

# PATIENT SUMMARY

**European Association of Urology**

Mr. E.N. van Kleffensstraat 5

6842 CV Arnhem

The Netherlands

## **Patient-Centered Approach to Develop the Patient's Preferences for Prostate Cancer Care (PreProCare) Tool**

Ravishankar Jayadevappa, Sumedha Chhatre, Joseph J. Gallo, S. Bruce Malkowicz, J. Sanford Schwartz, and Marsha N. Wittink

MDM Policy Pract. 2019 Jun 21;4(1): doi: 10.1177/2381468319855375. eCollection Jan-Jun 2019.

Patient summary by Louisa Fleure,  
PCa Specialist Nurse, Urology Centre  
Guy's Hospital, London (UK)  
EAU PI Working Group Member



### **Introduction**

Prostate cancer affects millions of men across the globe and deciding what treatment to have can be complicated. Men with early stage prostate cancer face challenging decisions, with a variety of treatments to choose from, each of which carries the potential of significant side effects.

It is important that patients engage in informed decision making to choose the best treatment for themselves. Informed decision making involves understanding all the options available and the positive and negative implications of each choice.

Patient (or person) centered care is about focusing care on the needs of individual, taking into account their circumstances and unique characteristics as well as their own beliefs, values and preferences. In patient-centred prostate cancer care, understanding what preferences a man has, and how that aligns with potential treatments and side effects may help improve outcomes of care. Outcomes include satisfaction with the treatment, quality of life after treatment and psychological wellbeing. Clinicians therefore need to be able to work with their patients in order to understand what is important to them.

This article by a team of American doctors describes the development of a tool to help men with localised prostate cancer to assess what matters to themselves in terms of treatments and potential side effects, so that they can work with their medical teams to make good decisions about their care.

### **What did they do?**

The team developed a tool (called the PreProCare tool) which used *adaptive conjoint analysis*. This is a technique that attempts to understand how people make complex choices. Many choices made in everyday life are trade-offs. This method ranks the relative importance of certain characteristics of a treatment or side effect through a series of questions and then calculates the value that the individual attaches to each. In order to do this, the researchers needed to understand what

attributes of a treatment were important to ask about in their tool. Attributes are factors that may influence the choice of treatment such as side effects, survival or the chance of recurrence, emotional effects, cost etc.

### **How was the tool developed?**

The researchers used a variety of methods to understand what attributes were important

- **Gathering and analysing published research.** This identified that survival, cancer recurrence, side effects, and complications were important treatment attributes
- **Interviews with 50 patients.** These men reported that anxiety, depression, treatment methods and side effects, and the effect on loved ones were important considerations for decision making.
- **5 Focus groups with health care professionals.** These groups identified clinical characteristics as important attributes (such as PSA level, stage, other health issues) as well as some of the attributes identified by research and patients.

With additional input from an advisory group and researchers, the PreProCare preference assessment tool was designed with 15 attributes (below). The tool asks how important a particular attribute was and then based on these responses, personalised scenarios are given which describe two hypothetical treatments. The respondents are asked to state their preference between the hypothetical options. The tool can then calculate how important the attributes are to the individual patient.

The attributes were:

1. Survival
2. Cancer recurrence or progression
3. Change in urinary function or bother
4. Change in sexual function or bother
5. Change in bowel function or bother
6. Psychological distress
7. Side effects (e.g. fatigue, loss of energy/weakness, hot flashes, weight changes)
8. How long the treatment took
9. The need for cutting (does the treatment involve cutting or surgery?)
10. The need for radiation (Does the treatment involve radiation or seed implants?)
11. Recovery time
12. Cancer control (Some treatments aim for complete “cancer control,” some may be for monitoring cancer)
13. Out of pocket expenses
14. Care giver burden
15. Social interaction

The resulting computer-based PreProCare tool was then pilot tested with patients.

## **Testing the tool**

The PreProCare tool was piloted with 52 men newly diagnosed with prostate cancer. They assessed the time needed to complete the PreProCare tool and participants were asked to rate how easy it was to complete, and the tool's usefulness in clarifying values.

On average, it took 30 minutes to complete the tool. 49 (94%) of the men said that the definitions were easy to understand, 45 (86%) felt that the tool was helpful in deciding treatment, and 46 (88%) said they would discuss the results with their physicians.

## **Why is this important?**

The tool was developed using a patient-centred approach and had substantial input from prostate cancer patients for all phases of the study. The information to design the tool was gathered from a variety of sources to ensure that the attributes used reflected real concerns for men.

Shared decision making allows patients and their health care providers to make decisions together, taking into account the best scientific evidence available and the patients' values and preferences. The goal of PreProCare, is to help newly diagnosed localised prostate cancer patients understand their preferences, and thereby facilitate informed treatment decision making. The pilot test results suggest that the PreProCare preference assessment tool is helpful and easy to use. Any initiative to support men to make the best possible decision for their treatment is important, in order to ensure satisfaction, quality of life after treatment and psychological wellbeing.

Read the full article [here](#)