



Patient & Carer Experiences with Bladder Cancer

Findings from a Global Survey

EXECUTIVE SUMMARY

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World Bladder
Cancer Patient
COALITION

UNITING THE VOICE OF PEOPLE AFFECTED BY BLADDER CANCER

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Project expert advisory committee

- **Dr Ashish Kamat**, (Project Chair), MD Anderson Cancer Center; International Bladder Cancer Group; International Bladder Cancer Network; International Society of Urology (USA)
- **Dr Patrick Hensley**, (Assistant Chair), University of Kentucky College of Medicine (USA)
- **Dr Lydia Makaroff**, World Bladder Cancer Patient Coalition; Fight Bladder Cancer (UK)
- **Dr Peter Black**, University of British Columbia; International Bladder Cancer Network; Société Internationale d'Urologie; Bladder Cancer Canada (Canada)
- **Dr Stephanie Chisolm**, Bladder Cancer Advocacy Network (USA)
- **Dr Stephanie Demkiw**, Bladder Cancer Awareness Australia; Access Health and Community (Australia)
- **Dr Mario I. Fernandez**, Clínica Alemana Universidad del Desarrollo; International Bladder Cancer Group (Chile)
- **Dr Mikio Sugimoto**, Kagawa University (Japan)
- **Dr Bente Thoft Jensen**, European Association of Urology Nurses (Denmark)
- **Dr Wim Witjes**, European Association of Urology Research Foundation (Netherlands)

World Bladder Cancer Patient Coalition

Ken Bagshaw
Dr Stephanie Chisolm
Lori Cirefice-Funk
Dr Stephanie Dekmiw
Alex Filicevas
Marie Magenhann Cueto
Dr Lydia Makaroff
Theodoros Yfantis

Our member organisations

Association PaLiNUro, Italy
Bladder Cancer Advocacy Network, USA
Bladder Cancer Awareness Australia
Bladder Cancer Canada
Bladder Cancer France
Bladder Cancer Norway
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Fight Bladder Cancer, UK
Living with Bladder or Kidney Cancer, Netherlands
Norwegian Bladder Cancer Society

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INDIVIDUALS

- Alessandro Boni
- Tony Cornacchia
- Melanie Costin
- Ferg Devins
- Dr Makarand Khochikar
- Dr Rajeev Kumar
- Dr Mohammed Shahait
- Dr Ignacio Duran
- David Guttman
- Ekaterina Iarkova-Vizuroiu
- Helen Lacy
- Robert McConkey
- Jack Moon
- Lauren Pretorius
- Anita Eik Roald
- Jim Scott
- Brittney Tellekamp



World Bladder Cancer Patient COALITION

About the World Bladder Cancer Patient Coalition (WBCPC)

The World Bladder Cancer Patient Coalition (WBCPC) worldbladdercancer.org was established in January 2019. The Coalition brings together patient groups across continents, uniting the vision and goals of bladder cancer patient groups.

Our vision is a world without bladder cancer.

Our mission focuses on three goals:

- to foster an international community of people affected by bladder cancer
- advocate for access to the best bladder cancer information, support and care
- build alliances with health professionals, policymakers, academics, researchers and industry.

We are driven by our ambition to have a bladder cancer patient organisation established in each country and that they are fully able to support people affected by bladder cancer, advocate for advancing research and providing the best information, treatment and care.

About this report

This research and report was initiated by WBCPC. Ongoing guidance was provided by WBCPC member organisations, the WBCPC board of directors, the WBCPC patient advisory panel and the project expert advisory committee.

The survey was conducted by IQVIA. 
<https://www.iqvia.com>

This report was written by Shannon Boldon, an independent Health Policy Consultant. The report was graphically designed by the team at Design Couch.

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CONTACT

The World Bladder Cancer Patient Coalition aisbl
Square de Meeûs 38-40
1000 Brussels, Belgium
Email: info@worldbladdercancer.org
Reg. Number: 0720.618.047
VAT ID: BE0720.618.047



Executive summary

ABOUT THE GLOBAL SURVEY

Few global studies detail the lived experiences of bladder cancer patients and carers [1, 2]. This survey was initiated by the World Bladder Cancer Patient Coalition to fill this knowledge gap and shed light on the experiences of bladder cancer patients and carers.

To our knowledge, this survey is the broadest international analysis of bladder cancer patient experiences – in terms of countries represented and breadth of topics covered. The survey achieved 1198 responses from 45 countries and had 65 questions covering the entire patient experience – from disease awareness, diagnosis, treatment and care, follow-up, life with and after cancer and the impact of the COVID-19 pandemic. It is the second global patient experience survey in bladder cancer, following that by Elliot et al (2019) [2].

ABOUT BLADDER CANCER

Bladder cancer is the 10th most common cancer and 13th leading cancer-related cause of death in the world [3]. Characterised by high recurrence rates for non-invasive disease and high mortality for advanced disease states, bladder cancer is one of the most challenging and expensive cancer types to diagnose and treat. For all stages combined, the 5-year relative survival rate is 77% (US data) [4]. The mental health impact is significant – due to long term invasive testing, treatment, and life-changing surgery – and patients often lack support to cope with the impact of this disease on their daily life [5, 6]. As a result, patients experience a lower quality of life, higher rate of depression, and higher risk of suicide when compared to other common cancers [5, 7].



1,198

Survey responses



45

Countries responded



65

Total questions

10th

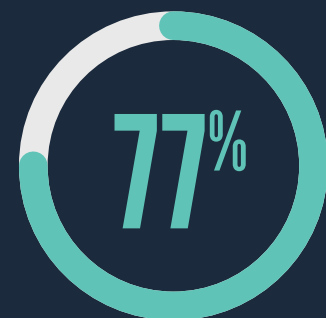
most common cancer and

13th

leading cancer-related cause of death in the world

All stages combined

5-year relative survival rate is



“The mental health impact is significant – due to long term invasive testing, treatment and sometimes life-changing surgery and patients often lack support to cope with the impact of bladder cancer on their daily life.”



Findings: awareness and diagnosis



54%

did not know the signs and symptoms of bladder cancer before diagnosis

64%

did not know visible blood in urine was a symptom of bladder cancer

32%

understood the signs and symptoms of bladder cancer, compared to other common cancers (completely, to some extent)

Our study found that prior awareness of bladder cancer was low. Over half of respondents (54%) did not know the signs and symptoms of bladder cancer before their diagnosis, and almost two thirds (64%) did not know visible blood in urine was a symptom of bladder cancer, even though it is the most common one [2]. When compared to other common cancer types, only a third (32%) understood the signs and symptoms of bladder cancer before diagnosis. Previous studies have also found that patients had a low awareness of bladder cancer and symptoms, prior to being diagnosed [2, 5].

described haematuria as deceptive due to its painless and inconsistent nature leading to delays in seeking help [1].



Most patients visited their doctor once (52%) or twice (23%) before being told they needed to see a specialist about bladder cancer.

However, 10% visited a doctor five or more times before being referred to a specialist. It was most common for young respondents (under 55) (16%), females (18%) and metastatic/advanced patients (21%) to visit their doctor five or more times before being referred to a specialist. A fifth (20%) of respondents felt their symptoms were not taken seriously when they first visited a doctor – again, this was higher for females (31%), advanced/metastatic cancers (31%) and younger respondents (under 55) (33%).



had visible blood in their urine as a symptom

Visible blood in urine was the most common symptom experienced by 67% of respondents. After noticing initial signs and symptoms, 43% sought medical attention immediately, while 32% waited longer than a month to seek medical attention. Delays in seeking medical attention were most commonly due to thinking the symptoms were caused by something else (36%) or that they were not serious (34%). In their review of the literature, Edmondson et al found that patients often



of patient felt their symptoms were not taken seriously when they first visited a doctor

Over half (57%) of respondents were diagnosed with another condition before bladder cancer, the most common being a urinary tract infection (28%). It was more common for females to be diagnosed with another condition first (69%), especially a UTI (39%). Females were twice as likely to be mis-diagnosed with a UTI (39%), compared to males (21%).

Most respondents (78%) were diagnosed within 3-months of first going to a doctor with signs and symptoms. It was more common for males (83%) to be diagnosed within 3-months, compared to females (70%). Moreover, younger respondents (under 55) were least likely to be diagnosed in 3-months (66%), compared to 55-74 (79%) and over 74 (81%). Most respondents understood their diagnosis (66% completely, 28% to some extent), however, 16% did not receive enough information about their diagnosis.

83%

of males diagnosed within 3-months



70%

of females diagnosed within 3-months



Previous studies show that women have greater delays in diagnoses and slower referrals

Our findings are consistent with literature showing that women have greater delays in diagnosis, and slower referral to a specialist [1, 8]. As Mancini, M et al pointed out, while men are at a higher risk of developing bladder cancer, women present with more advanced disease and have more unfavourable outcomes mostly due to a delay in haematuria evaluation [9]. Delays in bladder cancer diagnosis are associated with increased mortality, independent of tumour stage and grade [10].

Younger people and women have worst experiences at diagnosis.



Findings: treatment access

Most respondents were satisfied with their involvement in treatment decision-making. 60% said their treatment options were completely explained to them before their treatment started, and 28% said to some extent. 8% would have liked more treatment options explained to them, and 12% wanted to be more involved in making decisions about their care and treatment. Almost a third (32%) of respondents asked for a second opinion regarding their diagnosis and treatment and got one, and over half (51%) did not want or need one. The literature suggests that bladder cancer patients have overall less positive experiences in decision-making involvement compared to other cancer types [11].

Most respondents (72%) did not have barriers to accessing treatment. However, a few said treatment waiting times (7%) and lack of access to treatment/drugs (e.g., BCG) (5%). 16% received information about clinical trials – and half of them (8%) took part in one. Advanced/metastatic respondents were most likely to take part in a clinical trial (26%). There is a well described discrepancy in the clinical trial landscape, with most patients not being offered trials despite being willing to participate [12, 13].

Over a quarter (27%) of the total survey respondents had a radical cystectomy. A delayed diagnosis was associated with a higher rate of radical cystectomy. Respondents diagnosed in greater than 6-months (from symptom onset) were most likely to have radical cystectomy (36%), compared 3-6 months (33%), and less than 3-months (26%). Three quarters (74%) of respondents who had a radical cystectomy said that no other treatment options were discussed with them. Despite this, most respondents felt enough consideration was given to other treatment options (75%). The most common urinary reconstructions were ileal conduit (70%) and neobladder (24%).

Nearly half of all respondents (45%) were not counselled before radical cystectomy on sexual side effects. Males were three times more likely to be counselled on the sexual side effects (36%) compared to females (11%). Previous studies have found that patients undergoing radical cystectomy often experience problems with body image, sexual intimacy, and sexual enjoyment following surgery and should receive pre-treatment counselling and post-treatment support, but research suggests this is often omitted [14].



12%

wanted to be more involved in making decisions about their care and treatment



72%

most respondents did not have barriers to accessing treatment



27%

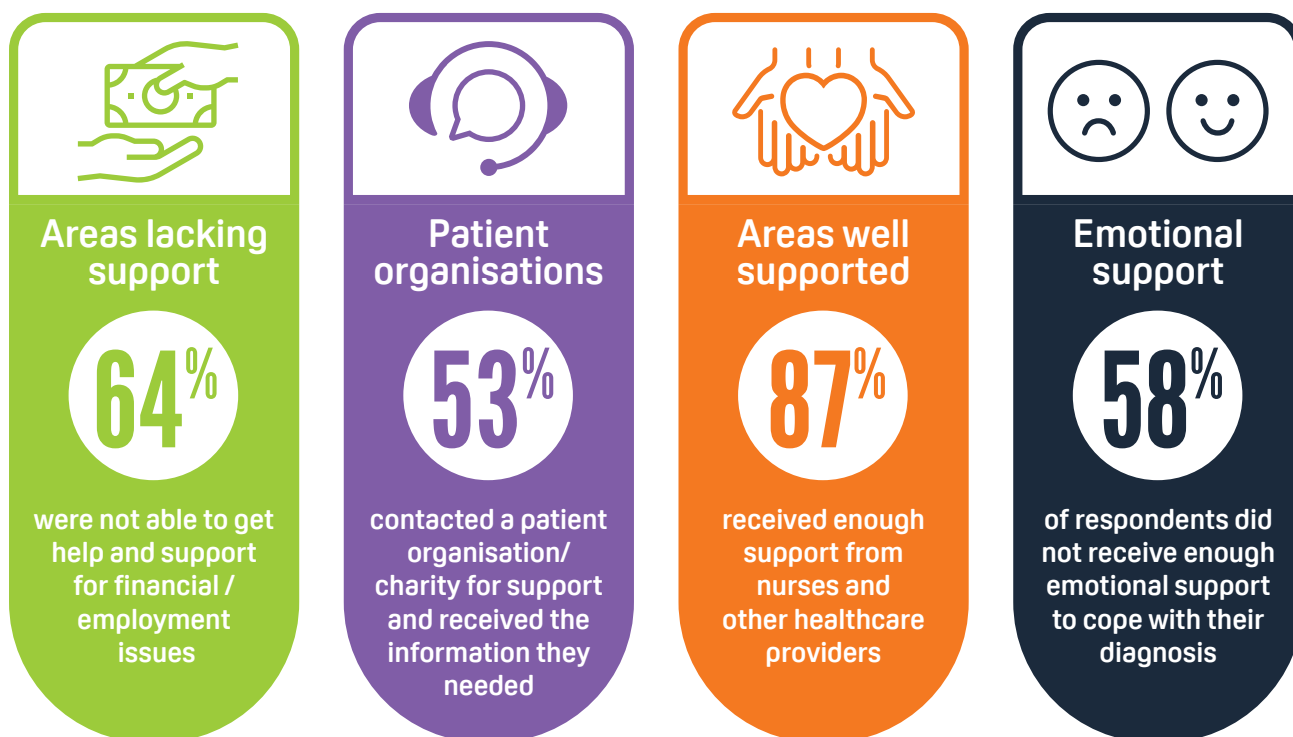
Over a quarter of the total survey respondents had a radical cystectomy



45%

nearly half were not counselled before radical cystectomy on the possible sexual side effects

Findings: supportive and complementary care



Respondents often lacked help and support in many areas, even though it was needed.

The areas where the highest proportion of people were not able to get help and support (if needed) were financial/employment issues (64%), alternative/complementary therapies (63%), and self-esteem / self-image (61%).

Almost all (82%) respondents needed more information at the time of diagnosis.

The greatest need for information was on treatment options and duration (51%), diagnosis and what it means (39%) and side effects of treatment (37%). Nearly three quarters of people (73%) did not receive information about peer-support groups and charities. Half (50%) contacted a patient organisation/charity for support, of them, over half (53%) definitely received the information and support they needed and 43% did to some extent.

Respondents felt well supported by the people involved in their treatment and care.

87% received enough support from nurses and other healthcare providers. 95% received enough support from family and friends. 81% received enough support from their doctors.

Respondents felt less satisfied with the practical and financial support provided throughout their treatment and care. 32% needed more practical support, such as help with daily tasks and getting treatments. 54% needed more financial support.

Emotional support access was lacking for most respondents.

Emotional support was needed the most at the point of diagnosis (42%), after the initial diagnosis (48%) and during treatment (48%). Nearly all respondents (91%) said they needed emotional support throughout their treatment and care experience, and 30% did not receive it. 58% of respondents did not receive enough emotional support to cope with their diagnosis. 55% of respondents were unable to get support for depression/ anxiety. This is even though bladder cancer patients report higher rates of depression, and have a higher risk of suicide, compared to other common cancers [5].

Respondents also described a lack of follow-up and support after treatment concluded.

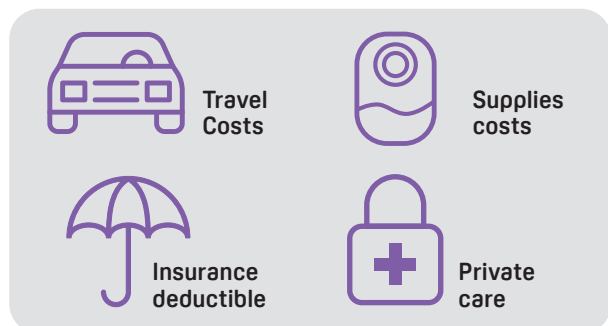
In free-text questions, they described feeling alone without appropriate tools to manage their condition after treatment.

Findings: impact on daily life

Having bladder cancer impacted people financially, to a varying degree. Nearly half (49%) of respondents said they were impacted financially (severely, to some extent or slightly). This was highest for advanced/metastatic cancer (57%), and younger respondents (under 55) (68%).

Additional costs due to bladder cancer caused financial strain. These included: travel costs, insurance deductibles, purchasing new supplies, or paying out of pocket to access private care. These rates of financial toxicity are higher than those previously reported in the literature [15].

Additional costs



(nearly half) of respondents said they were impacted financially (severely, to some extent or slightly)



of advanced/metastatic respondents said they were impacted financially

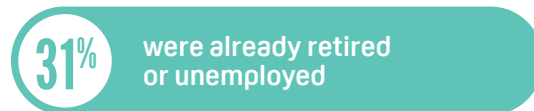


of younger respondents (under 55) said they were impacted financially

For some, having bladder cancer did not impact their employment status. A third of respondents (32%) had no change in their employment status, while another third (31%) were already retired or unemployed. However, 12% took an early retirement, 10% were temporarily off work, and 3% voluntarily left their job. Young respondents (under 55) were more likely to temporarily take time off work (27%).

Advanced/metastatic patients were more vulnerable to changes in employment status. Only 15% of advanced/metastatic cancers had no change to their employment status, and they were more likely to voluntarily leave their job (19%) or take an early retirement (26%).

Previous studies have shown that financial toxicity is especially common in younger patients receiving radical cystectomy or TURBT, with lower rates among older people having the same treatments [7].



The emotional impact of bladder cancer was most felt in:



36%

sexual performance



26%

hopes for the future



27%

stress/anxiety levels

The emotional impact of bladder cancer was felt severely across many aspects of life – especially in sexual performance (36%), stress/anxiety levels (27%), and hopes for the future (26%). Younger respondents (under 55) were more severely impacted emotionally across nearly all aspects of life. 46% of respondents said the long-term emotional impact of their treatment for bladder cancer have not been addressed – and was highest for advanced/metastatic cancers (60%).

Most respondents (87%) were able to cope with the impact of their diagnosis and treatment; however, 13% said they were not coping well or very badly. Additionally, 13% felt they were not able to live a full life after their diagnosis and treatment for bladder cancer – this was three times higher for respondents with metastatic/advanced cancer (39%).

13% could not cope

13% felt unable to live a full life



Findings: impact of COVID-19

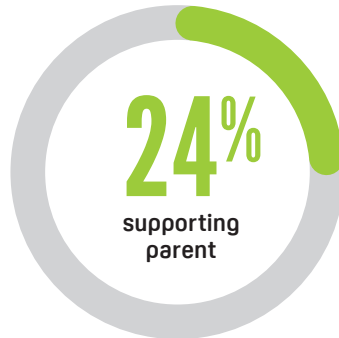
45% of respondents said the COVID-19 pandemic had no impact on their care and treatment. On the other hand, 8% said the pandemic severely impacted their care and treatment. The impact of COVID-19 on survey respondents was most evident in treatment appointments being delayed or cancelled, having to do virtual appointments when it was preferred to have appointments in person, and not being able to have family/friends attend medical facilities to visit them after treatment, or join them for consultations, due to restrictions.

The literature shows that the impact of COVID-19 on bladder cancer was significant. It led to a significant reduction in consultations during the pandemic, an increase in the presentation of high-grade and advanced tumours (in 2020, compared to 2019), increased surgery deferral and increased anxiety [16, 17].



Findings: impact on carers

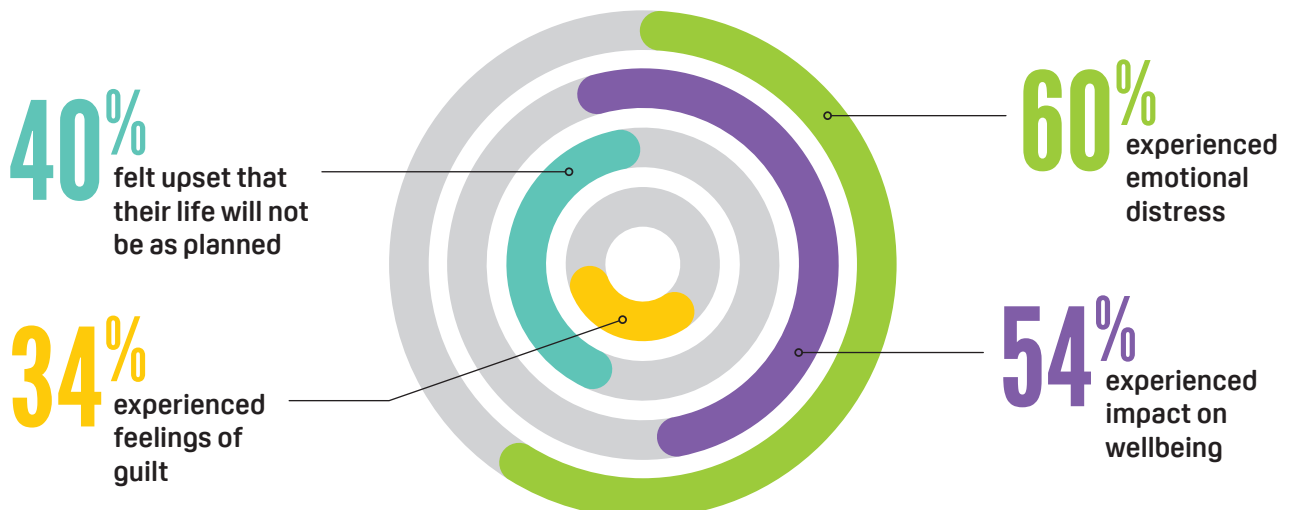
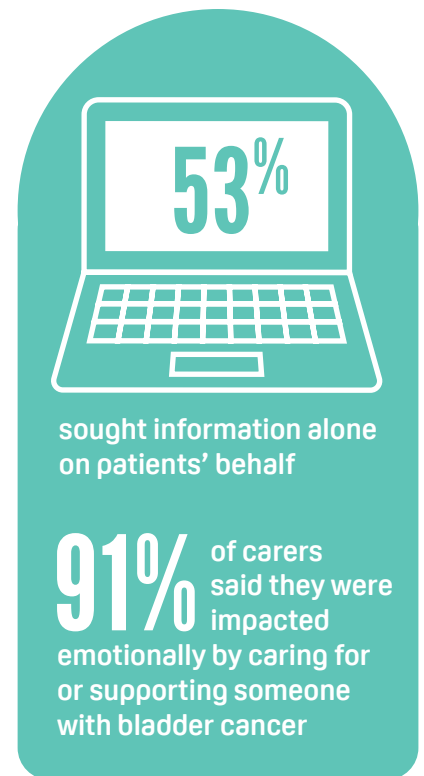
Carers provided care and support to their spouse/partner (64%) or parent (24%), and most had been doing so for more than a year (71%).



Carers played a crucial role finding information about bladder cancer – more than half (53%) said they sought out this information alone on the patients' behalf. Only a fifth (21%) found all the information that they needed on 'caring' for someone with bladder cancer. Emotional support (49%) was the most challenging type of care to provide.

Limited research has focused on the impact of being a carer, including on mental health and quality of life. In our survey, almost all (91%) carers said they were impacted emotionally by caring for or supporting someone with bladder cancer. This included feelings of fear that the person with bladder cancer will relapse (65%), experiencing emotional distress (60%), always placing the needs of the person they were caring for ahead of their own (55%), impact on wellbeing (54%), feeling upset that their life will not be as planned (40%), and feelings of guilt (34%).

Previous studies on unpaid carers have found that carers own needs are often overlooked, and increased support to carers, and recognition of carers is needed [18].



Drawing from the patient and carer experience findings presented in this report, and what is known from past research, the following priorities for action are recommended. Patient organisations, professional societies, healthcare system leaders, industry, and other stakeholders are encouraged to prioritise funding of projects, initiatives, and future work that will directly improve patient and carer experiences in these focus areas.

01.

Improve public awareness of bladder cancer signs and symptoms:



Our survey found low awareness of the common signs and symptoms of bladder cancer, prior to initial diagnosis. Awareness was especially low among younger respondents (under 55 years), possibly contributing to delays in diagnosis. Some respondents indicated in open-ended comments that they had seen public awareness campaigns in the UK and Canada helping them to recognise signs and symptoms of bladder cancer, and campaigns like these should be continued and expanded into other countries. Bladder Cancer Awareness Month in May should be harnessed to raise awareness among the public on the signs and symptoms of bladder cancer.

02.

Improve early detection of bladder cancer in women, young people (under 55) and people without noticeable symptoms (e.g., microhaematuria):

Our survey uncovered that a third of respondents did not have visible blood in their urine, necessitating strategies to help diagnose bladder cancer sooner. These may include screening of high-risk individuals such as smokers, those exposed to second-hand smoke, people with a family history of bladder cancer or people with regular exposure to carcinogens linked to bladder cancer. Additionally, women and young people (under 55 years) had relatively poorer experiences at diagnosis including having to see a doctor more times in order to be referred and feeling like initial symptoms were not taken seriously. Women had a higher likelihood of misdiagnosis, especially with urinary tract infections.



03.



Improve awareness of bladder cancer symptoms among primary care providers:

Resources and educational initiatives should be aimed at primary care providers and gynaecologists to support detection of bladder cancer symptoms and early referral to a specialist, especially for females and young people (under 55). Symptoms in females are commonly attributed to infections or gynaecological conditions which delay diagnosis and treatment. Low incidence of bladder cancer in younger age groups and in women can often lead to symptoms being dismissed. Delays in diagnosing bladder cancer is associated with increased mortality, independent of tumour stage and grade [10].

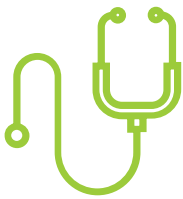
04.

Provide sexual counselling to all patients before radical cystectomy:

The sexual impact of bladder cancer treatment is well known and should be mitigated by pre-treatment counselling and post-treatment support. However, almost half of all respondents in our survey who had a radical cystectomy were not counselled beforehand about sexual side-effects. Notably, males were more than three times more likely to be counselled before surgery about sexual side-effects, compared to females. In addition to providing counselling to all patients, health professionals should guide patients to resources offered by national patient support organisations.



05.



Improve access to new and innovative treatments for bladder cancer, through clinical trials:

Clinical trials investigate new therapies or treatment approaches and are the backbone of improving bladder cancer outcomes for future generations of patients. Clinical trial access was poor among survey respondents. There is a well described discrepancy in the clinical trial landscape, with the vast majority of patients not being offered trials despite being willing to participate ^(12, 13). These data suggest funding mechanisms could be aimed at increasing patient awareness and participation in trials, and that referral to an academic centre and/or a bladder cancer specialist involved in clinical trials should be discussed with each patient to improve access. In addition, patient organisations can guide patients to suitable clinical trials.

06.

Improve access to information and support from initial diagnosis onwards:

Almost all respondents needed more information throughout their bladder cancer journey, especially on prognosis, treatment options and side effects. Women and younger respondents were least likely to receive the information that they needed, suggesting the importance of prioritising resources and information towards these patient populations. Supportive services were lacking across diverse areas, such as diet and nutrition, exercise and activity, sexual function, sleep problems, alternative and complementary therapies, self-esteem and self-image, stoma care, bowel function, financial and employment issues, and smoking cessation.



07.

Improve awareness of and access to patient support groups:

Patient organisations play a crucial role in supporting patients, representing their views and experiences, and advocating for better care. Our survey found that nearly three quarters of respondents did not receive information about peer-support groups and charities. Moreover, the presence and availability of patient-support groups should be expanded to all countries, especially low-income countries, to ensure patients have somewhere to turn for local support when they are diagnosed with bladder cancer.



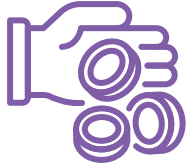
08.

Improve access to emotional support services for patients and carers:



Emotional support should be offered to patients and carers, from initial diagnosis onwards. Over half of respondents were unable to get support for anxiety, depression, and stress despite needing it. Over half of respondents were not offered emotional support to help them cope with their diagnosis, and nearly a third of respondents did not receive enough emotional support throughout their treatment and care experience. This was most prominent in young respondents (under 55).

09.



Offer greater financial protection to patients (especially those under 55) and carers to avoid severe financial toxicity:

10% of respondents were severely impacted in their financial situation, and this was twice as likely for younger people (under 55). Additionally, younger people were also more likely to be temporarily off work. Bladder cancer patients and carers in all countries should be provided with the right to paid time off work, to attend appointments and receive treatment for their bladder cancer.

10.

Better recognise the carer role and offer support to bladder cancer carers:

Carers often get little support or recognition for the work that they do but are essential for improving patient outcomes. They take on diverse and time-consuming roles – and as a result, many put the health of the person they are caring for above their own. There is an urgent need for increased support for carers globally, including providing information on how to care for someone with bladder cancer (especially on how to provide emotional support to the patient), offering paid time off work to fulfill caring responsibilities, and providing access to emotional support to navigate complex emotions that arise due to caring for a person/loved one with cancer.





Some respondents indicated they had seen public awareness campaigns in the UK and Canada, helping them to recognise signs and symptoms of bladder cancer, and campaigns like these should be continued and expanded into other countries.

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Email: info@worldbladdercancer.org
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**World Bladder Cancer
Patient Coalition**

Square de Meeûs 38-40
1000 Brussels
Belgium

Reg. Number: 0720.618.047
VAT ID: BE0720.618.047



World Bladder
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