine for BPH?	Yes
11c. Is tiredness a common side effect of alpha-blocker medicine for BPH?	Yes
11d. Is joint pain a common side effect of alpha-blocker medicine for BPH?	No
12. How do minimally invasive procedures work?	By heating the prostate

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 benign prostatic hyperplasia?”) 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 binary and often collapsed to: Surgery versus Non Surgical options and the independent variables are the individual goals. Patients with a predicted probability >0.5 and who had surgery for BPH or those with a predicted probability ≤ 0.5 and who did not have surgery, 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 patients (n=21) 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 patients diagnosed with BPH (n=5) 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. Benign Prostatic Hyperplasia Decision Quality Instrument v.1.0. ©Massachusetts General Hospital, 2010.

Sepucha KR. Decision Quality Worksheet: Treatments for Benign Prostatic Hyperplasia. v.1.0. ©Massachusetts General Hospital, 2010. Downloaded from: http://www.massgeneral.org/decisionsciences/research/DQ_Instrument_List.aspx.

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VIII. Selected References

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