EUROPA UOMO

IMPROVING PROSTATE CANCER CARE ACROSS EUROPE

A CALL TO ACTION

Recommendations to reduce the death rate and burden of prostate cancer by improving early detection and equal access to high quality care across Europe

IMPROVING PROSTATE CANCER CARE ACROSS EUROPE

Contents

FOREWORD ... 2

Why action is needed ... 2

EXECUTIVE SUMMMARY ... 4

Prostate cancer — the challenge ... 4

- *The picture across Europe* ... 5
- *Early diagnosis – mixed messages* ... 5
- *Overcoming the communication gap* ... 6
- *The personal impact of prostate cancer* ... 6
- *A specialist team approach* ... 7
- *Personalising care* ... 7
- *Differences in treatment access* ... 7
- *The need for more research* ... 7

Call to action recommendations ... 8

SUPPORTING EVIDENCE ... 11

Introduction — the picture in Europe ... 12

Recommendations ... 17

Conclusions ... 30

References ... 32

A CALL TO ACTION

WHY ACTION IS NEEDED

Mrs Nessa Childers MEP

Many people reading this report will have been touched by prostate cancer at some point in their lives. Currently, there are over 3 million men living with prostate cancer in Europe.[1] This figure is set to rise as the number of new annual cases reaches around 450,000 in 2020.[2]

In Europe, prostate cancer kills at least one man every 6 minutes, resulting in more than 90,000 deaths every year.[3] The picture across Europe is not uniform, however. There are wide inequalities both in resources and access to high quality care; these are likely to worsen as cancer levels rise and caps on healthcare expenditure continue. Because of these discrepancies, a diagnosis of prostate cancer can result in different outcomes depending on where in Europe the patient lives. In an EU where health inequalities and healthy ageing feature high on the health policy agenda, this is clearly unacceptable.

Initiatives like the drive for national cancer plans, instigated by the European Partnership Action Against Cancer (EPAAC) and best practice guidelines for urological cancers seem to have made progress. However, urgent action is required to implement these across all countries and to prioritise prostate cancer care and education.

So, where do we go from here? Prostate cancer is best treated if diagnosed early and accurately. The greatest social and financial costs associated with prostate cancer relate to metastatic disease.[4] After spreading to other parts of the body, the disease becomes incurable, is more difficult to treat, and the associated morbidity is more complex.

ONE MAN DIES OF PROSTATE CANCER every 6 minutes

We need to do more to help men with prostate cancer stay independent and out of hospital for as long as possible, which requires a holistic, personalised approach to care covering both physical and psychosocial symptoms. Prostate cancer is not a uniform disease in terms of its manifestation and in how it impacts people's lives. Recognising this and improving public awareness and services to ensure earlier and accurate diagnosis together with effective, personalised treatment or monitoring may save lives and help to release resources for those with aggressive or advanced disease. As highlighted by the 'State of Men's Health in Europe' report, too many men delay a visit to the doctor because of fear, embarrassment and lack of awareness. Empowering men with tailored information and support will help to inform them about signs to look out for, early diagnosis and management options.

To tackle the growing problem of prostate cancer and improve the lives of our brothers, fathers and sons now and in the future, we must work together. The Europa Uomo White Paper outlines recommendations to improve high quality care for all men in Europe, focusing on early detection and a multi-professional team approach to the management of prostate cancer, involving men in their care decisions, and investing in greater education, information and research.

Mrs Nessa Childers MEP

[1] White A et al. State of Men's Health in Europe. European Union report. 2011

[2] Cancer incidence, mortality, prevalence and disability-adjusted life years (DALYs) worldwide. Globocan; 2008 [cited Jun 28, 2013]. http://globocan.iarc.fr/burden_sel.asp (select worldwide, prostate cancer and 2020 predictions)

[3] Ferlay J et al. Cancer incidence and mortality patterns in Europe: Estimates for 40 countries in 2012. Eur J Can. 2013;49:1374–1403

[4] Roehrborn CG, Black LK. The economic burden of prostate cancer. BJU International; 2011 Sept; 108;6:806–13

PROSTATE CANCER

Prostate cancer kills at least 90,000 men every year in Europe.[3] For men living with the disease and their families, the symptoms can be devastating. Most countries have seen a rise in incidence with almost 417,000 new cases diagnosed in 2012 in Europe compared with around 273,000 in 1995-1999.[3,5]

THE CHALLENGE

The rising incidence of prostate cancer is partly due to an ageing population, although the greatest increase has been seen in men aged 45-64, which may be due to earlier diagnosis.[6]

Prostate cancer varies enormously and for this reason, it poses a considerable challenge. It ranges from slow-growing, relatively harmless tumours to aggressive disease that may spread to other parts of the body and ultimately prove fatal.

The challenge is to make an accurate assessment early on and tailor treatment or monitoring accordingly. At the moment, some men whose disease is considered indolent or slow-growing may be being over-treated. This is likely to cause them unnecessary suffering and adds to the financial burden on healthcare systems. At the other end of the spectrum, those with more aggressive disease may go undiagnosed or not receive the best available treatment. This failure increases their risk of metastatic disease and death.

Accurately predicting a man's risk of relapse is also critical. Despite recent advances in treatment, between a quarter and a half of men diagnosed and treated for prostate cancer will develop recurrence or spread within 10 years. Between 16–35% of patients need second-line therapy within 5 years of their first treatment.[7]

Access to better diagnostic technologies and treatments is essential to reduce this risk of relapse and to improve effective management.

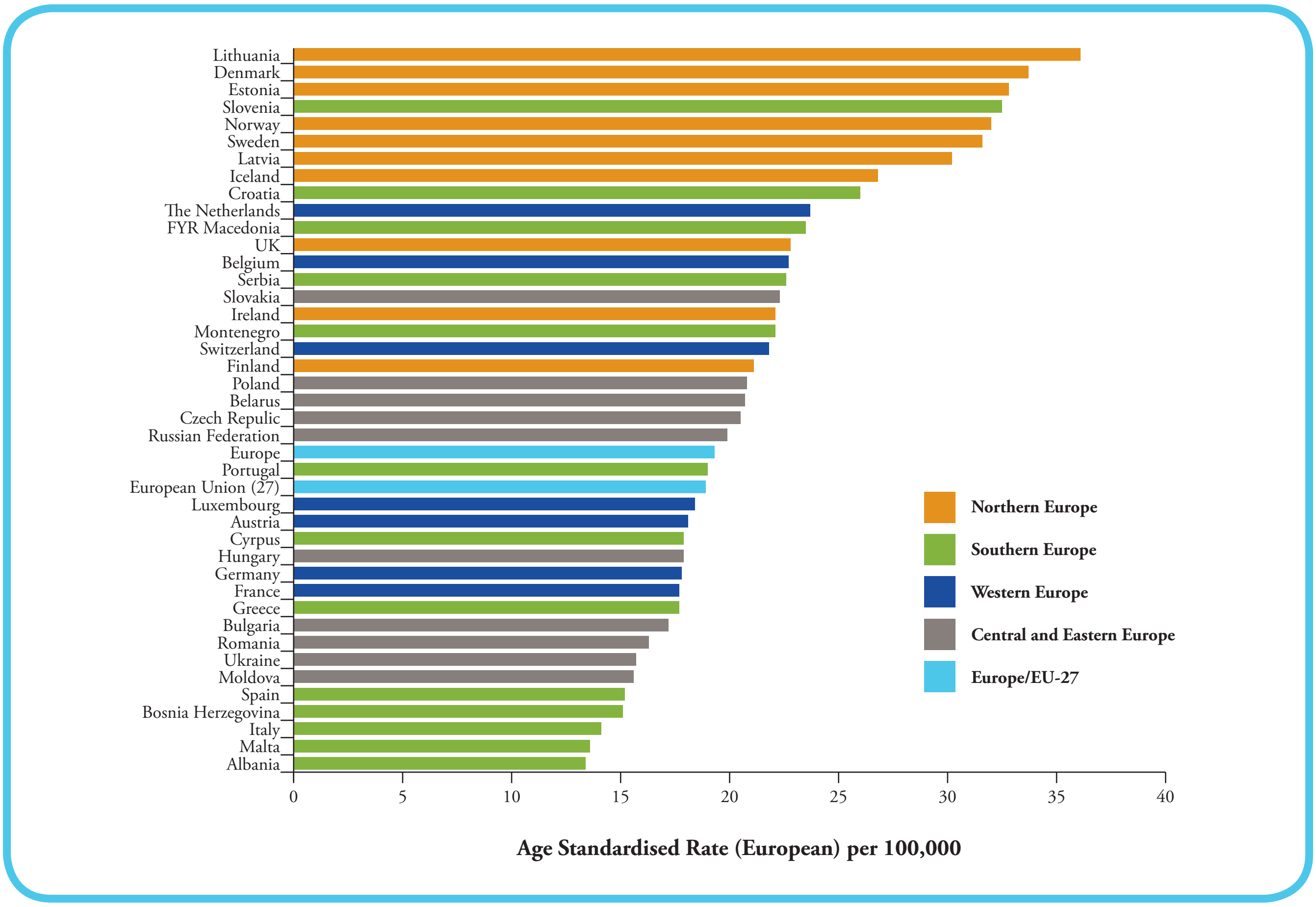


Illustration: *Estimated mortality of prostate cancer 2012*[3]

The picture across Europe

The number of men diagnosed with prostate cancer and dying from the disease varies regionally. Northern and Western EU countries, such as Norway, Sweden and France have some of the highest incidence rates, partly due to earlier detection with PSA testing.

Mortality rates are highest in Lithuania, Denmark, Estonia and Slovenia, closely followed by Norway and Sweden, and lowest in Albania, Malta and Italy. Reasons for this need to be fully explored, but many factors are likely to play a role, including the fact that European cancer registries sometimes present results differently. The adoption of a standard reporting system in European registries should make it easier to set benchmarks for improvement.

Early diagnosis – mixed messages

The recent public debate about PSA screening has caused some confusion about the benefits of early detection. Population-based PSA screening is not currently recommended because of the risk of over-diagnosing and over-treating men with indolent prostate cancer and alarming those with benign prostate conditions.

[5] Sant M et al. EUROCARE-4. Survival of cancer patients diagnosed in 1995–1999. Results and commentary. Eur J of Can. 2009;45:931–991

[6] Prostate cancer incidence statistics. http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/incidence/uk-prostate-cancerincidence-statistics. (Accessed September 2013)

[7] Heidenreich et al. European Association of Urology Guidelines. March 2013

At the same time, for individuals who are concerned about their risk or who may have possible signs and symptoms of prostate cancer, it cannot be overstated that early diagnosis is associated with improved outcomes. The earlier prostate cancer is caught, the more successfully it can be treated or monitored.

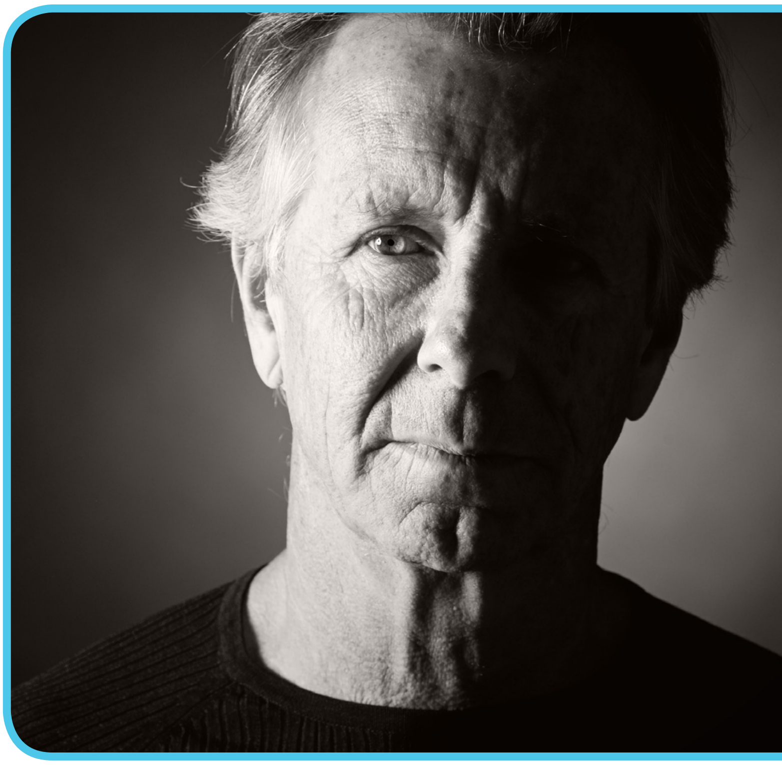
Better education is needed for men and healthcare professionals to encourage early diagnosis and prompt referral. This should be coupled with access to free, appropriate PSA testing and a digital rectal examination (DRE) if there are concerns about the risk of prostate cancer. In preparation for a PSA test, men should be informed about the benefits and drawbacks of tests and the consequences of a positive or negative result, including biopsy and management options. Biopsies should be performed in accordance with EAU guidelines.

PATIENT

> “When told you have prostate cancer the first thing that comes to mind is I must get my house in order. But thank God it was caught early and can be cured

Overcoming the communication gap

Fear and embarrassment about certain prostate cancer-related symptoms, including urinary problems and sexual dysfunction, can delay a man’s decision to visit the doctor. Furthermore, anxiety and confusion about specific treatments and their side effects may affect a man’s choice of therapy. Clear and appropriate information should be provided to address men’s fears and concerns about prostate cancer and to inform them about their management options. At the moment, this is not available everywhere.



The personal impact of prostate cancer

The impact of prostate cancer and its treatment is often unrecognised. Men may live in silence with physical and psychological effects that could be addressed by a specially-trained support worker. Attending to these effects may reduce suffering and promote the wellbeing of men, their partners and family members.

The personal burden of prostate cancer can vary depending on a man’s health status and individual circumstances. Men should have a say in their care, and be treated as individuals, depending on the level of risk from their particular disease, their circumstances and quality of life.

Counselling and support should be provided by health teams to address men’s information and care needs. The expanding role of peer-to-peer support from patient organisations should not be overlooked. These groups can be critical in helping men to cope with diagnosis, side effects and changes to their lifestyle.

A specialist team approach

As with breast cancer, best practice — as recommended by the The European Association of Urology (EAU) and supported by The European School of Oncology (ESO) — is a multi-professional team approach conducted within dedicated centres or networks of excellence. This may bring benefits from improving the accuracy of diagnosis and staging through to identifying the best treatment or observational management options. It can also ensure a more consistent and integrated care approach, potentially reducing treatment complications and helping men and their families cope with different stages of disease and treatment.[8] Standards and requirements for these dedicated centres are being defined by the collaborative Prostate Cancer Unit (PCU) Initiative in Europe.*

Personalising care

Each patient's disease type and risk profile will differ, as will lifestyle factors and quality of life priorities. An individual's treatment and follow up plan should be tailored to meet these specific needs so that an effective but appropriate management strategy is put in place. Patients should be involved in decisions about their care plan and offered a range of options, including active surveillance. Information should be provided to support them throughout their treatment journey.

PATIENT

> “I was fully prepared for the treatment but not supported for problems caused by the side effects. Patients should be treated as individuals and the treatment and support should take this into consideration to give them the best possible quality of life

PATIENT

> “A positive biopsy suddenly means you enter the cancer world, which feels like a long-term illness — treatable but impossible to delete or ignore

Differences in treatment access

Access to the latest up-to-date, evidence-based treatments and diagnostic technology can vary according to available expertise and funding. Barriers to new treatments may occur at a local hospital, regional or national level. Different decisions have been made by Health Technology Assessment bodies in Europe over new EMA-approved medicines for late-stage metastatic disease, despite evidence of improved overall survival. Improving the efficiency of how prostate cancer is classified and managed, while at the same time helping patients stay independent for as long as possible, may help with the fairer allocation of resources.

The need for more research

Currently, much research is industry-led with some trials unregistered and their results unknown. Greater government investment to support independent, academic research would increase the number of comparative trials, and improve our understanding of the risk factors for prostate cancer, how to prevent the disease and how to identify the most effective therapies. Research efforts need to be coordinated to avoid duplication and accelerate knowledge transfer into the clinical setting in order to benefit patients and reduce the costs of research.

[8] Valdangi et al. The requirements of a specialist Prostate Cancer Unit: A discussion paper from the European School of Oncology. Eur J Cancer 2011;47(1):1–7

* The PCU Initiative was launched by ESO, the Organisation of European Cancer Institutes and the German Cancer Society. It is endorsed by EAU, ESTRO, EONS, EAUN and IPOS and involves Europa Uomo representatives

CALL TO **ACTION** RECOMMENDATIONS

Europa Uomo, the European Prostate Cancer Coalition, has consulted with leading experts in Europe to develop recommendations, aimed at improving the lives of men with prostate cancer in Europe. These are summarised below.

Overall goal

Improve high quality care for all men with prostate cancer in Europe in order to reduce the death rate and growing burden of prostate cancer on individuals and society

To achieve this, we need to:

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

Specific recommendations for improving patient care

1

Risk assessment and PSA testing for prostate cancer should be available 'free of charge' if requested by men or their healthcare team

- Appropriate counselling and information should be provided
- Individual risk calculation should be carried out alongside PSA testing to ensure a more accurate assessment of a man's personal risk
- PSA analysis should be standardised across the EU and quality-assured
- Clearer guidance and consensus on PSA testing and biopsies should be provided to healthcare professionals to ensure appropriate use
- New diagnostic tools for early disease, such as biomarkers and MRI, should be urgently evaluated and adopted if proved effective to reduce the need for unnecessary, invasive biopsies

2

Improved education and information about risk factors and symptoms of prostate cancer should be provided to the public and healthcare professionals

- Information should emphasise the importance of early detection and referral in improving outcomes for men with prostate cancer, including advanced and metastatic disease
- The public and healthcare professionals should be made aware of signs and symptoms to look out for, including those suggestive of relapse
- Education materials should be tailored to men and developed in partnership with healthcare professionals and patient organisations

3

Prostate cancer care should be coordinated and managed by a multi-professional team within a certified centre or network of excellence

- Diagnosis and care should be managed by a team of healthcare professionals experienced in treating high volumes of prostate cancer patients
- Access to appropriate technology and testing techniques should be available to improve classification of prostate cancer and the effectiveness of treatment decisions
- Centres or networks in which care is delivered should be certified as meeting an agreed set of quality indicators and European standards. (This approach is recommended by ESO and EAU and follows similar models in the UK, Belgium, Italy, The Netherlands and Germany.)
- Where necessary to prevent or manage metastatic complications and improve palliative care, allied healthcare professionals should be integrated into the multi-professional team to offer coordinated, holistic care
- A key worker, e.g. a specialist nurse, should be made the main, consistent point of contact for patients' queries and follow up
- Centres or networks of excellence should include appropriate collaborations with patient organisations

4 Care plans should be comprehensive and tailored to the individual patient

- A personalised care plan for each patient should be decided by the multi-professional team based on prognostic, risk and quality of life factors, and involving the man and his family
- Access to a broad spectrum of effective licensed therapies or observational strategies, including active surveillance, should be guaranteed so that a management strategy is designed around individual circumstances
- Men should be counselled and their needs assessed before deciding on personalised management options. Follow up information and support should be offered throughout the treatment journey to address concerns and help men manage side effects
- Psychological and practical support, including psychosocial care, should be available and tailored to individual needs and the stage of disease to help men cope from diagnosis to end of life care
- Referral to patient peer support should be offered, if available
- Complications and concerns, such as incontinence, impotence and bowel problems, should be addressed with specialist support
- Information and support for end of life care should be provided at an appropriate time, allowing men and their families to plan ahead

5 Prostate cancer funding and research should be adequately funded to improve optimal care

- Improved and coordinated investment from governments across Europe would enable more academic-led research to identify the most effective treatments
- Research should focus not only on treatment but also on prevention, early detection and diagnostics, better ways to distinguish aggressive or lethal disease versus indolent, slow growing tumours, markers to evaluate treatment response and psychosocial issues/ survivorship
- Real-life data on routine treatment use and outcomes should be collected, reported and shared across Europe
- Information on clinical trials should be simplified for men and their families to support participation
- Clinical trials should be better designed to ensure study endpoints are of real benefit to patients and that effective treatments become available faster
- Patient organisations should be consulted to prioritise research options

SUPPORTING EVIDENCE

CONTENTS

Introduction — the picture in Europe 12
The size of the problem 12
What is prostate cancer? 14
Which men are at risk? 14
Classification of risk groups 15
Individual risk calculation 15
Mortality rates – discrepancies across Europe 16
Access to treatment — removing inequalities 16
The economic burden 16
Recommendations 17
Conclusion 30

INTRODUCTION – THE PICTURE IN EUROPE

The size of the problem

Prostate cancer is the most common male cancer in Europe, affecting around 3 million men and killing over 90,000 every year.[1] This figure is set to rise as the annual number of new cases reaches around 450,000 in 2020.[2] About one in six men will develop prostate cancer at some point in their lives.[9]

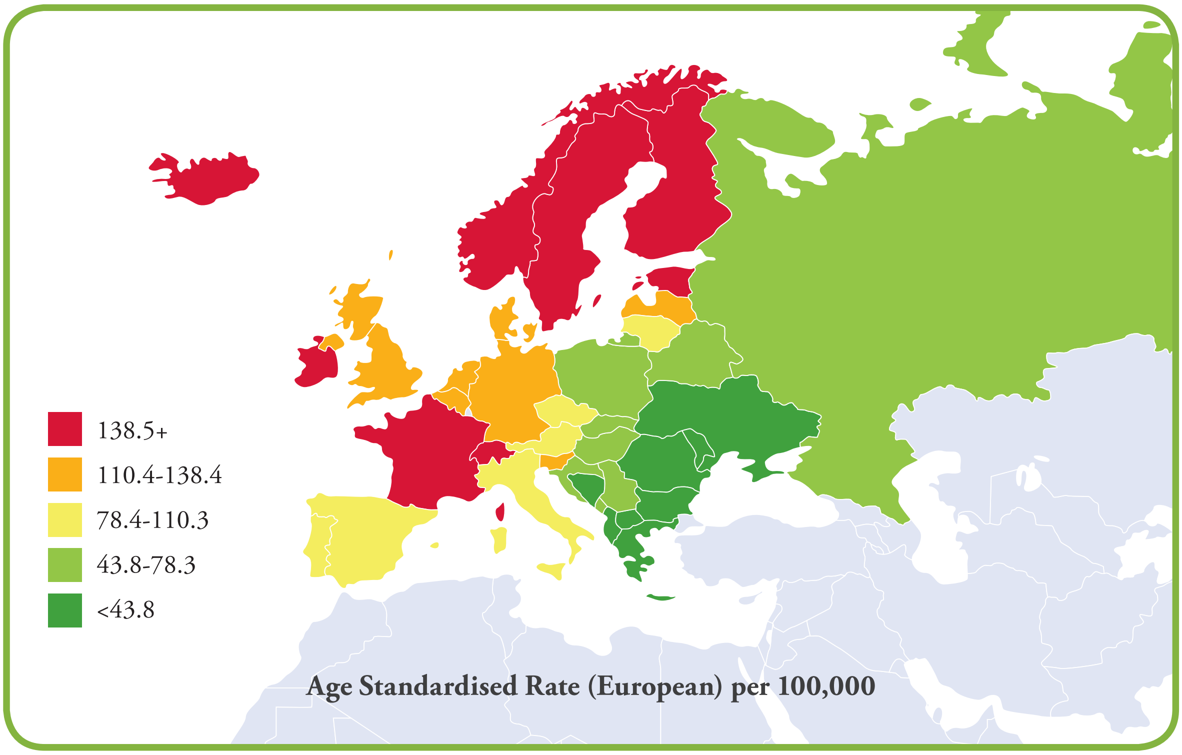
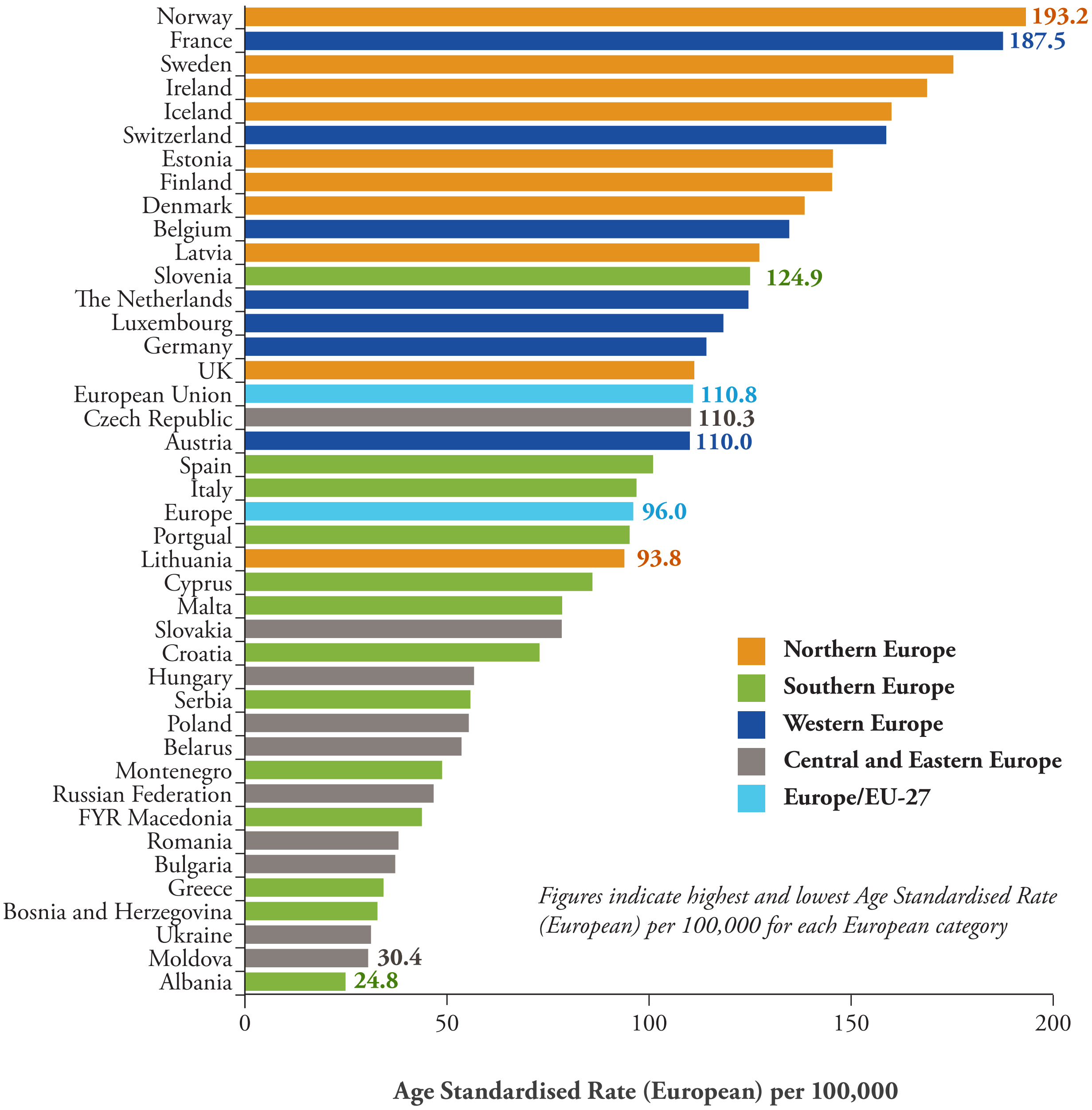


Illustration: *Estimated incidence from prostate cancer in men, 2012*[10]

---

[9] http://www.cancer.org/cancer/prostatecancer/detailedguide/prostate-cancer-key-statistics (Accessed September 2013)

[10] World Health Organisation, International Agency for Research on Cancer: http://eco.iarc.fr/eucan/CancerOne.aspx?Cancer=29&Gender=1#block-map-f (Accessed September 2013)



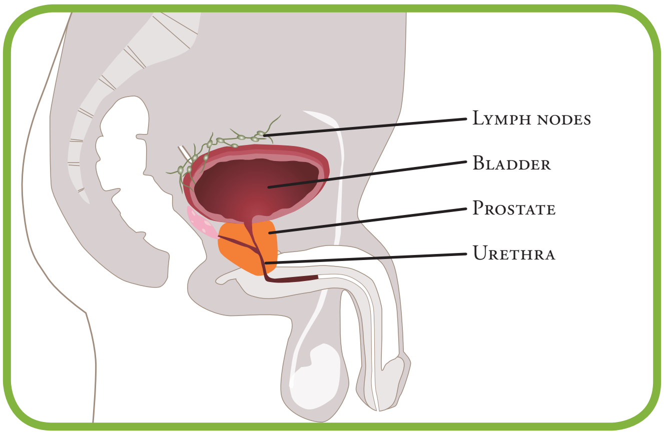
Figures indicate highest and lowest Age Standardised Rate (European) per 100,000 for each European category

Illustration: *Estimated incicdence of prostate cancer, 2012* [10]

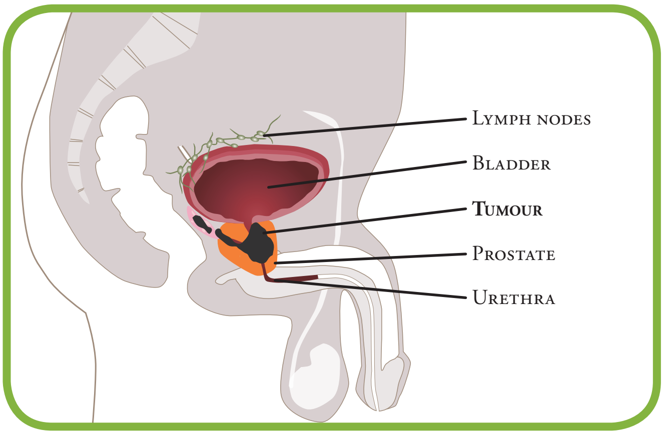
---

[10] World Health Organisation, International Agency for Research on Cancer: http://eco.iarc.fr/eucan/CancerOne.aspx?Cancer=29&Gender=1#block-map-f (Accessed September 2013)

What is prostate cancer?



The prostate is a small, walnut-shaped gland below the bladder and in front of the rectum that produces fluid to protect and nourish sperm



In prostate cancer cells grow abnormally in the tissues of the prostate to produce tumours

Prostate tumours vary considerably in their molecular makeup and aggressiveness. Many are slow growing and remain relatively harmless for many years. The more aggressive the tumour, the more likely it is to grow quickly and spread to other parts of the body, particularly the bones. The earlier prostate cancer is caught and diagnosed, the better it can be monitored, treated, and cured.

Which men are at risk?

Age is the greatest risk factor for prostate cancer. One man in 37 aged 40–59 years will develop the disease, rising to one in 15 for men aged 60–69, and one in eight for men aged 70 or older.[11]

Family history can increase risk. Men whose father or brother have had prostate cancer diagnosed before the age of 65 years are twice or three times more likely to develop the disease than someone with no close family history.[11] Recent studies have shown that inherited faults to the BRCA gene, although rare, can increase the risk of developing prostate cancer, and its biological aggressiveness.[12]

Ethnicity is a significant risk factor. Black African and Caribbean men in Europe are at increased risk of prostate cancer compared with white Europeans. Men in Asia have the lowest risk. However, their chances of developing the disease increase if they move to Europe, suggesting lifestyle and dietary factors play a role.[13]

Smoking, obesity and lack of exercise appear to play a part but research has yet been inconclusive.[11]

---

[11] http://www.cancer.gov/cancertopics/pdq/genetics/prostate/HealthProfessional/page1 (Accessed September 2013)

[12] http://www.ouh.nhs.uk/patient-guide/leaflets/files%5C120417brca1brca2.pdf (Accessed September 2013)

[13] http://cancerhelp.cancerresearchuk.org/type/prostate-cancer/about/prostate-cancer-risks-and-causes. (Accessed September 2013)

Classification of risk groups

Localised disease, stage 1 and 2, is categorised as low, intermediate, high risk and very high risk.[7] This is dependent on the aggressiveness of the tumour which is greatly determined by its Gleason score, by how far it has grown and spread inside the prostate, that is, tumour stage, and PSA measurements such as PSA velocity or PSA doubling time. The higher the risk, the more likely the chance of relapse and spread to other parts of the body.

According to international guidelines[7] CT or MRI are not requested for local, low-grade disease. Conversely, imaging may be useful in the detection of extraprostatic disease although caution should be exerted since false positives have been reported with clinical staging of the disease with CT.[14] MRI of the pelvis is probably more specific and sensitive. It is not routinely recommended for low-risk disease, but could be considered for intermediate and high-risk disease to detect extraprostatic spread, or nodal involvement. Skeletal metastases are assessed using bone scans if PSA levels reach a significant figure.

Individual risk calculation

PSA does have a role in detecting prostate disease, and is the most important predictive factor for identifying men at increased risk of developing prostate cancer. However, despite the mortality reduction that has been demonstrated in ERSPC[15] through PSA testing, this has also resulted in unnecessary biopsies, overdiagnosis, and over treatment in many men, with the associated harm resulting from side effects.[16, 17]

It is important to use an individualised risk calculator that uses the PSA level as the foundation, alongside consideration of other pre biopsy information such as age, family history, prostate volume and digital rectal examination (DRE) findings which together result in a more accurate risk assessment, and reduces the number of unnecessary biopsies.

---

[14] Horwich A et al. Prostate Cancer: ESMO Consensus Conference Guidelines 2012, Annals of Oncology 2013;00:1–9

[15] Schröder FH et al. Screening for prostate cancer decreases the risk of developing metastic disease: findings from the European Randomized study of screening for prostate cancer (ERSPC). Eur Urol;2012:62(5):745–52

[16] Roobel MJ et al. A risk-based strategy improves prostate-specific antigen-driven detection of prostate cancer. Eur Urol. 201p Jan;57(1):79–85

[17] Zhu X et al. Risk-based Prostate Cancer Screening. Eur Urol 2012;61:652–661

Mortality rates – discrepancies across Europe[3]

Mortality rates vary across Europe, where they are highest in Lithuania, Denmark, Estonia and Slovenia, closely followed by Norway and Sweden, and lowest in Albania, Malta and Italy. More research is needed to understand these apparent variations. Many factors are likely to play a role, including the fact that European cancer registries sometimes present results differently. The adoption of a standard reporting system in European registries should make it easier to set benchmarks for improvement.

Access to treatment — removing inequalities

All men with prostate cancer deserve equal access to early, reliable and accurate diagnosis, followed by effective treatment for their disease. But variations in national resources and policy have led to disparities in the quality of care. Access to certain diagnostic techniques and treatments can be denied, depending on national priority.

Change is needed, with more experienced centres or networks of excellence, improved standards of awareness, education, training and care, and more personalised treatment. All this will help to improve patient outcomes.

The economic burden

Prostate cancer represents a growing burden for health economies across Europe – costing around €7 billion every year (6% of the total €124 billion annual cancer costs in the EU).[18] This is likely to rise as the number of cases continues to increase.

The highest costs for prostate cancer are associated with advanced and metastatic disease.[4] Complications such as metastatic skeletal fractures can double the cost burden, largely due to hospitalisations.[19] Lost time and productivity increase indirect costs, although these data are limited.[4]

As cost pressures increase, new strategies and investment are needed to improve the early diagnosis, classification and management of prostate cancer. This will help ensure that resources are distributed appropriately and patients receive the most effective treatment. If governments fail to act, the economic burden of prostate cancer care will only worsen.

---

[18] Leal J. The economic burden of cancer across the European Union. Abstract NCRI Cancer Conference 2012

[19] Groot MT et al. Costs of Prostate Cancer, Metastatic to the Bone, in The Netherlands. Eur Urol. 2003;43:226–232

ACTING EARLY

1

Risk assessment and PSA testing for prostate cancer should be available ‘free of charge’ if requested by men or their healthcare team

- **Appropriate counselling and information should be provided**
- **Individual risk calculation should be carried out alongside PSA testing to ensure a more accurate assessment of a man's personal risk**
- **PSA analysis should be standardised across the EU and quality-assured**
- **Clearer guidance and consensus on PSA testing should be provided to healthcare professionals to ensure appropriate use**
- **New diagnostic tools for early disease, such as biomarkers and MRI, should be urgently evaluated and adopted if proved effective to reduce the need for unnecessary, invasive biopsies**

Appropriate counselling and information before a test

Many men are understandably worried by the prospect of a prostate cancer test. They should receive adequate information and counselling beforehand so they understand their options. In most cases, tests results will prove negative, although in some cases, cancer may be present, hence the need for repeated tests and a DRE.

A positive PSA test does not necessarily imply cancer diagnosis. Benign enlargement of the prostate, as already described, which represents a relatively common problem affecting older men, or prostatitis, an infection or inflammation of the prostate, are the most frequent causes of increased PSA. If PSA levels are elevated and the DRE abnormal, a biopsy is usually performed.

Empowering men with information from the start will help prepare them and their families to make informed decisions at the appropriate time and will alleviate anxiety.

Standardised PSA analysis – improving accuracy

PSA measurements have evolved in an effort to distinguish between prostate cancer and non-cancerous enlargement of the prostate. These additional PSA measurements include PSA density, velocity and free PSA ratio.

- Standardised measurements and assay tests should be used as recommended by EAU and the World Health Organisation to reduce misinterpretation and improve consistency and accuracy
- The same PSA assay system should be performed in the same laboratory, using the same testing format throughout the process of diagnosing and monitoring and if necessary, treating an individual, to improve consistency when comparing results

Access to testing

An early prostate cancer diagnosis increases a man's chance of curative treatment and his chance of long-term survival.[20] The more advanced the disease, the more complex it is to treat and the poorer the prognosis.[21, 22]

Men should have free access to risk assessment and testing which can lead to early detection of prostate cancer but should be fully informed of the risks and benefits of testing.

- The measuremet of PSA, an organ specific protein rather than cancer specific, has revolutionaised the treatment of prostate cancer. It has made possible the early detection of the disease and the subsequent monitoring. The downsides are also to be acknowledged and specifically, PSA testing can induce unnecessary biopsies and result in the overtreatment of indolent cancers, unlikely to progress
- With routine early testing, most men will first present with early stage prostate cancer (i.e. localised or regional disease that is confined to the prostate). Unfortunately, nearly 20% of men (and probably a far higher percentage in countries with lower survival rates) come forward only once the disease is advanced or has spread beyond the prostate.[23] This means their treatment options are likely to be more limited and their chances of survival reduced

New diagnostic techniques

New, accurate diagnostic tests and imaging techniques should be evaluated urgently. Improved imaging technology can help determine whether biopsies can help select appropriate management for early disease, and individualise the risk of progression. If proven effective, these techniques should be adopted and made available to patients.

---

[20] Fournier G et al. Prostate cancer. Treatment. Ann Urol (Paris) 2004 Oct;38(5):225–58

[21] Damber J and Aus G. Prostate cancer Seminar. Lancet 2008;371:1710–211

[22] http://www.cancerresearchuk.org/cancer-help/type/prostate-cancer/treatment/statistics-and-outlook-for-prostate-cancer (Accessed September 2013)

[23] Decision Resources Prostate Cancer. October 2012

THE IMPORTANCE OF EDUCATION AND AWARENESS

2

Improved education and information about risk factors and symptoms of prostate cancer should be provided to the public and healthcare professionals

- Information should emphasise the importance of early detection and referral in improving outcomes for men with prostate cancer, including advanced and metastatic disease
- The public and healthcare professionals should be made aware of signs and symptoms to look out for, including those suggestive of relapse
- Education materials should be tailored to men and developed in partnership with healthcare professionals and patient organisations

Information can save lives

Lack of awareness about the prostate, coupled with confusion, embarrassment and fear about prostate cancer and its treatment (castration and incontinence are well known treatment effects) can delay a visit to the doctor. Better education about prostate cancer and what signs and symptoms to look out for could increase early diagnosis of localised disease and the prompt detection of recurrent or metastatic disease.

In the case of suspected prostate cancer, whether an initial diagnosis or relapse, prompt referral to specialist services for further evaluation and diagnosis is critical. Understanding the risk of recurrence and implementing clear referral guidelines are also essential. Despite improvements in curative treatment, it has been estimated that 20–30% of men will relapse, requiring additional treatment,[24] and this increases to 75–85% for high-risk patients.[25]

Cancer hospitals, social services, primary care physicians and patient organisations should all work together to improve awareness, education and training about the symptoms of early disease and relapse.

Family practitioners and nurses should be trained in appropriate counselling, testing and referral for prostate cancer. This training should also enable them to initiate a discussion about prostate cancer with men who may be at increased risk.

Better materials on healthy lifestyles

Public health materials and education should provide information advising men on how to stay healthy, including advice on giving up smoking, losing weight if appropriate, eating a healthy diet and increasing their exercise levels where possible.

Healthcare professionals should be trained to counsel men on staying healthy and should also enable them to initiate a discussion about the signs and symptoms of prostate cancer with men who may be at increased risk.

Communication around prostate cancer testing and diagnosis needs to be clearer, with more publicly available information on prostate cancer tailored to men and specific cultures. It should address fears about prostate cancer and inform men about the options following diagnosis. This material should be produced in conjunction with healthcare professionals and patient organisations.

---

[24] http://www.pcf.org/site/c.leJRIROrEpH/b.5822791/k.1DC2/Recurrence.htm (Accessed September 2013)

[25] Zeliadt and Penson. Pharmacoeconomics of available treatment options for metastatic prostate cancer. Pharmacoeconomics. 2007;25(4):309–27

RAISING STANDARDS

3

NEW APPROACHES TO IMPROVE CONSISTENT HIGH QUALITY CARE: MULTI-PROFESSIONAL TEAMS AND CENTRES OR NETWORKS OF EXCELLENCE

Prostate cancer care should be coordinated and managed by a multi-professional team within a certified centre or network of excellence

- Diagnosis and care should be managed by a team of healthcare professionals experienced in treating high volumes of prostate cancer patients
- Access to appropriate technology and testing techniques should be available to improve classification of prostate cancer and the effectiveness of treatment decisions
- Centres or networks in which care is delivered should be certified as meeting an agreed set of quality indicators and European standards. (This approach is recommended by ESO and EAU and follows similar models in the UK, Belgium, Italy, The Netherlands and Germany.)
- Where necessary to prevent or manage metastatic complications and improve palliative care, allied healthcare professionals should be integrated into the multi-professional team to offer coordinated, holistic care
- A key team worker (part of treating team), e.g. a specialist nurse should be made the main, consistent point of contact for patients' queries and follow up
- Centres or networks of excellence should include appropriate communications and collaborations with patient organisations

A team approach

The best outcomes for men with prostate cancer appear to come from a team of experts working together within dedicated centres or networks of excellence with experience in managing high volumes of prostate cancer patients. The European Association of Urology (EAU), supported by the European School of Oncology (ESO) recommends this approach.[7, 8] The many potential benefits include improved life expectancy, more accurate assessment of higher risk disease, holistic care including psychological support, and a range of treatments and monitoring options tailored to the individual. This requires the primary care physician to be fully integrated in the management of the patient. Teams may need appropriate training to learn how to work together effectively.

Several countries have started to reorganise their services around multi-professional specialist units for prostate cancer, including the UK, Germany, Italy, The Netherlands and Belgium. Studies from the US show that a multi-professional approach improves 5 year and 10 year survival, particularly for patients with aggressive or locally advanced prostate cancer.[26, 27] In breast cancer, this has been shown to improve survival and reduce variation in survival between hospitals.[28] A similar approach could help standardise high quality prostate cancer care across Europe and improve quality control and auditing.

Diagnosis, classification and treatment

A discussion about biopsy results and prognosis by the multi-professional team is key to identifying the most effective treatment or observational strategy and follow-up plan. Centralised facilities can improve the accurate classification of prostate cancer, particularly where a range of tests and imaging techniques is required to assess risk, prognosis and spread of the disease.

A multi-professional approach involving urologists, radiation oncologists and medical oncologists can be particularly useful for prostate cancer because of the wide variety of treatment options. A team familiar with the complete range of treatment and monitoring strategies, including active surveillance, surgery, radiotherapy, hormonal treatment and chemotherapy can help tailor treatment to individual disease profiles and personal preferences, providing support with any adverse effects.

Quality criteria

In line with published recommendations,[8] these dedicated centres or networks of excellence should meet an agreed set of minimum criteria, and patient treatment and outcomes data should be collected in a uniform way to facilitate comparative research and regular audits. Standards for these centres are being produced by the Prostate Cancer Unit (PCU) Initiative, a collaborative pan-European project.

Centres should be able to treat patients with all stages of disease, from newly diagnosed to end of life care, with a range of healthcare professionals integrated in developing individual care plans, in collaboration with the patient's primary care physician.

[26] Gomella L et al. Enhancing prostate cancer through the multidisciplinary clinic approach: a 15-year experience. J of Oncol Pract. 2010; 6(6):e5–e10

[27] Aizer et al. Multidisciplinary Care and Management Selection in Prostate cancer. Seminars in Radiation Oncology 2013: 23(3): 157–164

[28] Kesson et al. Effects of multidisciplinary team working on breast cancer survival: retrospective, comparative, interventional cohort study of 13722 women. BMJ 2012; 344

Managing metastatic disease and complications

Metastatic prostate cancer can be particularly challenging. As well as exploring the most effective treatment options, multi-professional teams can provide urgent intervention for distressing physical symptoms. These include pain, urinary obstruction, skeletal events and spinal cord compression.[29, 30] An appropriately staffed team is also better equipped to tackle psychological distress and provide support to patients and their families.

Good palliative care should be provided close to home, in close cooperation with the centre or network of excellence. This requires effective integration of healthcare professionals, including social services, primary care professionals and patient organisations.

Pain management

Pain is common in advanced disease, affecting 70–90% of patients with metastatic prostate cancer.[30]

Despite guidelines on pain management, pain is often under-treated in cancer patients.[31] Access to a range of expertise, including palliative care specialists, psychologists and pain consultants can be beneficial.

Continuity of care

A consistent point of contact can make a real difference to the care experience for patients and their families. This should be a dedicated key worker, such as a clinical nurse specialist collaborating with the family doctor, who can provide information and support to patients and their families throughout the treatment journey and be the main point of contact for any queries and concerns. He or she can also help patients and their families access necessary support services, such as patient support groups, and prepare for end of life care.

Collaboration between patient organisations and centres or networks of excellence

Collaboration between patient organisations and stakeholders including centres or networks of excellence is becoming increasingly important for healthcare systems. Active collaboration can deliver better patient care and improved outcomes.

[29] Gater A et al. Pain in castration-resistant prostate cancer with bone metastases: a qualitative study. Health and Quality of Life Outcomes 2011;9:88

[30] Thompson JC et al. Prostate cancer: palliative care and pain relief. British Medical Bulletin July 2007;1–14

[31] British Pain Society's (BPS) Cancer Pain Management. A perspective from the British Pain Society, supported by the Association for Palliative Medicine and the Royal College of General Practitioners. Jan 2010

PERSONALISED CARE PLANS

4

GETTING PATIENTS INVOLVED

Care plans should be comprehensive and tailored to the individual patient

- A personalised care plan for each patient should be decided by the multi-professional team based on prognostic, risk and quality of life factors, and involving the man and his family
- Access to a broad spectrum of effective licensed therapies or observational strategies including active surveillance, should be guaranteed so that a management strategy is designed around individual circumstances
- Men should be counselled and their needs assessed before deciding on personalised management options. Follow up information and support should be offered throughout the treatment journey to address concerns and help men manage side effects
- Psychological and practical support, including psychosocial care, should be available and tailored to individual needs and the stage of disease to help men cope from diagnosis to end of life care
- Referral to patient peer support should be offered, if available
- Complications and concerns, such as incontinence, impotence and bowel problems, should be addressed with specialist support
- Information and support for end of life care should be provided at an appropriate time, allowing men and their families to plan ahead

Personalising treatment options

Every patient's disease is different, as is their prognosis, their risk profile and their priorities for quality of life. Care and follow up should be personalised to reflect this.

A man's general health, age, social activity and partnership status can all affect his reaction to diagnosis, his attitude to different management strategies, and how he copes with the disease over a long period of time. These factors should be incorporated in a personalised care plan.

Different risk profiles

Currently, men with low risk disease can be over-treated and their quality of life affected unnecessarily.[32, 33] However, all those whose disease is likely to progress or has progressed should have access to the full range of treatments and technologies to improve their chance of survival. Age should not limit a man's access to curative treatment, particularly where his health is generally good.

A range of care options are available:

- **Active surveillance.** This involves close monitoring to check the prostate cancer is not progressing. If it does, curative treatment is made available
- **Surgical and radiotherapy curative options.** These include keyhole keyhole surgical techniques, brachytherapy and intensity-modulated radiation therapy (IMRT)
- **Hormonal therapies and combination treatments.** These deplete levels of testosterone, the fuel for most prostate cancer tumours. Hormonal therapy may control disease for several years but eventually the prostate cancer becomes resistant to treatment. Castrate-resistant prostate cancer that continues to progress despite low levels of circulating testosterone is considered incurable. However, there have been major developments in treatment, offering improved overall survival[34]
- **Chemotherapy.** This is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells and is used to treat cancer that is no longer being controlled by hormonal therapy

---

[32] Schröder, et al. Screening and Prostate-Cancer Mortality in a Randomized European Study. N Engl J Med 2009;360:1320–1328

[33] Heijnsdijk et al. Overdetection, overtreatment and costs in protate-specific antigen screening for prostate cancer. Br J Cancer 2009;101(11):1833–8

[34] Beltran H et al. New therapies for castration-resistant prostate cancer: Efficacy and safety. Eur Urol. 2011; 279–290

Equal treatment access

Access to treatment can still be a 'postcode lottery', depending on national and regional funding decisions. Countries vary in how long they take to review an EMA-approved medicine and in the models and criteria they use to determine funding decisions.[35]

Funding end-of-life care is a particular challenge. Some countries have made special arrangements and others have accelerated the review of cancer medicines or enhanced access arrangements for patients. Denmark speeded up the review process for cancer drugs specifically to 3 months rather than the normal 1-2 years for non-cancer drugs, whilst France, Sweden, The Netherlands and the UK include 'disease severity' in their assessment of cancer drugs and allow for a higher cost threshold.[36]

We need innovative solutions to address funding challenges, coupled with a more standardised approach across Europe to evidence-based recommendations for new medicines.

We are calling for recommended evidence-based treatments to be made available to all men with prostate cancer, irrespective of where they live. The latest diagnostic technology, if proven effective, should be available in a similar way. The more accurately the disease can be defined and classified, the more effectively prostate cancer can be treated and hospital stays reduced.

> *" There have been significant advances in the understanding of prostate cancer over recent years in terms of disease pathology and new ways to treat the disease. It would be a great shame if our efforts to advance scientific research aren't able to translate into benefits for all our patients, irrespective of where they live."*
>
> Prof Sten Nilsson, Professor of Oncology,
> Karolinskia Institutet, Stockholm, Sweden

Keeping patients informed and involved

Men and their families need to make informed decisions about their treatment options in collaboration with healthcare professionals. Clear verbal and written information combined with counselling can help with this. Patient information should be easy to understand and clearly communicated by a trained healthcare professional. Any written information should be developed in consultation with patient organisations to ensure it is easily understandable for men and their families and is culturally sensitive.

Information, whether verbal or written should, from the outset, address fear of side effects such as incontinence, bowel problems and impotence which can affect patient decisions about treatment.

---

[35] Wilking N & Jönsson B. A pan-European comparison regarding patient access to cancer drugs. Karolinska Institutet in collaboration with Stockholm School of Economics, Sweden. Jan 2009

[36] Neuman PJ et al. Therapies for advanced cancers pose a special challenge for health technology assessment organisations in many countries. Health Affairs 2012. 31(4):700–708

Providing the right support

Whilst it is good news that many men with prostate cancer will live for at least 5 years following diagnosis[3], they may face the prospect of symptoms, side effects of treatment and diminished quality of life over a long period.[37] Coming to terms with diagnosis, the impact of the disease, the threat of recurrence and potential mortality can involve a complex psychological adjustment.

Psychological reactions and levels of distress can vary. For example, those with localised disease are likely to have very different needs to those with metastatic cancer.

In addition, adverse effects from treatment can be distressing, affecting sexual, urinary or bowel function. Fatigue and osteoporosis are not uncommon, and men with prostate cancer also report increased anxiety, irritability and depression. In advanced disease, there may be pain, fatigue and nausea.[37, 38]

All these issues should be addressed and managed by appropriate specialists to minimise their impact on patients' lives.

Dealing with distress

Psychological distress is common in prostate cancer as in other cancers. One man in five with the disease experiences depression, which is severe in half of all cases. This can lead to poorer social, physical and functional well-being.[37] There is also an increased risk of suicide in men with prostate cancer, even in low-risk disease.[39]

Impotence can be a particular concern following treatment A loss in libido or sexual intimacy with a partner can leave men feeling emasculated. Those suffering from sexual dysfunction should have access to a specialist with expertise in this area. Counselling for men and couples may be beneficial.

Urinary incontinence, bowel problems, leakage and smell can be humiliating, with urinary incontinence reported as more bothersome than erectile dysfunction.[38] This can lead to social withdrawal, anxiety and depression – particularly if ignored.

Care teams should identify those at risk, be alert to distress in a patient or couple, and be aware of programmes and strategies to help alleviate psychological complications

Supportive care from diagnosis to end of life may include:

- **Psychotherapy and cognitive behavioural therapy (CBT)** to help deal with changes arising from the disease or treatment
- **Information** on coping with and alleviating symptoms and reducing distress
- **Support networks** to help men deal with their feelings, particularly if they find it hard to discuss their condition. Facilitating communication for men with prostate cancer can have a dramatic effect on their ability to cope with their condition through follow up or disease progression
- **Good end of life care.** Specialist information and support gives patients choice about their care and where they want to die. It also reduces the number of inappropriate transfers to hospitals. The emotional, physical and spiritual needs of the patient and their family should be paramount. Access to counselors, specialists, support groups and financial services can alleviate stress and help men and their families plan ahead

---

[37] Bloch S et al. Psychological adjustment of men with prostate cancer: a review of literature. BioPsychoSocial Medicine. 2007;1:2 doi:10.1186/1751–0759–1–2

[38] Roth AJ et al. Prostate cancer: quality of life, psychosocial implications and treatment choices. Future Oncol. 2008 August; 4(4):561–568

[39] Carlsson S et al. Risk of suicide in men with low-risk prostate cancer. Eu J Can. 2013; 49(7): 1588–1599

FUNDING AND RESEARCH

5

Prostate cancer research should be adequately funded to improve optimal care

- Improved and coordinated investment from governments across Europe would enable more academic-led research to identify the most effective treatments
- Research should focus not only on treatment but also on prevention, early detection and diagnostics, better ways to distinguish aggressive or lethal disease versus indolent, slow growing tumours, markers to evaluate treatment response and psychosocial issues/survivorship
- Real-life data on routine treatment use and outcomes should be collected, reported and shared across Europe
- Information on clinical trials should be simplified for men and their families to support participation
- Clinical trials should be better designed to ensure study endpoints are of real benefit to patients and that effective treatments become available faster
- Patient organisations should be consulted to prioritise research options

A coordinated approach

Governments must provide appropriate investment for research into prostate cancer.

There are key areas where funding will make a significant difference:

- Improved understanding about personalised risk factors and the molecular structure of different tumour types will help with prevention and treatment. In particular, we need to know who is at risk of developing aggressive or advanced disease and develop ways to better evaluate treatment response
- The growing number of emerging treatments with different modes of action means that clinicians need to recognise which to use when and on whom
- More independent, academic-led research is necessary to compare therapies and work out the optimal sequencing of treatment, particularly for advanced disease

Research priorities

Research should be coordinated across Europe to avoid duplication and accelerate advances for patients: it is essential to improve shared databases and exchange knowledge and best practice.

- The European Commission is funding joint research projects and supporting policy initiatives to encourage this approach
- ECCO recommends a virtual European Cancer Centre to pool resources and encourage competition and innovative funding[40]

Sharing real-life data

Real-life data analyses should be shared between centres or networks of excellence and government health authorities to identify optimal treatment approaches and efficiencies in care. We need to know more about real-life treatment practices and how these affect patient outcomes, including survival rates and hospitalisations.

Trial patient recruitment information

Patient organisations should be consulted on clinical trial information for participants and families. Currently, such information is often unclear and complex, hindering clinical trial participation. Information should be concise and easy to understand, whilst following ethical and legal frameworks. Best practice examples can then be shared across research and treatment.

Appropriate trial design

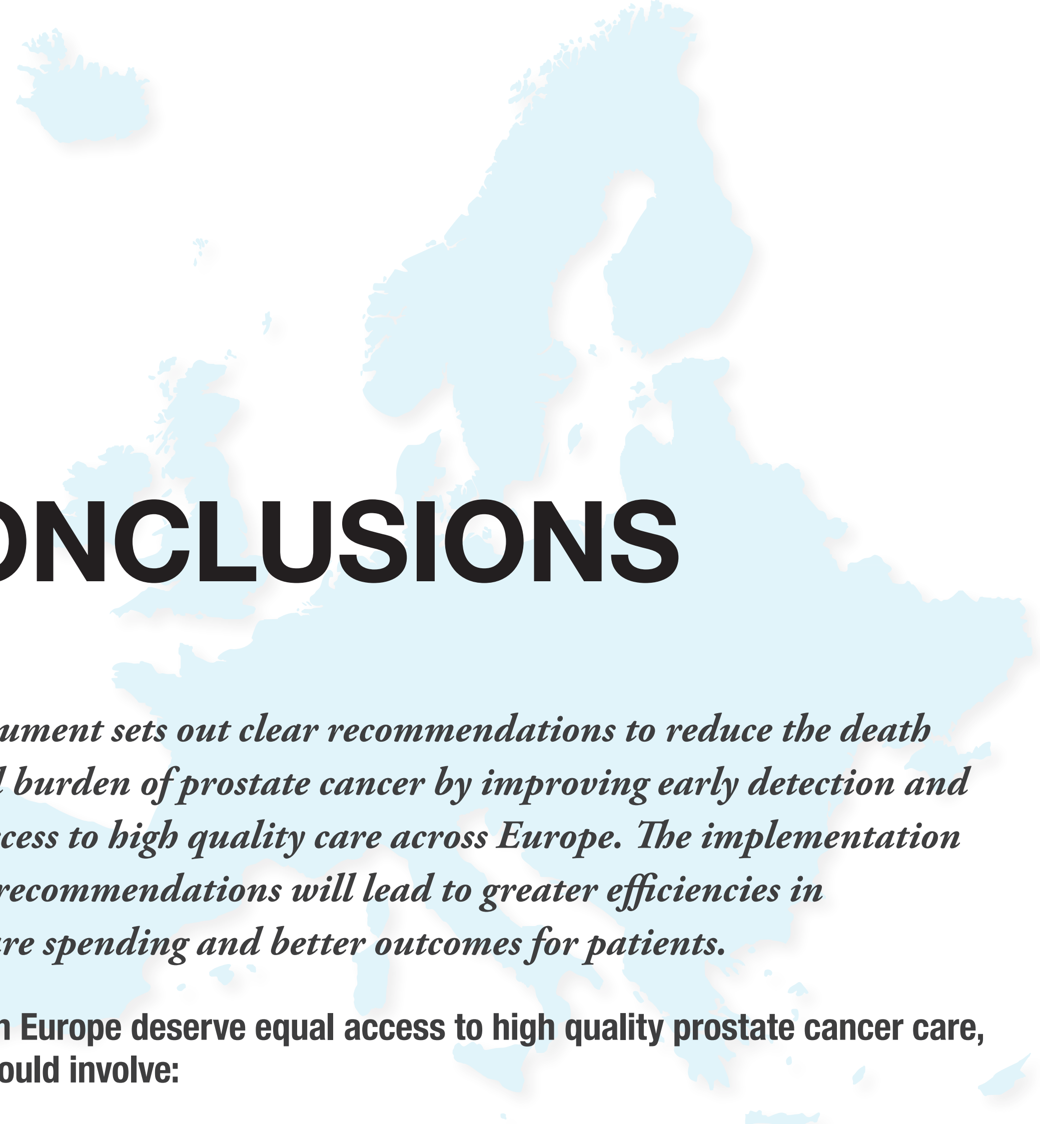
The design of clinical trials should reflect the real-life clinical setting and include end-points which are of value both to review bodies and patients. For example, quality of life may be just as important as overall survival to patients with metastatic disease.

Involving patient organisations

Patient organisations should also be consulted when deciding research priorities. Providing them with appropriate information on clinical research will allow them to comment and advise on study design, share information with patients and prepare for public enquiries.

---

[40] European CanCer Organisation (ECCO). Response to the European Commission Green Paper 'From Challenges to Opportunities: Towards a Common Strategic Framework for EU Research and Innovation Funding.' May 2011



CONCLUSIONS

This document sets out clear recommendations to reduce the death rate and burden of prostate cancer by improving early detection and equal access to high quality care across Europe. The implementation of these recommendations will lead to greater efficiencies in healthcare spending and better outcomes for patients.

All men in Europe deserve equal access to high quality prostate cancer care, which should involve:

- **Early detection and accurate diagnosis.** This will improve patient outcomes and identify those at risk of aggressive or advanced disease. Better differentiation of risk in prostate cancer will help focus treatment on those who need it rather than over-treating those who don't
- **Empowerment of men to have more say in their treatment and care plans.** This requires better education and information about prostate cancer and its management from early detection to end of life care. Quality of life factors and patient preferences should be given more weight
- **Reorganisation of prostate cancer care into multi-professional teams** within dedicated centres or networks of excellence to improve patient outcomes and the delivery of care
- **Personalised treatment based on risk factors and patient preferences** with access to a range of effective, evidence-based treatments
- **Improvement of psychological and practical support** to help men cope throughout the prostate cancer journey
- **Increased funding and coordination of European research into prostate cancer** to improve prevention and management strategies

About the Europa Uomo White Paper

Europa Uomo united with leading clinical experts from across Europe to form a working group and agree a ‘Call to Action’ for improving high quality care in prostate cancer for all men in Europe. The aims of the White Paper and its recommendations are to improve the lives of men living with prostate cancer and to reduce the death rate and burden from the disease.

The development of the Europa Uomo White Paper report has been supported by an unrestricted educational grant from Bayer Pharma AG, Berlin

RERERENCES

[1] White A et al. State of Men's Health in Europe. European Union report. 2011

[2] Cancer incidence, mortality, prevalence and disability-adjusted life years (DALYs) worldwide. Globocan; 2008 [cited Jun 28, 2013]. http://globocan.iarc.fr/burden_sel.asp (select worldwide, prostate cancer and 2020 predictions)

[3] Ferlay J et al. Cancer incidence and mortality patterns in Europe: Estimates for 40 countries in 2012. Eur J Can. 2013;49:1374–1403

[4] Roehrborn CG, Black LK. The economic burden of prostate cancer. BJU International; 2011 Sept; 108;6:806–13

[5] Sant M et al. EUROCARE-4. Survival of cancer patients diagnosed in 1995–1999. Results and commentary. Eur J of Can. 2009;45:931–991

[6] Prostate cancer incidence statistics. http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/incidence/uk-prostate-cancerincidence-statistics. (Accessed September 2013)

[7] Heidenreich et al. European Association of Urology Guidelines. March 2013

[8] Valdangi et al. The requirements of a specialist Prostate Cancer Unit: A discussion paper from the European School of Oncology. Eur J Cancer 2011;47(1):1–7

[9] http://www.cancer.org/cancer/prostatecancer/detailedguide/prostate-cancer-key-statistics (Accessed September 2013)

[10] World Health Organisation, International Agency for Research on Cancer: http://eco.iarc.fr/eucan/CancerOne.aspx?Cancer=29&Gender=1#block-map-f (Accessed September 2013)

[11] http://www.cancer.gov/cancertopics/pdq/genetics/prostate/HealthProfessional/page1 (Accessed September 2013)

[12] http://www.ouh.nhs.uk/patient-guide/leaflets/files%5C120417brca1brca2.pdf (Accessed September 2013)

[13] http://cancerhelp.cancerresearchuk.org/type/prostate-cancer/about/prostate-cancer-risks-and-causes. (Accessed September 2013)

[14] Horwich A et al. Prostate Cancer: ESMO Consensus Conference Guidelines 2012, Annals of Oncology 2013;00:1–9

[15] Schröder FH et al. Screening for prostate cancer decreases the risk of developing metastic disease: findings from the European Randomized study of screening for prostate cancer (ERSPC). Eur Urol;2012:62(5):745–52

[16] Roobel MJ et al. A risk-based strategy improves prostate-specific antigen-driven detection of prostate cancer. Eur Urol. 201p Jan;57(1):79–85

[17] Zhu X et al. Risk-based Prostate Cancer Screening. Eur Urol 2012;61: 652–661

[18] Leal J. The economic burden of cancer across the European Union. Abstract NCRI Cancer Conference 2012

[19] Groot MT et al. Costs of Prostate Cancer, Metastatic to the Bone, in The Netherlands. Eur Urol. 2003;43:226–232

[20] Fournier G et al. Prostate cancer. Treatment. Ann Urol (Paris) 2004 Oct;38(5):225–58

[21] Damber J and Aus G. Prostate cancer Seminar. Lancet 2008;371:1710–211

[22] http://www.cancerresearchuk.org/cancer-help/type/prostate-cancer/treatment/statistics-and-outlook-for-prostate-cancer (Accessed September 2013)

[23] Decision Resources Prostate Cancer. October 2012

[24] http://www.pcf.org/site/c.leJRIROrEpH/b.5822791/k.1DC2/Recurrence.htm (Accessed September 2013)

[25] Zeliadt and Penson. Pharmacoeconomics of available treatment options for metastatic prostate cancer. Pharmacoeconomics. 2007;25(4):309–27

[26] Gomella L et al. Enhancing prostate cancer through the multidisciplinary clinic approach: a 15-year experience. J of Oncol Pract. 2010; 6(6):e5–e10

[27] Aizer et al. Multidisciplinary Care and Management Selection in Prostate cancer. Seminars in Radiation Oncology 2013: 23(3): 157–164

[28] Kesson et al. Effects of multidisciplinary team working on breast cancer survival: retrospective, comparative, interventional cohort study of 13 722 women. BMJ 2012; 344

[29] Gater A et al. Pain in castration-resistant prostate cancer with bone metastases: a qualitative study. Health and Quality of Life Outcomes 2011;9:88

[30] Thompson JC et al. Prostate cancer: palliative care and pain relief. British Medical Bulletin July 2007;1–14

[31] British Pain Society's (BPS) Cancer Pain Management. A perspective from the British Pain Society, supported by the Association for Palliative Medicine and the Royal College of General Practitioners. Jan 2010

[32] Schröder, et al. Screening and Prostate-Cancer Mortality in a Randomized European Study. N Engl J Med 2009;360:1320–1328

[33] Heijnsdijk et al. Overdetection, overtreatment and costs in prostate-specific antigen screening for prostate cancer. Br J Cancer 2009;101(11):1833–8

[34] Beltran H et al. New therapies for castration-resistant prostate cancer: Efficacy and safety. Eur Urol. 2011; 279–290

[35] Wilking N & Jönsson B. A pan-European comparison regarding patient access to cancer drugs. Karolinska Institutet in collaboration with Stockholm School of Economics, Sweden. Jan 2009

[36] Neuman PJ et al. Therapies for advanced cancers pose a special challenge for health technology assessment organisations in many countries. Health Affairs 2012. 31(4):700–708

[37] Bloch S et al. Psychological adjustment of men with prostate cancer: a review of literature. BioPsychoSocial Medicine. 2007;1:2 doi:10.1186/1751–0759–1–2

[38] Roth AJ et al. Prostate cancer: quality of life, psychosocial implications and treatment choices. Future Oncol. 2008 August; 4(4):561–568

[39] Carlsson S et al. Risk of suicide in men with low-risk prostate cancer. Eu J Can. 2013; 49(7): 1588–1599

[40] European CanCer Organisation (ECCO). Response to the European Commission Green Paper 'From Challenges to Opportunities: Towards a Common Strategic Framework for EU Research and Innovation Funding.' May 2011

ABOUT EUROPA UOMO

Europa Uomo, The European Prostate Cancer Coalition, is a European advocacy movement for the fight against prostate cancer. Europa Uomo's objectives are to increase awareness of prostate cancer in Europe, to promote information about and access to high quality diagnoses and treatment, and to improve the quality of life of patients and their families. At present, Europa Uomo is represented in: Austria, Belgium, Bulgaria, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Ireland, Italy, Lithuania, Norway, Poland, Portugal, Romania, Slovak Republic, Spain, Sweden, Switzerland, The Netherlands and the United Kingdom

EUROPA UOMO WORKING GROUP

Hans Randsdorp, Chair, Europa Uomo; **Tom Hudson**, White Paper project lead and former Chair, Europa Uomo; **Erik Briers**, Secretary, Europa Uomo; **Christian Arnold**, ANAMACAP, France; **Günter Feick**, BPS, Germany; **Ken Mastris**, Prostate Cancer Support Federation, UK; **Tor Tausvik**, PROFO, Norway

Europa Uomo acknowledges the continued support from ESO the European School of Oncology and Europa Uomo's principal founding fathers Alberto Costa, Louis Denis and Tom Hudson

CLINICAL WORKING GROUP

Professor Malcolm Mason	Head of Oncology and Palliative Medicine Section School of Medicine, Cardiff University, Wales, UK
Dr Martin Spahn	Associate Professor and Senior Consultant Department of Urology, University Hospital Bern, Switzerland
Willem de Blok	EAUN Board Member and Nurse Practitioner Netherlands Cancer Institute, The Netherlands
Dr Riccardo Valdagni	Prostate Cancer Programme Coordinator, ESO, and Director of Prostate Cancer Programme Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Italy
Dr Juan Antonio Blasco	Director, Health Technology Assessment Unit (UETS) Unidad de Evaluación de Tecnologías Sanitarias, Madrid, Spain
Professor Sten Nilsson	Professor of Oncology Karolinska Institutet, Stockholm, Sweden
Dr Lara Bellardita	Clinical Psychologist Fondazione IRCCS Istituto Nazionale dei Tumori di Milano, Italy
Professor Val Lewington	Professor of Clinical Therapeutic Nuclear Medicine Guy's & St Thomas', London, UK
Professor Eilis McCaughan	Professor in Cancer Care, Institute of Nursing and Health Research University of Ulster, Northern Ireland, UK
Dr Caroline Moore	Honorary Consultant Urological Surgeon University College London Hospitals Trust, UK
Dr Chris Parker	Consultant Clinical Oncologist The Royal Marsden, London, UK
Professor Hendrik Van Poppel	EAU Adjunct Secretary General, Belgium Chairman, Department of Urology, University Hospitals Leuven, Belgium