



European Alliance for
Personalised Medicine

The fight against prostate cancer in Europe – White Paper

Brussels, Belgium



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the European Association of Urology.

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Foreword

This White Paper is a direct appeal to policymakers, legislators and regulators to encourage innovation, and to all stakeholders to work more closely together to reduce the burden of prostate cancer on patients and on society.

Much more research is needed into the disease. The number of men being diagnosed with prostate cancer in Europe has increased over recent years. This is most likely down to men becoming more aware and having tests to detect very early prostate cancers as well, of course, as the aging population that leaves us with more older men in society.

The actual causes of prostate cancer are still unknown, but some factors such as age and a family history of the disease increase the chances of developing it.

Age has been identified as the strongest risk factor when it comes to prostate cancer, with men under 50 having a very low risk. However, those reaching the age of 80 or more will have an 80% risk of developing the disease.

Also, those men with a close relatives (such as a father, a brother, a grandfather or even an uncle who have contracted the disease in the past are slightly more likely to develop it themselves.

Despite the best efforts of scientists, no specific gene has so far been identified with a direct link to prostate cancer, although research has flagged up that faulty genes linked to a higher risk of breast cancer could also increase the risk of getting prostate cancer.

Nothing, however, is certain although eating a healthy balanced diet which is high in fibre and low in fat and sugars may reduce the risk.

There is no doubt that more research is needed into a disease that not only will not go away, but will actually increase as our population ages.

EAPM's White Paper follows-up and complements a Europa Uomo call to action on the disease released in 2013.

The call to action highlighted the following needs:

- To provide access to free, appropriate early detection for prostate cancer, coupled with supporting information
- To improve prompt and accurate diagnosis of prostate cancer at all stages of disease
- To provide equal access to effective treatments and technology
- To improve the identification, assessment and treatment of those at risk of dying from prostate cancer
- To offer a range of management approaches, including active surveillance, to those whose prostate cancer is unlikely to progress
- To empower men and their families in order that they can be involved in decisions about their personalised care plans, whilst providing ongoing information and support

EAPM is in full agreement with these goals.

Sincerely,

Didier Jacqmin
EAPM Treasurer
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Introduction

The battle against prostate cancer needs to be fought at EU level.

Despite significant advances in treatment, it is a growing problem that has a major impact on men's health. In 2008 some 70,000 men died of this disease in Europe, which accounts for in the region of 10% of all male cancer deaths. The vast majority (92%) of these deaths occurred in the oldest age group, which is made up of 65-year-olds and over.

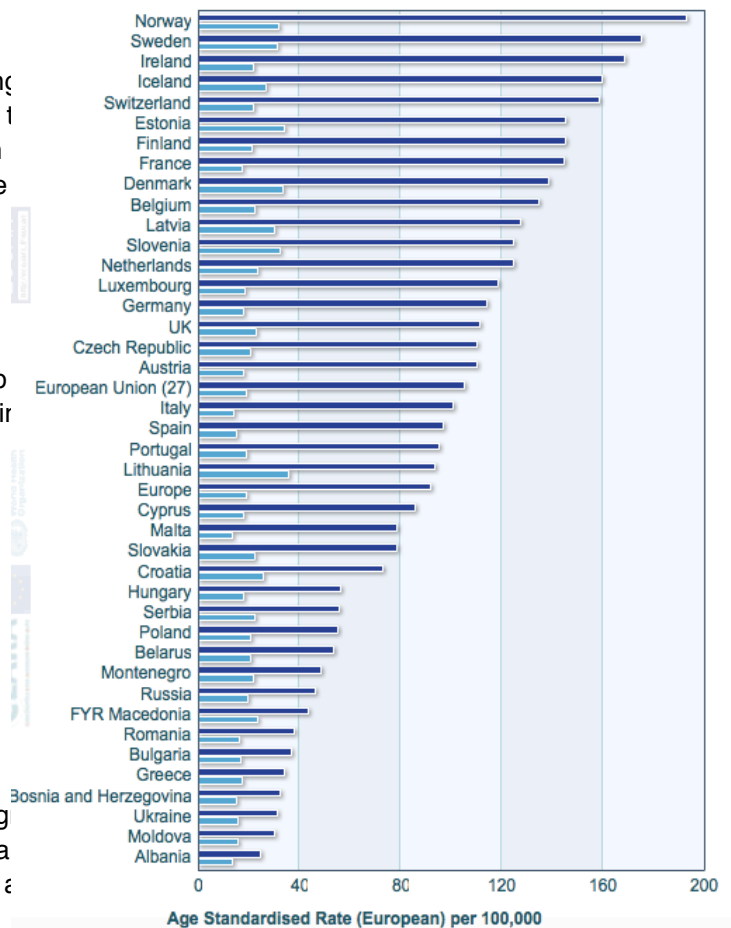
Mortality rates vary across the EU28, ranging from more 35 per 100,000 in Estonia and Latvia to 15/100,000 in Malta and Romania. Sweden and Denmark both have a rate of more than 33/100,000, which nearly 25% higher than the nearest other Western

Today, some 3 million European men are living with prostate cancer and the number will grow due to the EU's ageing population. There are in the region of 100 new cases per 100,000 men across the European Union each year. But there are significant differences between Member States with, for example, as many as 123 cases per 100,000 in Ireland.

The incidence of prostate cancer rocketed up since the 80ies and mortality is going down in many EU28 countries. The reason for this is that the majority of prostate cancer cases are slow growing and pose no immediate threat. These days, many men die with the disease rather than as a result of it.

Although the disease is most prevalent in the over-65s, there is one type of prostate cancer that can occur in younger (as well as older) men which is more aggressive and leads to a more rapid death if not detected at an early stage. Such tumours differ from the slow-growing tumours that affect the majority of men. Cancer in young patients is not more aggressive, there are aggressive tumors in old patients.

Estimated incidence and mortality from prostate cancer, 2012



It is important to note that prostate cancers often have no early symptoms. One problem with the disease has been over screening, which identified too many non-life threatening prostate cancer cases. This in



turn led to a great deal of unnecessary treatment and brought with it long-term side effects. A result of this has been some Member States deciding against national screening programmes for the disease.

The problem of prostate cancer will only worsen, with projections suggesting that, by 2060, there will be an increase by around 32 million in the number of men aged over 65.

Lifestyle and preventable risk factors in men

Poor lifestyles and preventable risk factors account for a high proportion of premature death in men. There is a strong gendered dimension to lifestyle choices and risky behaviours that place men at higher risk of ill health than women.

In all EU Member States it is clear that men who live in poorer social conditions are likely to eat less healthily, take less exercise, are more likely to be overweight and/or obese, drink more alcohol, are more likely to smoke and/or engage in substance misuse, and have more sexual behaviour that puts them at higher risk.

An agenda for change

Research into prostate cancer needs boosting, with platforms for effective collaboration between academia, industry and healthcare systems.

Because limited resources and patient numbers make it impossible for research to be conducted in all countries, sharing of knowledge and expertise is vital. A better structure of clinical prostate cancer research within the EU could create several centres with sufficient resources to attract and perform early trials of new treatments.

The European Commission should allocate long-term funds for research into prostate cancer, with increased investment in research centres, and with advanced databases of biological and clinical data. Patient registries and databases are essential to permit the pooling of data needed to achieve a sufficient sample size for clinical research. Regulations need to be adapted to allow more sharing of patient data and biological materials.

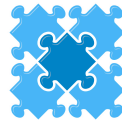
Improved coordination of clinical trials - and of recruitment – is needed, with better access to information for researchers, doctors and patients. New methodologies for clinical research should be accepted, especially relating to small subgroups patient populations.

A clear focus on late translational research, particularly into clinical effectiveness, can identify tangible benefits for the health economy in the short- to medium-term.

Putting patients at the centre

Empowerment and involvement of patients and patients' organisations would enrich reflection on how to tackle prostate cancer. They should be allowed to contribute to shaping an adequate comprehensive European response to the disease, and be given access to the information they need to perform this role.

Meanwhile, healthcare professionals (HCPs) need more information on the disease to increase the likelihood of an early diagnosis. Education programmes are lacking not only among healthcare professionals but also among the general population. The patients need knowledge to empower them.



The WHO defines patient empowerment as a 'prerequisite for health' and encourages a 'proactive partnership and patient self-care strategy to improve health outcomes and quality of life among the chronically ill'. In this context, prostate cancer patient organisations are crucial in direct support to individuals living with the disease and in their collective work in improving conditions for current and future patients.

Patients should be entitled as individuals to a voice in the choice of treatment and care that they are offered. Patients should have their rights to information respected, with access to centralised information about services and care nationally and around Europe (preferably in their own language) to help them make informed choices.

Patient information pathways with approved treatments should be developed at EU level, with cross-EU centres of excellence, and national strategies that will drive patients to them to ensure that access to best pathways is available to all.

Patients' representatives should also be allowed input into discussions of long-term budget planning.

Efficient and effective action for prostate cancer patients depends on a coherent European strategy, and a common approach to mobilising and integrating scarce and scattered resources.

The way forward, in brief

What Europe needs in the fight against prostate cancer is:

- An awareness-raising campaign (that includes health literacy) targeted at men and their families
- More research funding to ensure that the best treatment pathways are developed
- More training for medical professionals
- Better access to best diagnostics and treatment
- More social care support for prostate cancer patients
- Patients' information should be improve to favour patients' choice.

Patient story

David, a 49-year-old from Yorkshire in the UK, was diagnosed with prostate cancer and, after the prostate gland was removed, became depressed at the thought that he could not now have children.

He explained that he doesn't think that the emotional impact is really recognised.

David's father had the disease in his 80s and this was a factor. After testing David was told he had a



grading of six out of 10 which meant there was a small bit of cancer in the gland. He was recommended surgery as a relatively young and fit man.

David believes that men are not properly supported regarding some health concerns and will be in the care of a consultant for the rest of his life. He is aware of the problem of over screening but thinks men should be tested regularly.

"They need to be vigilant", he says.

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