



**University of  
Zurich**<sup>UZH</sup>

**Zurich Open Repository and  
Archive**

University of Zurich  
University Library  
Strickhofstrasse 39  
CH-8057 Zurich  
[www.zora.uzh.ch](http://www.zora.uzh.ch)

---

Year: 2024

---

## **Online decision aid for patients with prostate cancer evaluated by 11 290 patients and 91 urologists in Germany**

Huber, Johannes ; Karschuck, Philipp ; Valdix, Johanna ; Thomas, Christian ; Koch, Rainer ; Ihrig, Andreas ;  
Hölscher, Tobias ; Krones, Tanja ; Kessler, Elke ; Kliesch, Sabine ; Linné, Clemens ; Enders, Paul ; Michel,  
Maurice-Stephan ; Wülfing, Christian ; Groeben, Christer

DOI: <https://doi.org/10.1111/bju.16329>

Posted at the Zurich Open Repository and Archive, University of Zurich

ZORA URL: <https://doi.org/10.5167/uzh-268634>

Journal Article

Published Version



The following work is licensed under a Creative Commons: Attribution-NonCommercial 4.0 International (CC BY-NC 4.0) License.

Originally published at:

Huber, Johannes; Karschuck, Philipp; Valdix, Johanna; Thomas, Christian; Koch, Rainer; Ihrig, Andreas; Hölscher, Tobias; Krones, Tanja; Kessler, Elke; Kliesch, Sabine; Linné, Clemens; Enders, Paul; Michel, Maurice-Stephan; Wülfing, Christian; Groeben, Christer (2024). Online decision aid for patients with prostate cancer evaluated by 11 290 patients and 91 urologists in Germany. *BJU International*, 134(2):239-248.

DOI: <https://doi.org/10.1111/bju.16329>

## Original Article

# Online decision aid for patients with prostate cancer evaluated by 11 290 patients and 91 urologists in Germany

Johannes Huber<sup>1</sup>, Philipp Karschuck<sup>1</sup>, Johanna Valdivia<sup>2</sup>, Christian Thomas<sup>2</sup>, Rainer Koch<sup>1</sup>, Andreas Ihrig<sup>5</sup>, Tobias Hölscher<sup>3</sup>, Tanja Krones<sup>11</sup>, Elke Kessler<sup>6</sup>, Sabine Kliesch<sup>7</sup>, Clemens Linné<sup>4</sup>, Paul Enders<sup>8</sup>, Maurice-Stephan Michel<sup>9</sup>, Christian Wülfing<sup>10</sup> and Christer Groeben<sup>1</sup>

<sup>1</sup>Department of Urology, Philipps University of Marburg, Marburg, <sup>2</sup>Department of Urology, Medical Faculty Carl Gustav Carus, TU Dresden, <sup>3</sup>Department of Radiotherapy and Radiation Oncology, Faculty of Medicine and University Hospital Carl Gustav Carus, TU Dresden, <sup>4</sup>Urological Practice, Dresden, <sup>5</sup>Division of Psycho-Oncology, Department of General Internal Medicine and Psychosomatic, University Hospital Heidelberg, Heidelberg, <sup>6</sup>ASD Concepts GmbH & Co. KG – Institut für Patientenzentrierte Versorgungsformen, Reinheim, <sup>7</sup>Department of Clinical and Surgical Andrology, Centre for Reproductive Medicine and Andrology, University Hospital Münster, Münster, <sup>8</sup>Prostate Cancer Patient Support Organization of Germany (BPS), Bonn, <sup>9</sup>Department of Urology and Urosurgery, University Hospital Mannheim, Mannheim, <sup>10</sup>Department of Urology, Asklepios Klinik Altona, Hamburg, Germany, and <sup>11</sup>Institute of Biomedical Ethics and History of Medicine University of Zürich, University Hospital Zürich, Zürich, Switzerland

## Objective

To evaluate the nationwide online decision aid ‘Entscheidungshilfe Prostatakrebs’ (established in 2016, >11.000 users and 60 new users/week) for patients with non-metastatic prostate cancer (PCa), from the perspective of patients and urologists.

## Patients and Methods

To provide personalised information, the tool collects most of the International Consortium for Health Outcomes Measurement standard set, personal preferences, psychological features, and a validated rating of the tool. To evaluate urologists’ opinions, we developed a structured two-page questionnaire. All data were collected anonymously.

## Results

From June 2016 to December 2020, 11 290 patients used the PCa decision aid. Their median (interquartile range [IQR]) age was 67 (61–72) years. The median (IQR) time from initial diagnosis to using the tool was 4 (3–7) weeks. In all, 87.7% of users reported high satisfaction. In a multivariable model, predictors for considering observation were higher knowledge, using the decision aid alone, lower oncological risk, normal erectile function, and respective personal preferences. Of 194 urologists, 91 (47%) had implemented the decision aid in their clinical practice. The urologists’ mean (SD) satisfaction score (1 ‘very good’; 6 ‘unsatisfactory’) with it was 1.45 (0.55), and 92% recommended it. Half of the urologists reported time savings.

## Conclusion

Patients and urologists report a very high level of acceptance and satisfaction with this online tool. It offers advantages in shared decision-making and time efficiency. The usage of the decision aid might improve the adoption of active surveillance and watchful waiting when indicated.

## Keywords

decision making, decision aid, prostate cancer, health services research, shared decision-making

## Introduction

The treatment decision for localised prostate cancer (PCa) is particularly challenging [1], as very different treatment options with diverse risks and consequences have to be weighed against each other. In addition, the desire for patients to play an active

role in the decision-making process concerning their medical care is increasing [2–4]. Physicians and patients often have little interaction time to provide the patient with the necessary, validated information to make an informed decision. Multimedia decision aids can fill this gap and promote patient empowerment by providing knowledge that is in line with

guideline recommendations. As a Cochrane review showed [4], decision aids promote the active involvement of the patient by increasing their objective information and their conscious perception of their preferences. Moreover, they reduce uncertainty with the final decision.

Decision aids have been established in Anglo-Saxon countries since the beginning of this century [5]. Our project ‘Entscheidungshilfe Prostatakrebs’ (‘decision aid PCa’) is the first personalised patient decision aid for the treatment of non-metastatic PCa in Germany [6]. It provides guideline-based information [7] on their disease and treatment options within more than 1 h of educational videos. From the patient’s input, details of the presented information are personalised. The patient evaluates the pros and cons of the different treatments. All relevant results are summarised in one printable page that can serve as a basis for physician consultation. The online decision aid has been available online free of charge since June 2016 [8]. Up to September 2023, >20 000 patients had used the service, with ~60 new users/week throughout the last year.

The aim of this study was to evaluate this online decision aid for patients with non-metastatic PCa from the patients’ and urologists’ perspectives.

## Patients and Methods

The decision aid offers guideline-based content [7] in 17 educational videos with an attending physician played by an actor (Fig. 1). To provide personalised information, the tool collects health-related data. The decision aid is recommended, and the access provided to the patient at the first consultation upon diagnosis. Eight essential clinical parameters are collected: month of initial diagnosis, initial PSA value, clinical TNM stage, Gleason score, positive proportion of prostate biopsy cores, and maximum tumour involvement of positive cores. Therefore, the patient receives an access-card on which his urologist first enters the above named parameters. This ensures that the patient uses the correct parameters to personalise the decision aid. Other important inputs for the personalisation of the decision aid, such as erectile function or comorbidity, are obtained from the patient using the five-item version of the International Index of Erectile Function (IIEF-5) questionnaire or the Lee Comorbidity Index. The patient uses the decision aid at home on his computer, possibly with a partner or relatives. Finally, all relevant data are summarised for the patient in a single printed page, which the patient brings to the final therapy decision-consultation with his urologist. A video showcase of the decision aid is available as Video S1.

We defined active surveillance (AS) or watchful waiting (WW) as ‘observation’ as opposed to active therapy strategies (surgery, radiation, brachytherapy, or focal therapies).

## Development of the On-Line Decision Aid and Version History

In 2015, we started the development of the online decision aid ‘Entscheidungshilfe Prostatakrebs’ as an initiative of German urological professional societies (PatientenAkademie der Deutschen Urologen) in cooperation with the PCa Patient Support Organisation of Germany (BPS). The company ASD Concepts GmbH & Co. KG – Institut für Patientenzentrierte Versorgungsformen (Reinheim, Germany) produced the online tool, which was available online from 1 June 2016. Designed as an online information tool, the decision aid received timely content updates with every new version of the German S3 guidelines on PCa. In 2021, we completely reworked the decision aid with additional functionality as a registered medical device. Therefore, we chose the data cut-off for this study of 17 December 2020. Over the course of the project, Takeda Pharma Vertrieb GmbH & Co KG (since 2015), Janssen-Cilag GmbH (since 2020) and Apogepha Arzneimittel (since 2022) provided financial support. In 2021, the German Society of Urology (DGU; [www.urologenportal.de](http://www.urologenportal.de)) founded its subsidiary ‘Urologische Stiftung Gesundheit gGmbH’ (USG; [www.urologische-stiftung-gesundheit.de](http://www.urologische-stiftung-gesundheit.de)). Thereafter, the DGU assigned further project development to the USG. Current information on the project is provided at [www.entscheidungshilfe-prostatakrebs.info](http://www.entscheidungshilfe-prostatakrebs.info). Via this homepage, German urologists can order access cards for their patients free of charge.

## Questionnaires Included in the Decision Aid

The decision aid was evaluated using three basic parameters: Satisfaction, knowledge, and consideration of observation. The decision aid includes most of the International Consortium for Health Outcomes Measurement standard set [9], as well as the following survey instruments: the Lee Index [3,12] for comorbidity information and estimating life expectancy, the IIEF-5 score [10] for erectile function, the IPSS [2] for obstructive voiding symptoms, the Control Preferences Scale [11–13] for the degree of control an individual wants to assume in medical treatment decision-making, the Distress Thermometer [14] for psychological distress, and the four-item Patient Health Questionnaire (PHQ-4) [15] for anxiety and depression. Personal preferences and objective disease-related knowledge were assessed according to the ‘Decision Quality Worksheet: For Treating Prostate Cancer’ [16]. Patients were asked whether they considered one or more of the presented treatment options. Thus, the total percentages add up to >100%. To evaluate the tool, we applied the Acceptability E-scale and defined high satisfaction by  $\geq 80\%$  of the maximum sum score [17]. Finally, we collected basic sociodemographic data (Table 1).

Fig. 1 Outline of the decision aid structure.

## Der Weg Ihres Patienten durch die Entscheidungshilfe Your patient's journey through the decision aid



### Fragenabschnitt 1: Klinische Angaben / Question Section 1: Clinical Data



### Fragenabschnitt 2: Persönliche Präferenzen / Question Section 2: Preferences



### Fragenabschnitt 3: Evaluation / Question Section 3: Evaluation

Zusammenfassung für den Patienten  
Summary for the patient

Zusammenfassung für die Ärztin/den Arzt  
Summary for the physician

The decision aid's content is personalised according to erectile function (good vs limited; IIEF-5 cut-off score <17 points) [10], median life expectancy ( $\geq 10$  vs <10 years) as calculated by the Lee Index [3,12], and D'Amico oncological risk group (low vs early intermediate vs intermediate vs high). The 'early intermediate' subgroup is

separated from the intermediate-risk patients by the Gleason score of  $\leq 7a$  (3 + 4). We defined the subgroup of patients suitable for AS as those from the low- and early-intermediate-risk groups who had two or fewer positive biopsy cores and  $\leq 50\%$  maximum tumour involvement of positive cores [7].

**Table 1** Patients' sociodemographic data.

Variable	N (%)
<b>Age, years (n = 11 259)</b>	
≤50	212 (1.9)
51–60	2344 (20.8)
61–70	5214 (46.3)
71–80	3307 (29.4)
>80	182 (1.6)
<b>Marital status (n = 8508)</b>	
Firm partnership	7643 (89.8)
Divorced/separated	337 (4.0)
Single	451 (5.3)
Other	77 (0.9)
<b>Children (n = 8481)</b>	
Yes	7302 (86.1)
No	1179 (13.9)
<b>German language skills (n = 8516)</b>	
Mother tongue	7818 (91.8)
Fluent	638 (7.5)
Low	60 (0.7)
<b>Education (n = 8496)</b>	
A-Levels	3064 (36.1)
Medium	2545 (30.0)
Low	2215 (26.1)
Other	672 (7.9)
<b>Place of residence (n = 8508)</b>	
<10 000 inhabitants	3041 (35.7)
>10 000 inhabitants	5467 (64.3)
<b>Health insurance (n = 8509)</b>	
Public	6310 (74.2)
Private	2103 (24.7)
Other	96 (1.1)
<b>Income, Euros (n = 8475)</b>	
<1500 €	478 (5.6)
1500–4000 €	4813 (56.8)
>4000 €	1900 (22.4)
No information	1284 (15.2)

## Questionnaire for Evaluating the Urologists' View

To evaluate the urologists' opinions and experiences, we developed a two-page questionnaire by putting it through a structured test phase with several volunteers. The final questionnaire, after collecting basic sociodemographic data, asked whether the urologist was currently working with the decision aid. It asked users about the duration and frequency of their use of the tool, the urologist's and patient's satisfaction with it, their perceived effects, the time requirements and whether they recommend it to their colleagues. Participants who were not currently using the service were asked to provide their reasons for not using the tool. Finally, by using a previously established item, the questionnaire asked both groups for the supporting material they routinely used for counselling patients newly diagnosed with non-metastatic PCa [18]. Closed questions consisted of multiple-choice questions, ratings used German school grades (from 1 'very good' to 6 'insufficient'), and the needed time for counselling was judged in comparison to routine care on a 5-point Likert scale ('lower', 'slightly lower', 'equal', 'slightly

higher', 'higher'). Finally, a free-text question provided room for further comments. Appendix S1 provides an English translation of the urologist questionnaire.

## Study Course

We assessed the patients' view by prospectively collecting anonymous user data from 1 June 2016 to 17 December 2020. The month of the initial diagnosis was the only mandatory patient information and there were missing values throughout the dataset. To evaluate the urologists' perspective, data collection took place from May to September 2017. We sent questionnaires by mail to 175 urologists within a radius of 150 km around Dresden. Only for this subgroup do we know the response rate, 25% (44/175). Additionally, we distributed the questionnaire during urological meetings. For this share we could not calculate the exact response rate.

## Ethics Statement

This study was conducted in accordance with the Declaration of Helsinki in its latest version. All data were collected anonymously. Hence, there was no need for ethics committee approval.

## Analyses

Descriptive statistics include median, interquartile range (IQR), and range. Percentages refer to the entire sample. In the case of subgroups or deviating total case numbers, we also report relative frequencies. For group comparisons, we used the chi-square test (two-sided, significance level  $\alpha = 0.05$ ). For three key outcomes (knowledge, satisfaction, considering observation), we developed a statistically optimal logistic regression model by the stepwise method. The bootstrap cross validations of the estimated area under curve (AUC) of the receiver operating characteristic (ROC) curve based on the leave-one-out principle, i.e., dropping the data of one subject and re-estimating the parameter estimates. This analysis was performed with the Statistical Analysis System (SAS) version 9.4 (SAS Institute Inc., Cary, NC, USA). For all other calculations, we used the Statistical Package for the Social Sciences (SPSS) version 28.0 (IBM Corp., Armonk, NY, USA).

## Results

From June 2016 to December 2020, a total of 11 290 patients used the PCa decision aid. Their median (IQR, range) age was 67 (61–72, 39–90) years. The median (IQR) time from initial diagnosis to using the tool was 4 (3–7) weeks. The patients' sociodemographic data are summarised in Table 1. Clinical data are summarised in Table 2. The median (IQR) body mass index was 26.7 (24.7–29.3) kg/m<sup>2</sup>, and the median

**Table 2** Patients' clinical data.

Variable	N (%)
<b>Clinical T stage (n = 11 111)</b>	
cT1a/b	1182 (10.6)
cT1c	5495 (49.5)
cT2a	1695 (15.3)
cT2b	950 (8.6)
cT2c	1350 (12.2)
cT3	404 (3.6)
cT4	35 (0.3)
<b>Clinical N stage (n = 10 782)</b>	
cN0/x	10 663 (98.9)
cN1	119 (1.1)
<b>Clinical M stage (n = 10 723)</b>	
cM0/x	10 645 (99.3)
cM1	78 (0.7)
<b>Gleason Score (n = 11 193)</b>	
≤6	3677 (32.9)
7a	3915 (35.0)
7b	1877 (16.8)
≥8	1724 (15.4)
<b>Oncological risk group (n = 11 033)</b>	
Low	2683 (24.3)
Early intermediate	2313 (21.0)
Intermediate	2854 (25.9)
High	3183 (28.8)
<b>Suitable for AS (n = 10 458)*</b>	
Suitable	2254 (21.6)
Not suitable	8204 (78.4)
<b>Median life expectancy (n = 11 095)</b>	
≥10 years	10 769 (97.1)
<10 years	326 (2.9)
<b>Erectile function (n = 10 994)</b>	
No ED	2863 (26.0)
Mild ED	2421 (22.0)
Mild to moderate ED	1618 (14.7)
Moderate ED	986 (9.0)
Severe ED	3106 (28.3)
<b>Obstructive voiding (n = 9338)</b>	
Mildly symptomatic	4633 (49.6)
Moderately symptomatic	4047 (43.3)
Severely symptomatic	658 (7.0)
<b>Distress (n = 9478)</b>	
Normal	6208 (65.5)
Conspicuous value	3270 (34.5)
<b>Depression and anxiety (n = 9343)</b>	
Normal	8319 (89.0)
Conspicuous value	1024 (11.0)

ED, erectile dysfunction. \*Suitability for AS was defined by low or early intermediate oncological risk, two or fewer positive biopsy cores, and ≤50% maximum tumour involvement of positive cores.

(IQR) initial PSA level was 7.1 (5.3–10.3) ng/mL. The distribution of oncological risk groups was 24.3% low, 46.9% medium, and 28.8% high risk.

The median (IQR) IPSS score was 8 (4–12). Some 8.9% (840/9438) reported unwanted urine loss at least once a week, and 2.6% (244/9436) reported using at least 1 pad/day. In the past 4 weeks, 58.6% (6568/11 202) reported moderate or very strong sexual interest, and 60.7% (6792/11 193) had tried to have sexual intercourse at least once. The median (IQR) IIEF-5 score was 16 (6–22). No or

mild erectile dysfunction (IIEF-5 score ≥17) was present in 48.1% (5284/10 994) of patients.

Conspicuous findings in the psycho-oncological screening were detected in 9.2% (863/9426) for depression and in 10.4% (984/9421) for anxiety. The median (IQR) distress thermometer value was 4 (2–7), although distress was pathologically high in 34.5% (3270/9478) of the patients. Self-assessment, on the scale from 1 'very poor' to 7 'excellent', had a median (IQR) score of 6 (5–6) for health status and quality of life.

### Knowledge

Some 49.3% (5556/8322) of the patients answered at least of five knowledge questions correctly ('high knowledge'). Predictors for low knowledge (Fig. 2A) were older age, a paternalistic control preference, a low educational level, a low household income, and low satisfaction with the decision aid.

### Patients' Opinion

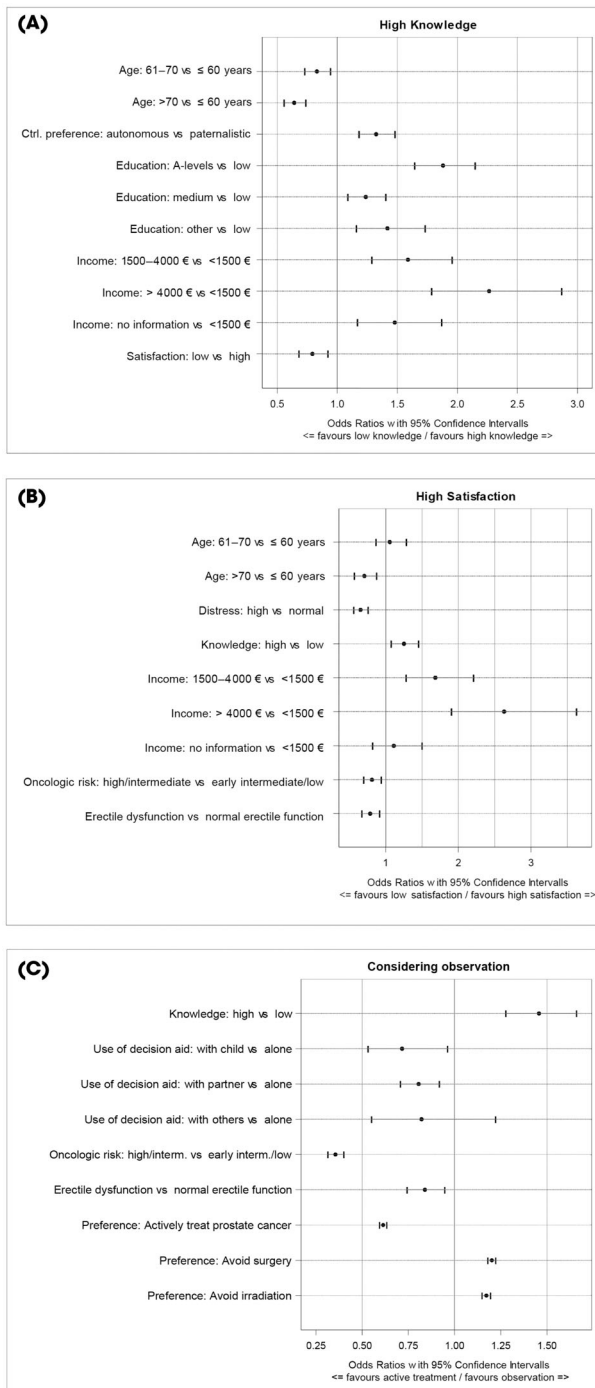
Some 59.4% (5056/8516) of patients used the tool together with their partner, 33.1% (2817/8516) alone, 5.1% (438/8516) with their children, and 2.4% (205/8516) with other relatives or friends.

The median (IQR) e-scale sum value was 28 (25–29), and 87.7% (7438/8477) reported high satisfaction (≥24 points). A logistic regression model for the analysis of predictors for high a high level of satisfaction with the decision aid (Fig. 2B) showed that the following characteristics were positively associated with high treatment satisfaction: younger age, less distress, high knowledge, higher income, lower oncological risk, and normal erectile function.

### Treatment Decision

Two-thirds of the patients (66.4%; 6291/9471) preferred collaborative decision-making, 28.9% (2732/9471) preferred an active role, and 4.7% (448/9471) preferred a passive role. Treatment options considered in principle (multiple answers possible) were radical prostatectomy in 57.5% (6494/11 290), external beam radiotherapy in 38.1% (4307/11 290), brachytherapy in 21.4% (2418/11290), cryotherapy in 4.9% (555/11 290), hyperthermia in 5.2% (591/11 290), high-intensity focused ultrasound in 11.3% (1276/11 290), others in 10.7% (1212/11 290), and observation in 30.7% (3469/11 290). The proportion of patients who considered observation (i.e., AS or WW) differed significantly between the different oncological risk groups: 79.6% of the low-, 55.8% of the early-intermediate-, 28.9% of the intermediate-, and 18.3% of the high-risk patients ( $P < 0.001$ ). Patients suitable for AS according to their clinical oncological features were considering

**Fig. 2** (A) Multivariable analysis of predictors for high PCa knowledge (the model is moderately well fitted to the data with  $P = 0.104$  in the Hosmer–Lemeshow test. The AUC of the ROC curve is 0.628 and bootstrap cross-validated AUC = 0.615,  $R^2 = 0.060$ .) (B) Multivariable analysis of predictors for high satisfaction with the decision aid (the model fits the data very well with  $P = 0.978$  in the Hosmer–Lemeshow test. The AUC of the ROC curve is 0.636 and bootstrap cross-validated AUC = 0.622,  $R^2 = 0.045$ .) (C) Multivariable analysis of predictors for considering observation (the model does not fit the data well with  $P = 0.037$  in the Hosmer–Lemeshow test. The AUC of the ROC curve is 0.858 and bootstrap cross-validated AUC = 0.857,  $R^2 = 0.482$ ).



observation in 58.8% (1326/2254) vs 23.5% (1925/8204) of patients who were not suitable for AS ( $P < 0.001$ ). Figure 2C shows a multivariable model of predictors for considering observation. Higher knowledge, using the decision aid alone, lower oncological risk, normal erectile function, and respective personal preferences were independently associated with considering AS or WW. Although the sociodemographic characteristics had no independent influence in the multivariable model, Table S1 shows the univariate group comparison of these parameters.

### Urologists' View

Of 194 urologists responding to the survey, 91 (47%) had implemented the decision aid in their clinical practice and used it for patient education. Table 3 summarises the sociodemographic data and habits of the patients. Female (22.2% vs 8.9%,  $P = 0.01$ ) and office urologists (97.8% vs 83.5%,  $P = 0.003$ ) were over-represented among the users of the decision aid. The non-users rarely worked with print media (46.6% vs 62.2%,  $P = 0.03$ ) or other decision aids (20.4% vs 73.3%,  $P < 0.001$ ) in visits with their patients newly diagnosed with localised PCa. Correspondingly, the proportion of colleagues who did not offer any supporting aid for the conversation was higher (29.1% vs 4.4%,  $P < 0.001$ ). In the group of non-users, 13.6% (14/103) stated that they had tried the decision aid but no longer used it. A total of 62.1% (64/103) had not yet tried the tool but would be open to it. And 8.7% (nine of 103) rejected this approach in principle.

Urologists' adopting the decision aid in their clinical practice ( $n = 91$ ) have offered the tool for a mean (SD, range) of 8.6 (3.6, 0–14) months and successfully recruited a mean (SD, range) of 1.1 (0.9, 0–5) patients/month. Thus, the survey included ~40% of all active physician users at that time. According to the urologists' estimates of 1556 patients with newly diagnosed localised PCa, 902 (58.0%) received the invitation for the decision aid, and 677 (43.5%) finally used it. The urologists' mean (SD, range) satisfaction with the offer was 1.45 (0.55, 1–3; based on German school grades from 1 'very good' to 6 'insufficient'). The recommendation rate to other colleagues was 92% (82/89). The reported advantages of using the decision aid were better-informed patients (85%, 76/89), higher patient satisfaction (76%, 68/89), better involvement of relatives (63%, 56/89), and benefits in terms of documentation (45%, 40/89). Half of the urologists reported time savings (49%; 44/90), 31% (28/90) did not report any change, and 20% (18/90) reported a higher time requirement.

### Discussion

We report a comprehensive evaluation of a PCa decision aid in German routine care based on the responses of 11 290 patients and 91 urologists who had used the tool. Both

**Table 3** Urologists' sociodemographic characteristics and patient information habits.

Variable	Total (n = 194)	Non-users of the decision aid (n = 103)	Users of the decision aid (n = 91)	P
Female urologist (n = 191), n (%)	29 (15.2)	9 (8.9)	20 (22.2)	<b>0.01</b>
Duration of practicing as board certified urologist, years (n = 177), mean (SD)	17.3 (9.4)	18.3 (9.5)	16.2 (9.1)	0.14
Urban location of practice or clinic, ≥10 000 inhabitants (n = 185), n (%)	168 (90.8)	91 (94.8)	77 (86.5)	0.052
Work setting (n = 186), n (%)				
Office urologist (1 physician)	79 (42.5)	35 (36.1)	44 (49.4)	<b>0.003</b>
Office urologist (≥2 physicians)	89 (47.8)	46 (47.4)	43 (48.3)	
Hospital	18 (9.7)	16 (16.5)	2 (2.2)	
Routinely used supporting material for counselling newly diagnosed patients with non-metastatic PCa (n = 193), n (%)				
No additional material	34 (17.6)	30 (29.1)	4 (4.4)	<b>&lt;0.001</b>
Print media	104 (53.9)	48 (46.6)	56 (62.2)	<b>0.03</b>
Videos	13 (6.7)	8 (7.8)	5 (5.6)	0.54
Internet sources	41 (21.2)	22 (21.4)	19 (21.1)	0.97
Decision aid for patients	87 (45.1)	21 (20.4)	66 (73.3)	<b>&lt;0.001</b>
Contact offer for peer-to-peer support	27 (14.0)	13 (12.6)	14 (15.6)	0.56

*Bold values statistically significant at P < 0.05.*

urologists and patients reported very high levels of acceptance and satisfaction. Half of the urologists emphasised time savings for themselves. Approximately 31% of patients who used the decision aid considered choosing observation. In line with the guideline recommendations, having high or intermediate oncological risk had the strongest negative impact on considering observation. This demonstrates an effective conveyance of guideline information through the decision aid to the patient.

The oncological risk groups had a typical distribution: 24.3% low, 46.9% medium, and 28.8% high risk. Only 0.7% reported clinical evidence for metastatic disease. Thus, the decision aid reached its target group of patients with non-metastatic PCa. Severe comorbidity appeared to be very low in this selected sample. Only 2.9% of the users had an estimated 10-year survival probability of <50%. This reflects thoughtful pre-selection by urologists, who diagnose and counsel patients who are physically and mentally eligible for active treatment. One-third (34.5%) of the users showed relevant distress, and 11% reported signs of anxiety or depression. The significance of mental health impairment and PCa has been shown in recent literature [19]. Revealing the necessity of psycho-oncological treatment within this patient group is one of the major benefits of decision aid use. Moreover, all relevant clinical information for meaningful counselling is provided within the one-page summary, including guideline-recommended nomograms for extracapsular extension and lymphatic spread.

There are a growing number of multimedia decision aids and interactive patient information websites, predominantly in the English language, to support treatment decision-making for patients with localised PCa. Fundamentally different approaches are implemented to convey the necessary

information and lead the user to an informed treatment decision [6,20,21]. Moreover, the outcomes and analytical parameters to measure and compare the effectiveness and quality of these tools are numerous and not yet sufficiently standardised. Nevertheless, several studies have tried to breach this gap, including a current Cochrane review [4–6,22]. They conclusively show that the use of decision aids is feasible and well accepted by their respective users. Regarding the qualitative outcomes, conclusions differ widely. Some authors detect improvements in knowledge, more active patient involvement in decision-making, and a decrease in anxiety and decisional conflict [4,5]. Others criticise the limited evidence because of the high risk of bias and inconsistent results cause impaired study comparability [22].

Patient satisfaction with decision aid use is an important parameter for the acceptance of the programme in general. The majority (87.7%) were highly satisfied. Generally, high rates of patient satisfaction are typical for patient-oriented projects [4,5]. The surveyed urologists reported very good satisfaction, with high recommendation rates to their colleagues. Half of the urologists reported saving time by using the decision aid. Further advantages reported by urologists were better-informed patients, higher patient satisfaction, and more involvement of relatives. This parallel evaluation among physicians and patients is an innovative approach that is not found in existing papers.

Objective knowledge is another relevant measure of the effectiveness of decision aids. As expected, [4–6,23], among others, we observed a positive correlation of better knowledge with higher education level and higher annual income. Interestingly, knowledge was higher in patients considering observation. This implies that increasing knowledge can help to increase guideline adherence for patients eligible for AS.



A major issue of discussion concerning decision aids is their potential impact on treatment decisions. In Germany, the rate of deferred treatment strategies in patients with low-risk PCa is too low [24]. In our cohort, 58.8% of patients suitable for AS according to their clinical oncological features were considering observation. Therefore, the decision aid improved the rate of deferred treatment decisions in suitable patients. An impact on treatment choice is also described by the current Cochrane review, demonstrating a 21% decrease in major elective, invasive surgery among patients who were exposed to a decision aid [4]. Other current studies underline this result by demonstrating that patients after the use of a decision aid are more likely to make self-confident therapy choices [25] and show higher knowledge and better understanding of surveillance strategies [26,27]. Well-informed patients could be the main drivers of higher AS rates in suitable cases, because the majority of our study participants (64%) wanted to make the treatment decision together with their physician or (29%) make it themselves while considering the opinion of their physician. In comparison to a survey of 464 members of German urological professional societies [18], these urologists showed an even stronger tendency toward greater patient autonomy.

### Limitations and Strengths

Generally, anonymous data cannot be verified for authenticity, but the integration of our survey into physician–patient contacts should result in sufficient reliability for an initial assessment. Answers that aim to conform with social desirability might be less likely due to the anonymity, which we expect resulted in more authentic feedback. The evaluation section was not included in the patient’s summary. Therefore, the above holds true even when patients decide to share their data summary with their urologist. A further limitation could be the response rate of the urologists, which brought the risk of a possible non-response bias. However, >60% of the urologists who had not used the decision aid, where considering doing so in the future. In our view, this demonstrates that there is still a need to broadly promote computer-based decision aids to the professional public. Nevertheless, comparable results in the current literature [28] argue against a strong selection bias. Urologists seem to pre-select patients for access to the decision aid, which must be considered when generalising the results to the total patient population. The proportion of better-educated patients with higher income and private insurance status was significantly higher among decision aid users than among the general population. This is understandable, as internet access and a basic degree of health literacy are utilisation requirements. We implemented validated instruments in the questionnaires to ensure comparability with the literature. However, the patient’s answers could differ according to their

disease profile. Thus, patients with a high oncological risk logically answered the question about the risk of death from PCa more critically than patients with low risk. An additional source of bias might result from the health literacy of patients, as not every patient with insufficient health literacy might respond adequately to all implemented questionnaires. In 2021, we re-worked parts of the decision aid with additional functionality as a registered medical device and including the subsequent changes in guideline recommendations. As the results from this study were based on data acquired before the changes made to the tool, results could slightly differ if repeated today with the current version. Finally, the special features of the German healthcare system also limit the generalisability of our results. For example, healthcare costs are covered for practically all patients due to the existing mandatory insurance. Therefore, prices of various treatment modalities were not taken into account in the decision aid.

Our study is the first systematic evaluation of a large number of users of a PCa-treatment decision aid in Germany. The large sample afforded deep insight into clinical and psychosocial factors in this population. It also provides important reference values for future studies. Our results demonstrate that patients and urologists accept the idea of a web-based decision aid very well and show high levels of satisfaction. The usage of the decision aid could improve guideline-supported treatment decision-making, which is suggested by the higher rate of patients with tendencies toward deferred treatment strategies in the low oncological risk group. However, the significance of these tendencies can only be proven in randomised controlled assessments. Therefore, the randomised controlled EvEnt-PCA study recruited 1115 patients to obtain a valid comparison of our decision aid with the current standard of a printed brochure. Its results are to be published soon. There are comparable projects in other national health care systems that address this question [29].

### Summary and Future Perspectives

After 7 years of implementation, >22 000 patients (until 2023) have used the German PCa decision aid. Patients and urologists report a very high level of acceptance and satisfaction with the decision aid. It offers advantages for shared decision-making and time efficiency, although the time-saving aspect surely is not the main focus. Furthermore, the usage of the decision aid might improve the adoption of AS and WW when indicated. The tool is easy to use for a wide range of patients and promotes patient participation in the decision-making process regarding their treatment through its personalisation and interactivity. However, the decision aid has not been developed to replace the consultation with the treating urologist, but to support the decision-making process for both sides. The final decision on treatment should remain with the patient and his urologist. The DGU has launched

another decision aid for patients with bladder cancer ([www.entscheidungshilfe-blasenkrebs.de](http://www.entscheidungshilfe-blasenkrebs.de)). Hopefully, the results of these projects will improve our standard way of informing our oncological patients in the long run. Digital patient information and treatment follow-up could also pave the way to capture long-term outcomes from a patient perspective after oncological treatments.

## Acknowledgements

The project 'Entscheidungshilfe Prostatakrebs' was awarded the Alexander von Lichtenberg Prize Special Award in 2016. At the 71st Congress of the German Society of Urology in 2019, the oral presentation summarising an earlier version of the present work was awarded the First clinical Lecture Prize. Johanna Valdex analysed part of this publication's data within her doctoral thesis. American Journal Experts provided language editing. We thank all contributing patients and urologists. Open Access funding enabled and organized by Projekt DEAL.

## Author Contributions

Johannes Huber had full access to all the study data and was responsible for the integrity of the data and the accuracy of the data analysis. Study concept and design: J Huber, Christer Groeben. Acquisition of data: Johannes Huber, Johanna Valdex, Philipp Karschuck. Analysis and interpretation of data: all authors. Drafting of the manuscript: Johannes Huber, Christer Groeben. Critical revision of the manuscript for important intellectual content: all authors. Statistical analysis: Johannes Huber, Rainer Koch. Administrative, technical, or material support: all authors. Study supervision: Johannes Huber.

## Disclosure of Interest

Takeda Pharma Vertrieb GmbH & Co KG, Janssen-Cilag GmbH and Apogepha Arzneimittel provided financial support for the decision aid 'Entscheidungshilfe Prostatakrebs'. Johannes Huber reports grants and non-financial support from Intuitive Surgical and Coloplast outside the submitted work. Moreover, Johannes Huber and Christian Wülfing are members of the medical board of the Urological Foundation for Health. Elke Kessler is Managing Director of ASD Concepts GmbH & Co. KG – 'Institut für Patientenzentrierte Versorgungsformen'. All other authors reported no disclosures.

## Funding

The online prostate cancer patient decision aid 'Entscheidungshilfe Prostatakrebs' is supported by Takeda Pharma Vertrieb GmbH & Co KG, Janssen-Cilag GmbH, and Apogepha Arzneimittel. The funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.

## References

- Ihrig A, Keller M, Hartmann M et al. Treatment decision-making in localized prostate cancer: why patients chose either radical prostatectomy or external beam radiation therapy. *BJU Int* 2011; 108: 1274–8
- Guadagnoli E, Ward P. Patient participation in decision-making. *Soc Sci Med* 1998; 47: 329–39
- Huber J, Ihrig A, Huber CG, Hadaschik B, Pahernik S, Hohenfellner M. Patient centeredness and decision-making in localised prostate cancer: possible fields of health services research in urology. *Urologe* 2011; 50: 691–6
- Stacey D, Légaré F, Lewis K et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017; 4: CD001431
- Lin GA, Aaronson DS, Knight SJ, Carroll PR, Dudley RA. Patient decision aids for prostate cancer treatment: a systematic review of the literature. *CA Cancer J Clin* 2009; 59: 379–90
- Groeben C, Streuli JC, Kronen T, Keck B, Wirth MP, Huber J. Treatment of nonmetastatic prostate cancer. *Urologe* 2014; 53: 854–64
- Baunacke M, Azawia A, Huber J, Groeben C, Thomas C, Borkowetz A. Robotic radical prostatectomy: difficult to start, fast to improve? Influence of surgical experience in robotic and open radical prostatectomy. *World J Urol* 2021; 39: 4311–7
- Groeben C, Ihrig A, Hölscher T et al. Evaluation of the decision aid "Entscheidungshilfe Prostatakrebs" from the patients' view: results from the first three months. *Urologe* 2016; 55: 1–8
- Martin NE, Massey L, Stowell C et al. Defining a standard set of patient-centered outcomes for men with localized prostate cancer. *Eur Urol* 2015; 67: 460–7
- Rosen RC, Cappelleri JC, Smith MD, Lipsky J, Peña BM. Development and evaluation of an abridged, 5-item version of the international index of erectile function (IIEF-5) as a diagnostic tool for erectile dysfunction. *Int J Impot Res* 1999; 11: 319–26
- Ihrig A, Maatouk I, Friederich HC et al. The treatment decision-making preferences of patients with prostate cancer should be recorded in research and clinical routine: a pooled analysis of four survey studies with 7169 patients. *J Cancer Educ* 2022; 37: 675–82
- Degner LF, Sloan JA, Venkatesh P. The control preferences scale. *Can J Nurs Res* 1997; 29: 21–43
- Huber J, Ihrig A, Peters T et al. Decision-making in localized prostate cancer: lessons learned from an online support group. *BJU Int* 2011; 107: 1570–5
- Mehnert A, Müller D, Lehmann C, Koch U. Die deutsche version des NCCN distress-thermometers. *Z Psychiatr Psychol Psychother* 2006; 54: 213–23
- Kroenke K, Spitzer RL, Williams JBW, Löwe B. An ultra-brief screening scale for anxiety and depression: the PHQ-4. *Psychosomatics* 2009; 50: 613–21
- Sepucha K. Decision quality worksheet: for treating prostate cancer v.1.0. ©Massachusetts General Hospital, last reviewed 2013. Available at: [https://mghdecisionciences.org/wp-content/uploads/2018/06/psa\\_dqi\\_sv.pdf](https://mghdecisionciences.org/wp-content/uploads/2018/06/psa_dqi_sv.pdf) [Accessed March 15, 2024].
- Tariman JD, Berry DL, Halpenny B, Wolpin S, Schepp K. Validation and testing of the acceptability E-scale for web-based patient-reported outcomes in cancer care. *Appl Nurs Res* 2011; 24: 53–8
- Groeben C, Baunacke M, Borkowetz A et al. Decision aids for patients are widely accepted by German urologists: a survey among members of the German Society of Urology (DGU) and the Federation of German Urologists (BDU). *Urologe* 2016; 55: 784–91
- Brunckhorst O, Hashemi S, Martin A et al. Depression, anxiety, and suicidality in patients with prostate cancer: a systematic review and meta-analysis of observational studies. *Prostate Cancer Prostatic Dis* 2021; 24: 281–9
- Baptista S, Teles Sampaio E, Heleno B, Azevedo LF, Martins C. Web-based versus usual care and other formats of decision aids to support prostate cancer screening decisions: systematic review and meta-analysis. *J Med Internet Res* 2018; 20: e228

- 21 Grune B, Kriegmair MC, Lenhart M *et al.* Decision aids for shared decision-making in uro-oncology: a systematic review. *Eur Urol Focus* 2022; 8: 851–69
- 22 Violette PD, Agoritsas T, Alexander P *et al.* Decision aids for localized prostate cancer treatment choice: systematic review and meta-analysis. *CA Cancer J Clin* 2015; 65: 239–51
- 23 O'Connor AM, Bennett CL, Stacey D *et al.* Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2009; 8: CD001431
- 24 Hager B, Kraywinkel K, Keck B *et al.* Integrated prostate cancer centers might cause an overutilization of radiotherapy for low-risk prostate cancer: a comparison of treatment trends in the United States and Germany from 2004 to 2011. *Radiother Oncol* 2015; 115: 90–5
- 25 Lamers RED, Cuypers M, de Vries M, van de Poll-Franse LV, Ruud Bosch JLH, Kil PJM. How do patients choose between active surveillance, radical prostatectomy, and radiotherapy? The effect of a preference-sensitive decision aid on treatment decision making for localized prostate cancer. *Urol Oncol* 2017; 35: e9–e17
- 26 Formica MK, Wason S, Seigne JD, Stewart TM. Impact of a decision aid on newly diagnosed prostate cancer patients; understanding of the rationale for active surveillance. *Patient Educ Couns* 2017; 100: 812–7
- 27 Knops AM, Legemate DA, Goossens A, Bossuyt PM, Ubbink DT. Decision aids for patients facing a surgical treatment decision: a systematic review and meta-analysis. *Ann Surg* 2013; 257: 860–6
- 28 Wang EH, Gross CP, Tilburt JC *et al.* Shared decision making and use of decision aids for localized prostate cancer. *JAMA Intern Med* 2015; 175: 792–9
- 29 Schofield P, Gough K, Hyatt A *et al.* Navigate: a study protocol for a randomised controlled trial of an online treatment decision aid for men with low-risk prostate cancer and their partners. *Trials* 2021; 22: 49

Correspondence: Johannes Huber, Department of Urology, Philipps University of Marburg, Baldingerstr. 35043 Marburg, Germany.

e-mail: [johannes.huber@uk-gm.de](mailto:johannes.huber@uk-gm.de)

Abbreviations: AS, active surveillance; AUC, area under curve; DGU, German Society of Urology; EORTC, European Organisation for Research and Treatment of Cancer; IIEF-5, five-item version of the International Index of Erectile Function; IQR, interquartile range; OR, odds ratio; PCa, prostate cancer; ROC, receiver operating characteristic; USG, Urologische Stiftung Gesundheit gGmbH; WW, watchful waiting.

## Supporting Information

Additional Supporting Information may be found in the online version of this article:

**Video S1** Video showcase of the decision aid 'Entscheidungshilfe Prostatakrebs'.

**Appendix S1** English translation of the urologist questionnaire.

**Table S1** Sociodemographic data comparing patients not considering vs considering observation.