

# How does prostate cancer affect partners?

**What Europa Uomo's EU-ProPER research found**



This booklet summarises the findings of the EU-ProPER study – a unique research project that examined the quality of life of partners of men with prostate cancer.

**The key messages are:**

- Prostate cancer and its treatments change men
- Prostate cancer brings significant changes to the lives, and quality of life, of partners supporting men with prostate cancer
- The changes that come with prostate cancer can bring partners closer together



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"The effects of prostate cancer can be profound on both partners because they experience them together."

# About EU-ProPER

**EU-ProPER stands for Europa Uomo Prostate cancer Partners in Europe Research. It is the first study investigating the quality of life of prostate cancer partners conducted by patients themselves. This booklet provides a non-academic overview of its findings, designed for the public.**

Europa Uomo (Italian for Europe man) is a European advocacy movement representing 27 prostate patients' groups in countries across Europe. One of its main focuses has always been understanding how prostate cancer affects quality of life and finding ways of improving that.

In 2019 and 2021 it conducted two ground-breaking surveys into the quality of life of men with prostate cancer named EUPROMS (Europa Uomo Patient Reported Outcome Studies). These revealed some of the ways that prostate cancer treatment affects daily life, with continence and sexual life

often significantly compromised. It was also clear that the impact of these challenges would affect those close to the person with prostate cancer – 83% of EUPROMS respondents lived with a partner.

Europa Uomo decided that this warranted further investigation, and launched a new study focusing on the quality of life of partners – Europa Uomo Prostate Partners' Experience Research (EU-ProPer).





## The survey and response

The research was based on an online survey, launched in October 2023 and open for two months. It was compiled with the help of a group of prostate cancer partners living in the Netherlands. The questionnaire was available in 17 languages and publicised internationally through Europa Uomo, its member organisations and other patient, professional and cancer organisations.

There was an impressive response rate – with 1135 people returning valid questionnaires online. There were responses from 23 European countries, plus the USA and Canada. Half of the responses were from Netherlands (224), Norway (212) and Germany (161). Other countries yielding responses were France (97), Belgium (54), Sweden (46), Lithuania (45), Italy (42), Denmark (37), UK (32), Hungary (26), Cyprus (20), Spain (19), USA (15), Austria (11), Ireland (11), Finland (9), Latvia (9), Canada (8), Portugal (8), Greece (7), Iceland (7), Slovakia (5), Switzerland (5) and Poland (4).

**The median age of respondent was 68, but their median age at the time of their partner's diagnosis was much younger – 61.**



## **The analysis**

The data from the responses was analysed by Professor Monique Roobol and her team at Erasmus University Medical Centre, Department of Urology, Rotterdam, the Netherlands. The first findings were presented at the European Association of Urology Congress in Paris in April 2024.

## **Significance of the results**

The findings present a valuable picture of the issues being faced by those close to men with prostate cancer across Europe and beyond.

Finding out about the burdens on partners helps define what types of support could have a significant impact on their lives after prostate cancer has been diagnosed. It could help define unmet needs and provide an agenda for action.

## **Note on findings**

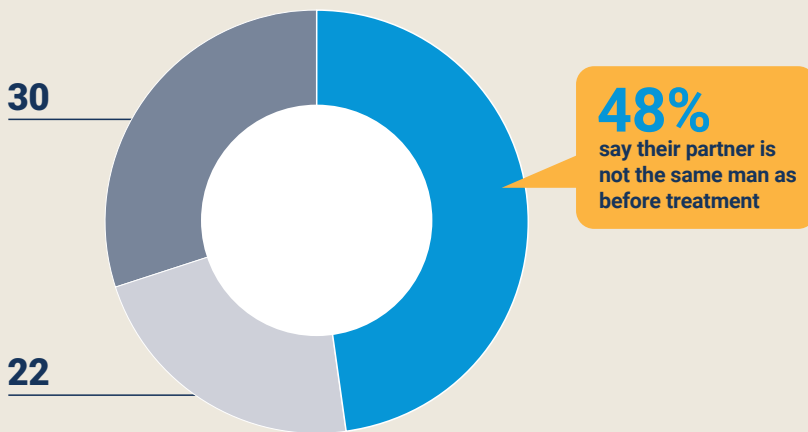
In many questions, survey respondents were asked whether they strongly agreed, agreed, disagreed, strongly disagreed or felt neutral about statements. In the results here, the responses have been aggregated into agreed, disagreed and neutral.

# EU-ProPER Findings

One of the most striking findings of the study is that many respondents think that their partner is not the same man he was before treatment for prostate cancer. This change can involve alterations in mental health, continence, libido and sexual abilities. (Figure 1)

## (1) Patients and partners change with prostate cancer treatment

● Agree ● Neutral ● Disagree



Many respondents felt that their male partners needed support for mental health issues. But they also acknowledged mental health problems themselves. (Figure 2, over page)

Prostate cancer has a significant impact on the lives of partners, affecting their social life and resulting in many becoming lonely. (Figure 3, over page)

## (2) Prostate cancer affects mental health

● Agree ● Neutral ● Disagree

*"I feel I should visit a mental health professional"*



**16%** of partners feel they should get help for mental health

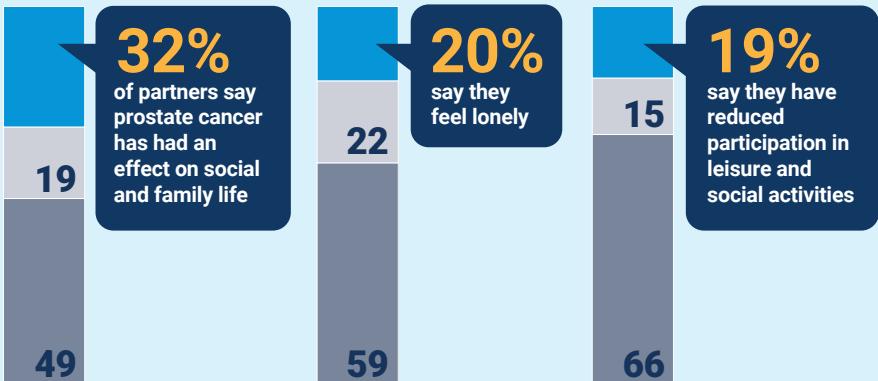
*"I feel my partner should visit a mental health professional"*



**20%** of respondents feel their partner should get help for mental health

## (3) Prostate cancer has a big effect on partners' quality of life

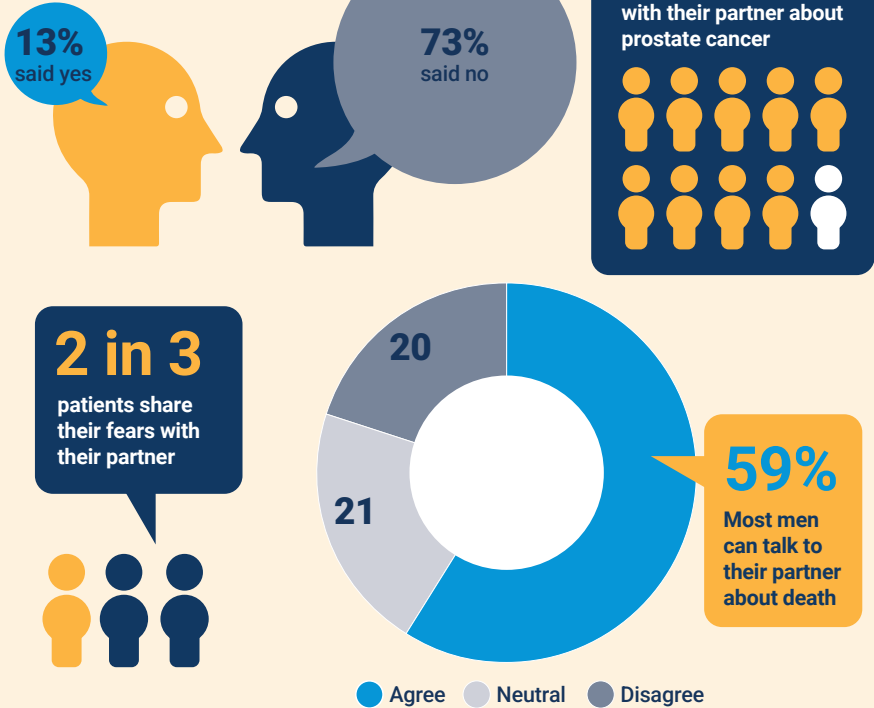
● Agree ● Neutral ● Disagree





#### (4) Patients and partners remain close

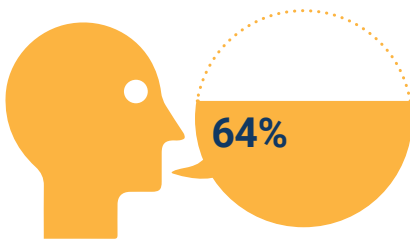
*"When asked whether communication between partners has got worse since prostate cancer diagnosis..."*



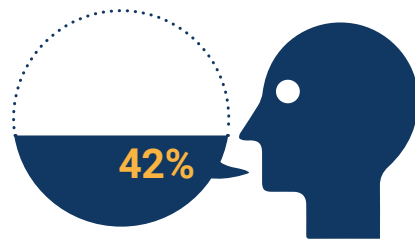
For all the strains that prostate cancer brings to couples, it seems that communications channels stay open – and most partners feel that communication has remained good or improved since the prostate cancer diagnosis. (Figure 4)



## (5) Patients and partners talk about sex



Two in three of partners say they can talk openly about his sexual abilities after treatment

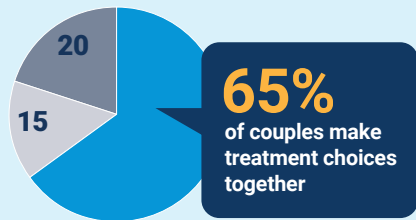
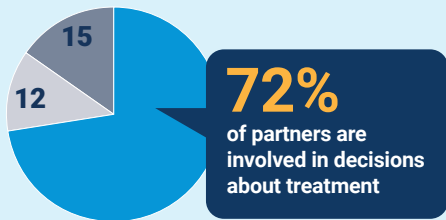


Less than half of partners find it easy to express their own feelings about sex with partner

## (6) Patients and partners share information and decisions

● Agree ● Neutral ● Disagree

**9 in 10** couples share information about a prostate cancer diagnosis with close family



Nearly all patients and partners share information about a cancer diagnosis with close family (Figure 6). However, it is worth noting that they are far less willing to share information about more “taboo” subjects such as incontinence. More than a third of respondents said that no-one, apart from them, was aware of their partner’s incontinence. (Figure 10, page 12)

## (7) Prostate cancer has an impact on relationships

● Agree ● Neutral ● Disagree

Nearly half of partners think prostate cancer has affected their relationship



"The prostate cancer influences our relationship"

Most partners are **not worried** about their relationship



"I am worried about our relationship"

Most partners think **prostate cancer has brought them closer**, not driven them apart



"Prostate cancer has brought us closer together"



Another striking finding of the study is that although many partners think that prostate cancer has affected their relationship, most of them believe that the change has been for the better, bringing them together rather than driving them apart. (Figure 7)

## (8) There are effects on sex life

● Agree ● Neutral ● Disagree

**3/4**

of partners say their sex life has deteriorated



**3/4**

of partners say they have learned to cope with their new sex life



**1/2**

say sex is important to them



## (9) There is frustration about sex life

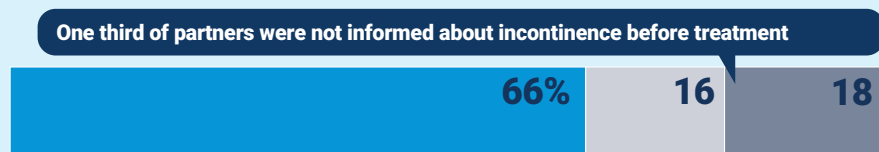


## (10) Incontinence is still taboo

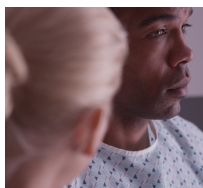
● Agree ● Neutral ● Disagree



*"Nobody apart from me is aware of my partner's incontinence"*



*"I was fully aware of the consequences of the treatment before the treatment started"*

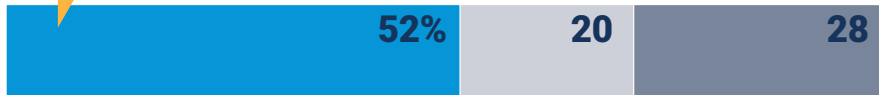


The influence of incontinence on quality of life is clearly substantial, affecting both social and sexual life. Even for partnerships that are coping well with the other side effects of prostate cancer and its treatments, coping with incontinence remains difficult. (Figure 11)

## (11) Incontinence is life-changing

● Agree ● Neutral ● Disagree

Incontinence has an effect on sex...



*"The incontinence of my partner has an influence on our sex life"*

...and social life



*"The incontinence of my partner has an influence on our social life"*

Perhaps the most unexpected finding of the whole study is that many partners are simply not receiving the information they need about the impacts of treatment before it begins. This means that the impacts on sex life can come as a shock and make changes harder to adapt to. It can also lead to regrets about having chosen the wrong treatment. (Figure 12)

Impacts on sex life can come as a shock and lead to regrets about treatment

## (12) Many partners do not get the information they need

● Agree ● Neutral ● Disagree

Only

70%

were aware of the effects of treatment before it began



Only

1 in 5

received information about sex after treatment



More than

1/2

have had to research sex after treatment themselves



# EU-ProPER key messages

## **Prostate cancer and its treatments change men**

It is perhaps inevitable that prostate cancer will bring physical and psychological changes in some men. But EU-ProPER now provides data demonstrating that only one third of partners think that their partner remains unchanged after treatment. This is a significant indicator of the impact of prostate cancer beyond mortality rates.



## **Prostate cancer brings significant changes to the lives of partners supporting men with prostate cancer**

Partners of prostate cancer have provided very honest and personal feedback in the EU-ProPER study, and the results show that prostate cancer significantly affects their social life, relationships, intimacy and sexual life.

## **The changes that come with prostate cancer can bring partners closer together**

The effect of prostate cancer can be profound on both partners because they experience them together. EU-ProPER results show that the journey couples embark on with prostate cancer can change their relationship – but sometimes for the better as they become closer.

## **There is an information gap for partners**

The results of the study indicate that there is a considerable gap between the information that patients and their partners need about life after prostate cancer treatment, and the information they actually receive. Work is clearly needed in this area.

# Acknowledgements

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## Credits

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## For more information

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<https://www.europa-uomo.org/eu-proper/>





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