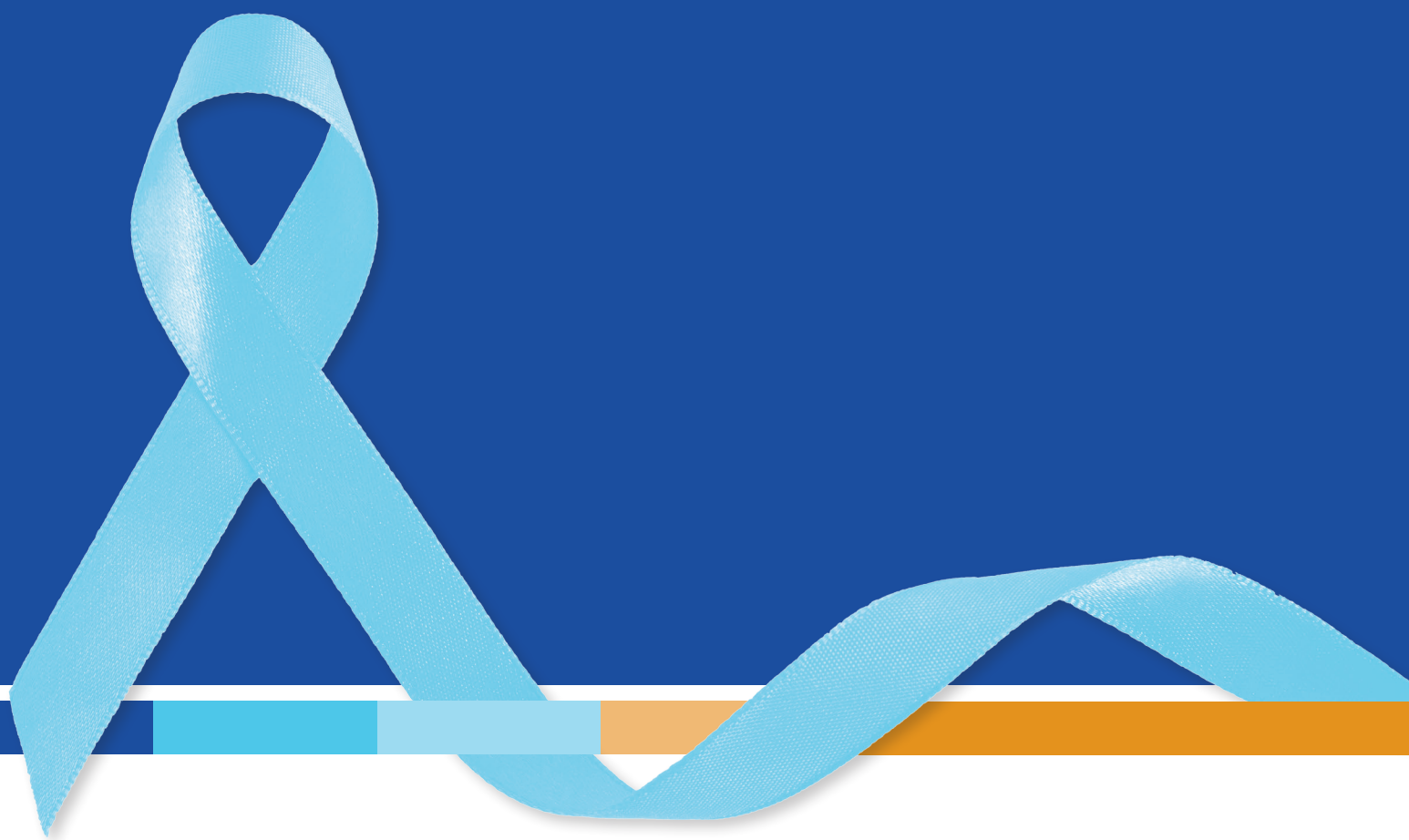




IMPROVING
**PROSTATE
CANCER
CARE**
ACROSS EUROPE

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



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

6
every
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. The 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 Sep; 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 latent 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 and 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.

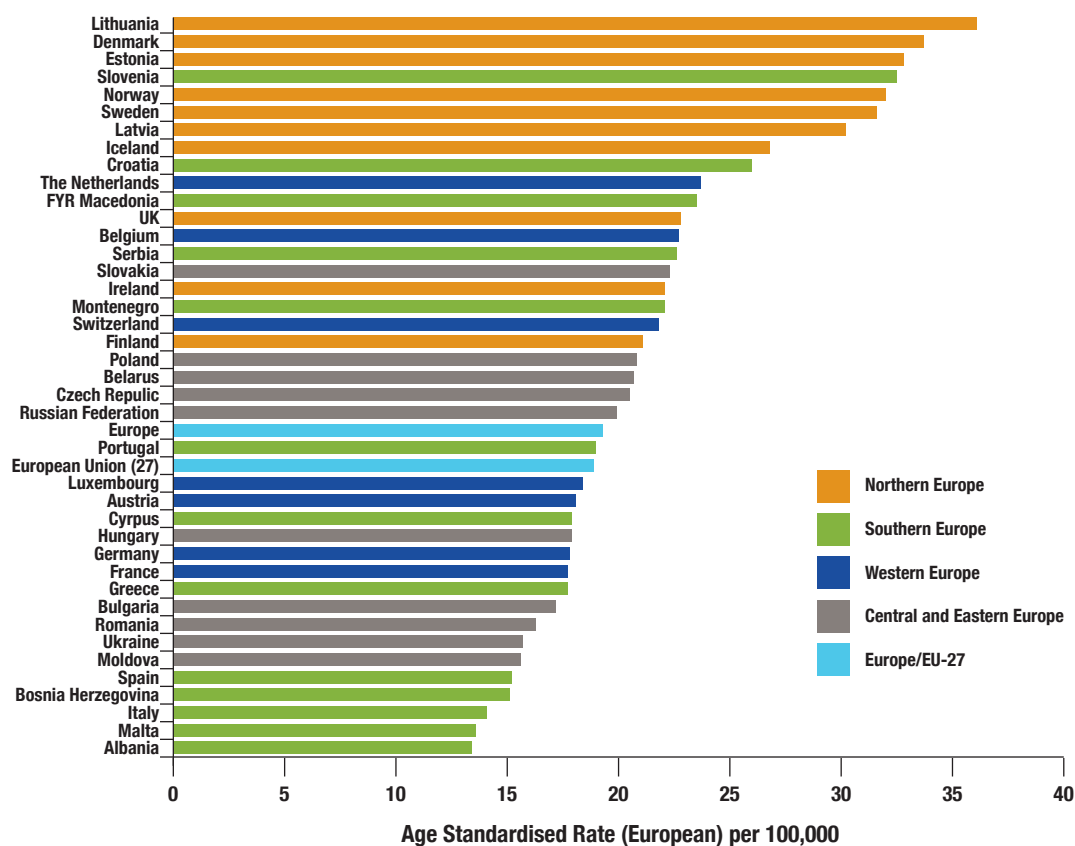


Illustration: *Estimated mortality of prostate cancer 2012*³

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. Reasons for this need to be fully explored but differences are likely to be explained by variations in health policy, cancer registries and environmental risk factors.³ In other instances, the death rate may be due to the quality of cancer services and access to early diagnosis and treatment. More research is needed to understand these inconsistencies and to develop strategies 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 latent prostate cancer and alarming those with benign prostate conditions.



⁵ Sant M et al. EUROCORE-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-cancer-incidence-statistics>. (Last updated 22/01/13)

⁷ Heidenreich A et al. European Association of Urology Guidelines. 2012;123

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.

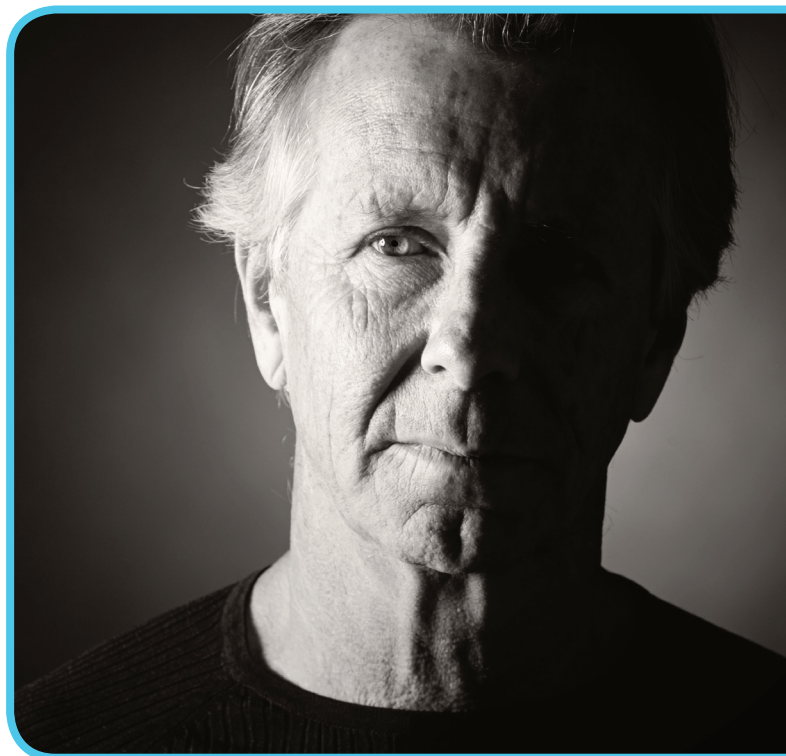
Better education is needed for men and healthcare professionals to encourage early diagnosis and prompt referral. This should be coupled with access to free, appropriate PSA testing and a digital rectal examination (DRE) if there are concerns about the risk of prostate cancer. In preparation of a PSA 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 lead to preventable 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 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 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. Certainly, we've seen different decisions 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, whilst 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, 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 Valdagni R et al. The requirements of a specialist Prostate Cancer Unit: A discussion paper from the European School of Oncology. *Eur J Can.* 2011;47:1–7

* 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

- Provide appropriate counselling and information beforehand
- 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 risks 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 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, 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 counseled 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 with 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 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 latent, slow growing tumours, markers to evaluate treatment response and psychosocial/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 and provided with appropriate information

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 burden and death rate from the disease. (The full White Paper report will be launched in September 2013 and available from www.europa-uomo.org)



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



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

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	Chairman, Department of Urology University Hospitals Leuven, Belgium