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Prostate Cancer

The Europa Uomo Patient Reported Outcome Study 2.0—Prostate Cancer Patient-reported Outcomes to Support Treatment Decision-making

Lionne D.F. Venderbos [a,*], *Sebastiaan Remmers* [a], *André Deschamps* [b], *John Dowling* [b], *Ernst-Günter Carl* [b], *Nuno Pereira-Azevedo* [c], *Monique J. Roobol* [a]

[a] *Department of Urology, Erasmus MC Cancer Institute, Erasmus University Medical Center, Rotterdam, The Netherlands;* [b] *Europa Uomo, Antwerp, Belgium;* [c] *Department of Urology, Entre o Douro e Vouga Medical Center, Santa Maria da Feira, Portugal*

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Abstract

Background: To further strengthen the voice of patients, Europa Uomo initiated the Europa Uomo Patient Reported Outcome Study 2.0 (EUPROMS 2.0) in October 2021.
Objective: To collect the self-reported perspective of prostate cancer (PCa) patients on physical and mental well-being after PCa treatment outside a clinical trial setting to inform future fellow patients about the impact of PCa treatment.
Design, setting, and participants: Europa Uomo invited PCa patients to complete a cross-sectional survey including the validated EQ-5D-5L, EORTC-QLQ-C30, and the EPIC-26 questionnaires. Furthermore, the nine-item Shared Decision Making Questionnaire (SDM-Q-9) and diagnostic clinical scenarios were included.
Outcome measurements and statistical analysis: Descriptive statistics was used to assess the demographic and clinical characteristics and to analyze the patient-reported outcome data.
Results and limitations: Between October 25, 2021 and January 17, 2022, 3571 men from 30 countries completed the EUPROMS 2.0 survey. The median age of respondents was 70 yr (interquartile range 65–75 yr). Half of the respondents underwent one treatment, most often radical prostatectomy. Men who are treated actively experience lower health-related quality of life than men on active surveillance, mainly regarding sexual function, fatigue, and insomnia. Lower urinary incontinence levels were seen for men who underwent radical prostatectomy (single treatment or in combination with other treatments). Of the respondents, 42% indicated that the determination of the prostate-specific antigen (PSA) value was part of a routine blood test; 25% wanted to undergo screening/early detection for PCa, and 20% indicated that the determination of the PSA value had a clinical reason.
Conclusions: A large sample of 3571 international patients has contributed patient experience after PCa treatment in the EUPROMS 2.0 study, confirming that treatment for PCa mainly affects urinary incontinence, sexual function, fatigue, and insomnia. Such

* Corresponding author at: Department of Urology, Room Na-1520, Erasmus University Medical Center Rotterdam, Wytemaweg 80, 3015 CN Rotterdam, The Netherlands. Tel. +31 6 5000 1668.
E-mail address: l.venderbos@erasmusmc.nl (L.D.F. Venderbos).

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information can be used to direct toward a better patient-doctor relationship, to offer patients ready access to responsible information and a better understanding of their disease and treatment.

Patient summary: Through the EUPROMS 2.0 survey, Europa Uomo has strengthened the voice of the patient. Such information can be used to inform future prostate cancer (PCa) patients about the impact of PCa treatment and to engage them in informed and shared decision-making.

1. Introduction

In 2019, Europa Uomo—the prostate cancer (PCa) patient coalition in Europe—initiated the Europa Uomo Patient Reported Outcome Study (EUPROMS), with the primary goal of collecting patient-reported outcomes (PROs) outside a clinical trial setting reflecting patients' quality of life (QoL) after PCa treatment [1]. From what they heard back from their members and supporters who underwent PCa treatment, the adverse effects of PCa treatment differed from the data of controlled clinical trials published in the literature [1]. Historically, the use of patient-reported outcome measures (PROMs) has been limited to a research setting: the inquiry of pre- and post-treatment QoL was done by clinicians who recorded patients' answers. This has slowly shifted toward the development of validated questionnaires and patients self-reporting their QoL [2]. Over the years, measuring treatment-related QoL has become an increasingly requisite component of delivering high-quality care for PCa patients. Collecting information on physical functioning and mental well-being directly from patients is important because such outcomes may be under-reported by physicians [3,4]. PROMs in that sense may guide clinical practice to be more responsive to individual patients' needs and, in addition, can inform ways in which patients can self-manage their condition and well-being.

An overwhelming number of 2943 men participated in the EUPROMS study, and all together they provided a cross-sectional picture of the European PCa population and their reported QoL [1]. In October 2021, Europa Uomo launched the EUPROMS 2.0 survey aiming to increase the collection of patients' self-reported perspective on physical and mental well-being outside a clinical trial setting, to be able to investigate the burden of PCa treatment from a patient-to-patient perspective. In addition, men were invited to share their reasons for initial prostate-specific antigen (PSA) testing and experiences on shared decision-making (SDM) with health care professionals.

2. Patients and methods

2.1. Patient screening criteria

The EUPROMS 2.0 survey was open to men diagnosed with PCa and currently undergoing PCa treatment or having received treatment for their PCa in the past.

2.2. Recruitment and data collection

Europa Uomo placed the EUPROMS 2.0 survey—available in 20 languages—on their website (www.europa-uomo.org). Europa Uomo used its network of, among others, national patient organizations and supportive urologists to promote the EUPROMS 2.0 survey as well as to stimulate PCa patients to complete it. Data collection was handled by Ydeal (ydeal.net) to meet with IT and legal requirements.

2.3. Patient-reported outcome measures

As in the previous EUPROMS survey [1], a set of validated measures, commonly accepted and used for research purposes, was included in the EUPROMS 2.0 survey to evaluate generic health (EQ-5D-5L) [5–7], cancer-specific QoL (EORTC-QLQ-C30) [8,9], and prostate-specific health (EPIC-26) [10,11]. In the EUPROMS 2.0 survey, the items of the nine-item Shared Decision Making Questionnaire (SDM-Q-9) were added, as well as questions on diagnostic clinical scenarios.

The characteristics of the validated EQ-5D-5L, EORTC-QLQ-C30, and EPIC-26 have been described previously [1]. The SDM-Q-9 is a self-report instrument developed to measure the process of SDM in a consultation as perceived by the patient [12,13]. All nine items are scored on a six-point Likert scale, ranging from 0 (“completely disagree”) to 5 (“completely agree”). Adding up the scores of the nine items leads to an overall SDM-Q-9 summary score between 0 and 45, with 0 indicating the lowest and 45 the highest level of perceived SDM [12,13].

Furthermore, clinical scenarios were included in the survey. The clinical scenarios started with an introduction to the prostate, its function, and its location. Then questions about reasons for determining the PSA value, whether a digital rectal examination (DRE) was performed, whether other diagnostic tests were performed, what the T stage and Gleason grade of the PCa tumor were, what the PSA at the time of initial diagnosis was, and which treatment(s) men underwent, including their timings, were asked.

2.4. Statistical analysis

Descriptive statistics were used to assess the demographic and clinical characteristics of the men who completed the EUPROMS 2.0 survey, and to analyze the outcomes of the EQ-5D-5L, EORTC-QLQ-C30, EPIC-26, SDM-Q-9, and clinical scenarios. We performed a sensitivity analysis to assess whether differences existed between the group of men who already participated in the initial EUPROMS study and “new participants”. R version 4.2.1 was used to perform all analyses [14].

PROs were described for the most frequently reported treatment modalities, that is, active surveillance (AS), radical prostatectomy (RP), radiotherapy (RT), AS + RP, RP + RT, RT + androgen deprivation therapy (ADT), RP-RT-ADT, and chemotherapy (either as a single treatment or after having received other treatments). For miscellaneous single or combinations of treatments, the numbers were too small to report PROs.

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3. Results

Between October 25, 2021 and January 17, 2022, 3571 men from 30 countries worldwide completed the EUPROMS 2.0 survey. A total of 1050 respondents (29.4%) indicated that they had participated in the first EUPROMS survey, and 2521 men were new respondents (70.6%). Sensitivity analyses showed no substantial differences between men who participated in the first EUPROMS survey and new respondents (data not shown). The median age of the total cohort at questionnaire completion was 70 yr (interquartile range [IQR] 65–75; Table 1). The majority of men (65.7%) received higher education. The median PSA at initial diagnosis was 8.0 ng/ml (IQR 5.0–14.0), 66% had either a T1 or T2 PCa tumor at diagnosis, and 52.9% reported a Gleason 6 or 7 PCa. Almost half of the men reported to have any comorbidities (48%). Of the comorbidities that were reported, high blood pressure was most frequent (26.7%). Half of the respondents (N = 1863, 52.2%) underwent a single treatment, with RP being the most reported single treatment (N = 1316). A total of 522 (14.6%) men underwent a combination of two treatments, and RP-RT-ADT was the most common combination of three treatments (N = 145, 4.1%).

3.1. Clinical scenarios

For the majority of men (41.8%), determining the PSA value was part of a routine blood test (Table 2). A total of 25.1% of men indicated that they wanted to undergo screening/early detection for PCa, 23% of men were having trouble urinating/peeing, and 21.2% of men indicated that the doctor felt something when performing a DRE. Of the respondents, 90% underwent a DRE and 81.7% was told by the doctor what was felt. Furthermore, 94.0% of men underwent a prostate biopsy, 49.8% an MRI scan, and 18% indicated that a PSMA/PET scan was performed.

3.2. Generic, cancer-specific, and PCa-specific health

3.2.1. EQ-5D-5L

Most respondents undergoing a single or two treatments reported no problems with mobility and self-care (Fig. 1). A somewhat larger proportion of men undergoing RT-ADT (14%), RP-RT-ADT (12%), or chemotherapy (24%) reported moderate/severe problems conducting their usual activities. With respect to pain/discomfort, 75–95% of respondents reported no or slight pain/discomfort. Men who were treated with RT-ADT (16%), RP-RT-ADT (18%), or chemotherapy reported a slightly higher level of pain/discomfort (25%). The rate of men reporting no or slight anxiety/depression ranges from 77% to 91%. The median EQ-VAS score for all 3571 men is 80 (IQR 70–90).

3.2.2. EORTC-QLQ-C30

Respondents reported no big impairments with respect to self-reported functioning (Table 3). Men who were treated with RT, either as a single treatment or in combination with other treatments (RP-RT, RT-ADT, or RP-RT-ADT), and chemotherapy had higher median fatigue and insomnia scores than those treated with the other treatment modalities.

3.2.3. EPIC-26

The impact of treatment is most prominently seen on the urinary incontinence (UI) and sexual function (SF) domains (Fig. 2A–E). Men who underwent RP as a single treatment or in combination with another treatment reported the lowest UI scores. The median self-reported SF score is highest for men following AS.

3.2.4. Gleason 6 and 7 (3 + 4 and 4 + 3) at diagnosis

When assessing UI and SF levels of men with Gleason 6 or 7 PCa at diagnosis, no large differences are seen for UI scores as compared with the overall treatment groups (including all Gleason scores). With respect to SF, some small differences are seen. Most notable is the 11.1 point higher score for men with Gleason 6 or 7 PCa who underwent RT as compared with the total RT group (27.8 [IQR 12.5–56.3] vs 16.7 [IQR 8.3–36.2]). This difference lies within the 10–12-point minimally important difference range of the SF domain [15].

3.2.5. Incontinence and SF for most common treatment(s) versus age at questionnaire completion

When assessing the UI domain score by age instead of treatment and Gleason score, men up to 69 yr of age reported the best UI score (60–64 yr: median 85.5 [IQR 58.5–100]; 65–69 yr: median 79.3 [IQR 52.3–100]). After passing the age of 70 yr, the score decreases to 75.0 yr for men aged 70–79 yr (52.3–100) and further to 73.0 yr for men aged ≥80 yr (IQR 43.8–93.8). With increasing age, men report that they more often use pads: 32% of men <60 yr use one or more pads per day versus 40.9% of men ≥80 yr. Regarding SF, a decline is seen with increasing age, from a median score of 25 (IQR 9.7–58.3) for men <60 yr to 12.5 (IQR 4.2–18.0) for men ≥80 yr.

3.3. Shared decision-making

The SDM-Q-9 summary scores for the overall cohort and per treatment group range between 32 and 35 (Table 4). The summary scores are at the top half of the score range; however, when looking at some of the individual items reflecting the various elements of SDM, minor nuances are seen between treatments. When assessing the SDM-Q-9 summary score by age, only men ≥80 yr report a somewhat lower score (30, IQR [20–39] vs <60 yr: 33 [IQR 24–40], 60–64 yr: 35 [IQR 26–41], 65–69 yr: 34 [26–41], and 70–79 yr: 34 [25–41]).

4. Discussion

After the first EUPROMS survey, Europa Uomo was able to collect another 3571 responses of PCa patients who underwent treatment and to collect their self-reported perspective on the adverse effects of PCa treatment outside a clinical trial setting (EUPROMS 1.0 and 2.0 [new patients] >5400 responses). The outcomes of the EUPROMS 2.0 cross-sectional survey confirm the results of the EUPROMS 1.0 study and highlight that men treated actively experience lower health-related QoL than men who opt for AS, mainly regarding SF, fatigue, and insomnia. Lower UI levels were seen for men who underwent RP, either as a single treatment or in combination with other treatments. When

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Table 1 – Patient characteristics

Demographic characteristics (N = 3571)	
Age at completing questionnaire	
Total cohort, median (IQR)	70 (65–75)
Age at diagnosis, *n* (%)	
<55	340 (9.5)
55–59	623 (17.4)
60–64	851 (23.8)
65–69	913 (25.6)
70–74	562 (15.7)
75–79	223 (6.2)
80+	59 (1.7)
Treatment profile of respondents for the most frequently reported treatment modalities, *n* (%)	
Single treatment	
AS	208 (5.8)
RP	1316 (36.9)
RT	339 (9.5)
Combination of treatments	
AS-RP	79 (2.2)
RP-RT	277 (7.8)
RT-ADT	166 (4.6)
RP-RT-ADT	145 (4.1)
Chemotherapy[a]	276 (7.7)
Age at completing questionnaire per treatment, median (IQR)	
AS	69 (64–75)
AS-RP	69 (63–72)
RP	70 (65–74)
RP-RT	71 (65–75)
RT	74 (69–79)
RT-ADT	73 (68–77)
RP-RT-ADT	68 (62–73)
Chemotherapy	68 (63–74)
Last employment (before retirement), *n* (%)	
Higher managerial	764 (21.4)
Intermediate managerial	1271 (35.6)
Junior managerial	474 (13.3)
Skilled manual worker	374 (10.5)
Semiskilled manual worker	61 (1.7)
Unskilled manual worker	32 (0.9)
Unemployed	43 (1.2)
Other	552 (15.5)
Education, *n* (%)	
University entrance certificate	1066 (29.9)
Entrance certificate for a higher technical college	1280 (35.8)
Comprehensive school	407 (11.4)
Intermediate/secondary school	313 (8.8)
Lower secondary school or equivalent	156 (4.4)
Other	341 (9.5)
None	8 (0.2)
Country of residence, *n* (%)	
Australia	8 (0.2)
Austria	25 (0.7)
Belgium	95 (2.7)
Canada	250 (7.0)
Cyprus	9 (0.3)
Czech Republic	5 (0.1)
Denmark	163 (4.6)
Estonia	11 (0.3)
Finland	52 (1.5)
France	143 (4.0)
Germany	365 (10.2)
Greece	7 (0.2)
Hungary	26 (0.7)
Iceland	11 (0.3)
Ireland	27 (0.8)
Italy	50 (1.4)
Latvia	10 (0.3)
Lithuania	3 (0.1)
Luxembourg	3 (0.1)
Norway	720 (20.2)
Poland	42 (1.2)
Portugal	114 (3.2)
Serbia	2 (0.1)
Slovakia	15 (0.4)
Spain	34 (1.0)
Sweden	205 (5.7)
Switzerland	13 (0.4)
The Netherlands	839 (23.5)
UK	176 (4.9)
USA	121 (3.4)
Other	27 (0.8)
Health insurance coverage, *n* (%)	
Statutory health insurance	2403 (67.3)
Private health insurance	812 (22.7)
None	222 (6.2)
Other	134 (3.8)
Self-reported tumor characteristics and comorbidities	
PSA at diagnosis	
Median (IQR)	8.0 (5.0–14.0)
T stage, *n* (%)	
T1	346 (9.7)
T2	2012 (56.3)
T3	489 (13.7)
T4	53 (1.5)
I don't know	281 (7.9)
Metastatic PCa	390 (10.9)
Gleason score, *n* (%)	
Gleason 6	455 (12.7)
Gleason 7 (3 + 4)	864 (24.2)
Gleason 7 (4 + 3)	572 (16.0)
Gleason 8	355 (9.9)
Gleason 9 (4 + 5 and 5 + 4)	454 (12.7)
Gleason 10	44 (1.2)
I don't know	827 (23.2)
Comorbidities, *n* (%)	
Diabetes mellitus	77 (2.2)
Diabetes mellitus + obesity	29 (0.8)
Obesity	68 (1.9)
High blood pressure	953 (26.7)
High blood pressure + diabetes mellitus	110 (3.1)
High blood pressure + diabetes mellitus + obesity	54 (1.5)
High blood pressure + obesity	104 (2.9)
I don't have any comorbidities	1713 (48.0)
I don't know if I have any comorbidities	258 (7.2)
None of the above, but other comorbidities	205 (5.7)

ADT = androgen deprivation therapy; AS = active surveillance; IQR = interquartile range; PCa = prostate cancer; PSA = prostate-specific antigen; RP = radical prostatectomy; RT = radiotherapy.

[a] Men who underwent chemotherapy as a single treatment or in combination with other, earlier treatments.

asking about reasons to determine the PSA value, 42% of respondents indicated that it was part of a routine blood test. A quarter of men indicated that they wanted to undergo screening/early detection for PCa, and approximately 20% indicated that determining the PSA value had a clinical reason. A total of 81.7% of respondents indicated that the doctor shared what was felt when a DRE was performed. An MRI scan and a prostate biopsy were the most frequent other diagnostic tests that were performed.

In light of the recent developments regarding the early detection of PCa and treatment of PCa in an earlier stage, we have looked into UI and SF levels according to Gleason score. When assessing UI and SF levels according to Gleason 6 or 7 PCa at diagnosis, no large differences were seen for UI scores as compared with the overall treatment groups. In the literature, in a study comparing prostate-specific functioning for men with Gleason 6 or 7 PCa at diagnosis undergoing AS, RP, or RT and having between 6 and 8 yr of follow-up after treatment, the mean EPIC UI scores were 90.0 for AS, 70.1 for RP, and 86.5 for RT [16], as compared with a median score of 100 for AS, 73.0 for RP, and 93.8 for RT in EUPROMS 2.0 (Supplementary Table 1). Healthy men without PCa reported a mean UI score of 90.4 [16], and the EPIC mean UI norm score for 112 controls without PCa was 92.9

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Table 2 – Clinical scenarios

	Overall (*N* = 3571)	AS (*N* = 208)	AS-RP (*N* = 79)	RP (*N* = 1316)	RP-RT (*N* = 277)	RT (*N* = 339)	RT-ADT (*N* = 166)	RP-RT-ADT (*N* = 145)	Chemo[a] (*N* = 276)
Clinical scenario 1—Can you indicate the reason(s) for determining your PSA value? Please select all that apply (multiple answers possible)									
I wanted to undergo screening/early detection for prostate cancer.	895 (25.1)	61 (29.3)	28 (35.4)	362 (27.5)	76 (27.4)	63 (18.6)	32 (19.3)	38 (26.2)	44 (15.9)
The doctor said that screening for/early detection of prostate cancer would be good for me.	528 (14.8)	50 (24.0)	15 (19.0)	180 (13.7)	52 (18.8)	49 (14.5)	23 (13.9)	23 (15.9)	19 (6.9)
I was having trouble urinating/peeing.	822 (23.0)	45 (21.6)	18 (22.8)	255 (19.4)	51 (18.4)	90 (26.5)	48 (28.9)	22 (15.2)	90 (32.6)
The doctor said there were other relevant symptoms that would allow for screening/early detection of prostate cancer (other than urinary complaints).	216 (6.0)	12 (5.8)	5 (6.3)	80 (6.1)	16 (5.8)	19 (5.6)	8 (4.8)	10 (6.9)	23 (8.3)
Determining the PSA value was part of a routine blood test.	1492 (41.8)	96 (46.2)	34 (43.0)	604 (45.9)	105 (37.9)	155 (45.7)	57 (34.3)	63 (43.4)	71 (25.7)
When the doctor performed a digital rectal examination (he/she was feeling the prostate with his/her finger) he/she felt something.	757 (21.2)	43 (20.7)	13 (16.5)	243 (18.5)	41 (14.8)	85 (25.1)	35 (21.1)	34 (23.4)	79 (28.6)
Had a full medical checkup for insurance policy/new employment and/or because of the passage of time since my last full check-up.	146 (4.1)	9 (4.3)	3 (3.8)	54 (4.1)	13 (4.7)	14 (4.1)	5 (3.0)	5 (3.4)	8 (2.9)
Other	452 (12.7)	13 (6.3)	9 (11.4)	169 (12.8)	34 (12.3)	33 (9.7)	23 (13.9)	15 (10.3)	60 (21.7)
I don't know what the reason was.	32 (0.9)	2 (1.0)	0 (0)	16 (1.2)	1 (0.4)	3 (0.9)	0 (0)	1 (0.7)	2 (0.7)
Clinical scenario 2—Did you undergo a digital rectal examination so that the doctor could feel the size, shape, and consistency of the prostate?									
Yes	3215 (90.0)	195 (93.8)	73 (92.4)	1176 (89.4)	246 (88.8)	292 (86.1)	151 (91.0)	137 (94.5)	246 (89.1)
No	356 (10.0)	13 (6.3)	6 (7.6)	140 (10.6)	31 (11.2)	47 (13.9)	15 (9.0)	8 (5.5)	30 (10.9)
Clinical scenario 3—When your doctor performed a digital rectal examination, did he/she tell you what he/she felt?									
Yes, the prostate felt smooth.	942 (29.3)	87 (44.6)	35 (47.9)	384 (32.7)	71 (28.9)	56 (19.2)	37 (24.5)	34 (24.8)	42 (17.1)
Yes, he/she felt something.	1685 (52.4)	69 (35.4)	27 (37.0)	569 (48.4)	121 (49.2)	172 (58.9)	92 (60.9)	81 (59.1)	167 (67.9)
No, he/she did not tell me what he/she felt.	333 (10.4)	20 (10.3)	6 (8.2)	121 (10.3)	34 (13.8)	30 (10.3)	15 (9.9)	12 (8.8)	21 (8.5)
I don't know.	255 (7.9)	19 (9.7)	5 (6.8)	102 (8.7)	20 (8.1)	34 (11.6)	7 (4.6)	10 (7.3)	16 (6.5)
Clinical scenario 4—Were other diagnostic tests performed? Please choose one or more of the following options									
Prostate biopsy	3355 (94.0)	196 (94.2)	75 (94.9)	1239 (94.1)	269 (97.1)	306 (90.3)	164 (98.8)	140 (96.6)	247 (89.5)
MRI scan	1777 (49.8)	119 (57.2)	52 (65.8)	619 (47.0)	111 (40.1)	164 (48.4)	104 (62.7)	74 (51.0)	131 (47.5)
PSMA/PET scan	641 (18.0)	9 (4.3)	7 (8.9)	159 (12.1)	56 (20.2)	57 (16.8)	51 (30.7)	34 (23.4)	91 (33.0)
Ultrasound imaging (sonography)	918 (25.7)	60 (28.8)	23 (29.1)	326 (24.8)	60 (21.7)	71 (20.9)	50 (30.1)	48 (33.1)	63 (22.8)
CT scan	959 (26.9)	18 (8.7)	13 (16.5)	251 (19.1)	85 (30.7)	94 (27.7)	74 (44.6)	49 (33.8)	131 (47.5)
Bone scan	1011 (28.3)	21 (10.1)	15 (19.0)	271 (20.6)	95 (34.3)	87 (25.7)	84 (50.6)	63 (43.4)	128 (46.4)

ADT = androgen deprivation therapy; AS = active surveillance; Chemo = chemotherapy; CT = computed tomography; MRI = magnetic resonance imaging; PET = positron emission tomography; PSA = prostate-specific antigen; PSMA = prostate-specific membrane antigen; RP = radical prostatectomy; RT = radiotherapy.

[a] Men who underwent chemotherapy as a single treatment or in combination with other, earlier treatments.

[17]. With respect to SF, some small differences were seen between treatments for men with Gleason 6 or 7 PCa at diagnosis. Most notable was the 11.1 point higher score for men with Gleason 6 or 7 PCa who underwent RT compared with the total RT group. In the study by Venderbos et al. [16], the mean EPIC SF scores were 53.9 for AS, 34.2 for RP, and 41.1 for RT, as compared with a median score of 66.7 for AS, 22.2 for RP, and 27.8 for RT in EUPROMS 2.0 (Supplementary Table 1). Healthy men without PCa reported a mean SF score of 35.3 [16], and the EPIC SF norm score for 112 controls without PCa was 55.8) [17]. Recently, Lane et al. [18] published PRO data of men who were randomized to, or chose one of, three treatments in the ProtecT study. In the ProtecT study, in both the randomized and the nonrandomized group, ≥97% of men had Gleason 6 or 7 PCa at diagnosis [19]. In the recent article, data were analyzed according to the treatment-received analyses [18]. For UI, the mean EPIC scores of 91.8 for active monitoring, 79.3 for RP, and 90.6 for RT were seen 3–4 yr after treatment. With respect to SF, the mean EPIC scores of 47.5 for active monitoring, 24.6 for RP, and 33.6 for RT were seen 3–4 yr after treatment [18]. In the study by Barocas et al. [20], EPIC-26 UI and SF domain scores 3 yr after treatment are described by D'Amico risk group. Men with low-risk PCa undergoing AS, RP, or RT reported mean UI scores of 86 , 75 , and 86 versus 83 , 71 , and 86 for men with intermediate-risk PCa following AS, RP, or RT, respectively. With respect to the SF domain scores, low-risk PCa patients on AS reported a mean score of 55 , those on RP reported a mean score of 46 , and those on RT reported a mean score of 47 . For intermediate-risk patients, these scores were lower: AS 52 , RP 39 , and RT 40 (Supplementary Table 1) [20].

As described in Section 3.2.5, age (next to treatment) plays a role in the reported UI and SF scores of men. This

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was acknowledged in the treatment-received analysis of the ProtecT PROs, where some impacts were greater in men aged 65–69 yr at diagnosis than in men aged 50–64 yr [18]. In the study by Barocas et al. [20], again a relation with age is seen on the reported UI and SF domain scores. Men aged 65–75 yr and following AS, RP, or RT had consistently lower scores than men aged 55–<65 yr. It should be noted, however, that results should be interpreted with caution.

International guidelines have been highlighting the importance of SDM for PCa treatment [21,22]. The SDM-Q-9 summary scores are at the top half of the score range for all treatments. However, when looking at some of the individual items reflecting elements of SDM, nuances are seen between treatments. For instance, 60.7% and 63.0% of men treated with RP-RT-ADT and chemotherapy, respectively, completely agreed that the doctor made it clear that a treatment decision needs to be taken, as opposed to 30.8%

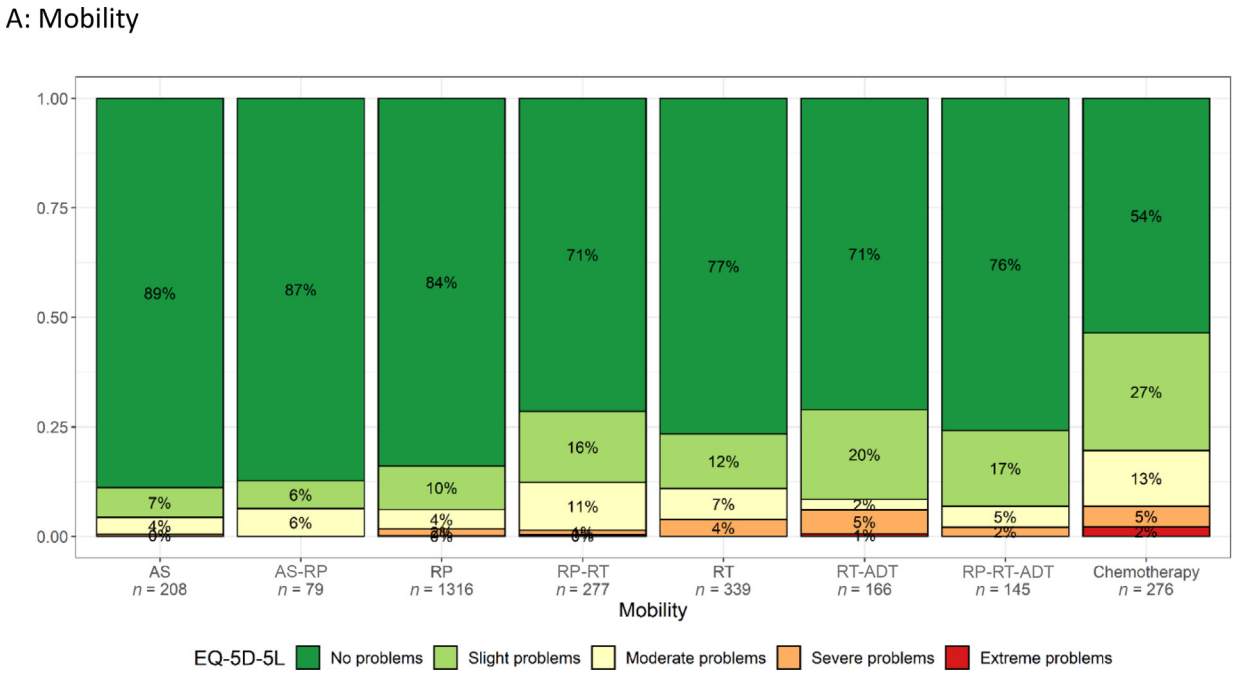

Fig. 1 – EQ-5D-5L dimension scores for: (A) mobility, (B) self-care, (C) usual activities, (D) pain/discomfort, and (E) anxiety/depression. ADT = androgen deprivation therapy; AS = active surveillance; RP = radical prostatectomy; RT = radiotherapy.

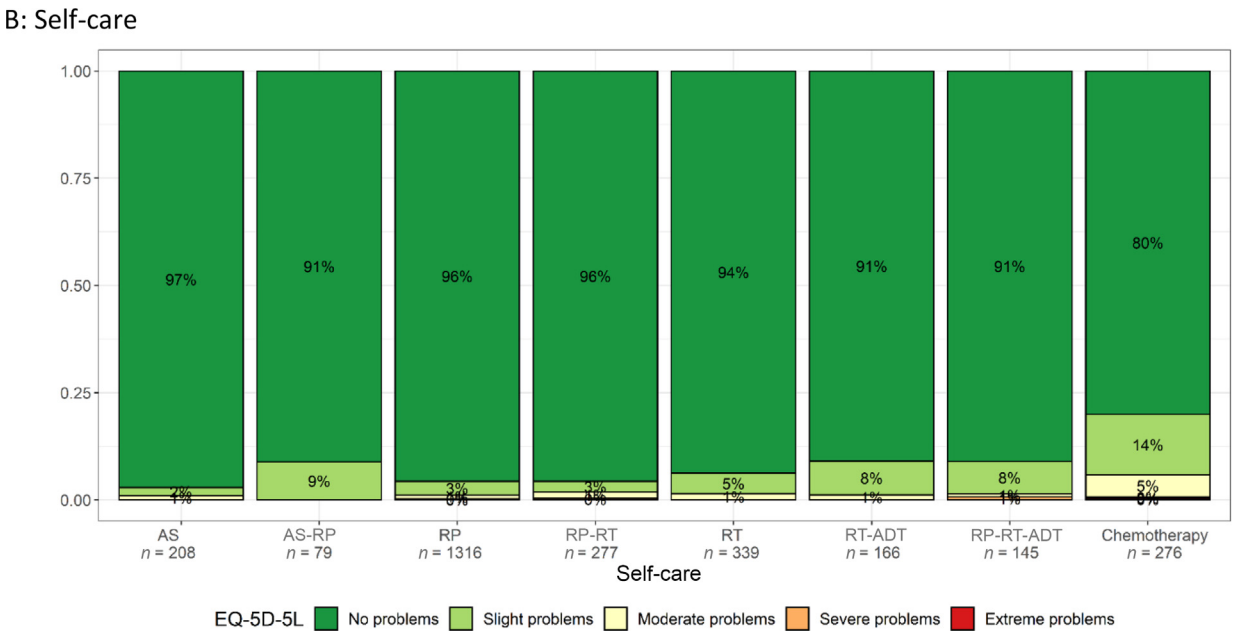

Fig. 1 (*continued*)

for men on AS and 35.4% on AS-RP. This might be related to the tumor characteristics of men who have already undergone RP-RT-ADT or chemotherapy and hence the urgency of subsequent treatment, as opposed to men having the option to choose treatment for lower-risk disease. Sharing individual item data from SDM-Q-9 for the various treatments may help future patients in understanding the concept of SDM better and learning what elements contribute to such an overarching phenomenon. There will always be a share of patients who prefer that the doctor makes the final treatment decision. However, when men realize that SDM encompasses more than just making the final treatment decision, they can still feel engaged and actively involved in the SDM process, potentially influencing future feelings of decisional regret.

The strength of EUPROMS 2.0 is that Europa Uomo was again able to mobilize a large sample of international PCa patients to complete the EUPROMS 2.0 survey. About 30%

C: Usual activities

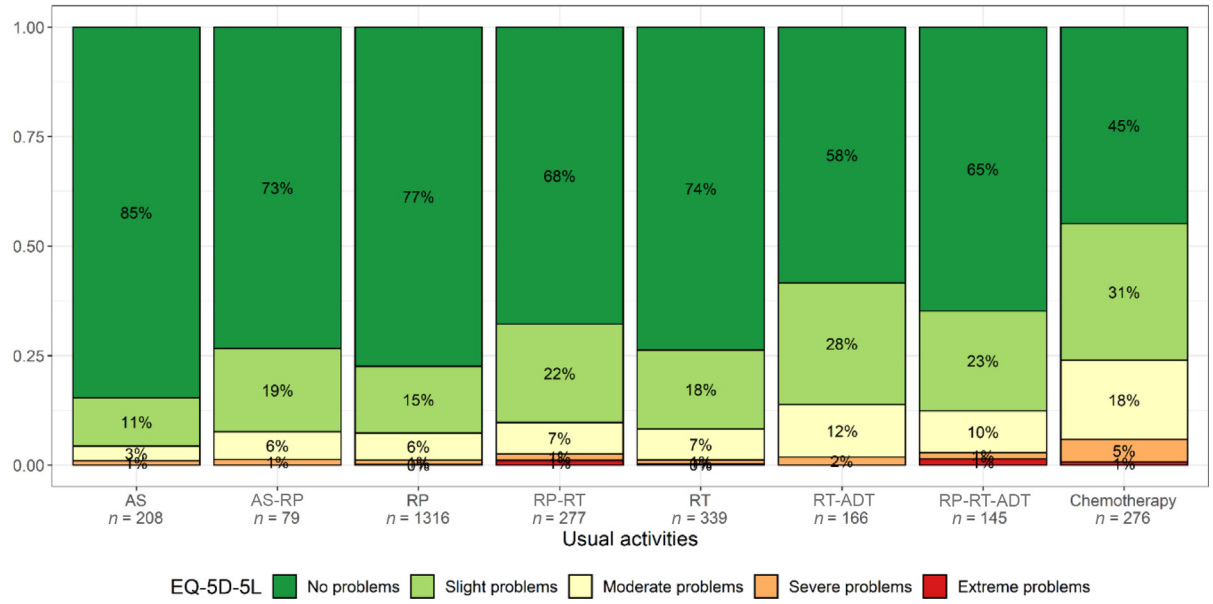

Fig. 1 (*continued*)

D: Pain/discomfort

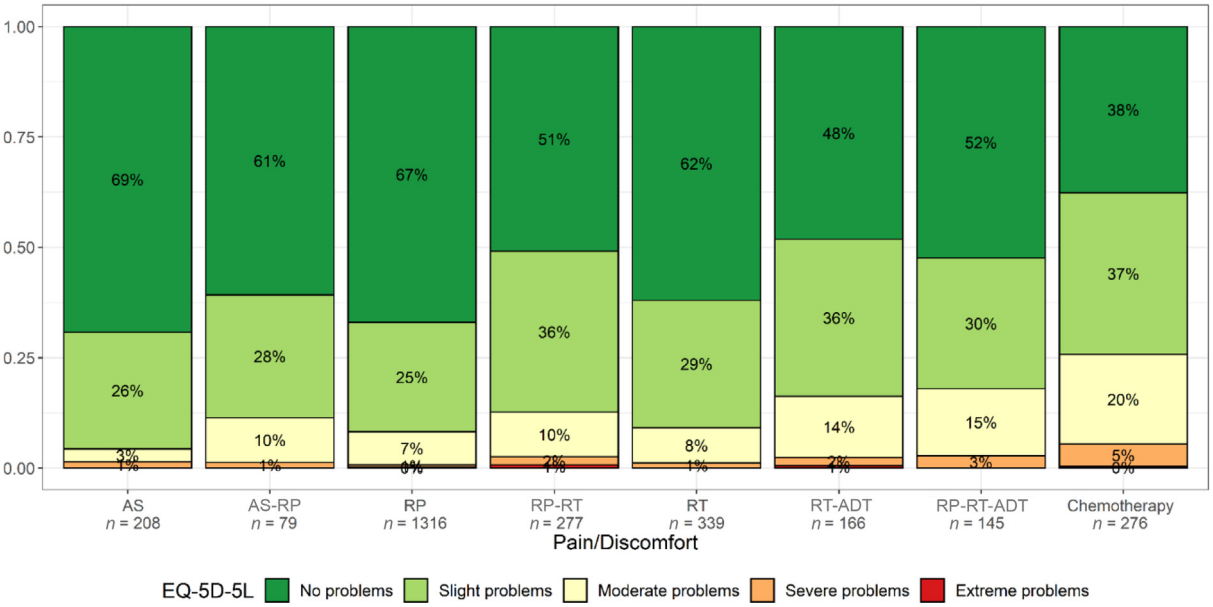

Fig. 1 (*continued*)

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E: Anxiety/depression

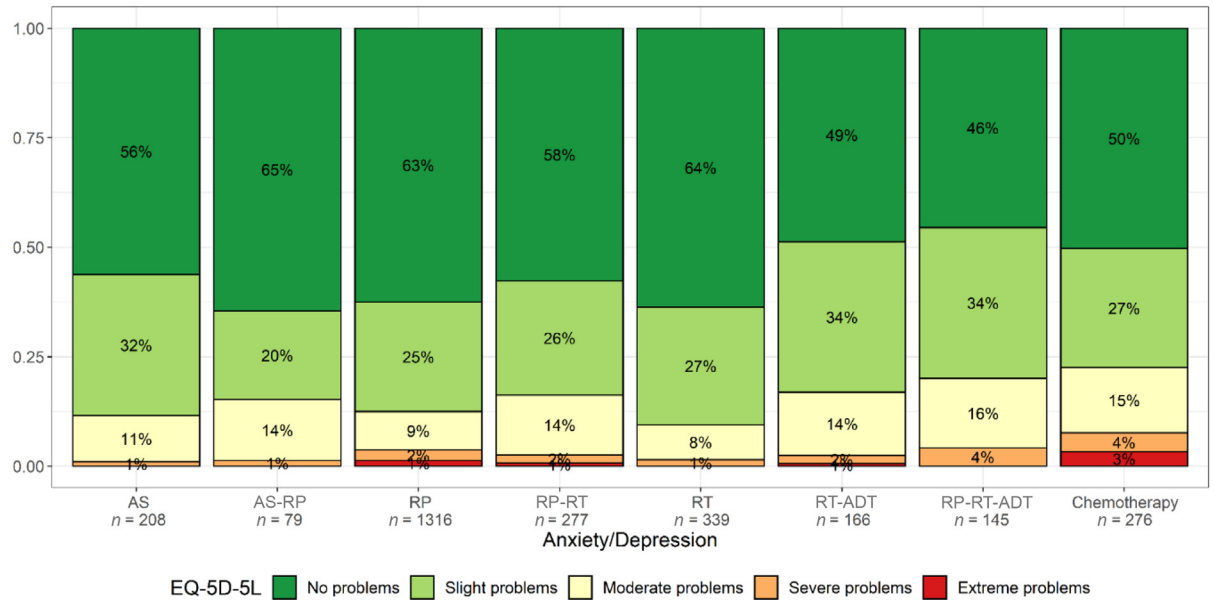

Fig. 1 (*continued*)

Table 3 – EORTC-QLQ-C30 scales

	AS (*N* = 208)	AS-RP (*N* = 79)	RP (*N* = 1316)	RP-RT (*N* = 277)	RT (*N* = 339)	RT-ADT (*N* = 166)	RP-RT-ADT (*N* = 145)	Chemo [a] (*N* = 276)
Functional scales[b], median (IQR)								
Physical	100 91.7–100	100 86.7–100	93.3 86.7–100	93.3 80–100	93.3 80–100	86.7 80–100	93.3 80–100	86.7 60–93.3
Role	100 100–100	100 83.3–100	100 83.3–100	100 66.7–100	100 83.3–100	100 66.7–100	100 66.7–100	83.3 62.5–100
Cognitive	100 83.3–100	83.3 83.3–100	83.3 83.3–100	83.3 83.3–100	83.3 83.3–100	83.3 66.7–100	83.3 66.7–100	83.3 66.7–100
Emotional	91.7 75–100	91.7 75–100	91.7 75–100	91.7 66.7–100	91.7 75–100	83.3 66.7–91.7	83.3 66.7–91.7	83.3 66.7–91.7
Social	100 83.3–100	83.3 66.7–100	83.3 66.7–100	83.3 66.7–100	83.3 66.7–100	83.3 66.7–100	83.3 66.7–100	83.3 66.7–100
Symptom scales[c], median (IQR)								
Fatigue	11.1 0–33.3	11.1 0–33.3	11.1 0–33.3	22.2 0–33.3	22.2 0–33.3	33.3 11.1–44.4	33.3 11.1–33.3	33.3 19.4–55.6
Pain	0 0–16.7	0 0–16.7	0 0–16.7	0 0–16.7	0 0–16.7	0 0–33.3	0 0–16.7	16.7 0–33.3
Nausea & vomiting	0 0–0	0 0–0	0 0–0	0 0–0	0 0–0	0 0–0	0 0–0	0 0–0
Single items[d], median (IQR)								
Dyspnea	0 0–33.3	0 0–0	0 0–8.3	0 0–33.3	0 0–33.3	0 0–33.3	0 0–33.3	0 0–33.3
Loss of appetite	0 0–0	0 0–0	0 0–0	0 0–0	0 0–0	0 0–0	0 0–0	0 0–33.3
Insomnia	0 0–33.3	33.3 0–33.3	0 0–33.3	33.3 0–33.3	33.3 0–33.3	33.3 0–33.3	33.3 0–66.7	33.3 0–66.7
Constipation	0 0–33.3	0 0–33.3	0 0–33.3	0 0–33.3	0 0–33.3	0 0–33.3	0 0–33.3	0 0–33.3
Diarrhea	0 0–0	0 0–0	0 0–0	0 0–33.3	0 0–33.3	0 0–33.3	0 0–33.3	0 0–33.3
Financial difficulties	0 0–0	0 0–0	0 0–0	0 0–0	0 0–0	0 0–0	0 0–0	0 0–0
Global health status[b], median (IQR)	83.3 75–91.7	83.3 66.7–91.7	83.3 66.7–91.7	83.3 66.7–83.3	83.3 66.7–91.7	75 66.7–83.3	83.3 66.7–83.3	75 50–83.3

ADT = androgen deprivation therapy; AS = active surveillance; Chemo = chemotherapy; IQR = interquartile range; RP = radical prostatectomy; RT = radiotherapy.
[a] Men who underwent chemotherapy as a single treatment or in combination with other, earlier treatments.
[b] Functional scales/global health status: a higher score indicates better functioning/better quality of life.
[c] Symptom scales: a higher score means more symptoms, worse functioning.
[d] Single items: a higher score means more symptoms, worse functioning.

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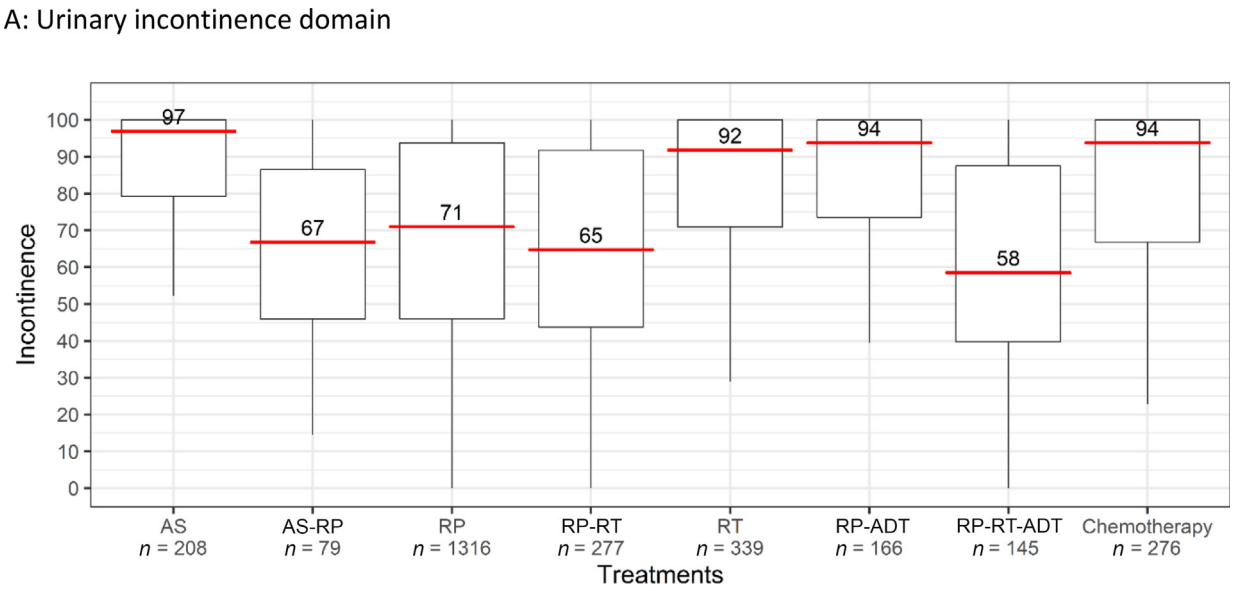

Fig. 2 – EPIC-26 domain scores for: (A) urinary incontinence domain, (B) urinary irritable/obstructive domain, (C) bowel domain, (D) sexual function domain, and (E) hormonal domain. ADT = androgen deprivation therapy; AS = active surveillance; RP = radical prostatectomy; RT = radiotherapy.

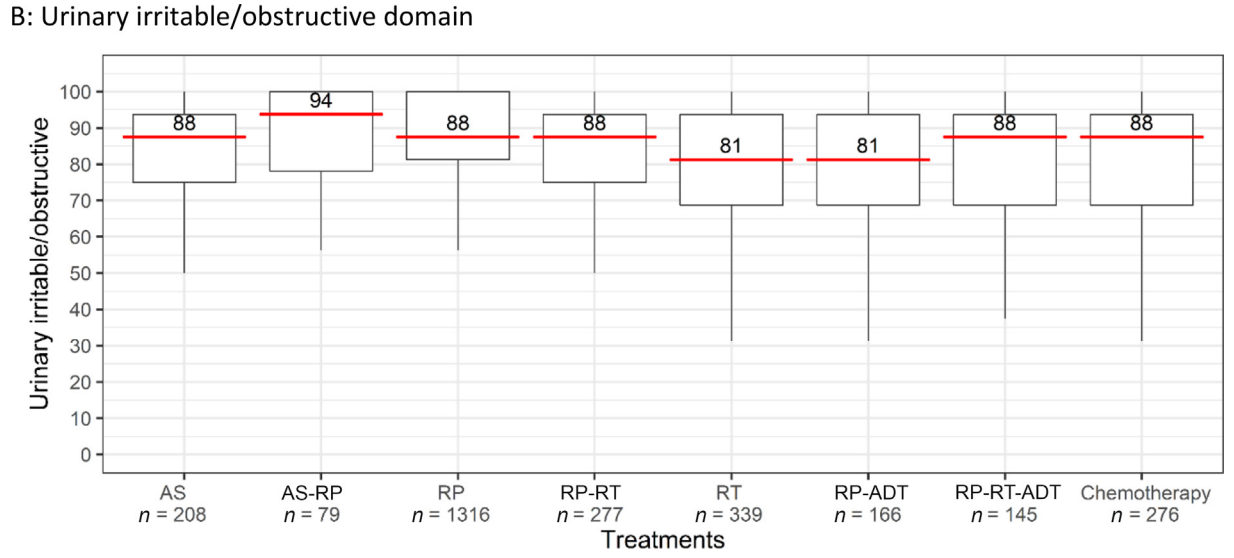

Fig. 2 (*continued*)

of men had already participated in the first EUPROMS survey, and 70% of men were new respondents. Sensitivity analyses showed that responses from new respondents did not differ significantly from the men who had already participated in the first EUPROMS survey. Besides European, Canadian and American PCa patients were also represented. Furthermore, we were able to confirm the results of the first EUPROMS study and additionally grasp knowledge on reasons for undergoing a PSA test and levels of SDM experienced. A limitation is that no pretreatment PRO data were available, and therefore the impact of, for example, time after treatment on self-reported PRO data could not be assessed. However, as indicated earlier by Europa Uomo, it is its goal to inform future PCa patients about the impact of PCa treatment through self-reported PRO data of fellow patients collected outside a clinical trial setting [1]. Furthermore, a total of 65.7% of participants achieved higher education, which is not likely to reflect the educational levels of the general population. While we were able to collect more information about tumor stage and grade, information on which men were treated with uni- or bilateral nerve-sparing RP is missing. We know, however, that 18.5% of men who underwent RP was treated between 2010 and 2014 and >65% of men since 2015.

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C: Bowel domain

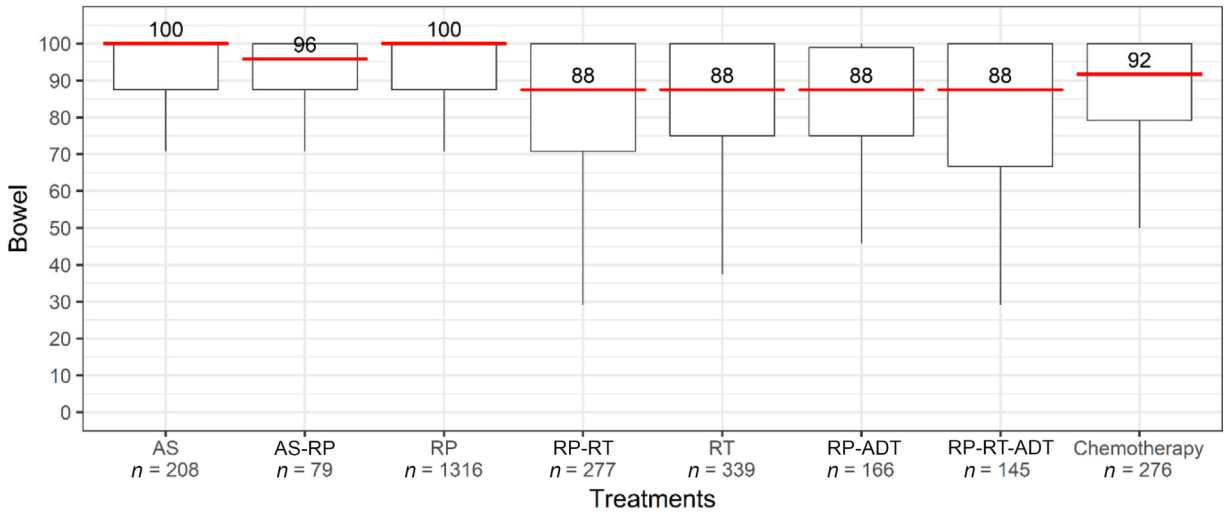

Fig. 2 (*continued*)

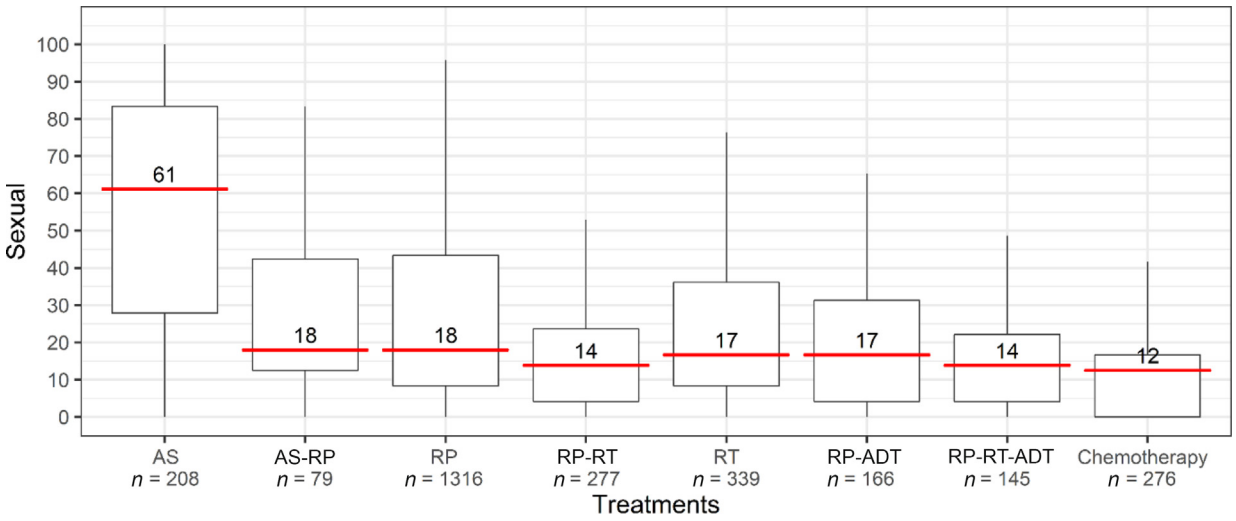

Fig. 2 (*continued*)

5. Conclusions

With the EUPROMS 2.0 survey, Europa Uomo has once more been able to collect a large sample of PROMS data outside a clinical trial setting on the adverse effects of PCa treatment. A total of 3571 international patients have contributed their experiences after PCa treatment confirming that treatment for PCa mainly affects UI (RP), functions, as well as fatigue and insomnia. Such information can be used to inform future fellow patients about the impact of PCa treatment and engage in informed decision-making and SDM. In doing so, Europa Uomo is bringing its mission forward to direct toward a better patient-doctor relationship, to offer patients ready access to responsible information and a better understanding of their disease and treatment.

Author contributions: Lionne D.F. Venderbos had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Venderbos, Remmers, Deschamps, Pereira-Azevedo, Roobol.
Acquisition of data: Deschamps, Dowling, Carl, Pereira-Azevedo.
Analysis and interpretation of data: Remmers, Venderbos, Roobol, Deschamps.
Drafting of the manuscript: Venderbos.
Critical revision of the manuscript for important intellectual content: Remmers, Deschamps, Dowling, Carl, Pereira-Azevedo, Roobol.
Statistical analysis: Remmers.
Obtaining funding: Deschamps.

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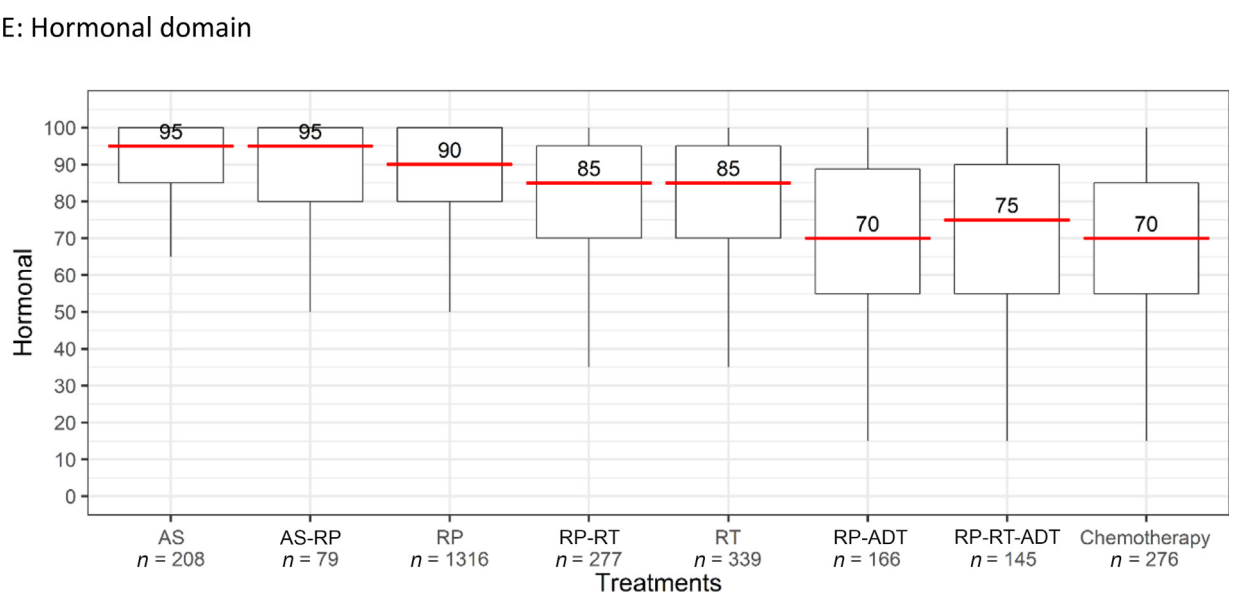

Fig. 2 (*continued*)

Table 4 – Outcomes of the nine-item Shared Decision Making Questionnaire (SDM-Q-9)

	Overall (*N* = 3571)	AS (*N* = 208)	AS-RP (*N* = 79)	RP (*N* = 1316)	RP-RT (*N* = 277)	RT (*N* = 339)	RT-ADT (*N* = 166)	RP-RT-ADT (*N* = 145)	Chemo [a], (*N* = 276)
SDM-Q-9 Summary score[b]									
Median (IQR)	34 (25–41)	33 (23–40)	34 (27–40)	35 (27–42)	32 (25–40)	33 (24–40)	33 (20–38)	34 (27–42)	31 (22–39)
My doctor made clear that a decision needs to be made.									
Completely disagree	166 (4.6)	11 (5.3)	4 (5.1)	63 (4.8)	17 (6.1)	16 (4.7)	5 (3.0)	2 (1.4)	13 (4.7)
Strongly disagree	106 (3.0)	12 (5.8)	2 (2.5)	29 (2.2)	12 (4.3)	6 (1.8)	12 (7.2)	4 (2.8)	3 (1.1)
Somewhat disagree	125 (3.5)	24 (11.5)	6 (7.6)	34 (2.6)	8 (2.9)	8 (2.4)	3 (1.8)	2 (1.4)	10 (3.6)
Somewhat agree	441 (12.3)	44 (21.2)	14 (17.7)	137 (10.4)	36 (13.0)	55 (16.2)	15 (9.0)	17 (11.7)	23 (8.3)
Strongly agree	926 (25.9)	53 (25.5)	25 (31.6)	384 (29.2)	68 (24.5)	97 (28.6)	39 (23.5)	32 (22.1)	53 (19.2)
Completely agree	1807 (50.6)	64 (30.8)	28 (35.4)	669 (50.8)	136 (49.1)	157 (46.3)	92 (55.4)	88 (60.7)	174 (63.0)
My doctor wanted to know exactly how I want to be involved in making the decision.									
Completely disagree	261 (7.3)	16 (7.7)	4 (5.1)	78 (5.9)	23 (8.3)	26 (7.7)	18 (10.8)	8 (5.5)	23 (8.3)
Strongly disagree	185 (5.2)	14 (6.7)	4 (5.1)	51 (3.9)	16 (5.8)	22 (6.5)	11 (6.6)	7 (4.8)	12 (4.3)
Somewhat disagree	256 (7.2)	21 (10.1)	5 (6.3)	85 (6.5)	21 (7.6)	23 (6.8)	14 (8.4)	13 (9.0)	20 (7.2)
Somewhat agree	627 (17.6)	40 (19.2)	14 (17.7)	197 (15.0)	47 (17.0)	68 (20.1)	28 (16.9)	31 (21.4)	53 (19.2)
Strongly agree	927 (26.0)	50 (24.0)	28 (35.4)	365 (27.7)	89 (32.1)	77 (22.7)	43 (25.9)	35 (24.1)	70 (25.4)
Completely agree	1315 (36.8)	67 (32.2)	24 (30.4)	540 (41.0)	81 (29.2)	123 (36.3)	52 (31.3)	51 (35.2)	98 (35.5)
My doctor told me that there are different options for treating my medical condition.									
Completely disagree	305 (8.5)	12 (5.8)	2 (2.5)	101 (7.7)	33 (11.9)	30 (8.8)	19 (11.4)	12 (8.3)	30 (10.9)
Strongly disagree	254 (7.1)	8 (3.8)	7 (8.9)	66 (5.0)	14 (5.1)	24 (7.1)	17 (10.2)	7 (4.8)	24 (8.7)
Somewhat disagree	214 (6.0)	15 (7.2)	6 (7.6)	77 (5.9)	19 (6.9)	21 (6.2)	13 (7.8)	15 (10.3)	35 (12.7)
Somewhat agree	549 (15.4)	37 (17.8)	12 (15.2)	181 (13.8)	47 (17.0)	57 (16.8)	25 (15.1)	19 (13.1)	48 (17.4)
Strongly agree	851 (23.8)	50 (24.0)	21 (26.6)	318 (24.2)	72 (26.0)	80 (23.6)	28 (16.9)	34 (23.4)	54 (19.6)
Completely agree	1398 (39.1)	86 (41.3)	31 (39.2)	573 (43.5)	92 (33.2)	127 (37.5)	64 (38.6)	58 (40.0)	85 (30.8)
My doctor precisely explained the advantages and disadvantages of the treatment options.									
Completely disagree	298 (8.3)	14 (6.7)	7 (8.9)	75 (5.7)	30 (10.8)	31 (9.1)	19 (11.4)	8 (5.5)	35 (12.7)
Strongly disagree	226 (6.3)	14 (6.7)	1 (1.3)	66 (5.0)	8 (2.9)	28 (8.3)	17 (10.2)	7 (4.8)	23 (8.3)

(*continued on next page*)

Table 4 (*continued*)

	Overall (*N* = 3571)	AS (*N* = 208)	AS-RP (*N* = 79)	RP (*N* = 1316)	RP-RT (*N* = 277)	RT (*N* = 339)	RT-ADT (*N* = 166)	RP-RT-ADT (*N* = 145)	Chemo [a], (*N* = 276)
Somewhat disagree	320 (9.0)	26 (12.5)	8 (10.1)	105 (8.0)	29 (10.5)	30 (8.8)	17 (10.2)	20 (13.8)	17 (6.2)
Somewhat agree	717 (20.1)	42 (20.2)	16 (20.3)	259 (19.7)	54 (19.5)	63 (18.6)	26 (15.7)	29 (20.0)	59 (21.4)
Strongly agree	835 (23.4)	49 (23.6)	23 (29.1)	315 (23.9)	77 (27.8)	79 (23.3)	43 (25.9)	27 (18.6)	61 (22.1)
Completely agree	1175 (32.9)	63 (30.3)	24 (30.4)	496 (37.7)	79 (28.5)	108 (31.9)	44 (26.5)	54 (37.2)	81 (29.3)
My doctor helped me understand all the information.									
Completely disagree	191 (5.3)	13 (6.3)	3 (3.8)	52 (4.0)	16 (5.8)	20 (5.9)	16 (9.6)	7 (4.8)	13 (4.7)
Strongly disagree	167 (4.7)	8 (3.8)	1 (1.3)	57 (4.3)	9 (3.2)	20 (5.9)	9 (5.4)	5 (3.4)	16 (5.8)
Somewhat disagree	343 (9.6)	22 (10.6)	7 (8.9)	111 (8.4)	35 (12.6)	30 (8.8)	16 (9.6)	17 (11.7)	25 (9.1)
Somewhat agree	763 (21.4)	48 (23.1)	16 (20.3)	266 (20.2)	56 (20.2)	62 (18.3)	38 (22.9)	36 (24.8)	51 (18.5)
Strongly agree	987 (27.6)	48 (23.1)	28 (35.4)	377 (28.6)	88 (31.8)	102 (30.1)	44 (26.5)	31 (21.4)	83 (30.1)
Completely agree	1120 (31.4)	69 (33.2)	24 (30.4)	453 (34.4)	73 (26.4)	105 (31.0)	43 (25.9)	49 (33.8)	88 (31.9)
My doctor asked me which treatment option I prefer.									
Completely disagree	434 (12.2)	18 (8.7)	5 (6.3)	122 (9.3)	33 (11.9)	64 (18.9)	35 (21.1)	13 (9.0)	49 (17.8)
Strongly disagree	248 (6.9)	12 (5.8)	6 (7.6)	72 (5.5)	13 (4.7)	20 (5.9)	20 (12.0)	10 (6.9)	29 (10.5)
Somewhat disagree	302 (8.5)	26 (12.5)	7 (8.9)	87 (6.6)	22 (7.9)	28 (8.3)	19 (11.4)	9 (6.2)	35 (12.7)
Somewhat agree	555 (15.5)	37 (17.8)	13 (16.5)	190 (14.4)	52 (18.8)	45 (13.3)	17 (10.2)	24 (16.6)	47 (17.0)
Strongly agree	758 (21.2)	46 (22.1)	20 (25.3)	294 (22.3)	66 (23.8)	71 (20.9)	36 (21.7)	35 (24.1)	48 (17.4)
Completely agree	1274 (35.7)	69 (33.2)	28 (35.4)	551 (41.9)	91 (32.9)	111 (32.7)	39 (23.5)	54 (37.2)	68 (24.6)
My doctor and I thoroughly weighed the different treatment options.									
Completely disagree	468 (13.1)	28 (13.5)	7 (8.9)	140 (10.6)	34 (12.3)	58 (17.1)	30 (18.1)	16 (11.0)	39 (14.1)
Strongly disagree	298 (8.3)	17 (8.2)	3 (3.8)	89 (6.8)	16 (5.8)	29 (8.6)	23 (13.9)	13 (9.0)	39 (14.1)
Somewhat disagree	434 (12.2)	24 (11.5)	14 (17.7)	152 (11.6)	41 (14.8)	35 (10.3)	26 (15.7)	19 (13.1)	36 (13.0)
Somewhat agree	692 (19.4)	37 (17.8)	15 (19.0)	239 (18.2)	65 (23.5)	63 (18.6)	22 (13.3)	35 (24.1)	51 (18.5)
Strongly agree	725 (20.3)	41 (19.7)	17 (21.5)	319 (24.2)	57 (20.6)	66 (19.5)	28 (16.9)	23 (15.9)	44 (15.9)
Completely agree	954 (26.7)	61 (29.3)	23 (29.1)	377 (28.6)	64 (23.1)	88 (26.0)	37 (22.3)	39 (26.9)	67 (24.3)
My doctor and I selected a treatment option together.									
Completely disagree	452 (12.7)	25 (12.0)	6 (7.6)	134 (10.2)	28 (10.1)	54 (15.9)	26 (15.7)	14 (9.7)	37 (13.4)
Strongly disagree	256 (7.2)	10 (4.8)	6 (7.6)	85 (6.5)	15 (5.4)	24 (7.1)	16 (9.6)	8 (5.5)	31 (11.2)
Somewhat disagree	365 (10.2)	24 (11.5)	7 (8.9)	111 (8.4)	31 (11.2)	41 (12.1)	16 (9.6)	14 (9.7)	29 (10.5)
Somewhat agree	674 (18.9)	38 (18.3)	13 (16.5)	243 (18.5)	56 (20.2)	67 (19.8)	35 (21.1)	25 (17.2)	56 (20.3)
Strongly agree	765 (21.4)	47 (22.6)	19 (24.1)	303 (23.0)	77 (27.8)	69 (20.4)	33 (19.9)	37 (25.5)	52 (18.8)
Completely agree	1059 (29.7)	64 (30.8)	28 (35.4)	440 (33.4)	70 (25.3)	84 (24.8)	40 (24.1)	47 (32.4)	71 (25.7)
My doctor and I reached an agreement on how to proceed.									
Completely disagree	218 (6.1)	14 (6.7)	2 (2.5)	57 (4.3)	17 (6.1)	25 (7.4)	11 (6.6)	6 (4.1)	18 (6.5)
Strongly disagree	140 (3.9)	5 (2.4)	3 (3.8)	39 (3.0)	9 (3.2)	13 (3.8)	8 (4.8)	5 (3.4)	20 (7.2)
Somewhat disagree	231 (6.5)	13 (6.3)	5 (6.3)	72 (5.5)	26 (9.4)	25 (7.4)	13 (7.8)	10 (6.9)	15 (5.4)
Somewhat agree	633 (17.7)	37 (17.8)	11 (13.9)	232 (17.6)	44 (15.9)	67 (19.8)	26 (15.7)	28 (19.3)	53 (19.2)
Strongly agree	898 (25.1)	44 (21.2)	31 (39.2)	345 (26.2)	82 (29.6)	83 (24.5)	40 (24.1)	38 (26.2)	61 (22.1)
Completely agree	1451 (40.6)	95 (45.7)	27 (34.2)	571 (43.4)	99 (35.7)	126 (37.2)	68 (41.0)	58 (40.0)	109 (39.5)

ADT = androgen deprivation therapy; AS = active surveillance; Chemo = chemotherapy; IQR = interquartile range; RP = radical prostatectomy; RT = radiotherapy.
[a] Men who underwent chemotherapy as a single treatment or in combination with other, earlier treatments.
[b] Score range 0–45; a higher score indicates a higher level of perceived shared decision-making.

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Appendix A. Supplementary data

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