

Let's  
Talk

Prostate  
Cancer

EXPERT GROUP

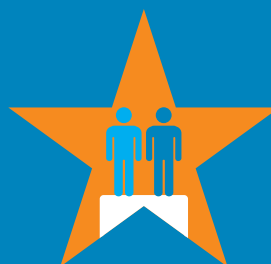


# Let's Talk Prostate Cancer Call to Action

## The LTPC Expert Group calls for...

1. *The identification of prostate cancer as a specific priority area for action*
2. *Support to research into the inequalities that affect people with prostate cancer*
3. *Prioritisation of early detection and timely access to high-quality multidisciplinary and multi-professional prostate cancer services*

Click [here](#) to jump to the recommendations



## About this Call to Action

The content of this Call to Action is informed by the Let's Talk Prostate Cancer (LTPC) Expert Group supported by Astellas Pharma Europe Ltd, Amgen Inc. and Pfizer Inc. to raise awareness of the challenges faced by people suffering from prostate cancer in Europe. The Expert Group is a collaborative initiative bringing together EU-level stakeholders with a shared interest in promoting policy change, education and awareness to ensure that people with prostate cancer, including those in advanced stages, receive the right treatment and care at the right time in a shared decision-making process between patients and medical professionals.

The Expert Group is co-chaired by MEPs Juozas Olekas, Irena Joveva, and Sirpa Pietikäinen and brings together non-affiliated prostate cancer advocates as well as representatives from key EU stakeholder organisations in the field of prostate cancer, including Europa Uomo, the European Oncology Nursing Society (EONS), the European Association of Urology (EAU), the European Association of Urology Nurses (EAUN). It is supported by Astellas Pharma Europe Ltd, Amgen Inc. and Pfizer Inc.

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“Cancer, as one of the most important health crises of our day, binds us all - no matter where we live or what language we speak.”

**Jouzas Olekas MEP**

*Co-chair of the Let's Talk Prostate Cancer expert group*

“The fight against non-communicable diseases, has only grown in importance in the context of an ageing population, which sees cancer as one of the main threats to its health and wellbeing.”

**Sirpa Pietikäinen MEP**

*Co-chair of the Let's Talk Prostate Cancer expert group*

“Health is the foundation of everything. For our society to flourish, no one should be left behind in the fight against cancer.”

**Irena Joveva MEP**

*Co-chair of the Let's Talk Prostate Cancer expert group*

# Foreword by the Chair



Prostate cancer is often wrongly perceived to be a 'less serious' cancer, with people thinking that prostate cancer is a disease men die with rather than of.<sup>1</sup> However, data shows that it affects more than two million people in the EU, representing the most common cancer among males and accounting for approximately 10% of male cancer deaths in Europe each year.<sup>1,2</sup> Furthermore, the incidence of metastatic prostate cancer has increased from 5.2 per 100,000 men in 2005 to 7.9 in 2019;<sup>3,4</sup> a situation which has been further worsened by delays in diagnosis due to the COVID-19 pandemic.<sup>5</sup>

Despite the scale of the disease, prostate cancer has not received adequate prioritisation. Awareness remains low, early detection is a challenge and patients do not always have access to the care they need to live longer and with the best quality of life possible. Inequalities in treatment and care persist and patient outcomes have been impacted by the severe disruption caused by the pandemic. Europe and Member States must make better prostate cancer care a reality for all affected citizens – making sure that no one, regardless of location or circumstances, is left behind.

The publication of Europe's Beating Cancer Plan<sup>6</sup> and of the updated Council Recommendation on cancer screening<sup>7</sup> mark important steps towards the eradication of inequalities in cancer diagnosis and treatment. This is therefore a crucial time to draw attention to these concerns, to give further momentum to the fight against cancer and ensure that tackling prostate cancer is a key pillar of efforts to build a true European Health Union.

I feel honoured to act as Co-chair of the Let's Talk Prostate Cancer Expert Group and am committed to working together with my colleagues in the European Parliament and with stakeholders from across Europe to ensure the success of the Let's Talk Prostate Cancer campaign. This Call to Action is one of several important materials developed by the Expert Group, and I would encourage you to find out more at [www.letstalkprostatecancer.com](http://www.letstalkprostatecancer.com).



**Sirpa Pietikäinen MEP**

**Co-chair of the Let's Talk Prostate Cancer Expert Group**

Let's  
Talk

## Prostate Cancer

EXPERT GROUP

"As one of the main voices for people affected by prostate cancer in Europe, Europa Uomo strives to increase awareness of prostate cancer and promotes equality of care. Quality of life should be a major driver in decision-making. We are delighted to be a member of this multi-stakeholder initiative and to contribute to making access to optimal care and treatment for people with prostate cancer in Europe reality."

André Deschamps  
(Wij Ook and Europa Uomo)

**EUROPA  
UOMO**  
The Voice of Men with  
Prostate Cancer in Europe

wij  
ook

"Caring for those affected by prostate cancer is the everyday task of many of our members. We see the impact that appropriate care infrastructure and adequately funded services have on those affected, their carers and family members. The recommendations in this Call to Action will provide policymakers with essential guidance on how we can achieve better care for prostate cancer patients together."

Philip Reynolds, European Association of  
Urology Nurses (EAUN)

**eaun**

"As the leading authority in Europe in urological practice, research and education, the European Association of Urology (EAU) welcomes this initiative and is fully committed to achieving its goals. We look forward to working with partners, patients and policymakers in the dissemination and implementation of the EAU Guidelines on Advanced Prostate Cancer to ensure early detection and treatment of prostate cancer, enabling a brighter future for those affected by it in Europe."

Hendrik van Poppel, European Association of  
Urology (EAU)

**EAU**

"When you receive a diagnosis of prostate cancer, it's not about the number of days until you get access to treatment, but about the number of sleepless nights until you do. People affected by prostate cancer are the ultimate beneficiaries of timely diagnosis, optimal treatment and care. This Call to Action highlights important challenges in ensuring optimal care for prostate cancer patients, whilst providing concrete recommendations for a valuable roadmap for policymakers to address these challenges at EU level and in individual Member States."

Jacqueline Daly, East Galway & Midlands cancer support



"Caring and supporting people affected by cancer and prostate cancer specifically across the cancer continuum is one of the European Oncology Nursing Society's (EONS) key objectives. We believe that every individual affected by prostate cancer should have access to personalised and multi-professional optimal quality care and treatment no matter where they live in Europe. This Call to Action provides an important step in achieving this common goal."

Andreas Charalambous, European Oncology Nursing Society (EONS)



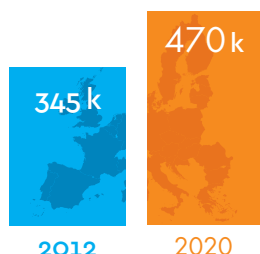
"Unfortunately, wide variations still exist in the care of prostate cancer patients across the EU. I am proud to be a member of the Let's Talk Prostate Cancer Expert Group, which aims to raise awareness of these variations and make strides towards ensuring patients receive access to the best possible treatment and care wherever they may live. It is crucial that policymakers recognise the burden of prostate cancer in Europe and take steps to address it through initiatives such as Europe's Beating Cancer Plan."

Mary Rogan, GP and Psychosexual Therapist

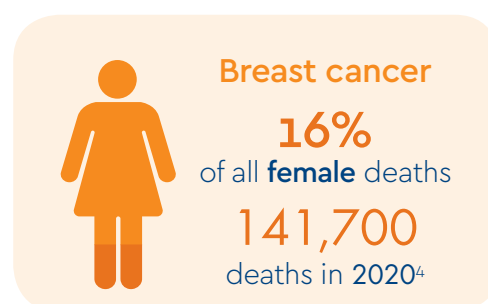
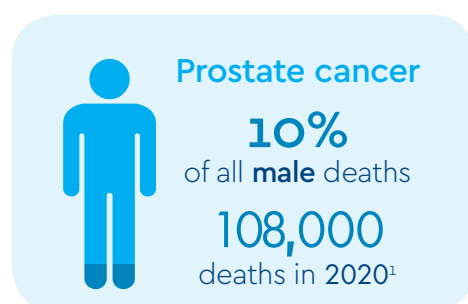
## Supportive statements

# Why do we need a Call to Action for prostate cancer?

Prostate cancer incidence in Europe<sup>4,5</sup>



In the EU, more than two million people are living with prostate cancer, the most frequently diagnosed cancer among men.<sup>1</sup> Diagnosis rates for prostate cancer are increasing and around 470,000 new cases were diagnosed in Europe in 2020, compared to an estimated 345,000 new cases in 2012.<sup>8,9</sup> Each year, prostate cancer accounts for around 25% of all new male cancers and 10% of male cancer deaths in Europe,<sup>2</sup> with over 108,000 people estimated to have died from the disease in 2020.<sup>8</sup> In comparison, breast cancer is estimated to have led to around 141 700 deaths in 2020.<sup>10</sup>



As prostate cancer often occurs with other diseases, people with prostate cancer often report existing unmet needs.<sup>11</sup> These relate particularly to a lack of adequate patient information,<sup>12</sup> as well as of access to cancer specialist nurses, tailored supportive care and psychological support around the impact of treatment.<sup>13</sup>

Prostate cancer and its treatment not only affect urinary, sexual and bowel function but also energy and performance in physical and social roles which have a significant impact on patients' quality of life.<sup>14</sup> The later prostate cancer is diagnosed, the more severely quality of life can be affected.<sup>15</sup> Early diagnosis is therefore vital for enabling people with prostate cancer to live longer and with a better quality of life.<sup>15</sup>

The economic impact of prostate cancer is significant, representing an annual cost of over €9 billion in the EU, of which direct healthcare costs account for €5.8 billion.<sup>1</sup> Early stage intervention can reduce the risk of complications and disease progression, presenting an opportunity to improve quality of life and reduce potential overtreatment.<sup>15</sup> In this sense, a further important step towards reducing inequalities in cancer diagnosis and treatment in the EU has been taken with the publication in September 2022 of the updated draft Council Recommendation on cancer screening, extending recommended screening programmes to prostate cancer.<sup>6</sup> The Council of Ministers, however, reduced the scope of the original proposal in relation to prostate cancer,<sup>16</sup> whose provisions were grounded in the scientific evidence provided by the EU's Scientific Advice Mechanism.<sup>17</sup>

€3.2 billion



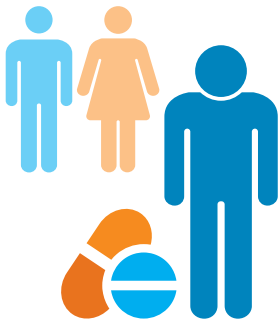
Annual direct healthcare costs of prostate cancer in the EU<sup>1</sup>

Annual indirect costs of prostate cancer in the EU<sup>1</sup>



This can be partly explained by a misunderstanding around prostate-specific antigen (PSA) screening.<sup>1</sup> PSA screening can reduce disease-specific mortality by 21%, however there is still debate within the medical community that PSA screening can lead to overdiagnosis and overtreatment.<sup>15</sup> Within this context, it is important to raise awareness of academic research and screening pilot programmes which demonstrate the efficacy and safety of risk-based PSA screening for prostate cancer patients, based on factors such as PSA level, family history, ethnicity, gene mutation and prostate size.<sup>18</sup>

We can also add that the impact of COVID-19 on prostate cancer patients should be acknowledged as an undeniable evidence-based fact. Delays in diagnosis caused by the pandemic have resulted in a peak in the number of cases of advanced cancer being diagnosed at presentation.<sup>5</sup>



Despite this, compared to cancers such as lung, colorectal or breast cancer, prostate cancer, and advanced prostate cancer in particular, is relatively low on the political and policy agendas in the EU and its Member States. Other cancers receive higher policy attention despite prostate cancer having the highest estimated incidence rate among all cancers in 2020, with 159 new prostate cancer cases per 100,000 being detected in the EU27 (in comparison, breast cancer counts 143, colorectal cancer 72 and lung 67 new cases per 100,000).<sup>19</sup> There is a clear absence of political pressure and policy action, particularly post-diagnosis, to address the issues facing people with prostate cancer.

This situation therefore calls for a renewed effort on behalf of the entire community to ensure prostate patients and their beloved ones are not left alone in their fight against the disease. We must bear in mind that behind facts and figures are real people still facing the challenges associated with prostate cancer, together with their families and friends as well as carers.<sup>11</sup>



To this end, this Call to Action sheds light on current barriers to early diagnosis and effective access to treatment and care for people with prostate cancer and identifies the means to overcome them through policy action, education and awareness at EU and national level. Without policy action, there is a risk that the challenges already facing patients living with prostate cancer across Europe and that their specific needs will not be considered in the post-pandemic recovery phase.

# Key challenges facing people with advanced prostate cancer

The *Let's Talk Prostate Cancer* Expert Group has identified six key policy challenges in access to timely diagnosis, treatment and care for people with prostate cancer.



## Late detection and diagnosis

Over the years, there has been a decrease in prostate-specific antigen (PSA)-based population screening programmes for prostate cancer in Europe.<sup>20</sup> This has contributed to prostate cancer becoming the most frequently diagnosed cancer amongst men and the second leading cause of male cancer death in Europe.<sup>2</sup>

As a result, prostate cancer is increasingly diagnosed at an advanced stage with studies showing an increasing proportion of individuals diagnosed with meta-static or late stage disease.<sup>4</sup> At this point, the cancer can become resistant to standard hormone therapies and no longer curable.<sup>1</sup> This impact manifests itself not only in terms of mortality and survival but also in relation to the daily quality of life of patients.<sup>21</sup>

In this sense, the inclusion of prostate cancer in the Council Recommendation on cancer screening, while not comprehensive, nonetheless represents an opportunity to ensure patients receive timely diagnoses all across Europe. The importance of EU and national implementation of risk-based screening for prostate cancer cannot be understated.



## Access to treatment

Given the decrease in quality of life in later stages of the disease, it is crucial that the needs of people with prostate cancer are addressed at the earliest opportunity. The condition, together with side effects of current therapies can impair the social and professional functioning of those living with the disease, affecting not only their personal life but also their ability to stay in the workforce.<sup>1</sup>

Yet despite these challenges, improvements in treatment<sup>22</sup> and care offer important opportunities to enable people with prostate cancer to live longer and more fulfilling lives. It is therefore important that they have access to the right treatment and care at the right time via an optimal care pathway supported by multidisciplinary professionals.



## Stigma

The stigma associated with the side effects of treatment of prostate cancer is multifaceted.

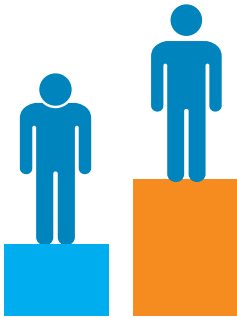
Current treatments for prostate cancer, including hormonal treatment, surgery, and radiation therapy can have a severe impact on patients' sexual functions.<sup>23, 24</sup> While early detection, diagnosis and treatment may contribute to reducing the likelihood of sexual dysfunction, men suffering from advanced cancer who have to undergo more radical treatment are faced with the twin challenges of erectile dysfunction and possibly urinary incontinence. Although urinary incontinence is not a sexual dysfunction per se it causes great discomfort and can impact men's sexual life. At the same time, sexual dysfunction or loss of libido affects patients and their families daily, causing emotional distress, guilt, isolation and anxiety, sensibility compromising the quality of their life.<sup>21, 24</sup>

Many patients feel uncomfortable talking about the condition to close friends, family and healthcare professionals, let alone becoming the face of awareness campaigns targeting the general public. This, in turn, affects access to support and treatment as well as preventing dialogue and awareness about the condition.<sup>25</sup>

The repercussions of prostate cancer treatment on sexual health are frequently overlooked by healthcare professionals themselves. This is often due to wrong assumptions about the sexual inactivity of the patients based on their age. Consequently, measures to tackle sexual dysfunction as well as incontinence, such as physiotherapy for pelvic floor strength, are rarely taken into consideration when tailoring therapies for prostate cancer patients.<sup>26</sup>

Similarly, counselling and sex therapy are seldom part of the treatment, regardless of the substantial impact prostate cancer can have both on patients and their relationship with their partners.<sup>27</sup>

Stigma, together with a reluctance to engage with the healthcare system during the COVID-19 crisis, may have increased the reluctance of men to seek the medical advice they require, further delaying access to vital support and treatment.<sup>5</sup>



## Healthcare inequalities

Healthcare inequalities along socio-economic, ethnic, national and regional lines affect every aspect of prostate cancer, including the stage of diagnosis, access to treatment and the availability of specialist support. Common forms of inequality in prostate cancer include the affected person's age,<sup>28</sup> with 40% of men aged over 70 less likely to receive aggressive types of treatment in case it deprives the patient of years of life.<sup>29</sup> Barriers to care also exist for some ethnic communities, despite studies suggesting that about 1 in 4 black men will have a higher risk of developing the condition.<sup>30, 31</sup>



## Clinical attitudes in relation to advanced prostate cancer

Age has been shown to impact clinical decision-making. In some cases, health-care professionals decide not to prescribe treatment based on the patient's age rather than their health or suitability for treatment.<sup>32, 33</sup> It is important that these attitudes change and that patients are treated based on their health status, rather than their birth date combined with patient choice and/or risk/benefit considerations.



## Health system organisation

Health services are not always organised in a way which is designed to manage the increasing health needs of prostate cancer patients or to make the most of the opportunities created by improvements in treatment. Healthcare professionals involved in the management of prostate cancer do not always work in a coordinated way or join up the care they deliver. This can result in fragmented care, wasted resources and delays in treatment.<sup>34</sup>

It is vital that healthcare systems capitalise on opportunities arising from the pandemic, such as the increased adoption of digital technology, considering the substantial impact the pandemic has had on patients and in light of the current economic crisis brought on by the War in Ukraine.

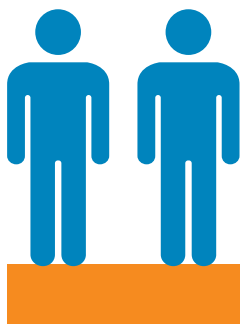
# Call to Action

The Let's Talk Prostate Cancer Expert Group proposes three Calls to Action to address the six key challenges identified. EU and national policymakers, notably Members of the European Parliament (MEPs) and national and regional parliamentarians across Europe should take urgent action to implement each of these recommendations. In close collaboration with members of the Let's Talk Prostate Cancer Expert Group, policymakers should incorporate the Calls to Action into their EU, national and regional level strategies and campaigns.



We call on policymakers to become ambassadors of awareness campaigns at EU, national and regional level, to increase the knowledge and understanding of the challenges facing people with prostate cancer, including in its advanced stage, and the burden of the disease.

- We call on the European Commission to launch an Initiative on Prostate Cancer, aimed at addressing the unmet needs of prostate cancer patients;
- The EU-wide 'Conquering Cancer: Mission Possible' initiative, which aims to prevent 3 million premature deaths by 2030,<sup>35</sup> should ensure that prostate cancer is identified as a specific priority area for action;
- All national cancer programmes and activities stemming from Europe's Beating Cancer Plan<sup>5</sup> should prioritise early screening – as recommended by the EU's Scientific Advice Mechanism<sup>17</sup> – and explicitly address the needs of people living with prostate cancer, including in its advanced stage, setting out the steps that will be taken to improve care, meet the increasing need for treatment and support and evaluate progress on these ambitions;
- We support the call for a cancer dashboard at the European level, supported by the European Health Data Space,<sup>36</sup> to include prostate cancer in national cancer plans, to showcase associated mortality and incidence across countries, and to raise awareness of socio-economic, ethnic, national and regional inequalities;
- With currently only 48% of men being aware of prostate cancer risks and of the availability and importance of PSA testing,<sup>37</sup> we call for campaigns and education programmes at all levels, supported by policymakers, to educate individuals about their risk, prevention methods and treatment options.



## ★ Healthcare inequalities

In addition to the European Commission's Cancer Inequalities Registry and the new European Cancer Pulse launched by the European Cancer Organization,<sup>38</sup> which map trends in key cancer data identifying inequalities between Member States and regions, we call on European, national and regional policymakers to support research into the inequalities that affect people with prostate cancer, including along socio-economic, ethnic, national and regional lines, as part of the innovation and research grants available under Horizon Europe, EU4Health and national health research budgets. Utilising funds available under the ambitious EU4Health programme<sup>39</sup> to implement actions in Europe's Beating Cancer Plan<sup>5</sup> will further facilitate investments in important research in this field. Comprehensive reporting on healthcare inequalities, including the increase in inequalities because of COVID-19, will facilitate the development of measures to overcome these in the long term.



## ★ European Guidance Implementation

We call for a timely implementation of the final revised Council of the European Union Recommendation on cancer screening within national cancer plans.

Member States should ensure timely access to high quality multidisciplinary and multi-professional prostate cancer services at every stage of the treatment and care pathway as promoted by ECO's Essential Requirements for Quality Cancer Care (ERQCC).<sup>40</sup> Efforts to improve services should be supported by investment in effective treatments for advanced prostate cancer and the implementation of existing guidelines and validated patient information across Europe.

Member States should moreover work along with the Commission to update the EU's Joint Action on Innovation Partnership for Action Against Cancer (IPAAC), to ensure that action to improve the prostate cancer care pathway at national level.<sup>41</sup>

## Conclusion



As highlighted in this Call to Action, the case for political prioritisation of prostate cancer at European, national and regional level has never been clearer.

A unique opportunity exists in the current mandate for the EU to tackle prostate cancer as a political priority, with the publication of Europe's Beating Cancer Plan, the Mission on Cancer and several new EU health policy initiatives both pre-existing and stemming from the COVID-19 pandemic. This is in addition to the funding available under initiatives such as the new EU4Health programme and Horizon Europe. Alongside patients and their families, healthcare professionals, researchers and industry, and policymakers at all levels, play a key role in highlighting the challenges faced by prostate cancer patients and how these can be better addressed.

The time to act is now.

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