

EUROPA UOMO

The Voice of Men with Prostate Cancer in Europe

Europa UOMO is a European advocacy movement representing 27 prostate patients' groups in countries across Europe and working towards improving diagnosis, treatment, support, and quality of life.

They carry out research and influence policy at national and international level, work with health professionals to help them understand patient perspectives, support their national member organizations as they strive to improve services and awareness, and conducting patient-initiated research.

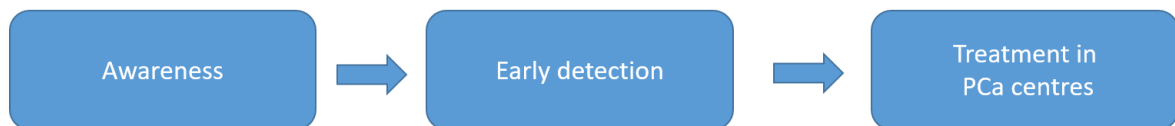
- We work to improve diagnosis, treatment, support and quality of life
- We carry out research and influence policy at national and international level
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STRATEGY

We believe that best care for prostate cancer (PCa) patients can be realised based on three pillars.



- Awareness of PCa is key and we must change perceptions and “taboos”.
- There is scientific evidence that early detection saves lives and improves the quality of life of patients and partners.
- Treatment in cancers centres must be the norm in order to assure equality of care and avoid overtreatment.
- All three elements are equally important and one does not work without the others.

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PRIORITIES

1.AWARNESS AND EARLY DETECTION

Raising awareness of prostate cancer among the public and politicians in Europe

2.QUALITY OF LIFE

Conducting ground-breaking research into quality of life of men with prostate cancer in Europe

3.SUPPORTING AND REPRESENTING PATIENTS

Helping and giving voice to patient support groups around Europe

4. PROMOTE AN ALLIANCE AMONG PUBLIC INSTITUTIONS/BODIES AND SOCIAL ACTORS

(Research, Health system, scientific societies, patients' associations and in general oncological volunteering, media)

In order to highlight the value and prominence of early detection of prostate cancer.

Europa Uomo is an alliance itself: patients, caregivers and specialists, all volunteers, work together.

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In Italy we are also building up an alliance among breast cancer patients' association, that always inspire us, and other oncological volunteer associations, as PalinUro.

We strongly believe in cooperation.

Thank You

Maria De Cristofaro, president Europa Uomo Italy

Cosimo Pieri, Italian member of Europa Uomo Europe Board

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QUALITY OF LIFE – EUOPROMS PROJECTS

In 2019, Europa Uomo commissioned Europe-wide research on the quality of life of men with prostate cancer.

It was the first time that such research has been conducted by patients themselves.

It was based on an online survey exploring experiences of treatment and life afterwards.

The Europa Uomo Patient Reported Outcomes Study (EUPROMS) gathered 2,943 questionnaire responses from men who have had prostate cancer from 24 European countries.

The responses were compiled by the research company Cello Health and analysed by Monique Roobol of the Erasmus University Medical Centre, Department of Urology, Rotterdam.

Early findings were first announced at a European Association of Urology meeting in Dublin in January 2020 and since then **findings have been reported at many scientific meetings and in various publications.**

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Among the findings are:

- significant numbers of men treated for the disease are struggling with mental health, sexual and tiredness problems after treatment
 - around 42% of men reported experiencing anxiety or depression after treatment
 - lack of sexual function is having the highest impact on quality of life, with a quality of life score significantly lower than recorded in previous clinical studies
 - use of, and satisfaction with, medication and devices to help erections is very low
 - patients who have received two or more treatments have substantial lower quality of life scores
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- [Go direct to EUPROMS page](#)

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EURPROMS 2.0

We launched EUPROMS 2.0 in autumn 2021. The survey was again a success thanks to the efforts of all members and the Board. Here are some key figures:

- 3600 patients answered (20% more than the original EUPROMS)
- 200 answers from Canada
- 120 answers from the US
- 2500 patients had not responded to the original EUPROMS and are new in the data set
- 2000 patients were willing to answer specific questions and left their email for future contact

The quality of the data is excellent and a first analysis shows that it will be possible to answer a lot of the remaining questions that were raised after the first EUPROMS study.

We expect first results in July 2022 and full results by the end of 2022.

We developed a booklet presenting the results of EUPROMS 1 especially designed for patients and their relatives.

Here is the link:

<https://www.europa-uomo.org/news/euproms-presentation-available-in-17-languages/>

ACTIVE SURVEILLANCE

Europa Uomo supports and promotes the use of active surveillance treatment for men with low-risk prostate cancer.

Properly implemented, it is an effective and safe means of avoiding over-treatment and ensuring optimal quality of life for as long as possible.

Active surveillance is a treatment in itself, and should be considered as valid as any other treatment in stages I and II of prostate cancer.

Active surveillance should not be confused with the watchful waiting programmes which are used in the later stages of cancer.

Recent years have seen considerable growth of knowledge on how to apply active surveillance safely.

Recent research indicates that this treatment can be useful for up to 30% of patients – those with low or intermediate risk.

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Active surveillance webinars

To explore patient experience and issues around the effective use of active surveillance, **Europa Uomo organised three online webinars in April to June 2021.**

Experts examined the successes and challenges of active surveillance (AS) as a treatment strategy, and patients from Italy, Cyprus and Iceland gave their perspectives on what it was like to be on AS.

A fourth event, on 29th March 2022 was a video virtual round table, aiming to summarise all the most important points of the previous webinars.

The webinars were designed as educational events, to inform men who are deciding whether to go on active surveillance and to provide support to those who are already on an AS programmes.

Board members Cosimo Pieri (Italy) and Tania Estapé (Spain), who are responsible for the AS project, are taking action on awareness of AS among psychologists.

Tania Estapé is working to undergo a survey of the 700 members of the International Psycho-Oncology Society to assess their knowledge and experience with prostate cancer patients.

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The first three webinars can be viewed in the active surveillance section of our website:

<https://www.europa-uomo.org/who-we-are/raising-awareness/active-surveillance/>.

And the fourth webinar at:

<https://www.europa-uomo.org/news/new-active-surveillance-webinar-discusses-psychological-impacts/>.

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EAU GUIDELINES COMMITTEE ON PROSTATE CANCER

Erik Briers represents Europa Uomo on the EAU Guidelines Committee on prostate cancer.

The EAU evidence-based guidelines are formulated in Europe, but are influential globally and are used in countries such as Argentina and China.

The prostate cancer guidelines are reviewed every year to reflect changes in science.

Patient representatives work with other members, provide a patient perspective and provide an honest opinion in discussions.

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EAU - EANM - ESTRO - ESUR - ISUP - SIOG Guidelines on Prostate Cancer

N. Mottet (Chair), P. Cornford (Vice-chair), R.C.N. van den Bergh, E. Briers, Expert Patient Advocate (European Prostate Cancer Coalition/Europa Uomo), M. De Santis, S. Gillessen, J. Grummet, A.M. Henry, T.H. van der Kwast, T.B. Lam, M.D. Mason, S. O'Hanlon, D.E. Oprea-Lager, G. Ploussard, H.G. van der Poel, O. Rouvière, I.G. Schoots, D. Tilki, T. Wiegel
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European Association of Urology



ESTRO
European Society for Radiotherapy & Oncology

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<http://uroweb.org/guideline/prostate-cancer/>