

EUROPA UOMO⁷

The Voice of Men with Prostate Cancer in Europe



Quality of life after prostate cancer treatment

**What Europa Uomo's EUPROMS
research found out**



This booklet summarises the findings of the EUPROMS studies – the first prostate cancer quality of life research conducted by patients for patients.

Contents

About EUPROMS	4
About the questionnaires	5
About the respondents	6
Geographical response	8
About the analysis	9
Reporting the study results	9
How we hope the results will be used	9

EUPROMS findings	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

Key messages from EUPROMS	25
----------------------------------	----

Further information	28
---------------------	----

Links	30
-------	----

About EUPROMS

EUPROMS stands for Europa Uomo Patient Reported Outcome Study. It is the first ever prostate cancer quality of life research conducted by patients for patients. This booklet, written by André Deschamps and Guenther Carl of Europa Uomo, with health writer Simon Crompton, is a non-academic overview of its findings, designed for the public.

Europa Uomo (Italian for Europe man) is a European advocacy movement representing prostate patients' groups in 27 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 multidisciplinary 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. It was based on online surveys exploring experiences of treatment and life afterwards. There were two surveys. The first, EUPROMS 1.0, which began in 2019, attracted nearly 3,000 responses. The second, EUPROMS 2.0, launched in 2021, drew 3,571 responses.



The findings of these surveys, combined in this summary, provide a new perspective. Most quality of life studies are conducted by doctors and nurses in a clinical environment, when patients are visiting for treatment or check-ups. However, the EUPROMS questionnaires were completed by men in their own time,

in the comfort of their homes. This meant they had more time to consider their answers and might feel more at ease to say what they really felt.

The findings here present an overview of what the EUPROMS surveys discovered. They provide an insight into what quality of life issues are really being experienced by men with prostate cancer at a particular point of time. The studies 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 research.

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 studies.

About the questionnaires

- 20-minute online surveys 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

About the respondents

As you will see from the distribution graph of age at first diagnosis (below), more than 50% of respondents were diagnosed before they were 65. 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.

Most patients had only received one treatment up to the start of the survey. A total of 57% of respondents had received radical prostatectomy, so the overall results will be influenced by the effects on quality of life of that particular treatment.

- 5,464 unique responses
- Average age: 70
- Average age at diagnosis: 64
- Most had had surgery as first treatment

Living situation

(EUPROMS 1.0 only)

82% 
With partner

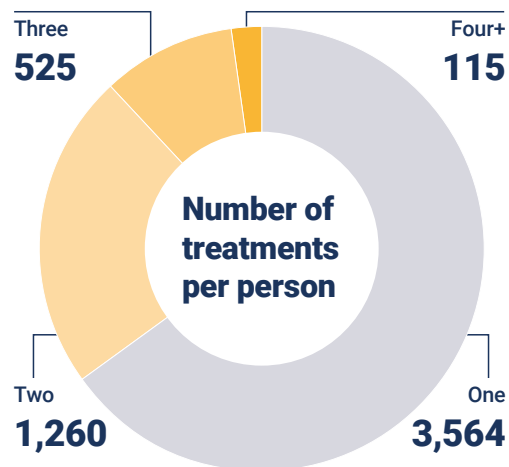
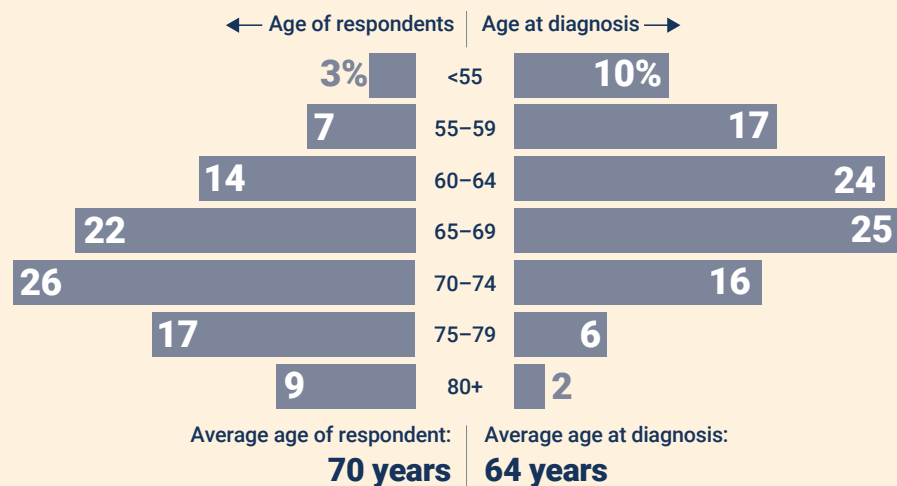
14% 
Alone

3% 
With other family

Education

Entrance certificate for a higher technical college	32%
University entrance certificate	31
Comprehensive school	12
Intermediate secondary school	10
Lower secondary school or equivalent	6
Other	9
None	0.5

As you will see from the distribution graph of age at first diagnosis, more than 50% of respondents were diagnosed before they were 65.



Most common first treatments:

1. Surgery
2. External beam radiotherapy (EBR)
3. Active surveillance (AS)

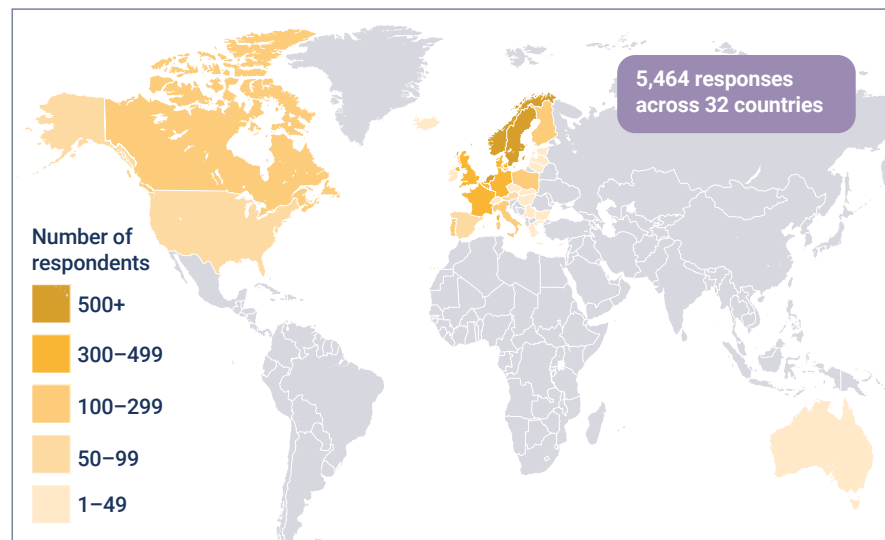
Most common second treatments:

1. Surgery and EBR
2. Androgen deprivation therapy and EBR
3. AS and surgery



Geographical response

There was a wide response across 32 countries, mainly in Europe but also including Australia, Canada and the United States of America.



Norway: 951	Canada: 234	Lithuania: 55	Czech Republic: 7
The Netherlands: 853	Portugal: 164	Ireland: 45	Cyprus: 6
Sweden: 540	Poland: 150	Hungary: 33	Luxembourg: 2
	Italy: 106	Latvia: 20	Serbia: 2
	Finland: 105	Slovakia: 19	Bulgaria: 1
Germany: 472		Estonia: 17	
Belgium: 404	USA: 97	Switzerland: 17	
Denmark: 312	Austria: 83	Australia: 8	
UK: 308	Spain: 72	Greece: 8	
France: 305	Other: 60	Iceland: 8	

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 still help provide important information for clinical decision-making.

Reporting the study results

The first results of EUPROMS 1.0 were reported in January 2020 and the first findings of EUPROMS 2.0 were presented in July 2022. Findings have been reported and discussed widely, for example at:

- European Association of Urologists (EAU) congresses
- 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 information on quality of life issues that will help patients and their doctors make decisions about treatments.

They may also help patient groups and others to campaign for early diagnosis of prostate cancer and promoting approaches such as active surveillance.





EUPROMS findings

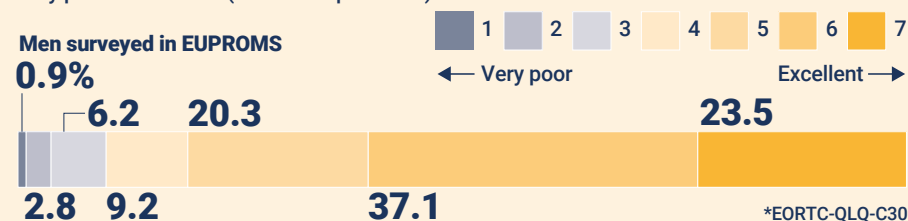
1. General findings about quality of life

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.

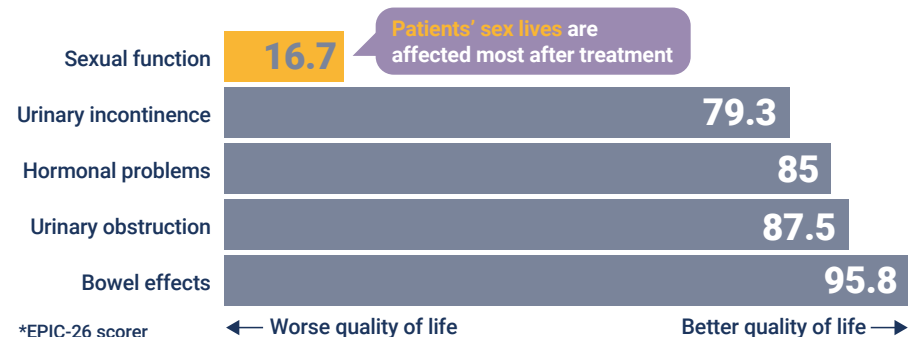
(G1) Quality of life during the past week

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. Scores are median scores for the overall cohort of 5,464 men)



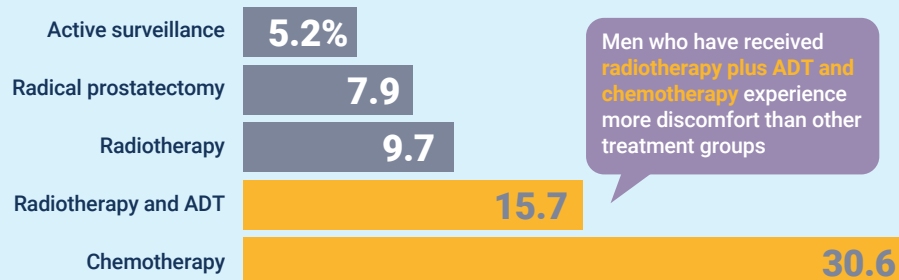


2. Findings about discomfort, tiredness and insomnia

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*)



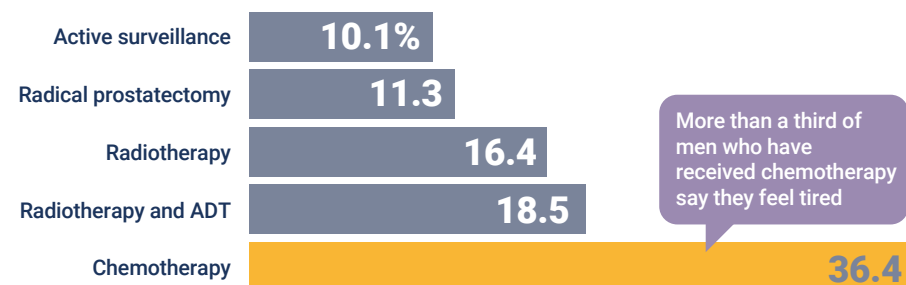
*EQ-5D-5L questionnaire

For tiredness, more than one third of men who had received chemotherapy said they had felt tired in the past week – considerably more than 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 disease and therefore treatment progresses.

(D2) Which treatments are linked with tiredness?

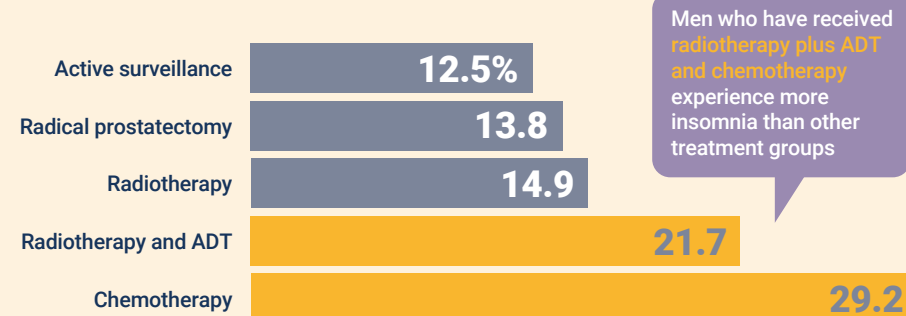
(Respondents who said they have been quite or very tired in the past week*)



*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



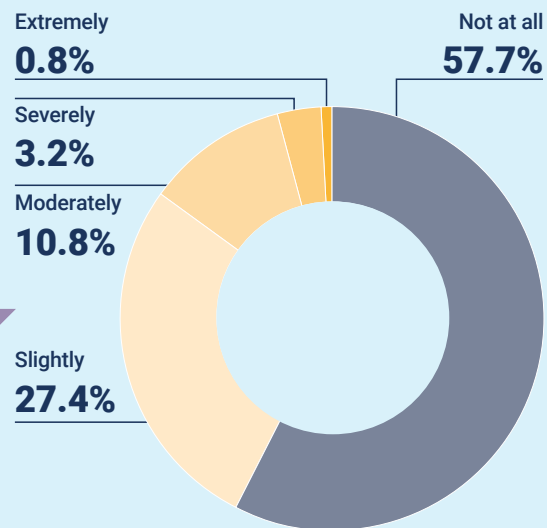
3. Findings about mental health

The study found that 42% of men who have been treated for prostate cancer say they are anxious or depressed to some extent (M1).

(M1) What proportion of men who have been treated for prostate cancer are anxious or depressed?

(At time of survey*)

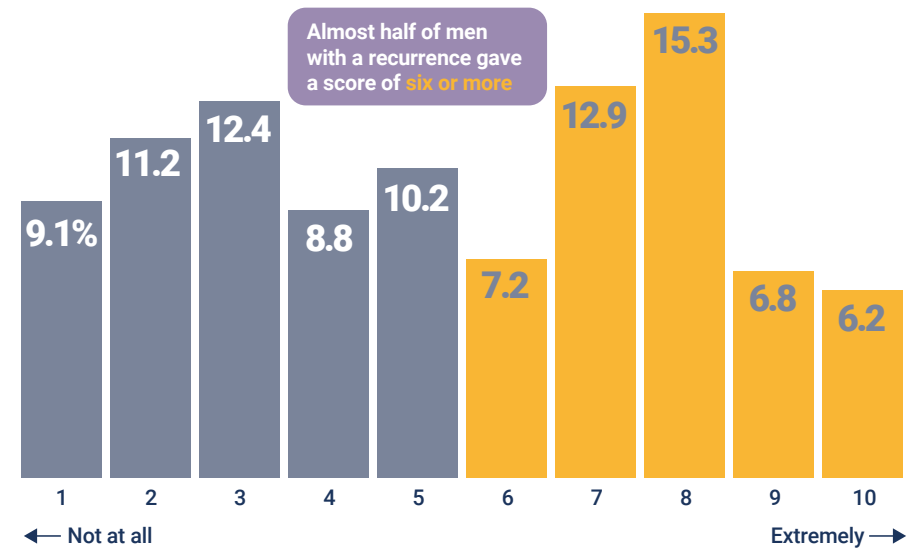
42% of men say they are anxious or depressed to some extent



*EQ-5D-5L questionnaire

(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)



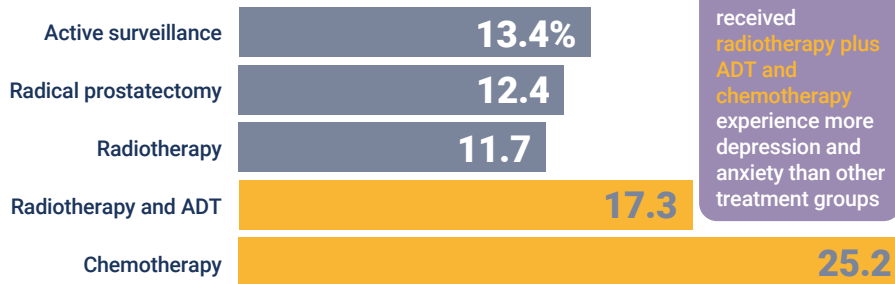
But a recurrence can affect mental health a great deal. Around half of the respondents who had a recurrence rate the effect on their mental health as six or more on a scale of one to ten – in other words, it had a significant effect (M2).



42% of men who have been treated for prostate cancer say they are anxious or depressed to some extent

(M3) 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

Which treatments are most linked with mental health problems? Chart M3 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.

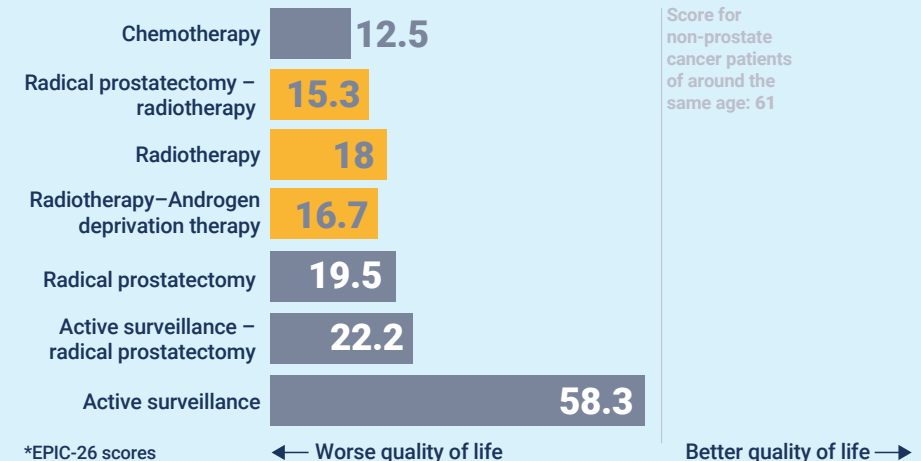


4. Findings about sexual function

Quality of life scores for both radical prostatectomy and radiotherapy are low compared with active surveillance. Comparing these figures to the general population, the average EPIC sexual function score for men without prostate cancer is 61, which is clearly very similar to the active surveillance score here.

(S1) How is sexual function after different treatments?

(Quality of life scores*. Lowest score indicates worst effects. Scores are median scores for the individual treatments)

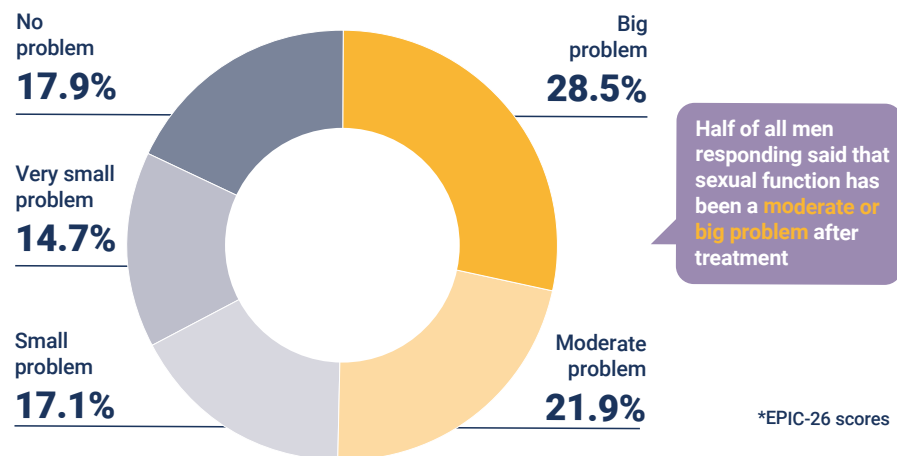




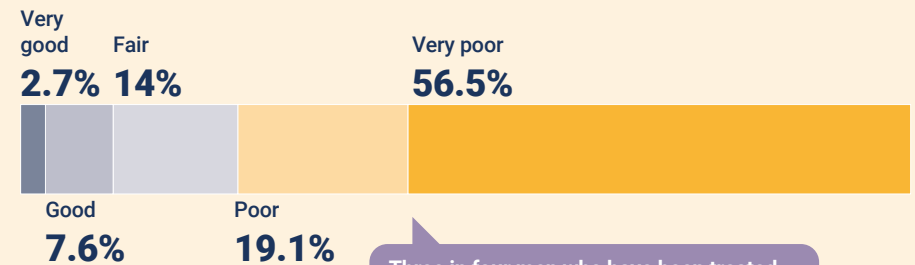
How big a problem is sexual functioning after treatment? Chart S2 shows it is a big or moderate problem in around half of men.

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).

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



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



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.

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 slightly less significant problem after radiotherapy: 47.3% of men who have had radiotherapy have significant problems compared with 54.8% 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*)



*EPIC-26 scores



Overall, the 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 one third of prostate cancer patients 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)

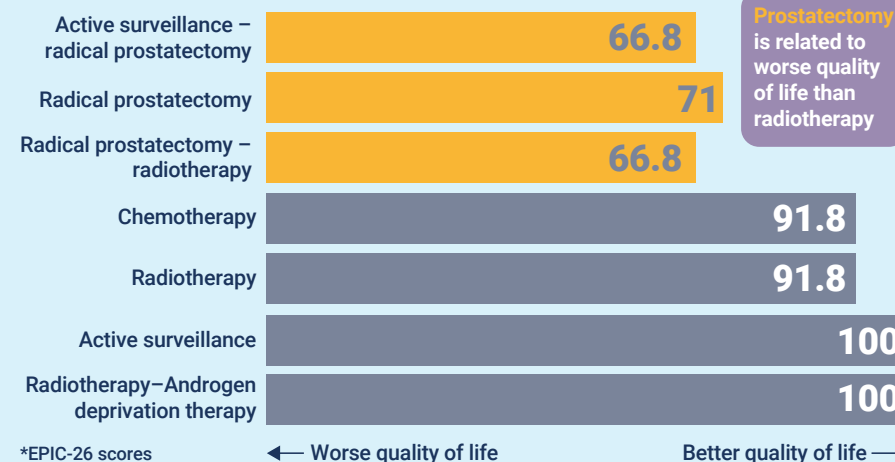


5. Findings about urinary incontinence

Looking at incontinence, prostatectomy is related to lower quality of life than radiotherapy. Other treatments have less impact on continence-related quality of life (U1).

(U1) How is continence after different treatments?

(Quality of life scores*. Lowest score indicates worst effects. Scores are median scores for the individual treatments.)



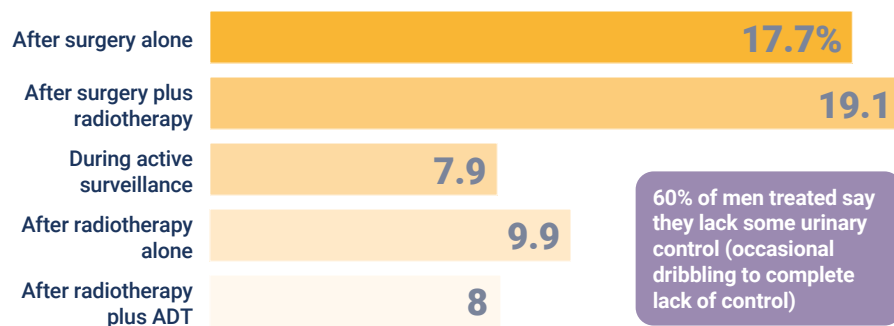
Prostatectomy is related to worse quality of life than radiotherapy



Overall, 60% 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.

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

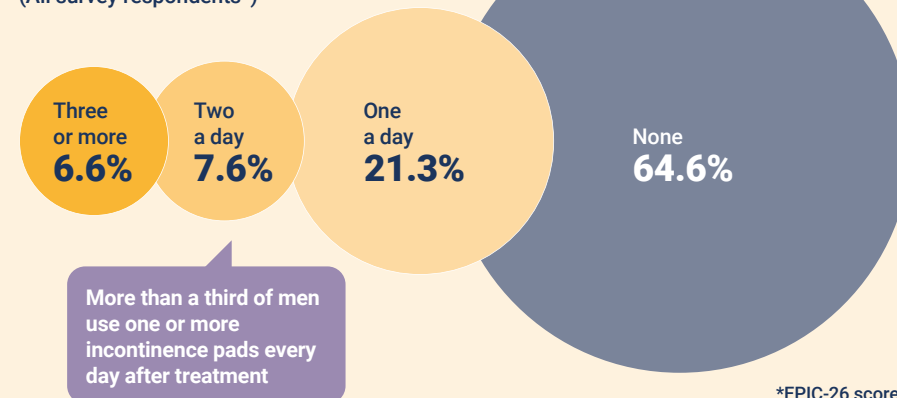
(Proportion of all men surveyed with frequent dripping or no control*)



*EPIC-26 scores

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

(All survey respondents*)



*EPIC-26 scores

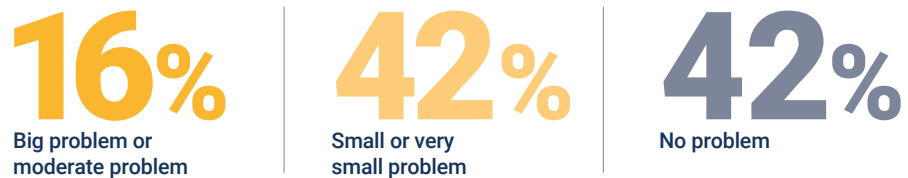
What does this mean for patients in practical terms? The survey asked men how many incontinence pads they use each day, and across all the survey respondents over a third use one or more pads a day (U3). To put this into context, a 2017 study of men with roughly the same age profile who had NOT been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

The survey found that 16% 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 received is a clear influence on this problem. For prostatectomy patients, 68% say dripping and leakage is a problem. While 47% of radiotherapy patients say that dripping and leakage is a problem (U5).

Help is available for men experiencing lack of urinary control, to reduce the impact on daily life. Unfortunately, however, this support is not sufficiently sought nor offered.

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

(All survey respondents*)



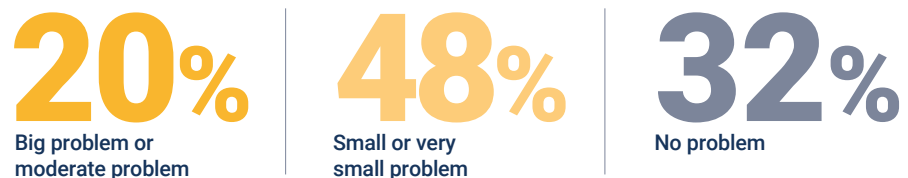
58% of men who have been treated for prostate cancer say dripping and leakage is a problem

*EPIC-26 scores

Help is available for men experiencing lack of urinary control, to reduce the impact on daily life. Unfortunately, however, this support is not sufficiently sought nor offered.

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

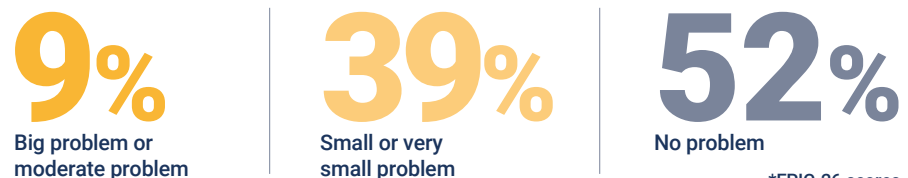
(Prostatectomy patients only*)



68% 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



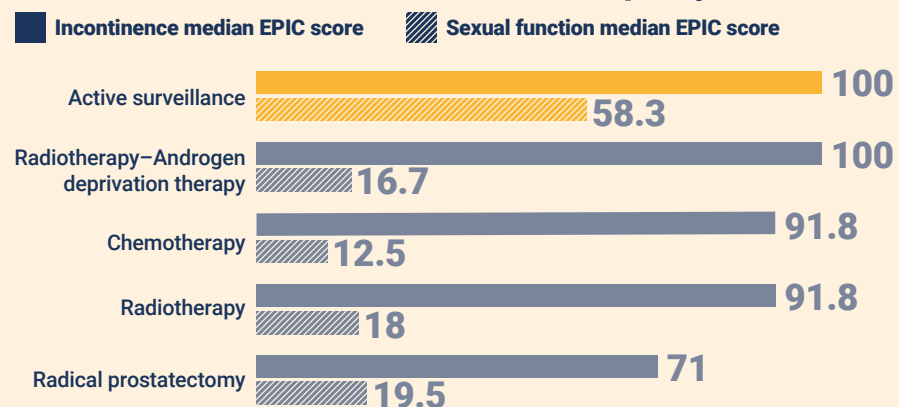
Key messages from EUPROMS



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

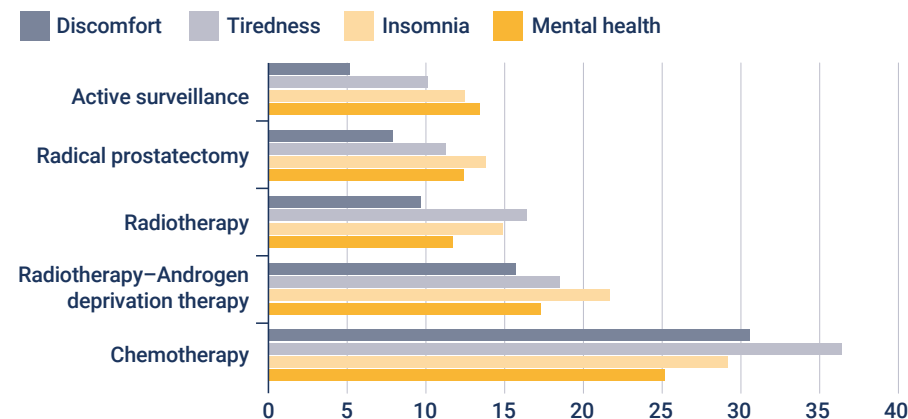
The first is that active surveillance should always be considered when safe (low risk disease), because overall it best protects quality of life. The contrast between active surveillance and other approaches is particularly clear in terms of incontinence and sexual function.

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.

Men need all the expertise and experience they can get during treatment and after, with information and support at each stage of the journey.

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 in February 2021 made the findings even more pertinent. The plan proposed prostate cancer early detection programmes throughout Europe. Europa Uomo, with organisations representing urologists, has been campaigning vigorously for such measures, pointing European politicians towards the findings of the EUPROMS studies.

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 studies 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 surveys: 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. The EUPROMS results provide a strong tool for such campaigning, and Europa Uomo hopes that patient advocacy groups and others will use them widely. Europa Uomo will be building on them to try and ensure that effective prostate cancer early detection and treatment systems are built throughout Europe.

The EUPROMS quality of life study substantially contributed to the inclusion of prostate cancer early detection in the Beating Cancer plan.

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

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

[Accessible presentation available in 17 languages](#)

[EUPROMS 2.0: new evidence of effects of treatment on patients' lives](#)

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: Advanced Accelerator Applications, Astellas, Astra Zeneca, Bayer, Ipsen and Janssen

Particular thanks go to every one of the people who responded to the EUPROMS questionnaires.

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 people who responded to the EUPROMS questionnaires."

© Europa Uomo 2023

EUROPA UOMO⁷

The Voice of Men with Prostate Cancer in Europe



Europa Uomo Central Office

Tel +32 3 244 18 40

info@europa-uomo.org

www.facebook.com/EuropaUomo

https://twitter.com/europa_uomo

www.europa-uomo.org