WOMEN UNSEEN

Tackling the gender care gap in **bladder cancer**

Call to Action Report

Contents

About Astellas

Women Unseen is an Astellas–led and funded report.

Astellas is a global life sciences company committed to turning innovative science into VALUE for patients. We provide transformative therapies in disease areas that include oncology, ophthalmology, urology, immunology, and women's health. Through our research and development programs, we are pioneering new healthcare solutions for diseases with high unmet medical need.

Learn more at **www.astellas.com**.

Foreword

Despite global, regional and national efforts to target cancer through policy measures, many approaches fail to address all types of cancer equally. Rarely do these efforts attempt to approach the stark gender disparities seen in some cancers.

Bladder cancer is the 5th most common cancer in Europe, and 9th most common globally.[1,2] Despite being more prevalent in men, women experience worse outcomes when diagnosed with bladder cancer, with a 14% higher mortality rate to incidence ratio than men.[3] Women also face a greater risk of recurrence and lower overall survival rates.[4] A 2017 study of 23,754 patients revealed that women have an 11% increased risk of disease recurrence after local treatment for non–muscle invasive bladder cancer compared to men.[5]

The reasoning for the bladder cancer gender care gap is multifaceted. There is currently no universal approach to screening available for bladder cancer; additionally, there have been limited advances in the availability of diagnostic tools. As such, women face complex pathways from diagnosis through to receiving appropriate treatment, care and support.

Meanwhile, a lack of bladder cancer awareness among women drastically hinders early detection, while insufficient understanding of the gender differences in bladder cancer symptoms amongst healthcare professionals further exacerbates the gender gap.

The **World Bladder Cancer Patient Coalition (WBCPC)** and the **European Association of Urology (EAU)** have worked to highlight the challenges faced by women with bladder cancer and share the important stories of people living with the disease. Our collaborative campaign, **'5 Women, 5 Experiences' campaign**[6] highlighted often-untold patient journeys, shining a light on what it is like to be diagnosed with bladder cancer as a woman, while also fostering a sense of community and advocacy across various cultures.

The **Global Bladder Cancer Patient & Carer Survey** report illustrated that women face a relatively poorer experience at diagnosis. For instance, women have to see a doctor more times than men to be referred and are almost three times more likely to report feeling that their initial symptoms were not taken seriously.[7]

Women Unseen—Tackling the Gender Care Gap in Bladder Cancer is an ambitious campaign that works to unite experts and patients across the world. It strives to build consensus around key policy asks, targeting gaps in care which are currently neglected in existing cancer plans, to close the gender care gap in bladder cancer.

Alex Filicevas

Executive Director, Brussels, Belgium
www.worldbladdercancer.org

Professor Dr. Hein Van Poppel

Chair of the EAU Policy Office, Professor of Urology, Katholieke Universteit, Leuven, Belgium
www.uroweb.org

Women Unseen—
Tackling the Gender Care Gap in Bladder Cancer

Bladder cancer is the 9th most common cancer globally

Cancer risk is influenced by several factors, such as nutrition, environment, physical activity, and genetics.[8] Cancer remains the second leading cause of mortality globally, behind only cardiovascular disease, and it is estimated that every sixth death in the world is due to cancer.[9] Cancer tends to be more prevalent in high–income countries due to screening programs as well as lifestyle factors such as obesity, and alcohol intake.[10] Although a decreasing percentage of cancer patients succumb to the disease, the total number of deaths from cancer continues to rise.[11] This is often attributed to the world's growing and ageing population.

However, not all cancers are treated equally, nor provided with the resources needed to reduce the pressure they place on health systems. Bladder cancer is a key example of this.

Bladder cancer is the 9th most common cancer globally,[12] as well as being the 5th most common in Europe, 6th in the United States[13], 8th in Southern, Eastern, and South-Eastern Asia[14], and 13th in Latin America and the Caribbean.[15]

It is also associated with a high-cost burden on health systems — across the United States and Europe, the estimated total cost of bladder cancer on health systems was estimated at $4.0 billion and €2.9 billion, respectively, in 2010 and 2012.[16]

69% of women are diagnosed with another condition first before a correct bladder cancer diagnosis

For women, there are many challenges across the patient pathway from diagnosis through to receiving gender-specific care:

- **Worse Outcomes**: Although the disease is more common in men, who are 3 to 4 times more likely to develop bladder cancer,[17] women experience worse outcomes with a higher mortality rate.[18]
- **Awareness of signs and symptoms**: Female patients with bladder cancer generally present late with more advanced tumor stages than males.[19] This is often due to a lack of awareness of bladder cancer symptoms among women and in primary care. The most common symptom of bladder cancer, gross hematuria, is frequently experienced by women with acute cystitis, leading both patients and physicians to misinterpret it.
- **Delayed diagnosis**: Women are diagnosed more frequently with a 6-month delay and present with a more advanced stage of disease at diagnosis.[20] Women are also more likely to present with muscle–invasive bladder cancer (MIBC) upon first diagnosis.[21]
- **Missed diagnosis**: Previous studies have illustrated that symptoms of bladder cancer can be trivialized and misdiagnosed for another condition.[22] It is more common for women to be diagnosed with another condition first (69%) before a correct bladder cancer diagnosis.[23]

All these factors contribute to the gender care gap in bladder cancer. Without action, these inequalities will continue to grow, and further disadvantage women with bladder cancer and women who are not yet to be diagnosed.

The Women Unseen—Tackling the Gender Care Gap in Bladder Cancer report builds on the foundation developed through a **White Paper on Bladder Cancer** coordinated and published by the World Bladder Cancer Patient Coalition (WBCPC), and the European Association of Urology (EAU).[24]

The White Paper noted a specific high unmet need in tackling the gender care gap in bladder cancer care, detailing many of the challenges facing women, such as worse outcomes, greater risk of recurrence, and challenges concerning misdiagnosis or late diagnosis.[25]

This White Paper laid bare the stark reality for women with bladder cancer and the need for action, highlighting the need to "address the gender gap in diagnosing and treatment for bladder cancer through better training of healthcare professionals" as one of its key policy recommendations.[26]

Thus, the Women Unseen—Tackling the Gender Care Gap in Bladder Cancer Report highlights specific actions to improve patient experience and outcomes for women with bladder cancer, collaborating with the global bladder cancer community to address this high unmet need and improve cancer care for women with bladder cancer.

There is an urgent need to address this challenge, better equip healthcare professionals, and collectively work towards meeting the needs of all bladder cancer patients, carers, and families—ensuring women are equally seen.

Women Unseen—Multi–Expertise Steering Committee

As part of the **The Women Unseen—Tackling the Gender Care Gap in Bladder Cancer** report, Astellas has convened a Multi–Country and Multi–Expertise Steering Committee to identify challenges and priorities, and to reach consensus among the bladder cancer community on how best to drive change for women with bladder cancer.

The Women Unseen Multi-Expertise Steering Committee is comprised of 17 members from 12 countries with a range of clinical expertise and patient experience in bladder cancer. Clinical members of the Steering Committee represent a range of clinical specialties involved across the bladder cancer pathway: urology, radiation and medical oncology, urogynecology, general practice.

Full details of the membership of the Multi–Expertise Steering Committee can be found at the end of this Report.

As part of our Multi–Expertise Steering Committee, we have the involvement of 17 stakeholders (12 countries represented) with expertise as urologists, radiation and medical oncologists, urogynecologists, general practitioners (GPs), and patient representatives.

Clinical Expertise

Prof. Dr. Ananya Choudhury—Chair and Honorary Consultant in Clinical Oncology, The Christie NHS Foundation Trust (representing the European Society for Radiotherapy and Oncology – ESTRO), United Kingdom

Prof. Dr. Anja Lorch—University Hospital Zürich, Vice Director Department for Medical Oncology and Hematology, Switzerland

Prof. Dr. Arnulf Stenzl—Director of the Department of Urology, University of Tuebingen Medical School, Germany

Prof. Dr. Cornelia Betschart—International Advisory Board Member, International Urogynaecological Association (IUGA), Switzerland

Prof. Dr. Hein Vein Poppel—Chair of the EAU Policy Office; Professor of Urology, KU Leuven, Belgium

Prof. Dr. Ho Kyung Seo—Dr., Department of Urology, Center for Urologic Cancer, National Cancer Center, South Korea

Prof. Dr. J.A. Witjes—Professor, Faculty of Medical Sciences, Radboudumc University; former Chairman of EAU Bladder Cancer Guidelines Panel, The Netherlands

Prof. Dr. Josep Vilaseca—Chief of Service, Primary Health Care at the Althaia Foundation, Spain; Associate Professor at the University of Vic - Central Catalonia University; Fellow of the Royal Academy of Medicine of Catalonia; Life Member of the World Organization of Family Doctors (WONCA) Europe, Spain

Dr. María José Méndez-Vidal—Medical Oncology Department, Maimonides Institute for Biomedical Research of Cordoba, Hospital Universitario Reina Sofía, Spain

Prof. Dr. Rosanna Berardi—Full Professor of Oncology at UNIVPM; Head of Oncology at AOU of Marche; President and Founder of Women for Oncology, Italy

Dr. Shao-Chuan Wang—Department of Urology, Chung Shan Medical University Hospital, Taiwan

Dr. Stephanie Demkiw—Chair and Founder of Bladder Cancer Awareness Australia; Board of Directors, World Bladder Cancer Patient Coalition; General Practitioner, Australia

Patient Expertise

Mr. Alex Filicevas—Executive Director, World Bladder Cancer Patient Coalition; Co-chair, Global Cancer Coalitions Network, Belgium

Ms. Antonella Cardone—Chief Executive Officer, Cancer Patients Europe, Belgium

Ms. Fatima Baig—Patient Advocate, Bladder Cancer India, India

Ms. Helen Lacy—Patient Advocate, Bladder Cancer Awareness Australia; Board Member, World Bladder Cancer Patient Coalition, Australia

Ms. Lori Cirefice—President, Association Cancer Vessie France, France

Women Unseen—Tackling the Gender Care Gap in Bladder Cancer: Calls to Action

The activity of the **Women Unseen—Tackling the Gender Care Gap in Bladder Cancer** content from this Report have been informed by insights provided during virtual meetings with Steering Committee members.

This Report outlines key insights and recommendations presented and is intended to set out a framework for change that is crucial to address the gender care gap in bladder cancer.

To deliver the change required to improve outcomes for women with bladder cancer, there is a need for collaboration between policymakers, health system leaders, clinical communities and crucially patients. This must include joint efforts to agree and deliver the standards of care required to address the gender care gap globally.

Based on discussions held, recommendations have been broken down into four key areas:

1. Early Detection and Diagnosis of Bladder Cancer in Women

2. Improving Healthcare Professional Education

3. Delivering Gender-Specific Bladder Cancer Care

4. Bladder Cancer within Women's Health

1 Early Detection and Diagnosis of Bladder Cancer in Women

A timely diagnosis is critical to better outcomes in bladder cancer. Early detection and diagnosis mean that people with the disease can begin treatment earlier, lowering the risk of disease progression and increasing the chance of survival. This also avoids the need for more aggressive treatments like radical cystectomy, ultimately leading to a longer and better quality of life.[27]

Timely and accurate diagnosis of bladder cancer in women remains a significant challenge. **Late diagnosis of bladder cancer is one of the main reasons why women experience worse outcomes of bladder cancer compared to men.**[28] Other biological factors may also impact outcomes.

1.1 Awareness of bladder cancer symptoms and risk factors amongst women

The WBCPC Patient and Carer Experience Survey, published in May 2023, found that over half of patients (54%) did not know the signs and symptoms of bladder cancer before their diagnosis.[29]

Almost two-thirds (64%) of patients did not know visible blood in urine was a symptom of bladder cancer, despite being the most common one—with many women ignoring this common symptom.[30]

To truly address the gender care gap in bladder cancer, it is critical to raise awareness of the risk factors and symptoms. Bladder cancer is associated with a range of symptoms, such as blood in urine, frequent urination, or pain when urinating, incontinence and repeated urinary tract infections (UTIs).[31]

There are preventable risk factors for bladder cancer that should be accounted for when elevating awareness amongst women. Smoking remains the most common risk factor, responsible for almost 50% of bladder cancer cases.[32] Smoking rates are declining among women globally, however, research shows that common alternatives, such as e-cigarettes, may also be linked to bladder cancer.[33] We need to do more to better understand this risk factor and educate women on the potential risks.

Blood in urine, called hematuria, is the most common symptom of bladder cancer. If the blood is visible, it is called gross hematuria, if it is not visible, and only found in a urine test (urinalysis), it is called microhematuria.[34]

67% of women

had visible blood in urine as initial symptom of bladder cancer

The link between hematuria and bladder cancer is important—the WBCPC survey found that 67% of women had visible blood in their urine as an initial symptom of their bladder cancer.[35] However, because many women are unaware that blood in the urine can be a sign of bladder cancer, it can be misinterpreted as menopause or menstruation, meaning they may not present to a healthcare professional with their concerns.

54% of patients

did not know symptoms of bladder cancer before diagnosis

Improving awareness and understanding regarding the role of hematuria as a key symptom, the types of hematuria, and when it should be referred for further investigation, could support not only in attaining a timely diagnosis, but also the referral pathway and which specialty to refer a patient to, as blood in the urine can be nephrological or urological.

Microscopic analysis of fresh urine samples can provide important diagnostic clues: intact red blood cells typically suggest a urological source, while damaged or dysmorphic red blood cells point to a nephrological cause. In cases of suspected urological hematuria, further evaluation with urine cytology, ultrasound and cystoscopy is usually required.

31% of women

felt their symptoms were not taken seriously

Insights shared by members of the Multi–Expertise Steering Committee highlighted that women can often disregard blood in their urine as 'normal', and as such don't seek out further healthcare support or investigation. If they do choose to seek support, they may believe that the correct specialist to see is a gynecologist rather than a urologist. **It is important to alter the public perception that a urologist is a 'male doctor', when in fact a urologist is a specialist who works with the urinary system and associated structures, for both females and males.**

Moreover, given bladder cancer is more common in men, it can often be perceived as a 'man's disease', so when women present with related symptoms, bladder cancer may not be front of mind when assessing female patients.[36]

Global health organizations should educate women about bladder cancer risk factors and symptoms, integrating bladder cancer awareness into existing campaigns.

Health systems need to identify the right pathway for women

1.2 Attaining a diagnosis

The **WBCPC Patient and Carer Experience Survey**, published in May 2023, found that women were over twice as likely to be first diagnosed with a UTI (39%), compared to male respondents (21%). 31% of women felt their symptoms were not taken seriously when they first visited a doctor—compared to 20% for all respondents.[37]

A 2009-2010 **English study of primary care diagnosis of bladder and renal cancer** found that 27% of women had three or more pre-referral consultations compared to 11% of men.[38]

Currently, there is no universal approach to screening bladder cancer symptoms like hematuria (visible blood in urine) or cystitis-like symptoms including burning when they urinate, or frequent urination, which are often interpreted as a UTI.[39]

When bladder cancer is then flagged for onward investigation, access to affordable and quality testing for bladder cancer is also variable and often associated with long wait times —further delaying a diagnosis.

Access to a cystoscopy—the gold standard for diagnosing bladder cancer—can be challenging due to long waiting times, contributing to delayed diagnoses.

Cystoscopy offers high sensitivity and specificity in detecting bladder cancer, making it the most reliable diagnostic tool currently available. However, since there is limited access to the test in primary care, women often wait too long to have the cystoscopy and subsequently receive a diagnosis. The absence of reliable and accessible diagnostic tools in primary care remains a critical gap. Ultrasonography as a first line of investigation may become important in the future to address this, although ultrasound is not consistently available across regions. Urinary markers are on the horizon, which could be the future of testing in primary care, given they are patient friendly and cost effective.

27% of women
had three or more pre-renal consultations

Many countries develop guidelines which instruct healthcare professionals how to appropriately refer patients to the right diagnostic test depending on the patient's symptoms, thus speeding up diagnosis. To fully address the bladder cancer diagnosis challenges for women, **health systems need to identify the right pathway for women that supports improved diagnosis in line with bladder cancer incidence and health system capacity within the respective country and region.**

In doing this, it is also important to consider the implementation of diagnostic tools throughout the pathway and explore opportunities for opportunistic screening when presenting with specific bladder cancer risk factors and symptoms—although the utility of screening is contested.

As such, there is a strong role for primary care professionals to play in delivering these pathways as well as gynecologists that can be viewed as a 'catch–all' for women's health issues.

Existing guidelines on bladder cancer could be extended by outlining a specific pathway for women to be assessed when they present with hematuria, to facilitate early referral and be used as an educational tool across clinical specialties.

39% of women
were first diagnosed with a UTI compared to
21% of men

Recommendations:

1. **Global and national health bodies should lead public education efforts to increase understanding amongst women of bladder cancer risk factors and symptoms.**
   - This should empower women to seek advice from their GP, gynecologist or urologist at an earlier stage, supporting both prevention efforts and earlier diagnosis.
   - Where current public education and institutional awareness campaigns are underway (for example, women's health/cancer/smoking and/or e-cigarette risk factors), bladder cancer should be included as part of this.
2. **Clinical communities could be supported to develop and disseminate practical, risk-stratified diagnostic pathways for women among primary care professionals, gynecologists and nephrologists.**
   - These pathways should provide clear and efficient guidance that outlines the steps required when women present with hematuria, recurrent cystitis, or urinary symptoms that do not resolve following initial treatment, ensuring accurate use of urine cytology and timely onward referral.
   - Providing clear guidance on when further investigation should be considered within the patient journey to support earlier diagnosis, such as for patients with risk factors or symptoms including—age >50 years, smoking history, occupational exposures, irritative lower urinary tract symptoms, history of gross hematuria, prior pelvic radiation oncology or recurrent urinary tract infections.
   - Patient organizations could help to distribute these pathways, which present clear diagnostic pathway recommendations and risk stratification for hematuria investigation and screening.
3. **Governments and national health services should increase levels of funding in bladder cancer research to develop accurate and cost-effective diagnostic tools to improve early detection.**
   - This could involve increased access and utilization of cystoscopy, urinary markers or point of care ultrasonography in primary care settings—particularly in areas with long referral wait times.
   - Opportunities to increase access to effective diagnostic testing should be explored, especially those with high sensitivity (such as uTERTpm testing developed by **The International Agency for Research on Cancer** (IARC40)). This could support improved rates of early diagnosis for women with bladder cancer.
   - Any consideration of screening programs should be risk stratified (screening of high–risk populations such as smokers and workers exposed to bladder carcinogens) and aligned to clear guidance for onward referrals, to ensure patients are referred to the right specialty.

2 Improving Healthcare Professional Education

Healthcare professional education (HCP) awareness and education on the gender differences in bladder cancer care can help reduce disparities in outcomes for women by promoting earlier diagnosis and ensuring equitable access to timely and appropriate treatment.[41]

2.1 Increased education to support diagnosis

General practitioners play a critical role in the pathway for women since they are frequently the first healthcare professional to identify symptoms of the disease and refer patients to a specialist to receive a confirmed diagnosis. To better support GPs, more can be done to **increase education on how to identify bladder cancer given that symptoms can often be missed or misdiagnosed.**

Insights discussed as part of the Multi-Expertise Steering Committee also highlighted the potential role of expert/specialist GPs, upskilled to become local experts in bladder cancer to support earlier diagnosis and further drive knowledge sharing and awareness of the symptoms of bladder cancer.

In tandem, along with GPs, there is a role for **improved education amongst wider healthcare professionals** who may see women directly following identification of symptoms.

These clinicians, such as gynecologists or nephrologists, can support with early detection of bladder cancer symptoms since women may present to these healthcare professionals with gross hematuria and/or concerns associated with repeat UTI's.

The Multi-Expertise Steering Committee also proposed a collaborative cross–specialty approach to develop best practices and a 'gold standard' for women with bladder cancer symptoms, to support primary care to make a timely diagnosis for women with bladder cancer.

> GPs, (uro) gynecologists and nephrologists play an important role to support early detection

In Australia, a team or urologists and general practitioners, with a special interest in bladder cancer, developed guidelines on **How to manage Hematuria**, including a suggested pathway for the initial management of micro and macro hematuria, with consideration to risk factors and what further investigations and/or referral should be prompted. Patient advocate and General Practitioner, Dr. Stephanie Demkiw of Bladder Cancer Awareness Australia was actively involved as one of the authors of this guideline. This guideline was published in the Royal Australian College of General Practitioner's AJGP (Australian Journal of General Practice) and developed into a leaflet that has been shared with Australian medical students, junior doctors and both trainee and qualified GPs in order to support onward education and awareness.

Recommendations:

1. **Medical education boards should support increased education on bladder cancer among healthcare professionals working across primary care, in centers of expertise, with junior doctors, medical students, and those working in female medical networks, to avoid growing gaps in expertise.**
   - This should include the development of targeted education campaigns for primary care practitioners including general practitioners, gynecologists, nephrologists, and primary care nurses, focusing on the gendered aspects of bladder cancer presentation, diagnostic red flags, and the importance of early referral pathways.
2. **Clinical guidelines could be updated to strengthen referral pathways for hematuria, and review available supporting tools, such as digital identification, to better enable referrals from primary care to the relevant specialist.**
   - AI can be better integrated into primary care computer software systems to prompt GPs on existing referral guidelines and patient pathways. This should support GPs to refer women who present with bladder cancer symptoms to the right diagnostic test/medical specialist the first time.

3 Delivering Gender-Specific Bladder Cancer Care

The delivery of gender-specific care is critical for providing women with tailored care, treatment and support for bladder cancer, acknowledging and addressing the gender care gap that exists. However, the delivery of this in practice is currently sub-optimal, with the expected standards not being met across countries.

3.1 Multi-disciplinary care

The provision of bladder cancer care from a multi-disciplinary team (MDT) should be the expected standard for all patients.

Across regions and countries, existing guidelines outline the importance of delivering MDT care. For example, the European Association of Urology (EAU) guidelines outline that the management of muscle-invasive and metastatic bladder cancer should be supported through collaboration between various clinical specialists, including urologists, medical and radiation oncologists, radiologists, and pathologists.[42] An MDT should work collaboratively to manage treatment, pre- and post-operative care and patient surveillance.

> Gender-specific care is critical for woman with bladder cancer

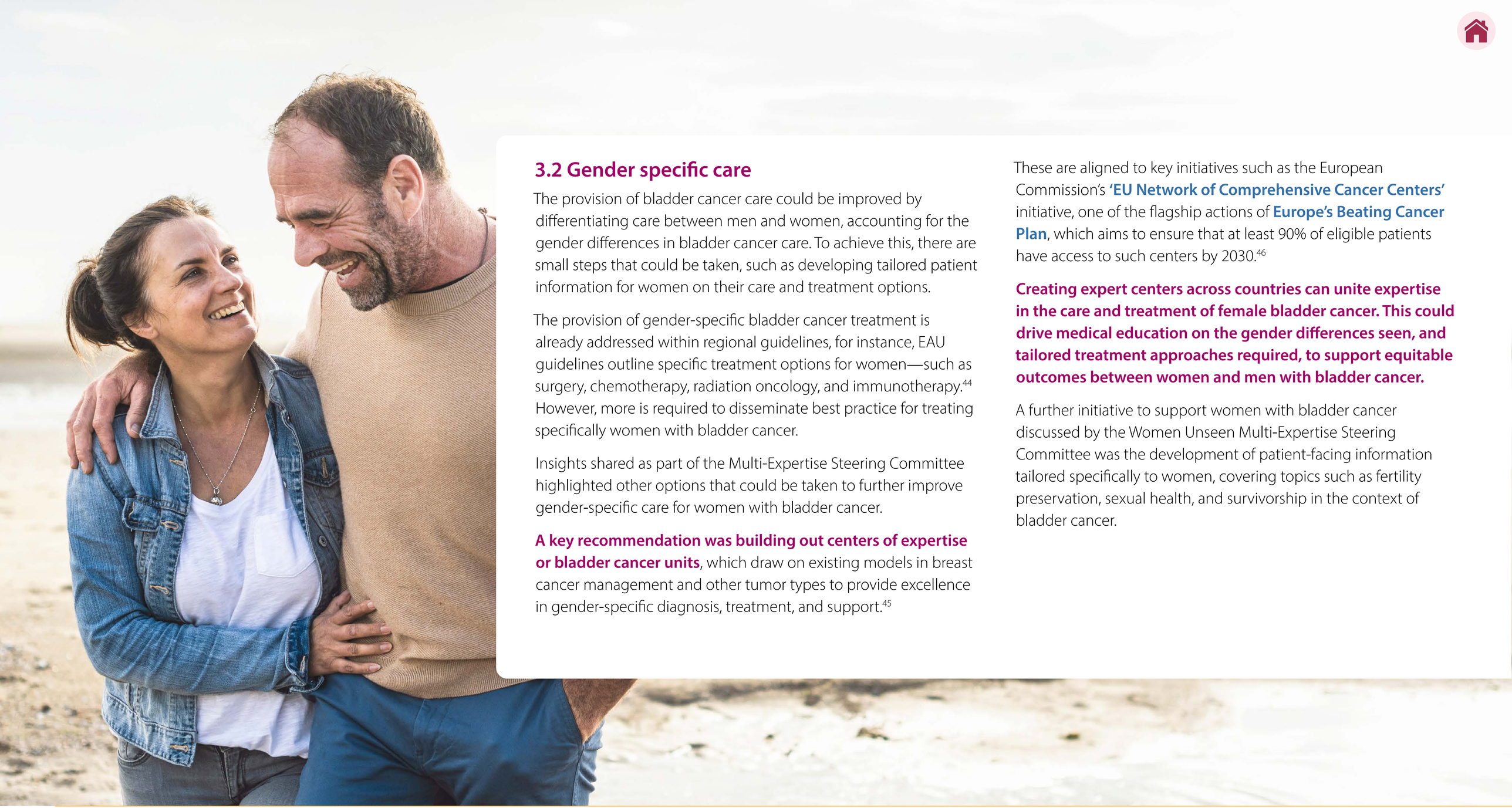
However, evidence shared as part of the **Woman Unseen Multi-Expertise Steering Committee highlighted that this multi-disciplinary approach to treating women for bladder cancer is not yet universal,** and more can be done to improve joint-working between healthcare specialties and ensure all guideline-recommended clinical specialties are included within MDT working.[43]

Moreover, to improve the experience of women receiving care, there should be a wider consideration of the clinical specialties required within MDTs as standard for women with bladder cancer.

For example:

- **Involving expanded clinical specialties** such as radiation and medical oncologists and immunotherapy experts as part of MDTs can play a crucial role in advancing care and treatment for women with bladder cancer, shifting support to designing bladder-preserving strategies for women.
- **Wider healthcare professionals** such as clinical nurse specialists and urology nurses, GPs, and gynecologists can support to ensure provision of the necessary pre- and post-operative care and holistic support required.

As part of this updated approach to MDT care, support should be given to **improve education of gender differences in bladder cancer across clinical specialties.**



3.2 Gender specific care

The provision of bladder cancer care could be improved by differentiating care between men and women, accounting for the gender differences in bladder cancer care. To achieve this, there are small steps that could be taken, such as developing tailored patient information for women on their care and treatment options.

The provision of gender-specific bladder cancer treatment is already addressed within regional guidelines, for instance, EAU guidelines outline specific treatment options for women—such as surgery, chemotherapy, radiation oncology, and immunotherapy.[44] However, more is required to disseminate best practice for treating specifically women with bladder cancer.

Insights shared as part of the Multi-Expertise Steering Committee highlighted other options that could be taken to further improve gender-specific care for women with bladder cancer.

A key recommendation was building out centers of expertise or bladder cancer units, which draw on existing models in breast cancer management and other tumor types to provide excellence in gender-specific diagnosis, treatment, and support.[45]

These are aligned to key initiatives such as the European Commission's **'EU Network of Comprehensive Cancer Centers'** initiative, one of the flagship actions of **Europe's Beating Cancer Plan**, which aims to ensure that at least 90% of eligible patients have access to such centers by 2030.[46]

Creating expert centers across countries can unite expertise in the care and treatment of female bladder cancer. This could drive medical education on the gender differences seen, and tailored treatment approaches required, to support equitable outcomes between women and men with bladder cancer.

A further initiative to support women with bladder cancer discussed by the Women Unseen Multi-Expertise Steering Committee was the development of patient-facing information tailored specifically to women, covering topics such as fertility preservation, sexual health, and survivorship in the context of bladder cancer.

Recommendations:

1. **National health systems and hospital boards should review the implementation of multidisciplinary team care as best practice for women with bladder cancer.**
   - Consideration should be given over whether to include wider healthcare specialties such as radiation and medical oncologists, nephrologists and immunotherapy experts, with potential to include clinical nurse specialists, GPs and gynecologists to ensure provision of the necessary pre-and post-operative care and the holistic support required.
   - This multi-disciplinary approach to bladder cancer care for women should also be supported through increased education across medical specialties, with a focus on junior doctors.
2. **Governments should consider establishing specialist centers for bladder cancer care, drawing on models from breast cancer and other tumor types to provide excellence in gender-specific diagnosis, treatment, and support.**
3. **Guideline committees should consider development and alignment of new approaches to and education on gender-specific care for bladder cancer in collaboration with cancer centers of expertise. Guidance should be disseminated among clinicians at all stages of the care pathway to increase knowledge, understanding and continuity of care.**
4. **Clinical societies and patient support networks should support the creation of gender specific patient information providing guidance and support around topics such as fertility preservation, sexual health, and survivorship in the context of bladder cancer.**
5. **The European Commission should:**
   - Deliver against its EU Network of Comprehensive Cancer Centers initiative, in collaboration with member states, working to improve access to quality-assured diagnostics and treatments, whilst also supporting improved training, research and clinical trials throughout the EU.
   - Implement proposals included in Europe's Beating Cancer Plan, including by delivering the agreed level of funding.
   - Continue to implement the EU Cancer Mission, working to leverage European collaboration to advance research, early detection, and treatment optimization.

4 Bladder Cancer within Women's Health

The specific challenges facing women with bladder cancer that have been outlined, illustrate the wider challenges and attitudes towards the unmet needs of women's cancer and health more broadly. As such, the gender care gap in bladder cancer should be viewed as a key example of a women's health challenge that requires action to address.

4.1 Clinical research

Research has highlighted that women are underrepresented in bladder cancer clinical trials.[47]

Clinical trial representation presents another systemic barrier to addressing the gender gap in bladder cancer. Women are often underrepresented in clinical trials, leaving a significant gap in knowledge about gender-specific responses to treatment.[48]

Specifically, **more clinical research is required into the gender differences in responses to bladder cancer treatment to better optimize treatment outcomes for women.**[49]

A 2013 study evaluating gender as a possible prognostic factor in bladder cancer patients treated with transurethral resection (TURBT) and radio- (RT) or radio-chemotherapy (RCT) found that female gender is an independent prognostic factor for reduced overall and cancer-specific survival in bladder cancer patients.[50]

More recently, in 2024, the Italian Association of Medical Oncology, as part of their review of gender oncology, recommended that "further studies should be conducted to obtain more information on the molecular differences related to sex-specific carcinogenesis in bladder cancer and possible therapeutic considerations."[51]

4.2 Prioritization of the bladder cancer gender care gap within policymaking

Bladder cancer was not mentioned in the EU's Beating Cancer Plan or within 10 OECD countries' national cancer plans.[52]

The challenges set out within this report are all exacerbated by a **lack of awareness and understanding of the gender care gap experienced by women with bladder cancer,** and in turn the lack of political prioritization to finding solutions and raising the gender gap as a policy priority.[53]

Across countries and regions such as the EU,[54] there have been various plans and strategies to improve cancer outcomes.

Despite these positive developments, strategies can often overlook bladder cancer, and in turn, the gender disparities in bladder cancer. As such, bladder cancer is referred to as 'the Cinderella of ancer' as it is often excluded.[55]

To address this, new or revised National Cancer Plans should prioritize addressing the burden of bladder cancer and the gender gap within this.

Strategies to improve gender medicine and reduce the gender gap are often overlooked

Moreover, there is an increasing focus globally on the need to improve women's health, as evidenced by the European Commission Communication's **'A roadmap for women's rights'**, which references the highest standards of health as a core principle of women's rights and gender equality.[56] When documents like these are produced by international, regional and national bodies, the impact of good, gender-specific bladder cancer care should act as an example of the need to address gender disparities to improve health outcomes for women.

Ongoing advocacy to ensure policymakers recognize the disparate gender outcomes is required. **To increase recognition of the symptoms of bladder cancer in women, public health campaigns targeting women should be developed, to encourage women to seek care for persistent urinary symptoms.**

Recommendations:

1. **Health Systems should ensure increased awareness and communication of existing support networks available for patients and reference the vital role peer-to-peer support delivers in patient support as part of clinical practice guidelines. Work should be undertaken to ensure all clinicians routinely detail the available avenues for peer-to-peer support as a key part of clinical best practice.**
2. **National Governments should prioritize addressing the gender care gap in bladder cancer as a key priority on their national cancer strategies. This should include policy action as part of national strategies to improve women's health outcomes through improved training of healthcare professionals.**
3. **Regional Policymakers should address the gender care gap in bladder cancer as part of cancer strategies and set targets to improve the diagnosis of bladder cancer amongst women. Public heath campaigns targeted at women to raise awareness of symptoms should be developed.**
   - As part of the European Commission Communication's 'A roadmap for women's rights', the Commission should consider addressing bladder cancer as part of its mission to achieve the highest standard of care for women.
   - Regional bodies should allocate funding from regional funds to improve and modernize medical infrastructure. While cystoscopy is key to diagnosing bladder cancer, there are other diagnostic tools which could be used more extensively such as multiparametric MRI, urinary markers and Computed Urography (CT).

Summary of recommendations

Early Detection and Diagnosis of Bladder Cancer in Women

1. Global and national health bodies should lead public education efforts to increase understanding amongst women of bladder cancer risk factors and symptoms. are.
2. Clinical communities could be supported to develop and disseminate practical, risk-stratified diagnostic pathways for women among primary care professionals, gynecologists and nephrologists.
3. Governments and national health services should increase levels of funding in bladder cancer research to develop accurate and cost-effective diagnostic tools to improve early detection.

Improving Healthcare Professional Education in Women

4. Medical education boards should support increased education on bladder cancer among healthcare professionals working across primary care, in centers of expertise, with junior doctors, medical students, and those working in female medical networks, to avoid growing gaps in expertise.
5. Clinical guidelines could be updated to strengthen referral pathways for hematuria, and review available supporting tools, such as digital identification, to better enable referrals from primary care to the relevant specialist.

Delivering Gender-Specific Bladder Cancer Care

6. National health systems and hospital boards should review the implementation of multidisciplinary team care as best practice for women with bladder cancer.
7. Governments should consider establishing specialist centers for bladder cancer care, drawing on models from breast cancer and other tumor types to provide excellence in gender-specific diagnosis, treatment, and support.
8. Guideline committees should consider development and alignment of new approaches to and education on gender-specific care for bladder cancer in collaboration with cancer centers of expertise. Guidance should be disseminated among clinicians at all stages of the care pathway to increase knowledge, understanding and continuity of care.
9. Clinical societies and patient support networks should support the creation of gender specific patient information providing guidance and support around topics such as fertility preservation, sexual health, and survivorship in the context of bladder cancer.
10. The European Commission should:
    - Deliver against its EU Network of Comprehensive Cancer Centers initiative, in collaboration with member states, working to improve access to quality-assured diagnostics and treatments, whilst also supporting improved training, research and clinical trials throughout the EU.
    - Implement proposals included in Europe's Beating Cancer Plan, including by delivering the agreed level of funding.
    - Continue to implement the EU Cancer Mission, working to leverage European collaboration to advance research, early detection, and treatment optimization.

Bladder Cancer within Women's Health Prioritization

11. Health Systems should ensure increased awareness and communication of existing support networks available for patients and reference the vital role peer-to-peer support delivers in patient support as part of clinical practice guidelines. Work should be undertaken to ensure all clinicians routinely detail the available avenues for peer-to-peer support as a key part of clinical best practice.
12. National Governments should prioritize addressing the gender care gap in bladder cancer as a key priority on their national cancer strategies. This should include policy action as part of national strategies to improve women's health outcomes through improved training of healthcare professionals.
13. Regional Policymakers should address the gender care gap in bladder cancer as part of cancer strategies and set targets to improve the diagnosis of bladder cancer amongst women. Public heath campaigns targeted at women to raise awareness of symptoms should be developed.
14. Regional bodies should allocate funding from regional funds to improve and modernize medical infrastructure. While cystoscopy is key to diagnosing bladder cancer, there are other diagnostic tools which could be used more extensively such as multiparametric MRI, urinary markers and Computed Urography (CT).

Acknowledgements

The above-mentioned recommendations have been co-created with members of the Women Unseen Multi-Expertise Steering Committee.

The recommendations have been endorsed by the following Steering Committee members:

- Mr. Alex Filicevas—Executive Director, World Bladder Cancer Patient Coalition; Co-chair, Global Cancer Coalitions Network; Past-President All.Can International, Belgium
- Professor Dr. Ananya Choudhury—Chair and honorary consultant in clinical oncology at the University of Manchester and The Christie NHS Foundation Trust; representative of the European Society for Radiotherapy and Oncology, United Kingdom
- Professor Dr. Anja Lorch—University Hospital Zürich, Vice Director Department for Medical Oncology and Hematology, Switzerland
- Ms. Antonella Cardone—Chief Executive Officer, Cancer Patients Europe, Belgium
- Professor Dr. Arnulf Stenzl—Secretary General, EAU; Director of the Department of Urology, University of Tuebingen Medical School, Germany
- Professor Dr. Cornelia Betschart—International Advisory Board Member, International Urogynaecological Association (IUGA), Switzerland
- Ms. Fatima Baig—Patient Advocate, Bladder Cancer, India
- Professor Dr. Hein Van Poppel— Chair of the EAU Policy Office; Professor of Urology, KU Leuven, Belgium
- Dr. Ho Kyung Seo—Department of Urology, Center for Urologic Cancer, National Cancer Center, South Korea
- Professor Dr. J.A. Witjes—Professor of Urology, Faculty of Medical Sciences, Radboudumc University; former Chairman of EAU Bladder Cancer Guidelines Panel, The Netherlands
- Professor Dr. Josep Vilaseca—Chief of Service, Primary Health Care at the Althaia Foundation, Manresa, Spain; Associate Professor at the University of Vic - Central Catalonia University; Fellow of the Royal Academy of Medicine of Catalonia; Life Member of the World Organization of Family Doctors Europe (WONCA), Spain
- Ms. Lori Cirefice—President, Association Cancer Vessie, France
- Dr. María José Méndez-Vidal—Medical Oncology Department, Maimonides Institute for Biomedical Research of Cordoba, Hospital Universitario Reina Sofía; Member, Spanish Society of Medical Oncology, Spain
- Professor Dr. Rossana Berardi—Full Professor of Oncology at UNIVPM; Head of Oncology at AOU of Marche; President and Founder of Women for Oncology, Italy
- Dr. Shao-Chuan Wang—Department of Urology, Chung Shan Medical University Hospital, Taiwan
- Dr. Stephanie Demkiw—Chair and Founder of Bladder Cancer Awareness Australia; Board of Directors, World Bladder Cancer Patient Coalition; General Practitioner, Australia

References

1 WBCPC (2023). White Paper on Bladder Cancer. **https://worldbladdercancer.org/wp-content/uploads/2023/09/Bladder_Cancer-White_Paper-Final.pdf**. [Accessed March 2025].

2 WBCPC. GLOBOCAN 2022: Bladder cancer 9th most common worldwide. **https://worldbladdercancer.org/news_events/globocan-2022-bladder-cancer-is-the-9th-most-commonly-diagnosed-worldwide/#:~:text=Bladder%20cancer%20has%20moved%20up,the%20data%20reported%20in%202020**. [Accessed March 2025].

3 Wang, SC., Sung, WW., Kao, YL. et al. The gender difference and mortality-to-incidence ratio relate to health care disparities in bladder cancer: National estimates from 33 countries. Sci Rep 7, 4360 (2017). **https://doi.org/10.1038/s41598-017-04083-z**

4 Anke Richters et al. (2020) The Global Burden of Bladder Cancer: an update, in World J Urol: 2020 Aug;38(8):1895-1904.

5 Uhlig A, Strauss A, Seif Amir Hosseini A, et al. Gender-specific Differences in Recurrence of Non-muscle-invasive Bladder Cancer: A Systematic Review and Meta-analysis. Eur Urol Focus. 2018;4(6):924-936.

6 WBCPC (2025). Sharing 5 unique stories of women with bladder cancer. Sharing 5 unique stories of women with bladder cancer. [Accessed March 2025].

7 WBCPC (2025). Patient & Carer Experiences with Bladder Cancer – Findings from a Global Survey. **https://worldbladdercancer.org/wp-content/uploads/2023/06/WBCPC-Patient-Survey-Report.pdf**. [Accessed March 2025].

8 Anand, P., Kunnumakkara, A. B., Sundaram, C., Harikumar, K. B., Tharakan, S. T., Lai, O. S., Sung, B., & Aggarwal, B. B. (2008). Cancer is a preventable disease that requires major lifestyle changes. Pharmaceutical research, 25(9), 2097–2116. **https://doi.org/10.1007/s11095-008-9661-9**.

9 World Health Organization. Cancer. Available at: **https://www.who.int/health-topics/cancer#tab=tab_1**. [Accessed March 2025].

10 World Cancer Research Fund. Cancer Rates by Human Development Index. Available at: **https://www.wcrf.org/preventing-cancer/cancer-statistics/cancer-rates-by-human-development-index/**. [Accessed March 2025].

11 World Health Organization. Global cancer burden growing, amidst mounting need for services, 1 February 2024. Available at: **https://www.who.int/news/item/01-02-2024-global-cancer-burden-growing--amidst-mounting-need-for-services**. [Accessed March 2025].

12 WBCPC (2025). GLOBOCAN 2022: Bladder cancer 9th most common worldwide. **https://worldbladdercancer.org/news_events/globocan-2022-bladder-cancer-is-the-9th-most-commonly-diagnosed-worldwide/#:~:text=Bladder%20cancer%20has%20moved%20up,the%20data%20reported%20in%202020**. [Accessed March 2025].

13 Saginala, K., Barsouk, A., Aluru, J. S., Rawla, P., Padala, S. A., & Barsouk, A. (2020). Epidemiology of Bladder Cancer. Medical sciences (Basel, Switzerland), 8(1), 15.

14 The Cancer Atlas. Southern, Eastern & South-Eastern Asia. Available at: **https://canceratlas.cancer.org/the-burden/south-east-se-asia/**. [Accessed March 2025].

15 International Agency for Research on Cancer. 2022. Latin America and the Caribbean. Available at: **https://gco.iarc.who.int/media/globocan/factsheets/populations/904-latin-america-and-the-caribbean-fact-sheet.pdf**. [Accessed March 2025].

16 Lee LJ, Kwon CS, Forsythe A, Mamolo CM, Masters ET, Jacobs IA. Humanistic and Economic Burden of Non-Muscle Invasive Bladder Cancer: Results of Two Systematic Literature Reviews. Clinicoecon Outcomes Res. 2020;12:693-709.

17 Shariat SF, Sfakianos JP, Droller MJ, Karakiewicz PI, Meryn S, Bochner BH. The effect of age and gender on bladder cancer: a critical review of the literature. BJU Int. 2010;105(3):300-308.

18 Bilski K, Zapała Ł, Skrzypczyk MA, Oszczudłowski M, Dobruch J. Review on gender differences in non-muscle invasive bladder cancer. Transl Androl Urol. 2019;8(1):12-20.

19 Hamade, A., Li, D., Tyryshkin, K. et al. Sex differences in the aging murine urinary bladder and influence on the tumor immune microenvironment of a carcinogen-induced model of bladder cancer. *Biol Sex Differ* 13, 19 (2022).

20 Pignot G, Barthélémy P, Borchiellini D. Sex Disparities in Bladder Cancer Diagnosis and Treatment. Cancers (Basel). 2024;16(23):4100.

21 Scheller T., Hofmann R., Hegele A. Sex-related differences in urothelial cell carcinoma of the bladder in Germany. Cancer Manag. Res. 2019;11:309–316. doi: 10.2147/CMAR.S181532.

22 Elliott J, Rotterud R, Maddox-Smith A, Bagshaw K, Cirefice LBF, Knight A, et al. The bladder cancer patient survey: Global perspectives on awareness and treatment of bladder cancer. Journal of Cancer Policy. 2019;22:100207.

23 Cohn, J. A., Vekhter, B., Lyttle, C., Steinberg, G. D., & Large, M. C. (2014). Sex disparities in diagnosis of bladder cancer after initial presentation with hematuria: a nationwide claims-based investigation. *Cancer, 120(4)*, 555–561.

24 WBCPC (2023). White Paper on Bladder Cancer. **https://worldbladdercancer.org/wp-content/uploads/2023/09/Bladder_Cancer-White_Paper-Final.pdf**. [Accessed March 2025[.

25 WBCPC (2023). White Paper on Bladder Cancer. **https://worldbladdercancer.org/wp-content/uploads/2023/09/Bladder_Cancer-White_Paper-Final.pdf**. [Accessed March 2025].

26 WBCPC (2023). White Paper on Bladder Cancer. **https://worldbladdercancer.org/wp-content/uploads/2023/09/Bladder_Cancer-White_Paper-Final.pdf**. [Accessed March 2025].

27 Choi, H., Park, J. Y., Bae, J. H., & Tae, B. S. (2020). Health-related quality of life after radical cystectomy. *Translational andrology and urology, 9*(6), 2997–3006.

28 Cohn, J. A., Vekhter, B., Lyttle, C., Steinberg, G. D., & Large, M. C. (2014). Sex disparities in diagnosis of bladder cancer after initial presentation with hematuria: a nationwide claims-based investigation. Cancer, 120(4), 555–561. https://doi.org/10.1002/cncr.28416.

29 WBCPC. 2023. Patient & Carer Experiences with Bladder Cancer – Findings from a Global Survey. **https://worldbladdercancer.org/wp-content/uploads/2023/06/WBCPC-Patient-Survey-Report.pdf.** [Accessed March 2025].

30 WBCPC. 2023. Patient & Carer Experiences with Bladder Cancer – Findings from a Global Survey. **https://worldbladdercancer.org/wp-content/uploads/2023/06/WBCPC-Patient-Survey-Report.pdf**. [Accessed March 2025].

31 WBCPC. Symptoms & risk factors. Available at: **https://worldbladdercancer.org/bladder-cancer-article/signs-risk-factors/?gad_source=1&gclid=EAIaIQobChMIgZHy6KSHjAMVvYtQBh17CDtVEAMYASAAEgJQU_D_BwE**. [Accessed March 2025].

32 Bladder Cancer Advocacy Network. Smoking and Bladder Cancer Risk. Available at: **https://bcan.org/smoking-bladder-cancer-risk/**. [Accessed March 2025].

33 Bandara NA, Zhou XR, Alhamam A, Black PC, St-Laurent MP. The genitourinary impacts of electronic cigarette use: a systematic review of the literature. *World J Urol*. 2023;41(10):2637-2646.

34 Leslie SW, Hamawy K, Saleem MO. Gross and Microscopic Hematuria. [Updated 2024 Feb 29]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2025 Jan-. Available from: **https://www.ncbi.nlm.nih.gov/books/NBK534213/**

35 WBCPC. Patient & Carer Experiences with Bladder Cancer. Available at: **https://worldbladdercancer.org/wp-content/uploads/2023/06/WBCPC-Patient-Survey-Report-Executive-Summary-2.pdf**.

36 Bladder Cancer Advocacy Network. Bladder Cancer in Women – Signs, Symptoms and Treatments. Available at: **https://bcan.org/women-bladder-cancer/**. [Accessed March 2025].

37 WBCPC. 2023. Patient & Carer Experiences with Bladder Cancer – Findings from a Global Survey. **https://worldbladdercancer.org/wp-content/uploads/2023/06/WBCPC-Patient-Survey-Report.pdf**. [Accessed March 2025].

38 WBCPC. 2023. Patient & Carer Experiences with Bladder Cancer – Findings from a Global Survey. **https://worldbladdercancer.org/wp-content/uploads/2023/06/WBCPC-Patient-Survey-Report.pdf.** [Accessed March 2025].

39 Bladder Cancer Advocacy Network. Bladder Cancer in Women – Signs, Symptoms and Treatments. Available at: **https://bcan.org/women-bladder-cancer/**. [Accessed March 2025].

40 International Agency for Research on Cancer, World Health Organization. Promising urine test could improve early detection and clinical management of bladder cancer: IARC Evidence Summary Brief No. 3. Available at: **https://www.iarc.who.int/wp-content/uploads/2022/05/pr314_E.pdf**. [Accessed March 2025].

41 WBCPC (2023). White Paper on Bladder Cancer. **https://worldbladdercancer.org/wp-content/uploads/2023/09/Bladder_Cancer-White_Paper-Final.pdf**. [Accessed March 2025].

42 European Association of Urology. Muscle-invasive and Metastatic Bladder Cancer. Available at: **https://uroweb.org/guidelines/muscle-invasive-and-metastatic-bladder-cancer/chapter/introduction/**. [Accessed March 2025].

43 Astellas Global Data on File. Insight provided during Multi-Expertise Steering Committee meetings. Available on request.

44 European Association of Urology. Muscle-invasive and Metastatic Bladder Cancer. Available at: **https://uroweb.org/guidelines/muscle-invasive-and-metastatic-bladder-cancer/chapter/introduction/**. [Accessed March 2025].

45 International Breast Cancer Center. About us. Available at: **https://ibcc.clinic/en/about-us/**. [Accessed March 2025].

46 European Commission. Europe's Beating Cancer Plan. Available at: **https://health.ec.europa.eu/system/files/2022-02/eu_cancer-plan_en_0.pdf**. [Accessed March 2025].

47 Batra N, Miyagi H, Bozorgmehri S, et al. Gender disparities in the clinical trials and real-world utilization of systemic therapy in the management of urothelial carcinoma. Paper presented at: 2022 Society of Women in Urology Annual Clinical Mentoring Conference; February 7-9, 2022; New Orleans, Louisiana. Poster 6176.

48 Pignot, G., Barthélémy, P., & Borchiellini, D. (2024). Sex Disparities in Bladder Cancer Diagnosis and Treatment. *Cancers, 16*(23), 4100.

49 Astellas Global Data on File. Insight provided during Multi-Expertise Steering Committee meetings. Available on request.

50 Keck B, Ott OJ, Häberle L, Kunath F, Weiss C, Rödel C, Sauer R, Fietkau R, Wullich B, Krause FS. Female sex is an independent risk factor for reduced overall survival in bladder cancer patients treated by transurethral resection and radio- or radiochemotherapy. World J Urol. 2013 Oct;31(5):1023-8.

51 Berardi, R., Rossi, F., Papa, R., Appetecchia, M., Baggio, G., Bianchini, M., Mazzei, T., Maria Moretti, A., Ortona, E., Pietrantonio, F., Tarantino, V., Vavalà, T., & Cinieri, S. (2024). Gender oncology: recommendations and consensus of the Italian Association of Medical Oncology (AIOM). ESMO open, 9(2), 102243.

52 European Commission. Europe's Beating Cancer Plan. Available at: **https://health.ec.europa.eu/system/files/2022-02/eu_cancer-plan_en_0.pdf**. [Accessed March 2025].

53 T. Ecke, F. Le-Calvez Helm, H. Van Poppel: Why we need more attention on Bladder Cancer: Establishing Policy recommendations for Health Care Professionals and Politicians. Eur. Urol. (2025).

54 European Commission. Europe's Beating Cancer Plan. Available at: **https://health.ec.europa.eu/system/files/2022-02/eu_cancer-plan_en_0.pdf**. [Accessed March 2025].

55 European Federation of Pharmaceutical Industries and Associations. Bladder cancer: the Cinderella of cancers. Available at: **https://www.efpia.eu/news-events/the-efpia-view/blog-articles/bladder-cancer-the-cinderella-of-cancers/**. [Accessed March 2025].

56 European Commission. A Roadmap for women's rights – Commission Communication. Available at: **https://commission.europa.eu/document/0c3fe55d-9e4f-4377-9d14-93d03398b434_en**. [Accessed March 2025].

WOMEN UNSEEN

Tackling the gender care gap in **bladder cancer**

Call to Action Report