

# EUROPA UOMO<sup>7</sup>

The Voice of Men with Prostate Cancer in Europe



## EUPROMS

Europa Uomo's study on quality of life  
after prostate cancer treatment

**SUMMARY OF FINDINGS**



EUPROMS (the Europa Uomo Patient Reported Outcome Study) is the first ever prostate cancer quality of life survey conducted by patients for patients.

**EUROPA UOMO**

The Voice of Men with Prostate Cancer in Europe

# Contents

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<b>About EUPROMS</b>	4
About the questionnaire	4
Geographical response	5
About the respondents	5
About the analysis	9
Reporting the study results	9
How we hope the results will be used	9

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<b>EUPROMS findings</b>	10
1. General findings about quality of life	11
2. Findings about discomfort, tiredness and insomnia	12
3. Findings about mental health	14
4. Findings about sexual function	17
5. Findings about urinary incontinence	21

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<b>Key messages from EUPROMS</b>	25
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Further information	28
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Links	30
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# About EUPROMS

**The EUPROMS study (Europa Uomo Patient Reported Outcome Study), which reported in 2020, is the first ever prostate cancer quality of life survey conducted by patients for patients. This booklet, written by André Deschamps, Chairman of Europa Uomo, and health writer Simon Crompton, is a non-academic overview of its findings.**

Europa Uomo (Italian for Europe man) is a European advocacy movement representing 27 prostate patients' groups in countries across Europe. Quality of life for men with prostate cancer is intrinsic to all Europa Uomo's work. Early diagnosis brings quality of life benefits because the effects of cancer and its treatments are likely to be far greater if diagnosed late.

High quality, personalised treatment in specialised centres can also bring better quality of life. Up until now, good research about the effects of prostate cancer and its treatments on day-to-day living has been thin on the ground. This means that treatment choices and policy decisions may not always be based on sound evidence.

So in 2019, Europa Uomo commissioned Europe-wide research on the quality of life of men with prostate cancer – the first time such research has been conducted by patients themselves. It was based on an online survey exploring experiences of treatment and life afterwards.

Based on nearly 3,000 responses, the survey findings provide a new perspective. Most other quality of life studies are conducted by doctors in a clinical environment, when patients are visiting for treatment or check-ups.

The EUPROMS questionnaire was completed by men in their own time, in the comfort of their homes, meaning they had more time to consider their answers and might have felt more at ease to say how they really feel.

The findings here present an overview of what EUPROMS discovered, and are designed for a general, rather than a scientific, audience. They are a “snapshot” picture of what quality of life issues are being experienced by men with prostate cancer at a particular point of time. The study could not look at individual respondents' medical condition before treatment, or the details of how prostate cancer patients differ from the population in general. That would have been a different kind of study.

The findings provide information that may:

- help patients and their doctors make decisions about treatments
- help in campaigning for early diagnosis of prostate cancer and promoting approaches such as active surveillance

You are welcome to publicise the results or charts without permission, but they must always be credited to Europa Uomo's EUPROMS study.

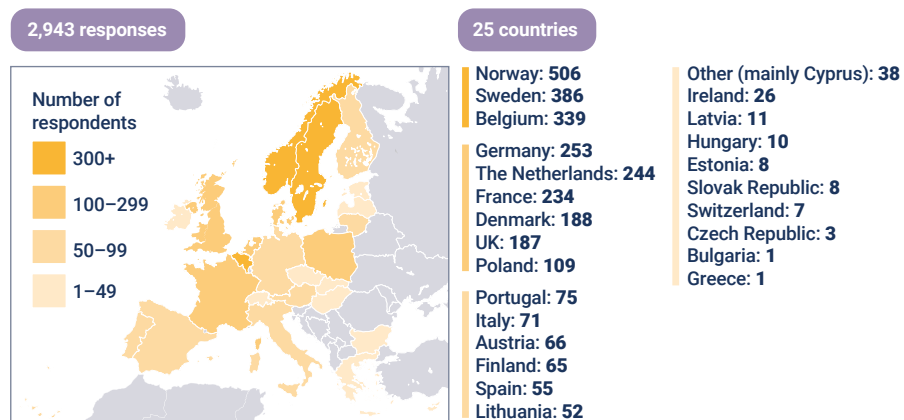
## About the questionnaire

- 20-minute online survey for men who had received treatment for prostate cancer
- Available in 19 languages
- Used validated quality-of-life questionnaires: EPIC-26 and EORTC-QLQ and EQ-5D-5L
- Responses were anonymous



## Geographical response

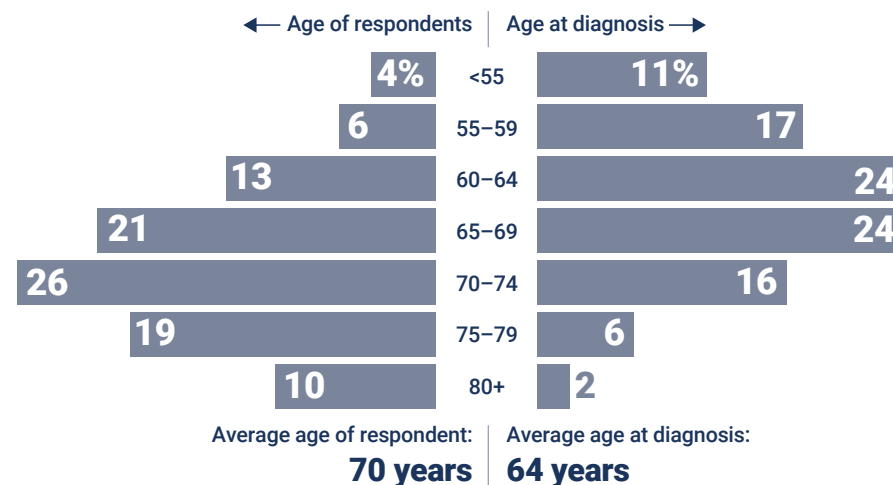
There was a wide response across 25 countries, but there was an under-representation from Eastern Europe and some under-representation from Southern Europe.



## About the respondents

- 2943 responses from 25 countries
- Average age: 70
- Average age at diagnosis: 64
- 82% live with a partner
- Most had had surgery as first treatment

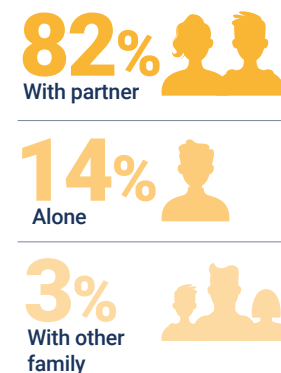
As you will see from the distribution graph of age at first diagnosis, more than 50% of respondents were diagnosed before they were 65 (see page 7). This counters the idea that prostate cancer is a disease of old men.



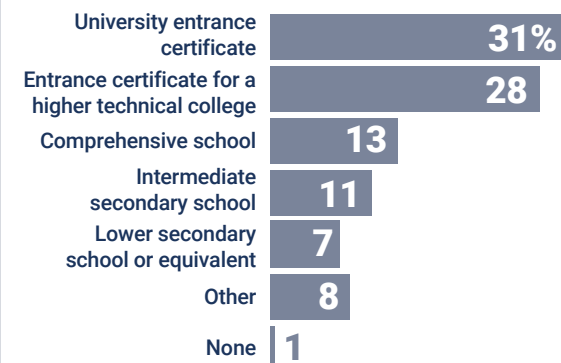
Most respondents were living with a partner, which is important given the effects that treatment can have on sexual function.

There is a slight bias in respondent profile towards a higher level of education.

## Living situation

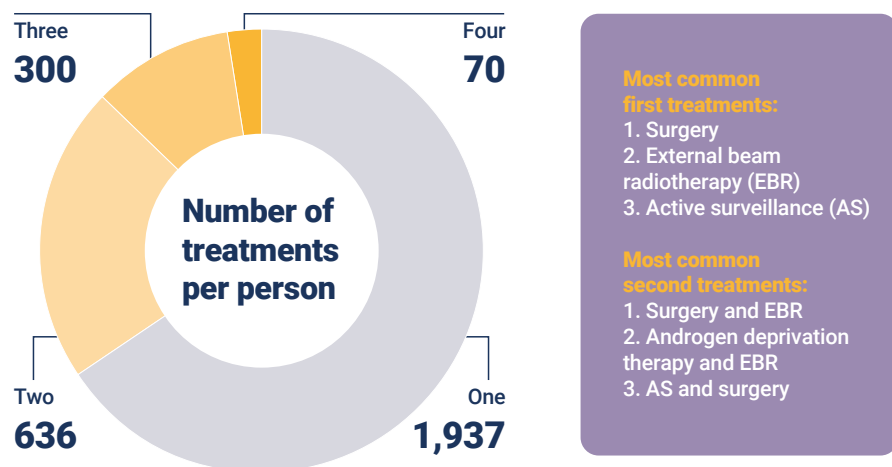


## Education





Most patients had only received one treatment up to the start of the survey. About 60% of respondents had received radical prostatectomy, so the overall results will be influenced by the effects on quality of life of that particular treatment.



## About the analysis

Data was analysed by Professor Monique Roobol and her team at Erasmus University Medical Centre, Department of Urology, Rotterdam.

Some of the findings here are based on raw survey responses and statistical significance has not been calculated or displayed. However, the findings may help provide vital information for clinical decision-making.

## Reporting the study results

The study began in August 2019 and the first results were reported in January 2020. Since then, its findings have been reported and discussed widely, for example at:

- The European Association of Urologists (EAU) Congress 2020
- The EAU Section of Oncological Urology annual meeting
- The European Society for Medical Oncology (ESMO) Congress
- The European Multidisciplinary Congress on Urological Cancers (EMUC)
- A European Organisation for Research and Treatment of Cancer (EORTC) webinar

Findings have also been published in various publications including European Urology Focus magazine.

## How we hope the results will be used

The EUPROMS findings provide a “snapshot” picture of the quality of life issues experienced by men with prostate cancer across Europe at a particular point of time. They provide information that may help patients and their doctors make decisions about treatments.

They may also help in campaigning for early diagnosis of prostate cancer and promoting approaches such as active surveillance.





# EUPROMS findings

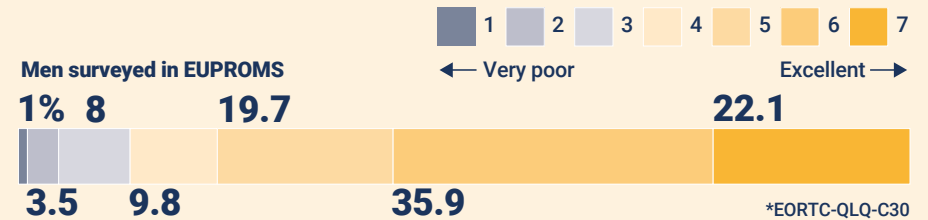
## 1. General findings about quality of life

Taken overall, respondents' quality of life is good. Chart G1 shows all the respondents rating their quality of life from one to seven, and the percentage in each category.

But some aspects of life are much better than others. Chart G2 shows how different aspects of quality of life are affected after treatment. The lower the score, the lower the quality of life. It's clear that lack of sexual function, and to a lesser extent incontinence, affect men's quality of life much more than other treatment after-effects.

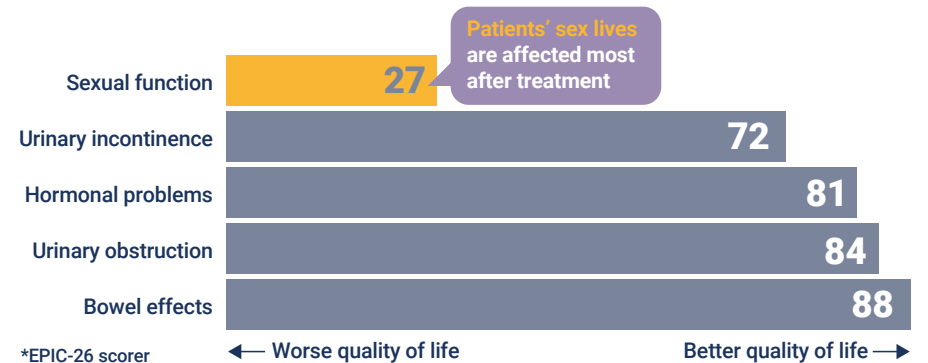
### (G1) Quality of life during the past week

Very poor to excellent (% of all respondents)



### (G2) How does treatment affect quality of life?

(Quality of life scores\*. Lowest score indicates most troublesome effects)



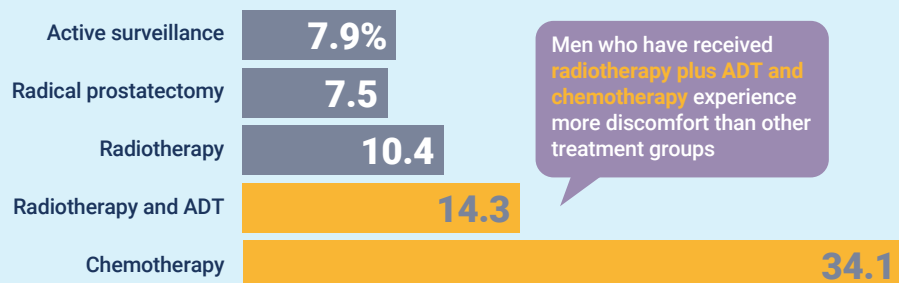


## 2. Findings about discomfort, tiredness and insomnia

Looking at specific aspects of quality of life after prostate cancer treatment, when it comes to pain and discomfort, this increases as men move through the treatment stages. More than three times the pain and discomfort are reported after chemotherapy compared with early stage treatments (D1).

### (D1) Which treatments are linked with pain or discomfort?

(% of respondents saying they were in moderate, severe or extreme pain/discomfort at time of survey\*)



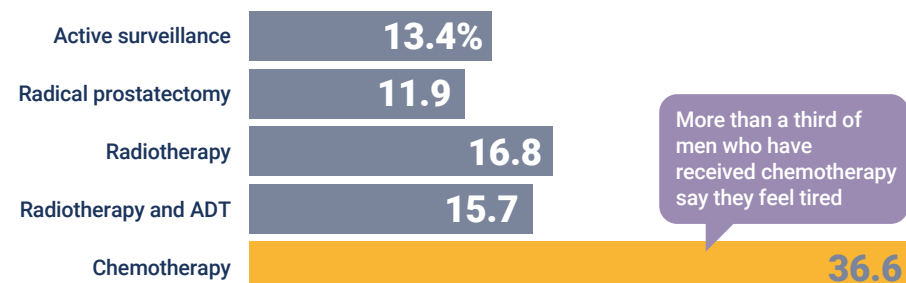
\*EQ-5D-5L questionnaire

For tiredness, more than one third of men who had received chemotherapy said they had felt tired in the past week – twice the number of other treatment groups (D2).

And with insomnia, the study found men were affected more after radiotherapy with ADT and also after chemotherapy (D3). The effects nearly double as treatment progresses.

### (D2) Which treatments are linked with tiredness?

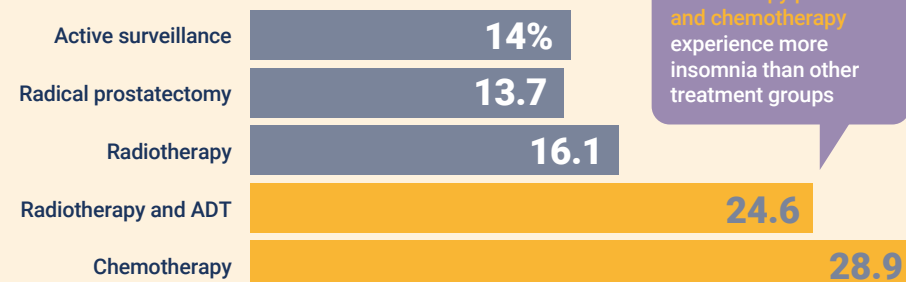
(Respondents who said they have been quite or very tired in the past week\*)



\*EORTC-QLQ-C30

### (D3) Which treatments are linked with insomnia?

(Respondents who said that have had 'quite a bit' or 'very much' trouble sleeping in the past week\*)



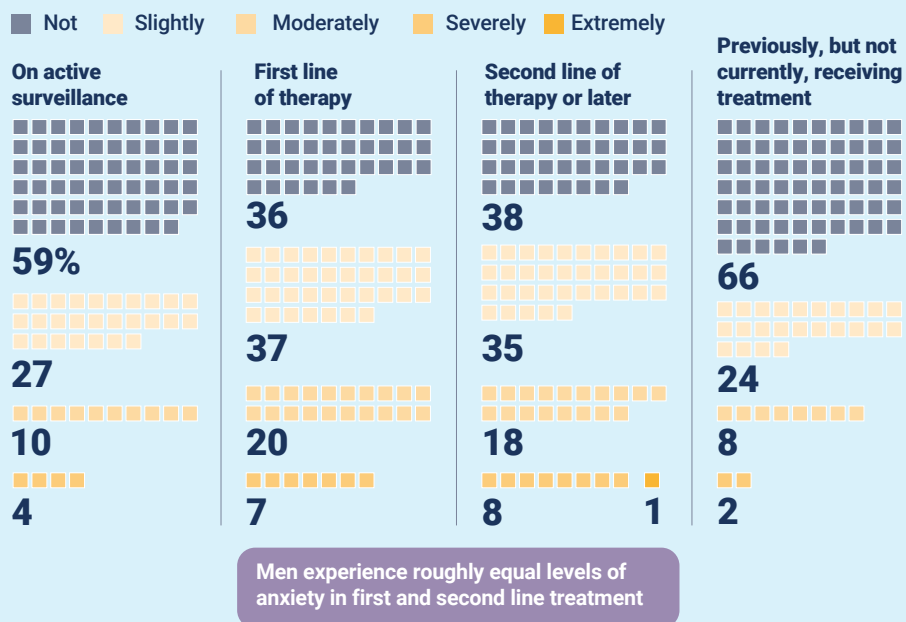
\*EORTC-QLQ-C30



### 3. Findings about mental health

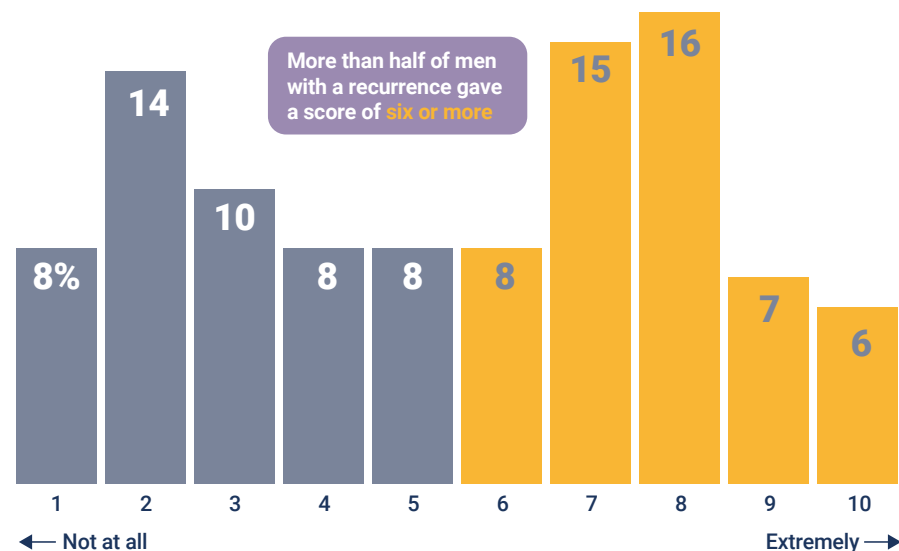
The study found that men experience roughly equal levels of anxiety in the first and second line of treatment, and anxiety and depression tend to diminish after treatment ends (M1).

#### (M1) How depressed/anxious are men at different stages of treatment?



#### (M2) How much does a recurrence of prostate cancer affect mental health?

(Respondents who had a cancer recurrence on a rating scale of 1 to 10)



But a recurrence can affect mental health a great deal. More than half of the respondents who had a recurrence rate the effect on their mental health as six or more on a scale of one to ten – in other words, it had a significant effect (M2).

The study found that 42% of men who have been treated for prostate cancer say they are anxious or depressed to some extent (M3, page 16).

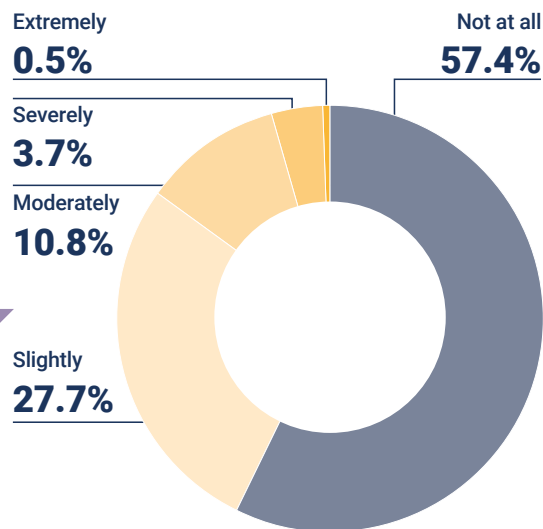




**(M3) What proportion of men who have been treated for prostate cancer are anxious or depressed?**

(At time of survey\*)

42% of men say they are anxious or depressed to some extent



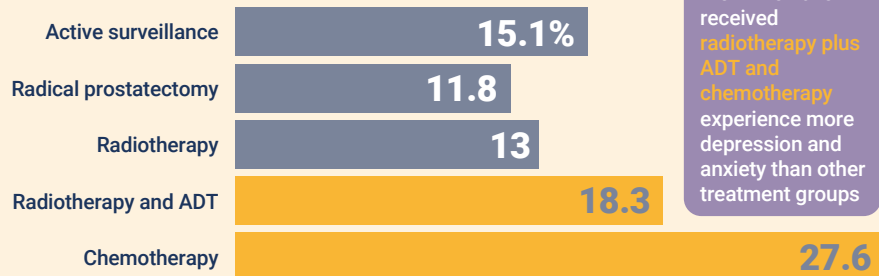
\*EQ-5D-5L questionnaire

Which treatments are most linked with mental health problems? Chart M4 shows that the problems seem to get worse the more advanced the cancer, when men are more likely to be receiving ADT and chemotherapy.

Active surveillance seems to be associated with higher levels of depression or anxiety than treatments such as radical prostatectomy and radiotherapy. This may be related to the long-term worry that can be brought by regular testing, and the fact that treatment decisions may still have to be made.

**(M4) Which treatments are linked with mental health problems?**

(% of respondents saying they were moderately, severely or extremely depressed or anxious at time of survey\*)



Men who have received radiotherapy plus ADT and chemotherapy experience more depression and anxiety than other treatment groups

\*EQ-5D-5L questionnaire

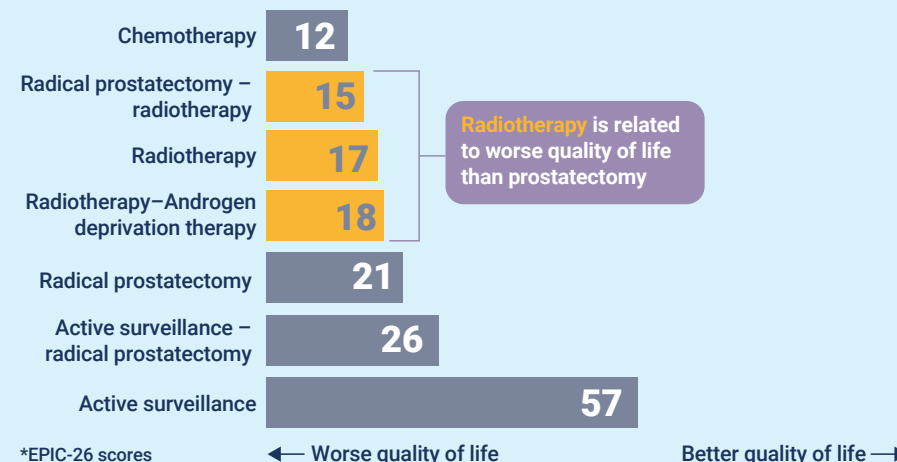


**4. Findings about sexual function**

When it comes to sexual function after treatment, the study indicated that quality of life is better after prostatectomy than radiotherapy (S1). This may be surprising, given the risks of nerve damage during surgery. But the difference between radiotherapy and radical prostatectomy is small and may not be clinically relevant.

**(S1) How is sexual function after different treatments?**

(Quality of life scores\*. Lowest score indicates worst effects)



\*EPIC-26 scores

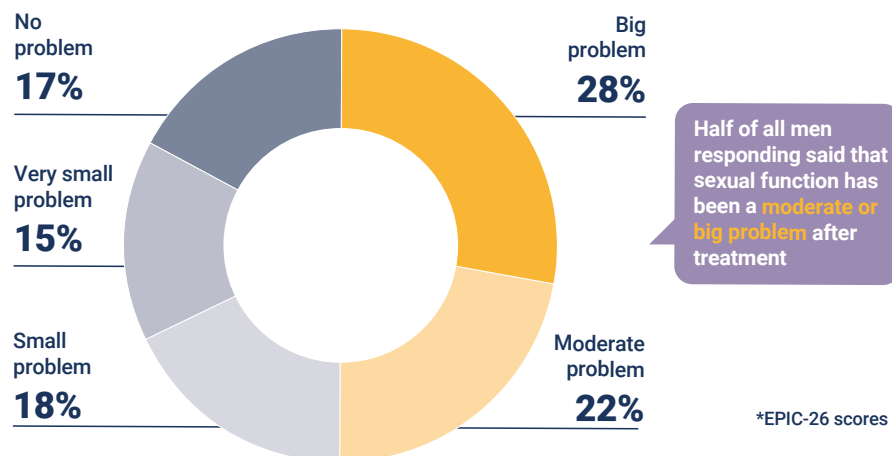
← Worse quality of life

Better quality of life →

Quality of life scores for both treatments are obviously low compared with active surveillance. Comparing these figures to the general population, the average EPIC sexual function score for men without prostate cancer is 55.8, which is clearly very similar to the active surveillance score here.

How big a problem is sexual functioning after treatment? Chart S2 shows it is a big or moderate problem in around half of men.

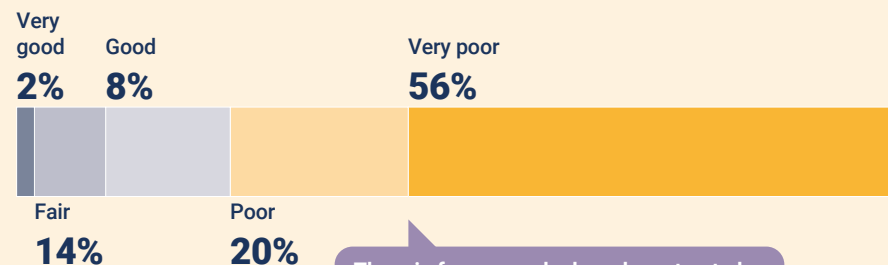
### (S2) How big a problem is sexual functioning? (All respondents\*)



When asked how they rated their ability to function sexually, around three quarters of men with prostate cancer rated it as poor or very poor (S3).

For comparison, it is interesting to look at a 2017 study of men of slightly older age (average age 74.5) who did not have prostate cancer, which used the same EPIC-26 measures (Venderbos et al, PMID: 28168601). It found that 50% of these men rated their ability to function sexually as poor or very poor. Clearly, this is a significantly lower percentage than the 76% of men with prostate cancer in our study.

### (S3) How do men rate their current ability to function sexually after treatment? (All respondents\*)



Three in four men who have been treated for prostate cancer rate their current ability to function sexually as poor or very poor.

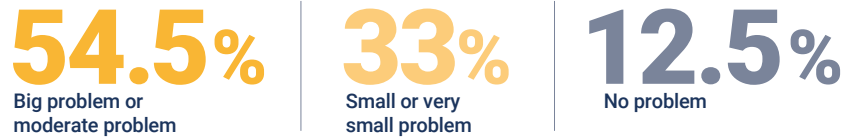
\*EPIC-26 scores

Looking at how different treatments affect sexual functioning (S4, see page 20), more than half of men who have had a prostatectomy find that sexual functioning is a big or moderate problem for them. Sexual functioning seems to be a less significant problem after radiotherapy: 44.5% for radiotherapy had significant problems compared with 54.5% for prostatectomy.



### (S4) How big a problem is lack of sexual functioning after surgery?

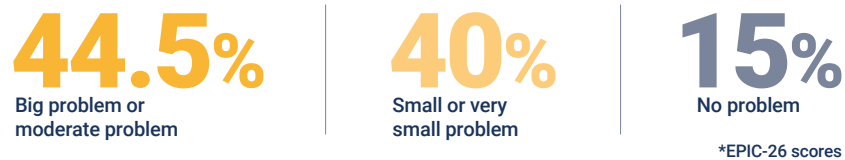
(Prostatectomy patients only\*)



More than half of prostatectomy patients say lack of sexual function is a significant problem to them.

### How big a problem is sexual functioning after radiotherapy?

(Radiotherapy patients only\*)



This is a clearer finding than we saw in chart S1, where sexual function values were quite similar between radiotherapy and prostatectomy. But both findings indicate that, when it comes to sexual function, the two major first treatments for prostate cancer have an important effect on quality of life.

Only 34% of men have tried medications and devices to improve erections, so there's clearly a need to give men more advice on these approaches to help overcome any problems (S5).

### (S5) How many prostate cancer patients have tried medications and devices to improve erections?

(All survey respondents)

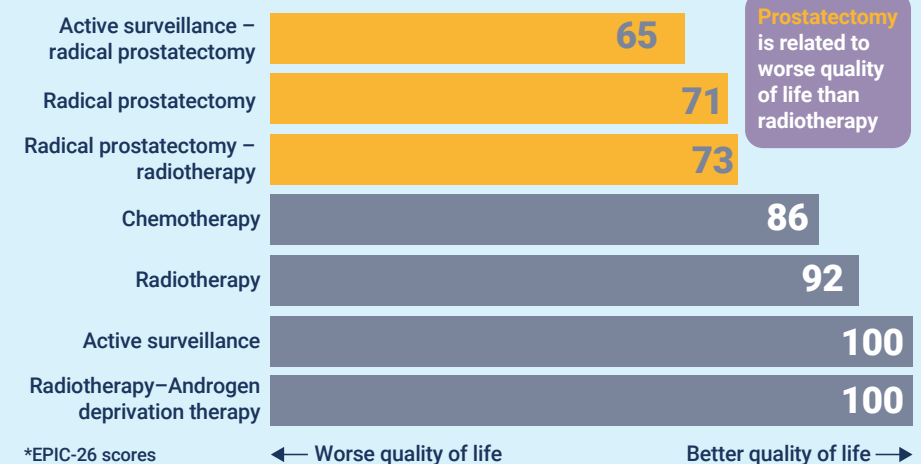


## 5. Findings about urinary incontinence

Looking at incontinence, prostatectomy is related to lower quality of life than radiotherapy. Other treatments show fewer effects (U1).

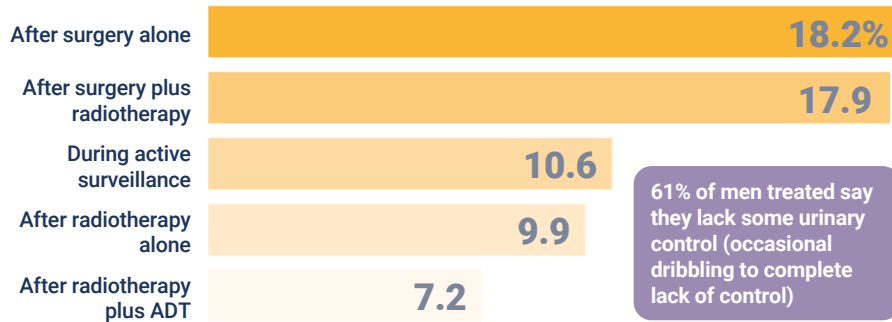
### (U1) How is continence after different treatments?

(Quality of life scores\*. Lowest score indicates worst effects)



## (U2) What proportion of men lack urinary control after treatment?

(Proportion of all men surveyed with frequent dripping or no control\*)



\*EPIC-26 scores

Overall, 61% of the men surveyed said they lacked some urinary control (frequent dripping or no control) (U2). Those who have had a prostatectomy report less urinary control than those who have had radiotherapy or other treatments, and this results in a lower quality of life related to urinary symptoms. Comparing the surgery figure with active surveillance suggests that surgery doubles the rate of incontinence.

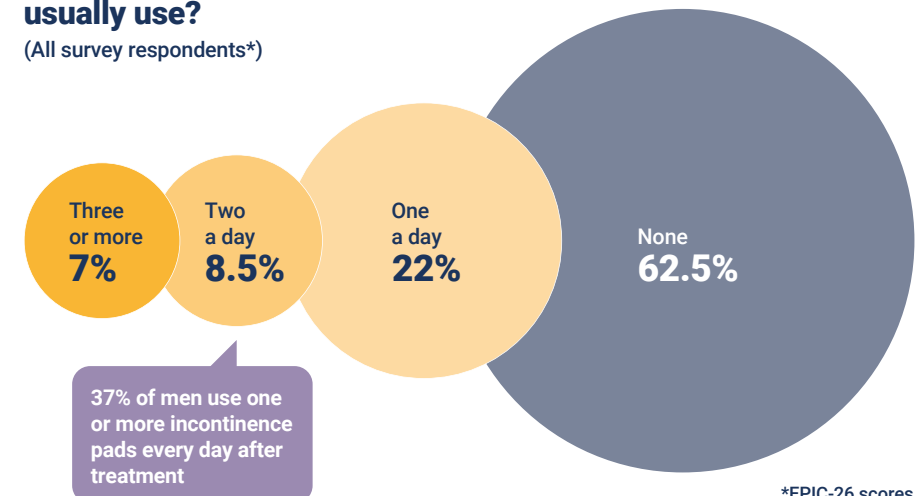
What does this mean for patients in practical terms? The survey asked men how many incontinence pads they use each day, and across all the survey respondents over a third use one or more pads a day (U3). Of respondents who had had a prostatectomy, half were using pads. To put this into context, a 2017 study of men with roughly the same age profile who had NOT been treated for prostate cancer found that around 10% wear pads (PMID: 28168601). So there is clearly a significant effect here.

The survey found that 17% of men judged dripping and leakage to be a big or moderate problem (U4, see page 24). And if you break down this figure into those who have received prostatectomy and radiotherapy, treatment



## (U3) How many pads do men who have been treated usually use?

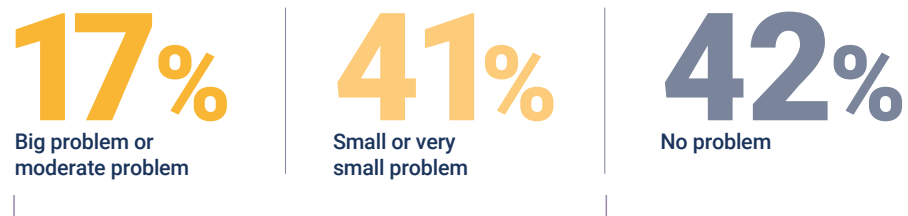
(All survey respondents\*)



\*EPIC-26 scores

#### (U4) How big a problem is dripping and leakage?

(All survey respondents\*)



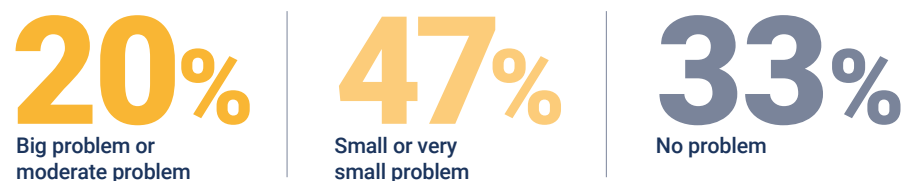
58% of men who have been treated for prostate cancer say dripping and leakage is a problem

\*EPIC-26 scores

received is a clear influence on this problem. For prostatectomy patients 67% say dripping and leakage is a problem. While 48% of radiotherapy patients say that dripping and leakage is a problem (U5).

#### (U5) How big a problem is dripping and leakage after surgery?

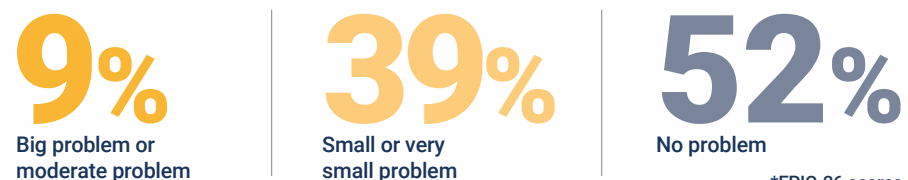
(Prostatectomy patients only\*)



67% of prostatectomy patients say dripping and leakage is a problem

#### How big a problem is dripping and leakage after radiotherapy?

(Radiotherapy patients only\*)



\*EPIC-26 scores

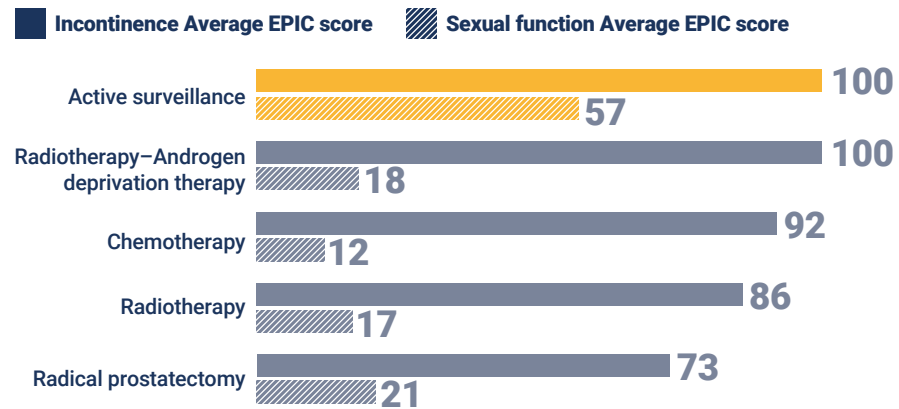


## Key messages from EUPROMS

There are three main take-home messages from the EUPROMS findings.

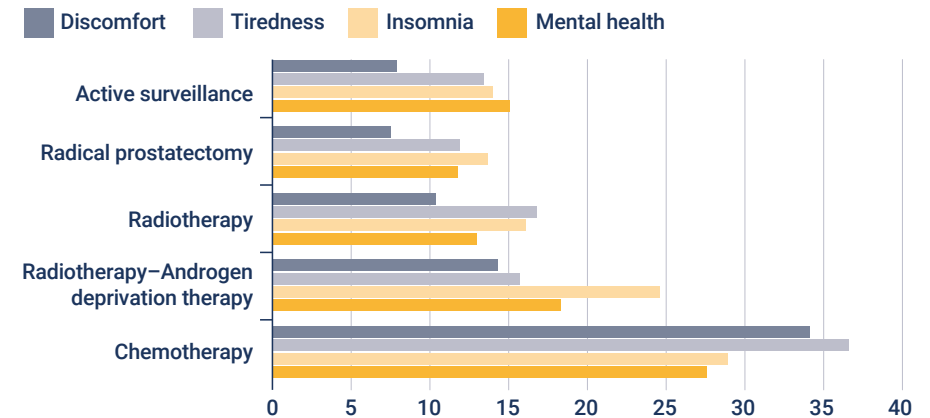
The first is that active surveillance should always be considered, because overall it best protects quality of life. The contrast between active surveillance and other approaches is particularly clear in terms of incontinence and sexual function.

### 1. Active surveillance should be considered as the first treatment in order to ensure the best quality of life



### 2. Early detection is key

(% of patients with moderate, severe and very severe problems)



The second message is that early detection of prostate cancer is of the utmost importance. The more advanced the prostate cancer at diagnosis, the worse the effects of treatment on quality of life. The research clearly shows that many symptoms that affect quality of life are experienced more severely with treatments associated with more advanced prostate cancer.

Finally, high quality treatment and support are essential. The EUPROMS results show the severe effects that can come with treatment for prostate cancer. Men need all the expertise and experience they can get during treatment and after, with information and support at each stage of the journey. Every man with prostate cancer should be treated in a cancer centre with multidisciplinary teams.

# Further information

## The quality of life measures used

The survey questions were composed, and their responses analysed, on the basis of three validated measures used widely in Europe to evaluate patient quality of life. They are:

EQ-5D-5L – used to evaluate generic health status

EORTC-QLQ-C30 – used to evaluate quality of life related to cancer

EPIC-26 – used to evaluate quality of life related to prostate cancer specifically

The findings presented in this paper summarise some of the detailed findings arising from EUPROMS, using these measures.

## Impact of EUPROMS

Since early 2020, the EUPROMS findings have been widely reported at conferences, in journals, at conferences and webinars. The publication of the European Commission's Beating Cancer plan has made the findings even more pertinent. The plan, published in February 2021, raises the prospect of prostate cancer early detection programmes throughout Europe. Europa Uomo has been campaigning vigorously for such measures, pointing European politicians towards the findings of the EUPROMS study.

Early detection clearly affects quality of life. EUPROMS found that quality of life scores are best in patients where the cancer is discovered in an early, curable stage. So efforts toward early detection and awareness are essential to avoid unnecessary deterioration of quality of life.

The EUPROMS quality of life study substantially contributed to the inclusion of prostate cancer early detection in the Beating Cancer plan, so special thanks must go to all the patients who took time to answer the survey: their efforts have made a difference.



## What happens next?

Campaigning and information work needs to continue, to provide evidence supporting the need for early detection, awareness and treatment and care improvements. That is why Europa Uomo is now planning a follow-up to EUPROMS study to strengthen the research base and fill possible gaps. At time of writing this booklet, the EUPROMS 2 questionnaire was being prepared.

# Links

You can find out more about the EUPROMS study by following the links below:

## PowerPoints and summaries

[Early presentation of findings](#) by Europa Uomo Chairman André Deschamps, January 2020

[Main findings presented to the European Association of Urology \(EAU\)](#) by André Deschamps, July 2020

[New findings on mental health](#) from EUPROMS announced, November 2020

[New accessible presentation](#) of results launched, November 2020

[Accessible presentation available in 17 languages](#)

## Journal papers and conference reports

[Presentation at EAU](#), July 2020

[Presentation at EMUC](#) (Multidisciplinary Congress on Urological Cancers), November 2020

[Paper on chemotherapy effects](#) in Annals of Oncology, September 2020

[Paper in European Urology Focus](#) presenting EUPROMS results, December 2020

# Acknowledgements

Europa Uomo owes a huge debt of thanks to those who have supported EUPROMS, in many different ways.

They include:

- Professor Monique Roobol, Lionne Venderbos and Sebastian Remmers from the Department of Urology at Erasmus MC, Rotterdam
- The European Association of Urology
- Our EUPROMS sponsors: Bayer, Ipsen and Janssen

Particular thanks go to every one of the 2,943 people who responded to the EUPROMS questionnaire.

## Credits

This booklet was compiled by:  
Simon Crompton, editing and writing  
Wesley Fernandes, graphics  
Hils Tranter, design



"Particular thanks go to every one of the 2,943 people who responded to the EUPROMS questionnaire."

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# EUROPA UOMO<sup>7</sup>

The Voice of Men with Prostate Cancer in Europe



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