



Patient & Carer Experiences with Bladder Cancer

Findings from a Global Survey

FINAL REPORT

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World Bladder
Cancer Patient
COALITION

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UNITING THE VOICE OF PEOPLE AFFECTED BY BLADDER CANCER

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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.

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CITING THIS REPORT

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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 provide the best possible information and support to patients.

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Foreword

A MESSAGE FROM DR ASHISH KAMAT AND DR LYDIA MAKAROFF

Publishing this report is an exciting milestone for us. This multi-year, multi-national, research project was done in collaboration with national bladder cancer patient organisations from around the world. This is a global survey of bladder cancer patients and not only did it seek to hear from patients but is also, to our knowledge, the first survey to seek input from carers about their experiences supporting a loved one with bladder cancer.

The World Bladder Cancer Patient Coalition was founded in 2019 based on the need for a uniting force to represent people affected by bladder cancer. Bladder cancer is a highly complex and recurrent disease and one of the most challenging, and expensive, to diagnose and treat. Despite an annual global incidence of nearly 600,000 people, much work needs to be done to amplify the voices of patients.

Patient and carer experience data are key to driving care improvements, yet this data is lacking. Where the data exist, it points to low overall awareness of bladder cancer signs and symptoms, common delays in diagnosis and referral, especially for women and younger people, a lack of support to cope with the after-effects of treatment and returning to a 'new normal', and worse patient experiences compared to other common cancers.

Our research found similar trends as detailed previously in the literature. Awareness of the signs and symptoms of bladder cancer prior to diagnosis was low. Young patients and female patients were at most risk for delayed referral to a specialist and definitive bladder cancer diagnosis, with their symptoms commonly being attributed to other causes, including urinary tract infection. Similarly, female patients who underwent radical cystectomy for treatment of their bladder cancer were three times less likely to be counselled on the sexual side effects of surgery. These factors contributed to female patients being less satisfied with the support and information they received throughout their treatment and care, compared to male patients.

The overwhelming majority of patients (95%) received support from family and friends, exhibiting the crucial role of carers in the bladder cancer patient journey. However, the carers surveyed lacked sufficient information and support and found emotional support the most challenging to provide patients.

We hope these findings serve as a tool to improve bladder cancer care experience. By providing a holistic view of patient and carer experiences for the first time – from awareness and diagnosis, through survivorship and coping with life after cancer – we hope this report will serve to move the needle forward on implementing patient-centred care improvements.



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Executive summary

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

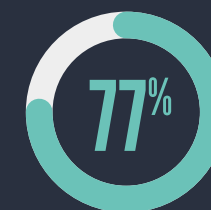
most common cancer and

13th

leading cancer-related cause of death in the world

All stages combined

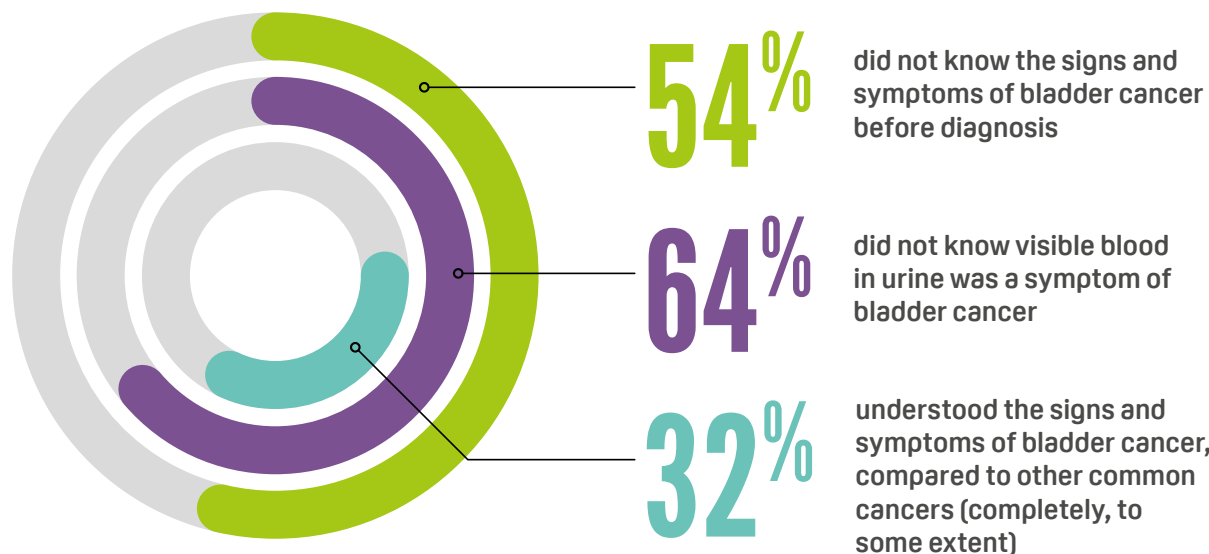
5-year relative survival rate is



“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



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].

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 it was not serious (34%). In their review of the literature, Edmondson et al found that patients often described haematuria as deceptive due to its

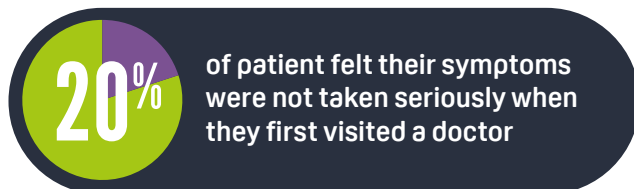


67% had visible blood in their urine as a symptom

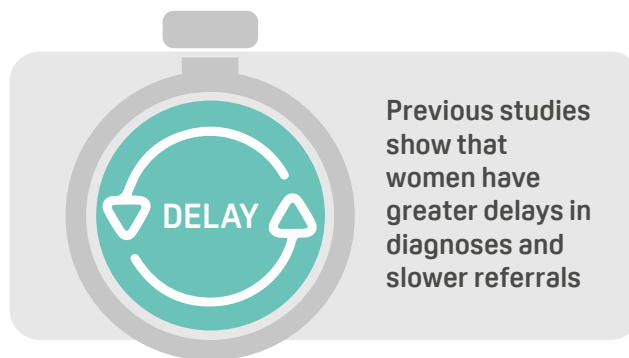
painless and inconsistent nature leading to delays in seeking help [1].



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%).



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%).



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

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



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.

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: 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].

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.

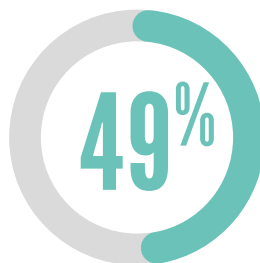
Findings: impact on daily life

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].



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

For some, having bladder cancer did not impact their employment status.

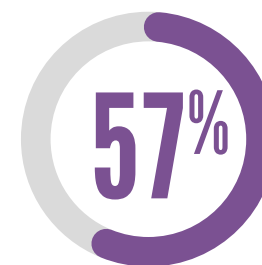
A third of respondents (32%) had no change in their employment status, while another third (31%) were already retired or unemployed.

However, 12% took an early retirement, 10% were temporarily off work, and 3% voluntarily left their job. Younger 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].

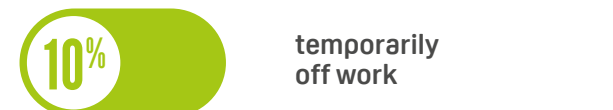
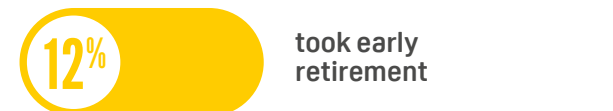
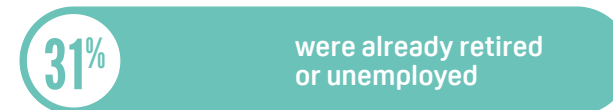
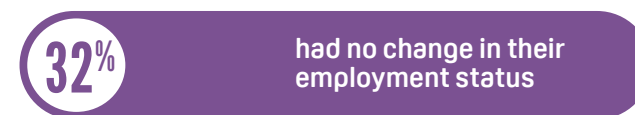
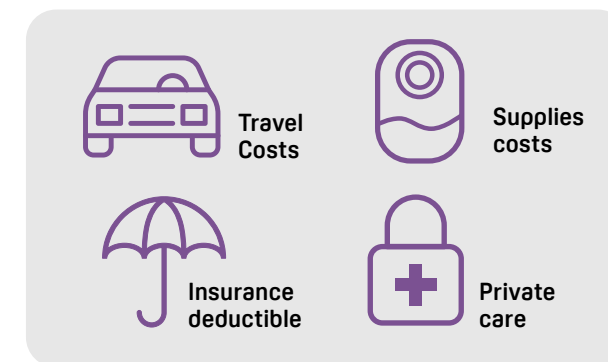


of advanced/metastatic respondents said they were impacted financially.



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

Additional costs





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

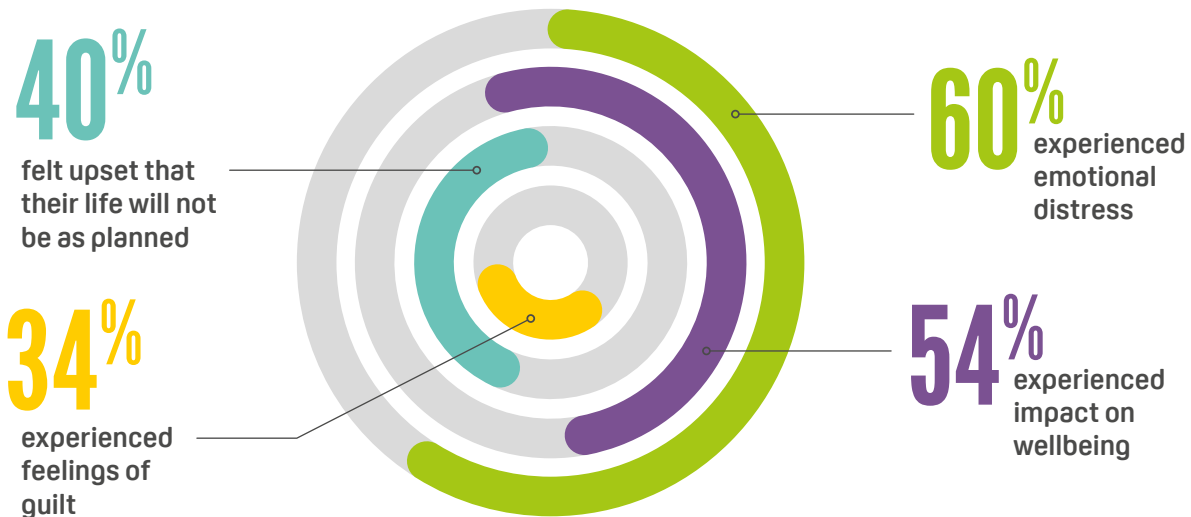
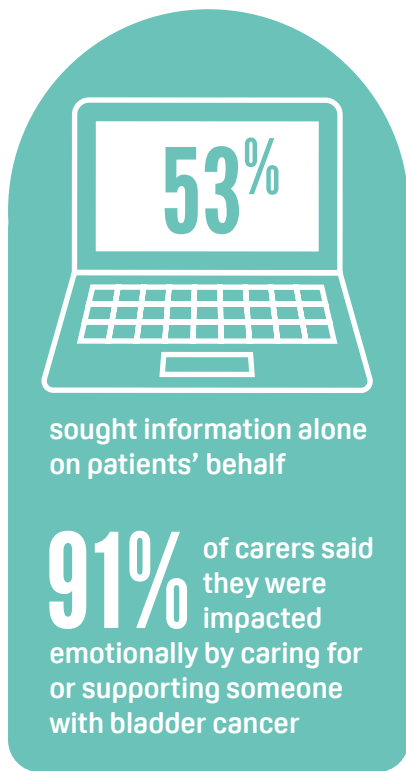
Carers provided care and support to their spouse/partner (64%) or parent (24%), and most had been doing so for more than a year (71%).

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].



Call to action

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].

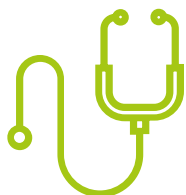
04.

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.



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.

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.

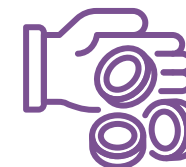
**Improve access to emotional support services for patients and carers:**

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.



01. The
global impact
of bladder
cancer

01. Introduction: The global impact of bladder cancer

The global impact of cancer is significant and increasing [19].

One in every five people will now face a cancer diagnosis before the age of 75, and one in every six people will die from the disease [19]. Cancer accounts for 19.3 million new cases, and almost 10 million deaths worldwide in 2020 [20].

Global cancer control efforts have been varied – with less progress in low- and middle- income countries [19].

For example, in high-income countries, premature deaths from cancer have been reduced by 20% from 2000 to 2015 [19]. In low-income countries, this only decreased by 5% in the same time period [19]. By 2040, it is projected that more than two thirds of the world's cancers will occur in low- and middle- income countries, where patients are diagnosed at a more advanced stage, when treatment is generally less effective, more expensive and disabling [19].

Based on 2020 global statistics, bladder cancer is the tenth most commonly diagnosed cancer and thirteenth leading cancer-related cause of death in the world [3]. It makes up 3% of all new cancer diagnoses (573,278 new cases) and 2.1% of all cancer-related deaths (212,536 deaths) [3, 19]. It is significantly more common in men, representing 75% of all cases – although females tend to be diagnosed later, and have a higher rate of mortality [8, 21]. In the US it is estimated that 90% of patients are older than 55 years old, with the average age at diagnosis of 73 years [22].

Smoking is the most common risk factor for bladder cancer, and incidence patterns tend to reflect this in populations [20, 21]. Tobacco smoking is responsible for nearly 50% of all bladder cancer cases, and 40% of all deaths [20, 21]. Tobacco use is highest among the lowest income communities [23].

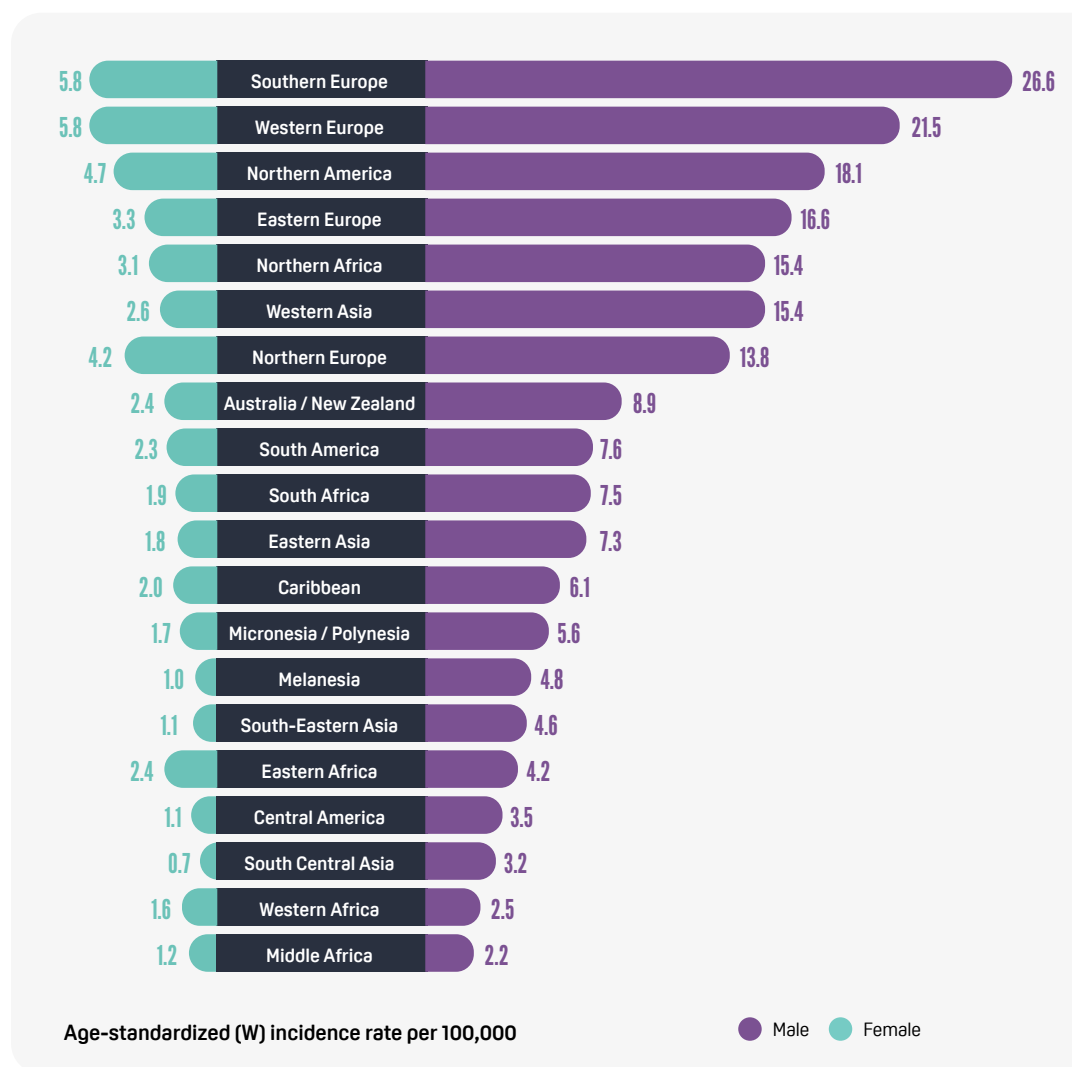
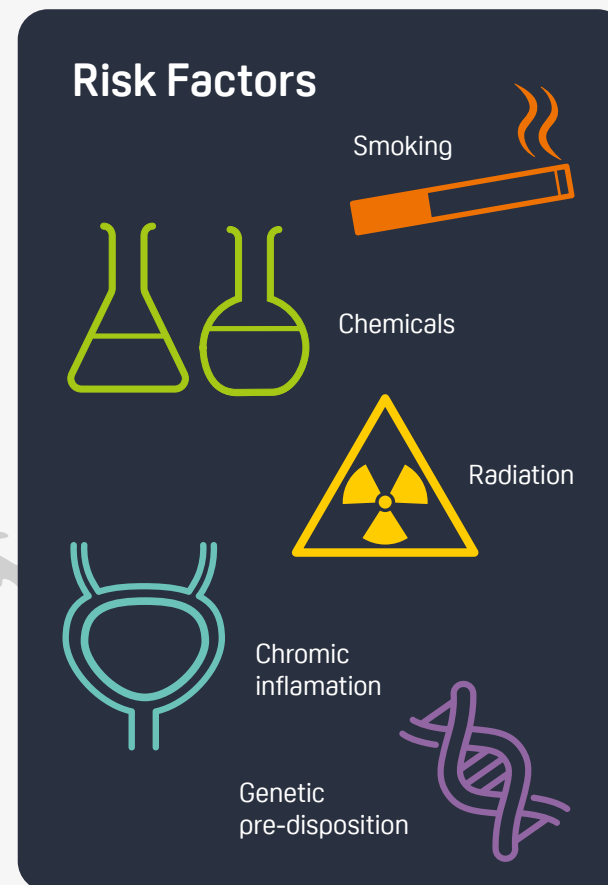


Figure 1. Region-specific bladder cancer rates by sex in 2020, adapted from Sung et al (2020) [20]

The South-East Asia Region is estimated to have the highest average rate of tobacco use compared to all other WHO regions, and the lowest average rates are estimated to be in the African Region [24].

Additionally, infection with schistosomiasis is a risk factor for bladder cancer and remains a public health problem in several parts of the world, particularly in Africa [25].

Other risk factors include occupational exposures to chemicals, and arsenic contamination in drinking water - which are also major causes of bladder cancer in some populations [20]. Past radiation exposure, chronic bladder inflammation and genetic pre-disposition can also increase the risk of bladder cancer [2, 26].



Bladder cancer incidence rates are highest in Southern and Western Europe, and North America (Figure 1, Figure 2) [20].

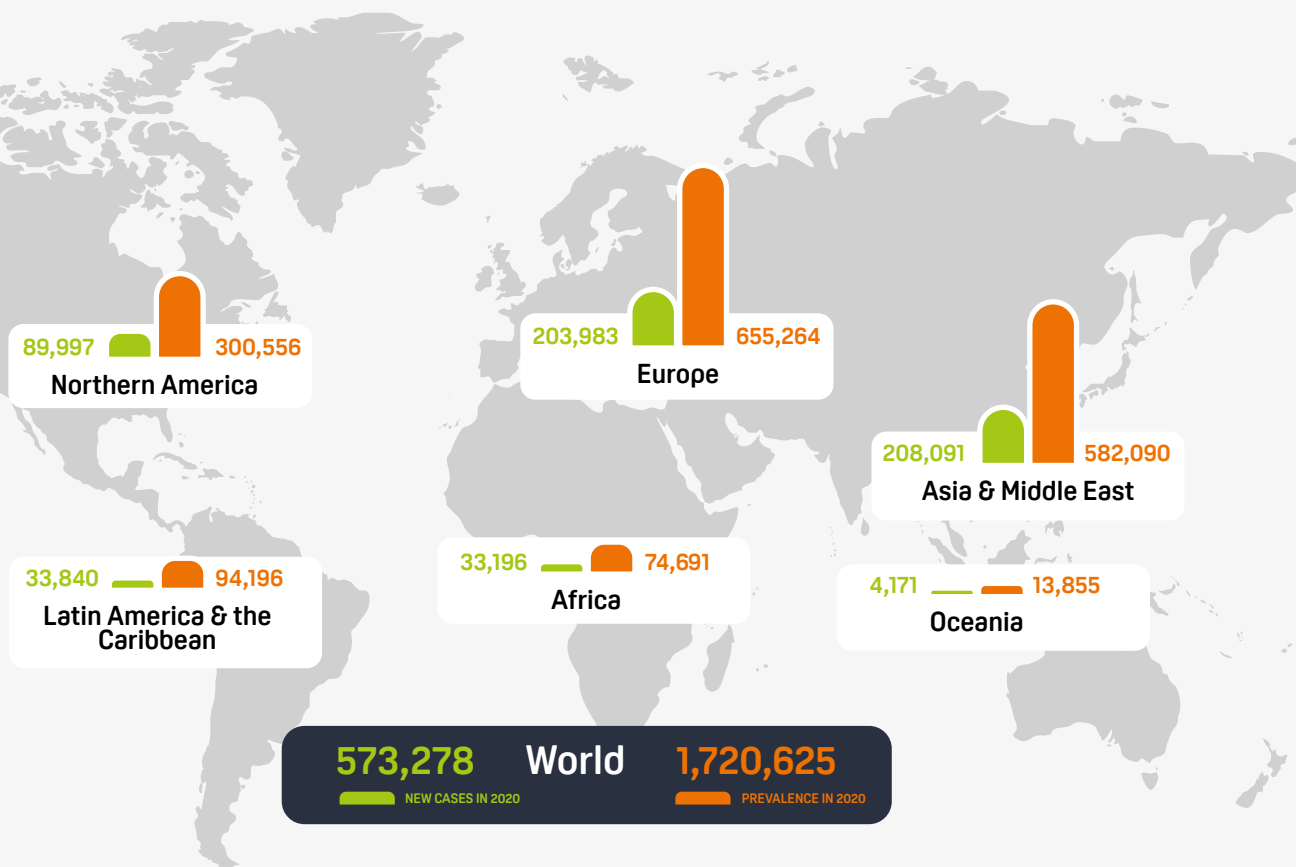


Figure 2. Bladder cancer global statistics – incidence and prevalence in 2020, by world region ⁽³⁾

There are three primary stages of bladder cancer. [2]

01. Non-muscle invasive bladder cancer, which has not invaded the bladder muscle wall.

02. Locally invasive bladder cancer, which has invaded the bladder muscle wall and/or spread to nearby organs or lymph nodes.

03. Metastatic bladder cancer, that has spread to another part of the body.

Non-muscle-invasive bladder cancer represents 75% of all cases and has a more favourable prognosis, however, 50–70% of these cases will recur and 10–30% will progress to an advanced disease at 5 years [27, 28].

Mortality rates have been declining in most developed settings due to improvements in treatment [20], but bladder cancer still has a high rate of recurrence, long and invasive surveillance and expensive treatments [5, 27].

Few studies detail the lived experience of patients and carers [1, 2]. The evidence that does exist, points to bladder cancer patients experiencing a lower quality of life compared with other common cancers [5, 7].

General public awareness of bladder cancer is low – many do not know about bladder cancer until they are diagnosed for the first time, and there is poor awareness of common symptoms [2, 5]. Diagnosis is often delayed due to the inconsistent nature of symptoms and poor awareness [1].

Treatment can have a detrimental effect on the sexual organs of patients and can bring high rates of sexual dysfunction that are typically overlooked and learning to cope with a ‘post-surgery body’ and incontinence can be distressing [1, 6, 7].

Patients lack support in dealing with the long-term implications of bladder cancer. The mental health impact of a bladder cancer diagnosis, long term invasive testing, treatment and sometimes life-changing surgery for bladder cancer patients and their families is significant [5]. Treatments can often limit a persons’ ability to work, creating financial toxicity – especially among younger patients [7].

“To our knowledge, this is the first survey of its kind and scope – representing the views of 1,198 bladder cancer patients, from 45 countries.”

Key Points



Few studies detail the lived experience of affected patients and carers.

General public awareness of bladder cancer is low.



Treatment can bring high rates of sexual dysfunction.

Resulting incontinence can be distressing.



Mental health impact significant.

Treatments can create financial toxicity.



Often, people lack appropriate support to cope with the impact of this condition [6]. Bladder cancer patients report higher rates of depression, and have a greater risk of suicide, compared with other cancer types [5].



02. Respondent characteristics

02. Respondent characteristics

The survey had two parts – a patient survey and a carer survey. We received 1198 total responses to the patient survey, and 67 total responses to the carer survey.

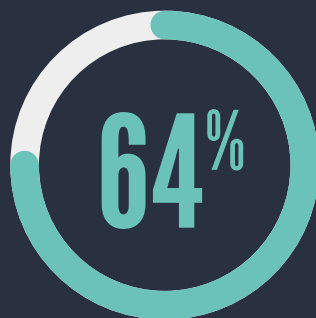


1,198
Survey responses



67
Responses to carer survey

The most common initial diagnosis was non-muscle invasive bladder cancer



4%

progressed from non-muscle invasive to muscle invasive

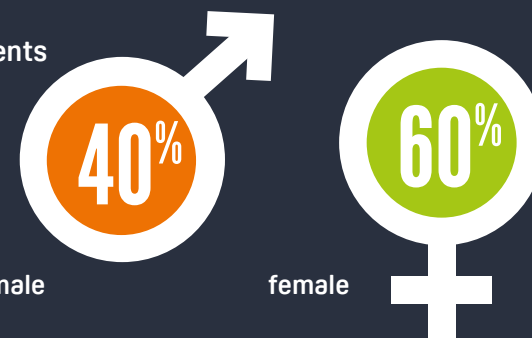
2%

progressed from non-muscle invasive to advanced / metastatic

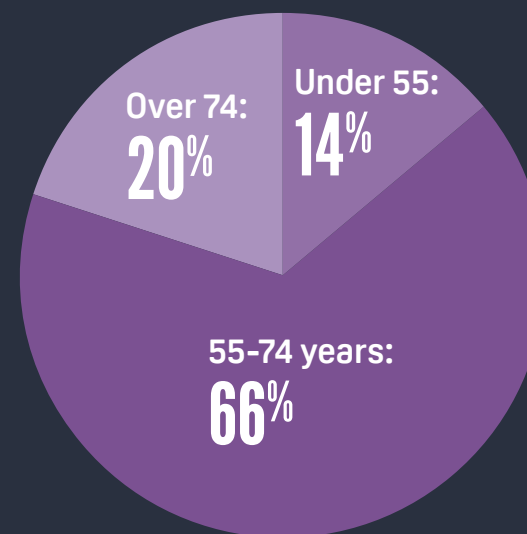
“Most respondents were diagnosed in the last five years.”



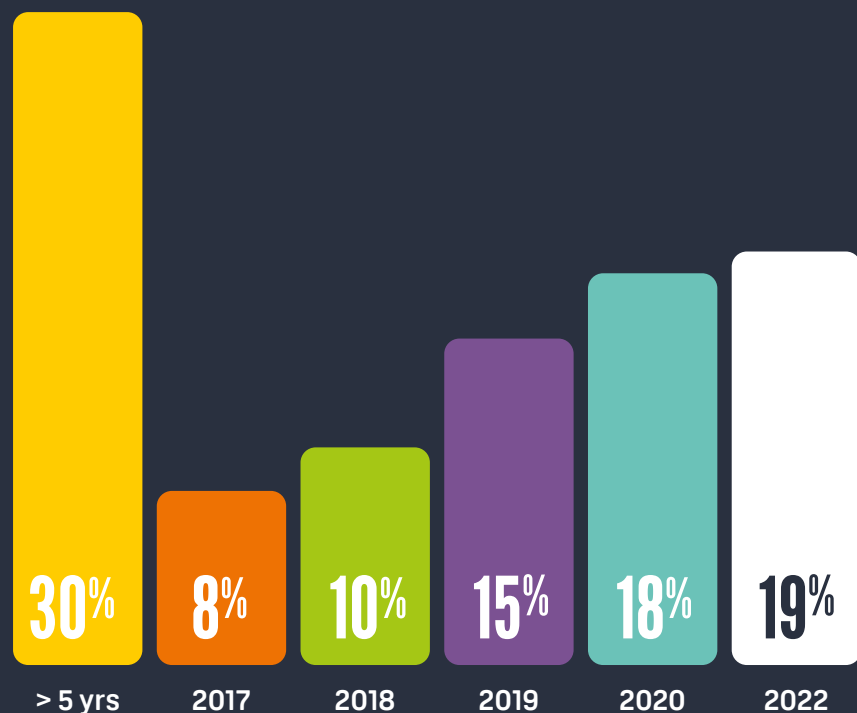
Respondents were



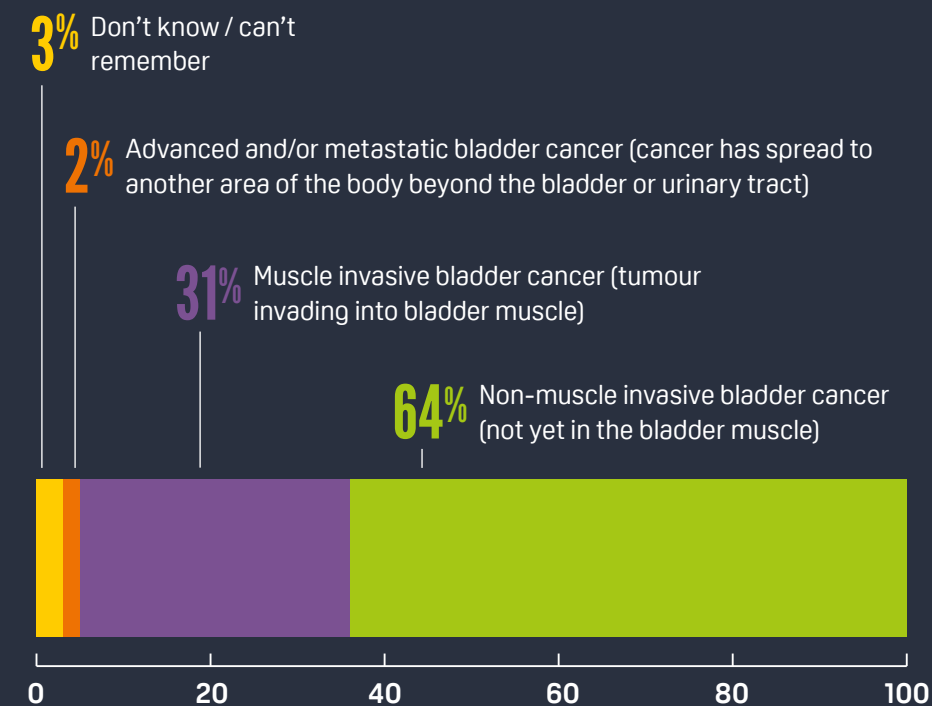
Most respondents were over the age of 55 years



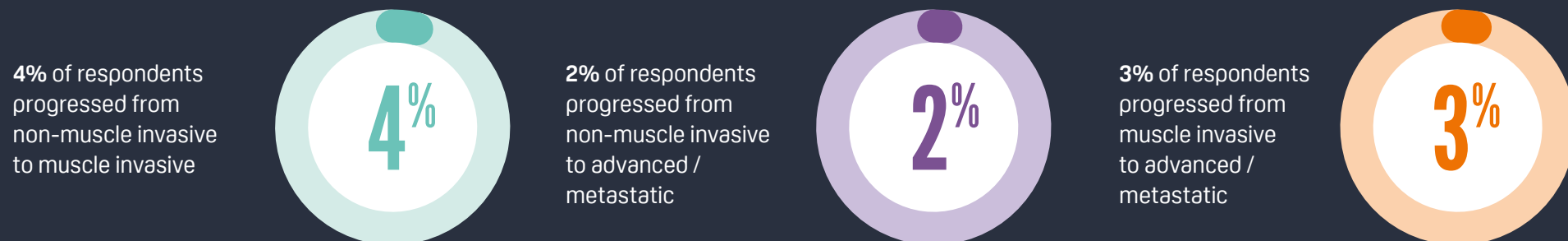
Most respondents were diagnosed in the last five years:



The most common initial diagnosis was non-muscle invasive bladder cancer:



The most common initial diagnosis was non-muscle invasive bladder cancer:



Respondents came from a total of 45 countries



Breakdown of respondents by country %, (n)

20% United Kingdom (227)

13% United States of America (150)

10% Australia (112)

9% France (103)
Italy (106)
Norway (103)

7% Canada (1)

3% Argentina (29)
Poland (34)

2% Chile (21)
Ireland (24)
Japan (24)
Spain (22)

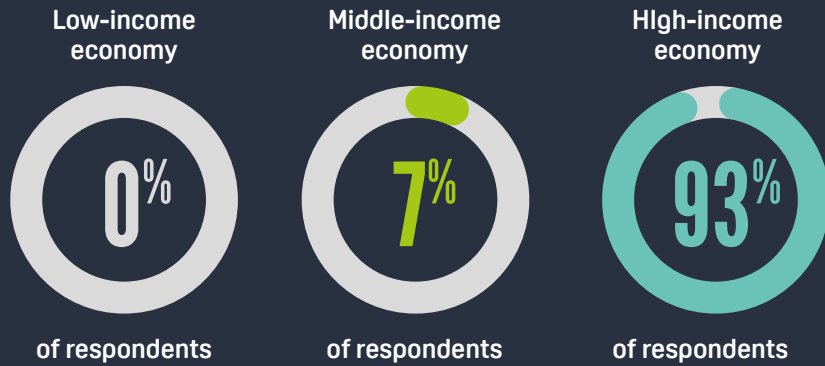
1% Belgium (9)
Finland (7)
Mexico (6)
New Zealand (10)
Pakistan (1)
Sweden (7)
Tunisia (8)
Venezuela (8)

<1%

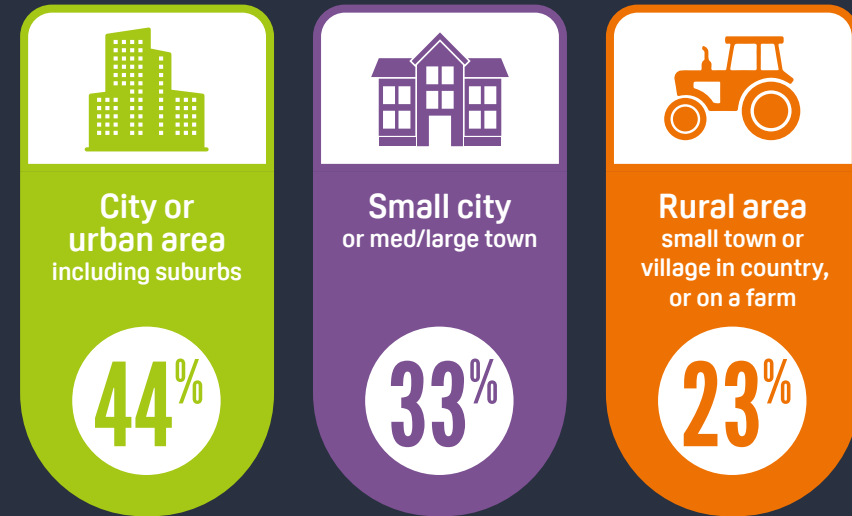
Algeria (4)	Greece (3)	Peru (3)
Bahamas (1)	India (4)	Portugal (1)
Colombia (4)	Iraq (1)	Russia (4)
Cyprus (1)	Israel (3)	Senegal (2)
Denmark (1)	Jordan (1)	Slovenia (1)
Ecuador (3)	Kuwait (1)	Switzerland (3)
Georgia (1)	Lebanon (1)	Turkey (2)
Germany (1)	Netherlands (4)	UAE (4)

Almost all respondents lived in high-income economies

Percentage of respondents by per capita Gross National Income (GNI) ¹



The percentage of respondents by geographic area was:



Most respondents lived in the European Region or Region of the Americas

Percentage of respondents by World Health Organization world region

World Region	Respondents (%)
The Africa Region (AFRO)	1%
The Region of the Americas (AMRO)	27%
The Western Pacific Region (WPRO)	13%
The European Region (EURO)	58%
The South-East Asia Region (SEARO)	0%
Eastern Mediterranean Region (EMRO)	1%



The survey was available in 11 languages.

Number of survey responses per language:

Language	Percentage (%)
Arabic	1%
English	54%
French	12%
Hindi	<1%
Italian	10%
Japanese	2%
Norwegian	8%
Polish	3%
Portuguese	<1%
Russian	<1%
Spanish	9%

¹ Low-income is defined as those with a GNI per capita of USD 1,045 or less; Lower middle-income is between USD 1,046 and USD 4,095; upper middle-income between USD 4,096 and USD 12,695; and high-income is USD 12,696 or more (2020 figures) (Definitions from <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups>)



RADICAL CYSTECTOMY

This section was completed only by respondents that had a radical cystectomy. This represents 27% of the respondents in this chapter. When referring to respondents who had a radical cystectomy (CRS).

Most radical cystectomies were performed for muscle-invasive bladder cancer

70% of radical cystectomies were performed for muscle-invasive bladder cancer. It was less common for people with non-muscle invasive (24%) and advanced and/or metastatic bladder cancer (5%) to have a radical cystectomy.

Respondents with a delayed diagnosis were more likely to have a radical cystectomy

The longer it took to be diagnosed, the more likely it was for respondents to go on to have a radical cystectomy. People diagnosed in more than 6-months were most likely to have radical cystectomy (26%), compared to 3-6 months (23%), and under 3-months (26%).

Radical cystectomy was often the only treatment option presented

Nearly three quarters (74%) of people who had a radical cystectomy said that no other treatment options were discussed with them to retain their bladder (Figure 16). Despite this, most respondents still felt that enough consideration was given to other treatment options that would allow them to keep their bladder (Figure 17).

Figure 16. Did your surgeon discuss with you any of the following options to retain your bladder?

Response options

- No, only radical cystectomy (removal of entire bladder) was discussed
- Yes, Continued bladder instillation of chemotherapy or immunotherapy
- Yes, Radiation therapy (with / without chemotherapy)
- Yes, Partial cystectomy (i.e. surgical excision of just the tumor)
- Yes, Other

Response Option	Percentage
No, only radical cystectomy (removal of entire bladder) was discussed	74%
Yes, Continued bladder instillation of chemotherapy or immunotherapy	12%
Yes, Radiation therapy (with / without chemotherapy)	4%
Yes, Partial cystectomy (i.e. surgical excision of just the tumor)	4%
Yes, Other	4%

Figure 17. If you had radical cystectomy (removal of your bladder) do you feel treatment options that would allow you to keep your bladder?

Response options

- Yes, definitely
- Yes, to some extent
- No
- This was not discussed with me

Response Option	Percentage
Yes, definitely	53%
Yes, to some extent	33%
No	11%
This was not discussed with me	22%

03. Results

3.1 Findings: Awareness and diagnosis

PATHWAY TO DIAGNOSIS

Nearly all respondents had noticeable signs and symptoms of bladder cancer

91% of survey respondents experienced signs and symptoms of bladder cancer (one or more). They were: ²

- Visible blood in the urine: 67% of respondents
- Needing to urinate more often than usual: 40% of respondents
- Needing to urinate right away even when the bladder isn't full: 28% of respondents
- Having to get up several times during the night to urinate: 27% of respondents
- Pain or burning during urination: 24% of respondents
- Feeling tired or weak: 16% of respondents
- Having trouble urinating or having a weak urine stream: 15% of respondents
- Lower back pain on one side: 13% of respondents
- Being unable to urinate: 6% of respondents
- Loss of appetite and weight loss: 5% of respondents
- Swelling in the feet: 4% of respondents
- Bone pain: 3% of respondents
- Other: 4% of respondents

It is typical for bladder cancer patients to experience visible haematuria (i.e., blood in urine) and altered urination patterns (urgency, frequency, and dysuria) prior to diagnosis [1, 2, 27].

The initial signs and symptoms of bladder cancer in females and males were (Figure 3): ³

Male Respondents	Female Respondents
71% had visible blood in urine	65% had visible blood in urine
37% had to urinate more often than usual	45% had to urinate more often than usual
24% needing to urinate right away even when the bladder isn't full'	34% needing to urinate right away even when the bladder isn't full'
26% had to get up to urinate many times during the night	30% had to get up to urinate many times during the night
21% pain or burning during urination	28% pain or burning during urination

Figure 3. Most common signs and symptoms of bladder cancer by sex

Younger respondents had several noticeable differences (Figure 4):⁴

	Under 55 years	55-74 years	Over 74 years
Pain or burning during urination	39%	23%	20%
Needing to urinate right away even when the bladder isn't full	36%	27%	26%
Lower back pain on one side	24%	12%	9%
Feeling tired or weak	22%	17%	9%

Figure 4. Initial signs and symptoms of bladder cancer found more frequent among younger respondents

^{2, 3, 4} This was a 'tick all that apply' question

A third of respondents (33%) did not have visible blood in their urine before diagnosis.

In some cases, respondents had microscopic haematuria, which is only detectable by testing.

Respondents without noticeable signs and symptoms (9%) were diagnosed during an annual check-up with a doctor, or during testing for another condition (e.g., prostate issues, kidney, liver, etc.).

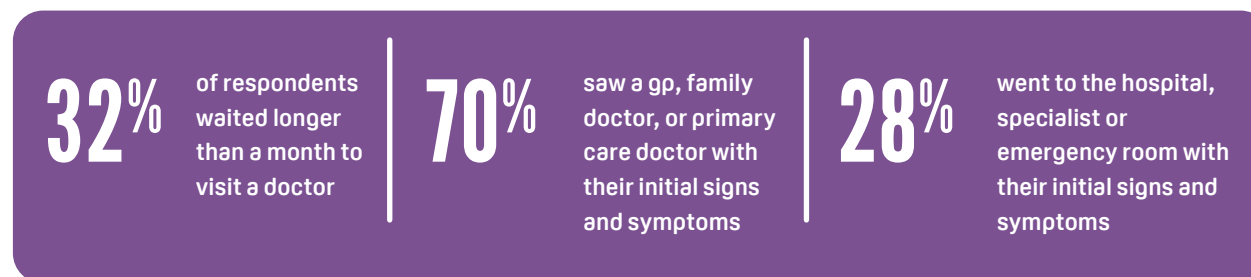
"Microscopic blood was detected in my urine during my regular blood work and urinalysis that I do quite regularly due to heart medication."

"I had no symptoms of bladder cancer. Luckily, I provided a urine sample as part of my annual physical with my GP and my doctor detected haematuria."

"I never had any symptoms of bladder cancer, but luckily at my yearly blood test my GP saw that the PSA reading had gone up and asked me to have an ultrasound on my prostate. The scan showed no problems with my prostate but found a 'mass' in my bladder."

⁵ Respondents who indicated they did not have any signs and symptoms of bladder cancer were removed from the base size for this question. This was 160 people, or 14% of total respondents.

Visiting a doctor with initial signs and symptoms



While most respondents visited their doctor immediately, or within a month after noticing signs and symptoms of bladder cancer, nearly a third (32%) waited longer than a month (Figure 5)⁵. Respondents usually saw a general practitioner, family doctor, or primary care doctor (70%), or went straight to the hospital, specialist, or emergency room (28%) with their concerns.

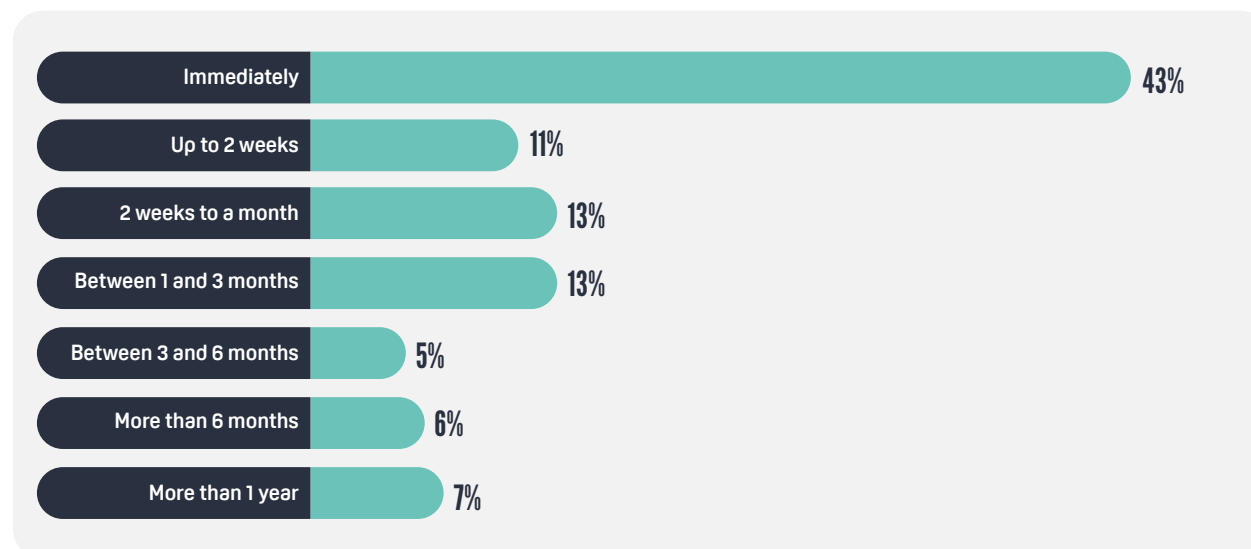
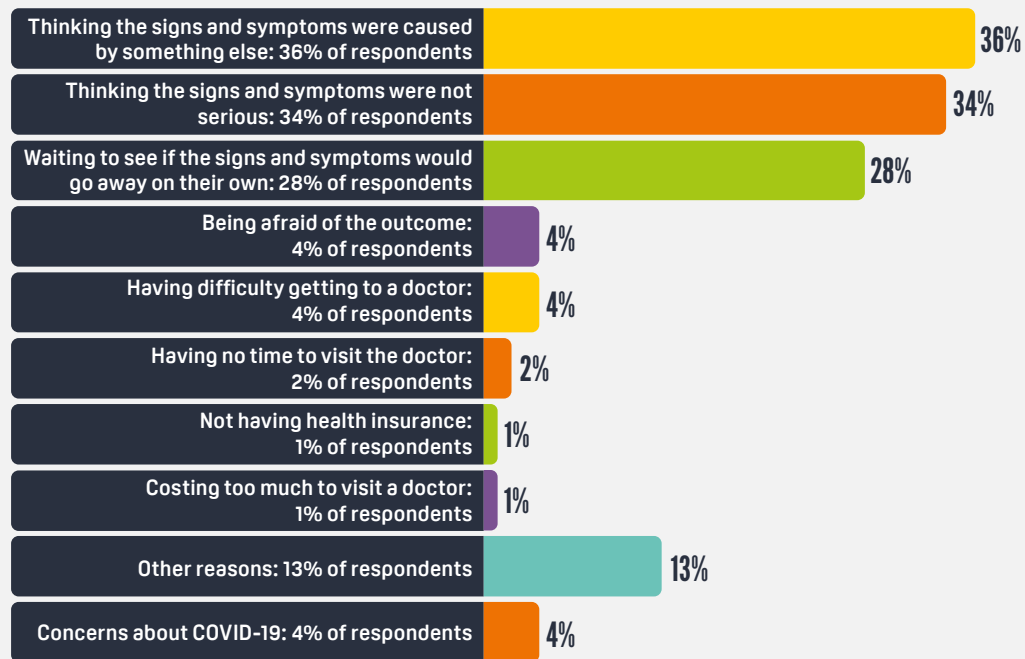


Figure 5. How long after you noticed any signs and symptoms of bladder cancer for the first time did you seek medical attention?

The inconsistent nature of symptoms, lack of pain, and poor understanding about bladder cancer can contribute to delays in seeking help and delays to an eventual diagnosis [1]. Haematuria, a key symptom, can be deceptive due to its painless and inconsistent nature [1].

Delays in visiting a doctor about signs and symptoms were due to: ⁶



Younger respondents (under 55 years) were far more likely to delay visiting a doctor because they thought the signs and symptoms were caused by something else (49%) or they were waiting to see if they would go away on their own (39%).

Most respondents visited a doctor once or twice, before being referred to a specialist

Most respondents visited a general practitioner, primary care doctor, or family doctor once (52%) or twice (23%) before being referred to a bladder cancer specialist. Some respondents visited their doctor three or four times (15%).

Patient story: John* (Canada)

I have heard of bladder cancer before, but did not know much about it before I was diagnosed. The only the symptom that I had, and unfortunately I ignored it for several months, was small amounts of red in my urine and I could not figure out why it was happening. My urine had a red tinge to it, but I never thought that it was blood, as it wasn't present all the time. I'm the type of person who doesn't go to the doctor for small problems, so I didn't go to my doctor right away.



When it started to happen more frequently, I decided that it might be time to see a doctor. However, it was months before I actually did because I was hoping that it would go away on its own.

"My diagnosis was all very quick. I experienced sudden haematuria and was diagnosed with bladder cancer within a week."

10% visited a doctor five or more times, before being referred to a bladder cancer specialist. This was highest for young respondents (under 55)(16%), females (18%), and metastatic/advanced cancers (21%).⁷

"My GP told me it was unlikely to be bladder cancer as I was too young. In my 50's at the time. I was the one who insisted on being referred to a urologist."

⁶ This was a 'tick all that apply' question. Respondents who said they 'did not delay seeing a doctor' were removed from the base size for this question. This was 669 people or 56% of total respondents. ⁷ Only 2% of total survey respondents were originally diagnosed with metastatic and/or advanced cancer therefore the sample size is limited for this population (n=28 people).



One in five respondents felt their symptoms were not taken seriously

A fifth (20%) of respondents felt their symptoms were not taken seriously when they first visited a doctor. 65% said their symptoms were definitely taken seriously, and a 15% said that their symptoms were taken seriously, to some extent.

Females (31%), younger respondents (33%), and respondents with metastatic/advanced cancer (31%) were more likely to say their symptoms were not taken seriously.⁸

“My long time GP never took my complaints about frequent peeing seriously, telling me to cut down on the amount of coffee I drank. I got a new GP and the first time I saw him he did a urine test and sent me for testing immediately.”

Previous studies have indicated that symptoms of bladder cancer can be trivialised and misdiagnosed for another condition. Women especially tend to have greater delays in diagnosis, and slower referral for blood in urine possibly due to higher rates of urinary tract infections or because bladder cancer occurs less frequently in women [1, 2].

Over half of respondents were diagnosed with another condition first, before bladder cancer

It is common for bladder cancer patients to be diagnosed with another condition first [2]. A previous global survey of bladder cancer patients found that this occurred for up to 75% of patients, leading to delays in treatment and worsening prognosis [2].

Young respondents (under 55) (66%) and females (69%) were most likely to be diagnosed with another condition first, before bladder cancer. Moreover, females were over twice as likely to be first diagnosed with a UTI (39%), compared to male respondents (21%).

“I am a woman and non-smoker. I had visible blood in my urine for 6 months. My GP prescribed me 4-5 rounds of antibiotic treatments for urinary infection before sending me for bladder cancer testing.”



⁸ Only 2% of total survey respondents were originally diagnosed with metastatic and/or advanced cancer therefore the sample size is limited for this population (n=28 people).

In our survey, over half (57%) of respondents were diagnosed with another condition before bladder cancer – the most common being a urinary tract infection (28%) (Figure 6).⁹

No, only bladder cancer



Yes – urinary tract infection



Yes – cystitis



Yes – overactive / underactive bladder



Yes – kidney or bladder stone



Yes – prostate problem



Yes – gynaecological problem



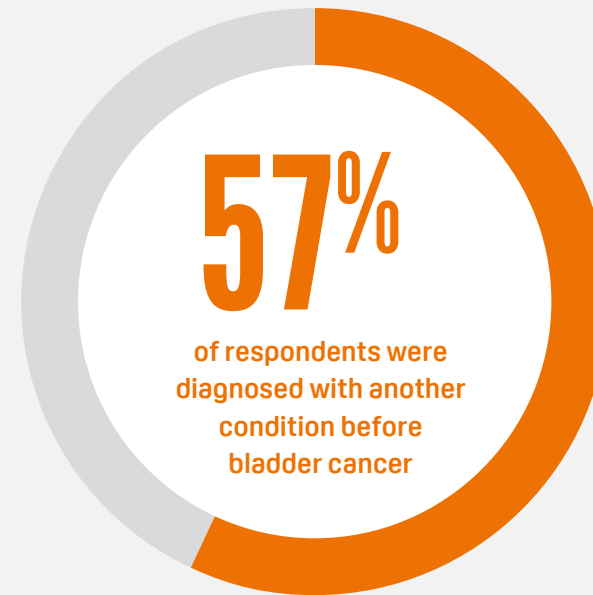
Yes – another cancer



Yes – other



Don't know / can't remember



● Male ● Female ● Under 55 ● All survey

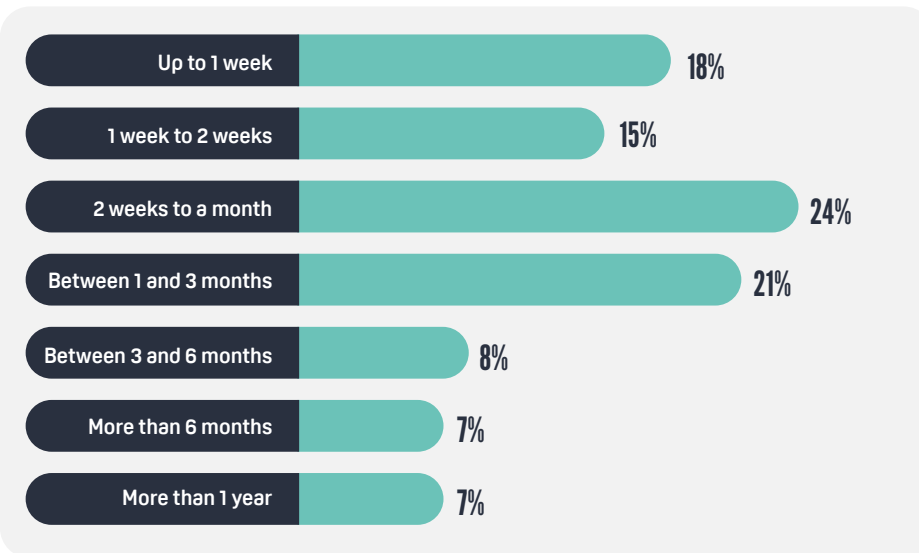
Figure 6. Responses to the question: “Were you diagnosed with another condition before you were diagnosed with bladder cancer?”

⁹ This was a ‘tick all that apply’ question.

A bladder cancer diagnosis was usually given within 3 months of visiting a doctor

Of those who experienced symptoms, over three quarters (78%) were diagnosed with bladder cancer within 3-months from first seeing a doctor (Figure 7). Many respondents (65%) said the length of time to be diagnosed caused them extra concern or worry.

Figure 7. How long was it between you first seeing a doctor about the signs and symptoms you had, to being diagnosed with bladder cancer?



Females, younger respondents, and respondents with metastatic/advanced cancer had a longer time to diagnosis:

- 70% of females were diagnosed within 3-months of first seeing a doctor about the signs and symptoms experienced, compared to 83% of males.
- 66% of respondents under 55 years were diagnosed within 3-months of first seeing a doctor about the signs and symptoms experienced, compared to 79% in respondents 55-74 years and 81% in respondents 74 years or older.

- 62% of respondents with metastatic/advanced bladder cancer were diagnosed within 3-months of first seeing a doctor about the signs and symptoms experienced, compared to 77% for muscle invasive and 78% for non-muscle invasive respondents.

BREAKING BAD NEWS: COMMUNICATING A DIAGNOSIS

Most respondents were diagnosed in a face-to-face meeting with a doctor

Most respondents (64%) were told that they had bladder cancer for the first time in a face-to-face meeting with a doctor. In other cases, this was during a medical procedure (21%), over the phone (9%), in the hallway (1%) or in another way (5%). Some respondents learned they had bladder cancer for the first time when reading their test results on their electronic medical records or medical charts.

"I learned that I had bladder cancer for the first time when I read the doctor's note online after a cystoscopy – did not tell me in person."

Most respondents (66%) said that they 'completely understood' their diagnosis when it was communicated to them. Fewer respondents said that they only understood 'some of it' (28%) and some said that they understood 'none of it' (6%).

"I was diagnosed with a low grade, non-aggressive bladder cancer. In the appointment with my specialist, I had so many questions that I wanted to ask, but I felt hurried, like I was at the bottom of the diagnostic pile..."

More than half of respondents (57%) were not told they could bring friends or family to their diagnosis appointment for support – however, it is likely that COVID-19 negatively impacted this result due to hospital restrictions.

Patient story: Joyce* (United Kingdom)

I was in bed, and planning to meet with some friends for lunch, when the phone rang and a nurse I had never spoke to before said “we’ve got your results”. It was obvious to me that she was reading from a script. She never said the word cancer, instead she said “you have got a high-grade aggressive tumour” I asked her “Are we talking cancer?”, and she still wouldn’t say it outright to me. The conversation finished with “If you don’t hear anything from us, give us a call.” And that was it. I was absolutely devastated.

I was very upset with how I found out. I was home alone, my husband was at work and I was in absolute shock. I spoke to a colleague who recommended that I go to Maggie’s for support. I quickly went there, and they were absolutely amazing in providing me with the information I needed. If it wasn’t for them, I don’t know how I would have coped.

Years earlier, my husband had also been diagnosed with cancer. His experience was much different. Once he was told he had cancer, he was taken to another room, where he sat down with two nurses who talked us through everything and allowed us to ask questions. They also gave us a contact number. I was dissatisfied with how I found out about having bladder cancer, and think that having the time to sit down and talk to someone about my diagnosis would have made all the difference.



Respondents needed more information about their diagnosis

Nearly a fifth of respondents (16%) said they did not receive all the information they needed about their diagnosis. Females and young respondents (under 55) were the least likely to have their information needs met at diagnosis (Figure 8). Only 13% of respondents did not have access to their test results, if they needed them.¹²



Figure 8. Did you receive all the information you needed about your cancer diagnosis?

	Male	Female	Under 55	All survey
Yes, definitely	51%	38%	38%	46%
Yes, to some extent	37%	41%	41%	38%
No	13%	22%	22%	16%

Currently, pathology report sharing is poor and reactive – patients only receive this if they ask for access. People are more and more pro-active about their health, and these reports need to become more readable for patients to enable them to understand their diagnosis better.

Bladder Cancer Canada (BCC)

¹² Respondents who said, ‘I did not need them’ (55 people, or 5% of total) or ‘don’t know / can’t remember’ (36 people, or 3% of total) were removed from the base size.

PRIOR AWARENESS OF SIGNS AND SYMPTOMS

Prior awareness about the bladder cancer signs and symptoms was low

Previous research shows that awareness of bladder cancer signs and symptoms is low.

A global survey of bladder cancer patients in 2019 found that 55.6% had not heard about bladder cancer prior to their diagnosis [2].

Our survey had similar results. More than half (54%) of respondents did not know any signs and symptoms of bladder cancer before their diagnosis (Figure 9).

Young respondents (under 55) were even less likely to know about the signs and symptoms of bladder cancer, compared to older age groups. 69% of respondents under 55 years said they were not aware of any signs or symptoms of bladder cancer before they were diagnosed. This compared to 56% for 55–74 years, and 42% for over 74 years of age.

"I had no idea of the symptoms before being diagnosed. Now I try and share this knowledge with family and friends to raise awareness."

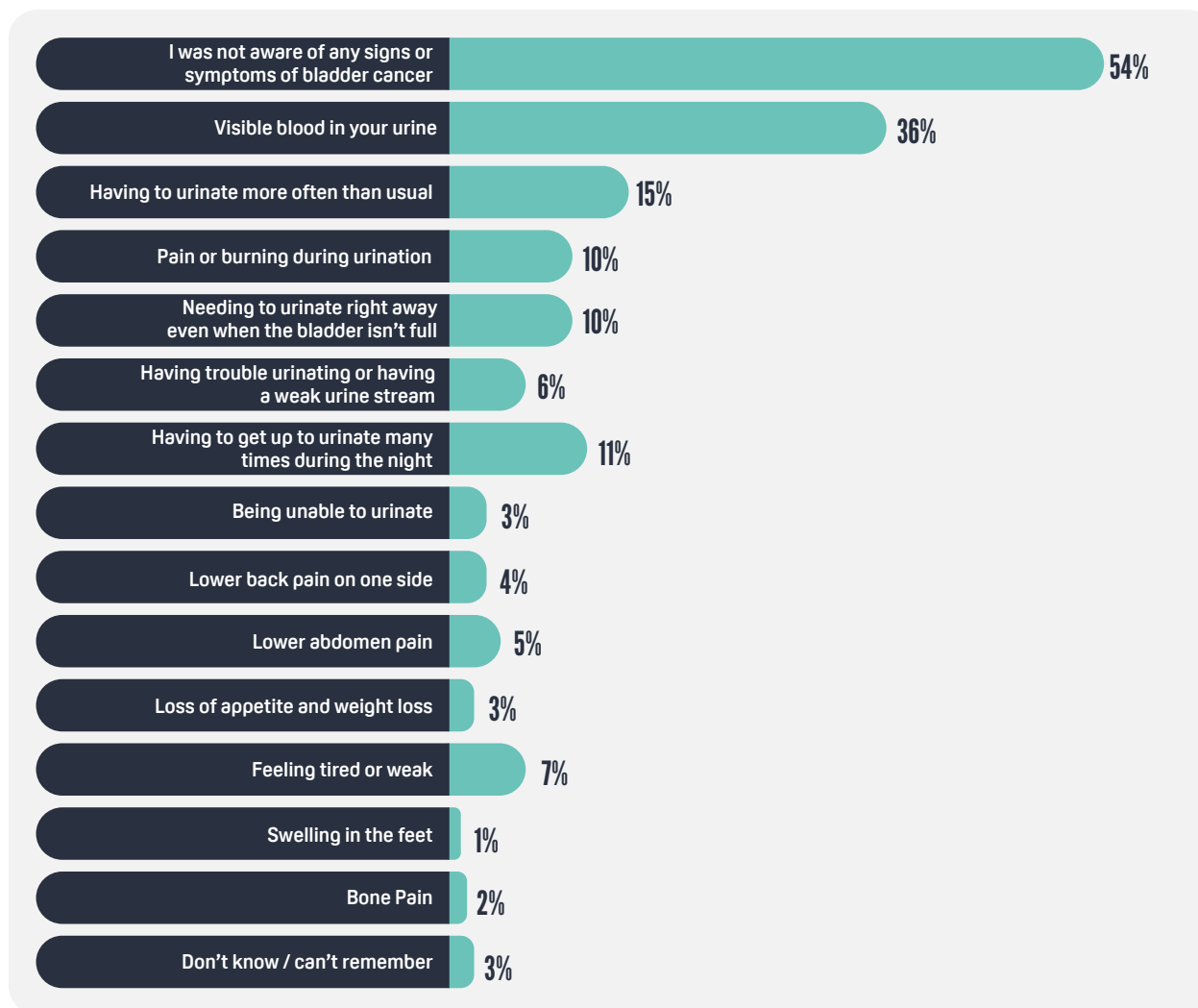


Figure 9. Answer to the question "Before you were diagnosed with bladder cancer, did you know about any signs and symptoms of bladder cancer?"¹³

¹³ This was a 'tick all that apply' question

The respondents who had a prior awareness of bladder cancer (46%) received it from a primary care doctor (30%), a website (24%), friends and family (16%), or other sources (24%).

Others had seen public awareness campaigns on the signs and symptoms of cancer. For example, the NHS campaign in the United Kingdom on “Blood in pee” and a campaign by Bladder Cancer Canada showing a “lemon with blood dripping from it” were mentioned.

“The NHS TV advertising campaign was what alerted me and thus I knew to get checked out with a single episode of blood in my urine preceded by passing a small clot of blood.”

“There was a poster I recall seeing of a lemon dripping blood. It said, “If you see red, see a doctor”.

Compared to other common cancer types, only 32% people understood the signs and symptoms of bladder cancer before diagnosis (completely or to some extent), with 68% of people not recognising the symptoms at all.

“I think more awareness of bladder cancer symptoms is a must, I can honestly say I still don’t recall seeing anything before or after my diagnosis on any format that would make me think I might possibly have bladder cancer, unlike breast, bowel, and prostate which people are made more aware of.”

Patient story: Nick* (Canada)

Years ago, I remember seeing a poster in a food court at the mall. I think it was Bladder Cancer Canada. They had an awareness campaign at that time, and I remember seeing they had a lemon, with red dripping from it. It was telling the public to see a doctor if you have blood in your urine, as this is a sign of bladder cancer. One of the first symptoms I noticed was blood in my urine, which caused me to see a doctor. I would have likely gone anyway, but the memory of the poster definitely prompted me to take it seriously.



The doctor assumed it was bladder infection, so they put me on antibiotics, but the symptoms kept getting worse. I was having more discomfort when I was going to the bathroom, there was still blood in my urine, and I was in persistent pain. I had more tests, and within a few days of my biopsy coming back, I was confirmed to have bladder cancer and started treatment right away.

3.2 Findings: Treatment Access

INITIAL DIAGNOSIS AND TREATMENT OPTIONS

Treatment access among respondents

Once bladder cancer is detected, a staging process will determine the depth of tumour invasion, and grade (e.g. how aggressive the cancer cells look under the microscope) to decide the best treatment course [29]. Initial staging with biopsy and TURBT is often combined with imaging to evaluate possible metastatic disease. Treatment will depend on if the bladder cancer is non-muscle invasive, muscle invasive, or metastatic/advanced.

Among survey respondents, 64% had an initial diagnosis of non-muscle invasive bladder cancer (NMIBC). Treatments for this stage include transurethral resection of bladder tumour (TURBT), followed by single-dose intravesical immunotherapy with BCG, or intravesical chemotherapy in tumours with greater risk of progression [22]. Where available, clinical trials may be considered (e.g., immunotherapy, radiation, etc.). Radical cystectomy can be considered in high-risk cases. Respondents actual treatments for NMIBC were: ¹⁴

- 86% had endoscopic surgery (e.g., cystoscope) or TURBT
- 54% had intravesical therapy (treatment with medication in the bladder) with immunotherapy (e.g., BCG)
- 24% had chemotherapy in bladder (e.g., gemcitabine, mitomycin)
- 12% had radical surgery – a complete removal of the bladder

31% of respondents had an initial diagnosis of muscle-invasive bladder cancer (MIBC). Treatment options for this stage commonly include cystectomy with urinary diversion (a surgery to remove the bladder and lymph node) with or without chemotherapy, or immunotherapy, trimodal therapy (bladder sparing therapy with

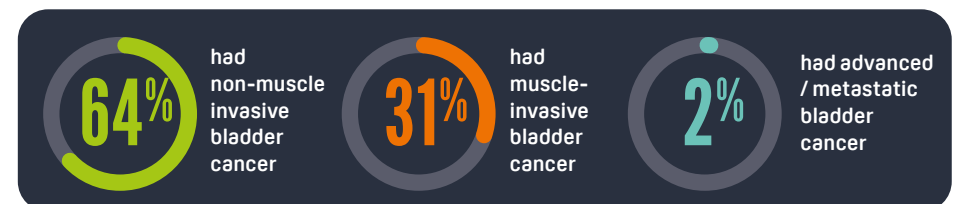
radiation therapy and chemotherapy), or a clinical trial [30]. Bladder preservation is an option in certain patients [22]. Respondents with MIBC had the following treatments: ¹⁵

- 57% had radical surgery – a complete removal of the bladder
- 55% had endoscopic surgery (e.g., cystoscope) or TURBT
- 39% had chemotherapy in vein (e.g., gemcitabine, cisplatin, carboplatin)
- 14% had intravesical therapy (treatment with medication in the bladder) with immunotherapy (e.g., BCG)

2% of respondents had an initial diagnosis of advanced / metastatic bladder cancer. Treatment options are more limited and can include radical cystectomy, radiotherapy, chemotherapy, and/or immuno-oncology therapy, and where available, clinical trials [30]. Chemotherapy is the preferred treatment for patients with metastatic disease or unresectable bladder cancer [22]. Respondents actual treatments for this stage were: ¹⁶

- 50% had endoscopic surgery (e.g., cystoscope) or TURBT
- 46% had chemotherapy in vein (e.g., gemcitabine, cisplatin, carboplatin)
- 43% had radical surgery – a complete removal of the bladder
- 21% had systemic therapy (in vein) other than chemotherapy (such as immunotherapy)

Initial bladder cancer diagnoses for survey respondents



^{14, 15, 16} This was a 'tick all that apply' question

A third of respondents asked for a second opinion and got one

Seeking a second opinion from another specialist is encouraged as it can help a person feel re-assured by allowing the individual to confirm their bladder cancer diagnosis and treatment options [31]. It can also change the stage, grade, or histological subtype – with one study demonstrating it changed in more than a third of cases [32].

Nearly a third (32%) of respondents asked for a second opinion and got one. However, 51% did not want or need a second opinion (Figure 10).

Figure 10. Did you ask for a second opinion from another specialist regarding the diagnosis and treatment for your bladder cancer?

Response options	Respondents (%)
Yes, but I did not get one	4%
Yes, and I did get one	32%
No, but I wanted to/didn't know how to	5%
No, but I did not want or need one	51%
I did not know I could get a second opinion	8%

"I was given a couple of different treatment options – with a recommendation. We chose to get a second opinion, which allowed us to eventually have confidence in the option that we ended up choosing."

Most respondents felt their treatment options were fully explained to them

60% of respondents said treatments were 'completely' explained to them. However, 8% said treatments were not explained, and they would have liked more options (Figure 11).¹⁷

¹⁷ Respondents who indicated that 'only one treatment type was available/suitable to me' were excluded from this question and removed from the base size.

Figure 11. Before your bladder cancer treatment started, were your treatment options explained to you?

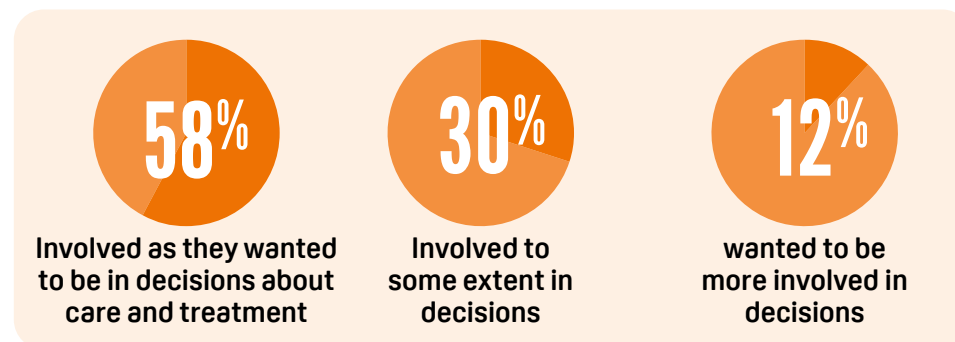
Response options	% Total
Yes, completely	60%
Yes, to some extent	28%
No, and I was satisfied	4%
No and I would have liked more treatment options	8%

"I was just told about what treatment I would be getting, but there was no discussion of any other options that might be available to me."

Metastatic and/or advanced respondents had a much higher rate of satisfaction – with 71% saying their treatment options were 'completely' explained to them, compared to 65% of muscle invasive, and 57% of non-muscle invasive cancers.

"I was diagnosed with a low grade, non-aggressive bladder cancer. In the appointment with my specialist, I had so many questions that I wanted to ask, but I felt hurried, like I was at the bottom of the diagnostic pile ..."

When asked if they were involved as much as they wanted to be in decisions about treatment and care, most respondents answered positively:

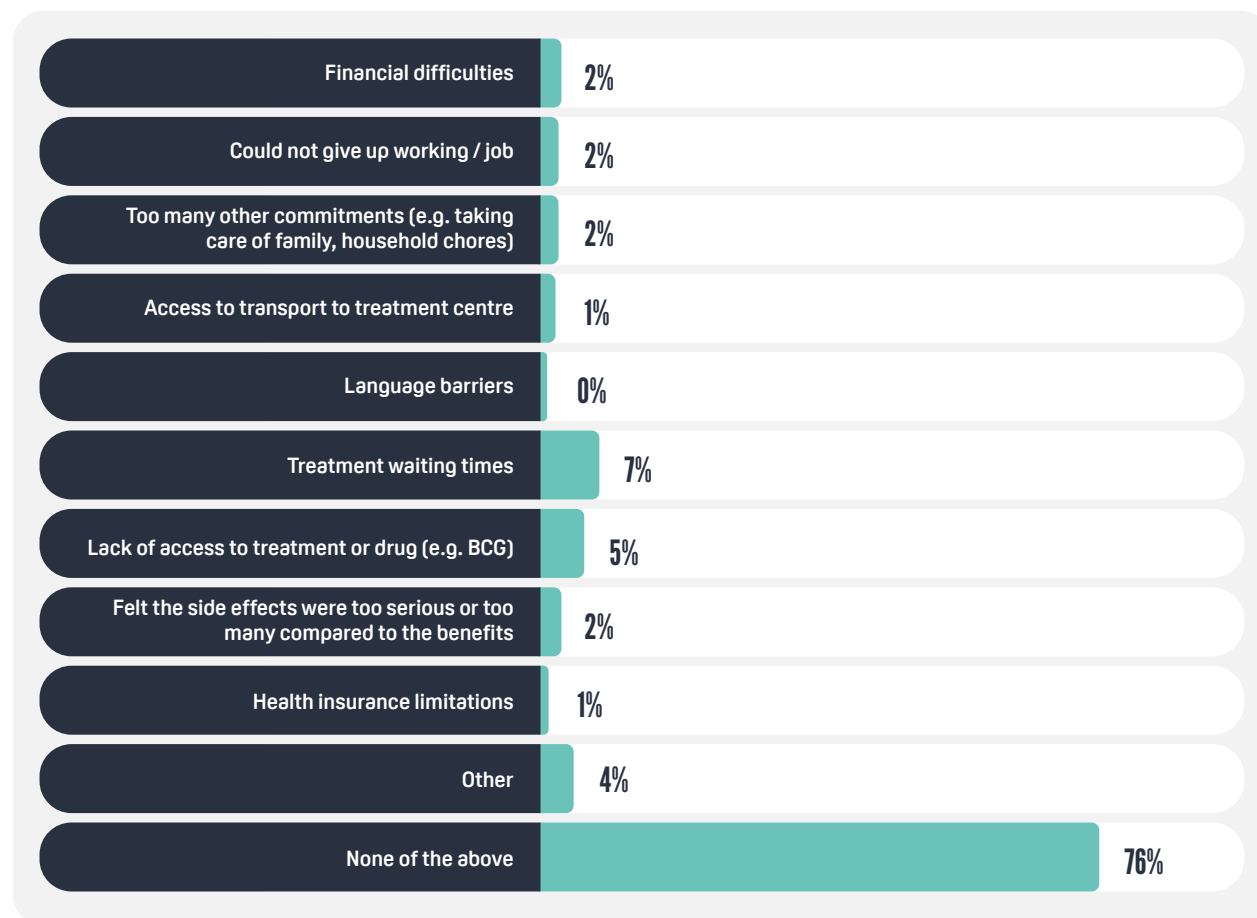


TREATMENT ACCESS

Most respondents did not have barriers to accessing treatment

Most respondents (72%) reported no barriers to accessing treatment. The most frequently reported barriers were waiting times (7%) and a lack of access to treatment or drug (e.g., BCG) (5%) (Figure 12).

Figure 12. Have any of the following stopped you from getting your treatment? ¹⁸



76% of respondents said it was easy to travel to their treatment appointments.

A smaller percentage (10%) found it difficult to travel to their treatment appointments. The remaining 15% of respondents said it was 'neither easy nor difficult'.

Lastly, most respondents did not have issues with delayed or cancelled treatments.

72% of respondents did not experience any delayed or cancelled treatment appointments. The remaining respondents said they had their treatment delayed or cancelled once (17%) or in some cases, more than once (11%).

Of those who had delays or cancellations, 27% said it was because of the COVID-19 pandemic, while 55% said it was not.

The remaining 17% said it was "because of the pandemic and for other reasons" and 1% of respondents did not know or could not remember.

"Choices were always left to me. But all the medical staff gave me pros and cons to each stage of treatment. And helped by making recommendations."

"I felt pressured to decide quickly. Looking back, I would have chosen a different treatment if I was supported more."

¹⁸ This was a 'tick all that apply' question.

Patient story: Omar* (Senegal)

I wasn't really aware of bladder cancer before my diagnosis. I knew about cancer in general, because there are some well-known people who have passed away from of cancer.



I started to realise something was wrong after a few months of pain and blood in my pee. With the help of my relative who I work with, we saw a urologist who specialised in bladder cancer. He asked me to do tests, ultrasounds and scans followed by TURBT, which was very expensive for me, thankfully I had my relative at my side, who gave me both moral and financial support.

I tried to find support groups since BCG treatment doesn't yet exist in Senegal or in West Africa. It was difficult but thankfully we were able to find a clinic in North Africa where I could get BCG treatment (here in Senegal it's only possible to get ablation) and it's really a shame for us Senegalese and West Africans.

The main thing that needs to change is to make it possible to be treated wherever you are located, or to receive support to be able to travel for treatments where it is available.

ACCESS TO CLINICAL TRIALS

Respondents were poorly informed about clinical trials

Bladder cancer research is significantly underfunded compared to other cancer types, with the fewest clinical trials of all common cancers [33].

Most respondents (84%) did not receive any information about participating in clinical trials. 16% received information about clinical trials – and half took part in one (Figure 13). Respondents with advanced and/or metastatic bladder cancer were most likely to take part in a clinical trial. Respondents received information about clinical trials from a variety of sources (Figure 14).

Figure 13. When you were diagnosed, did you receive any information about clinical trials?

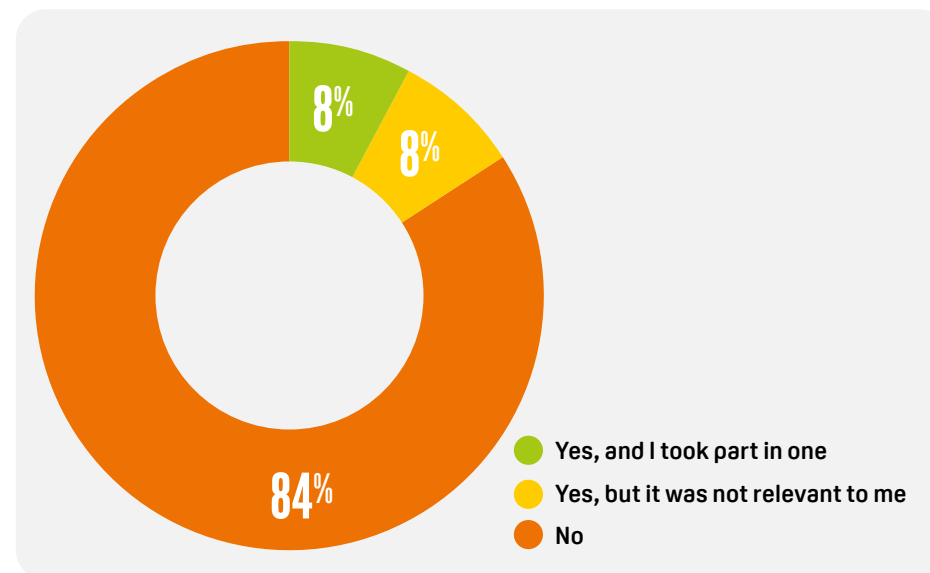
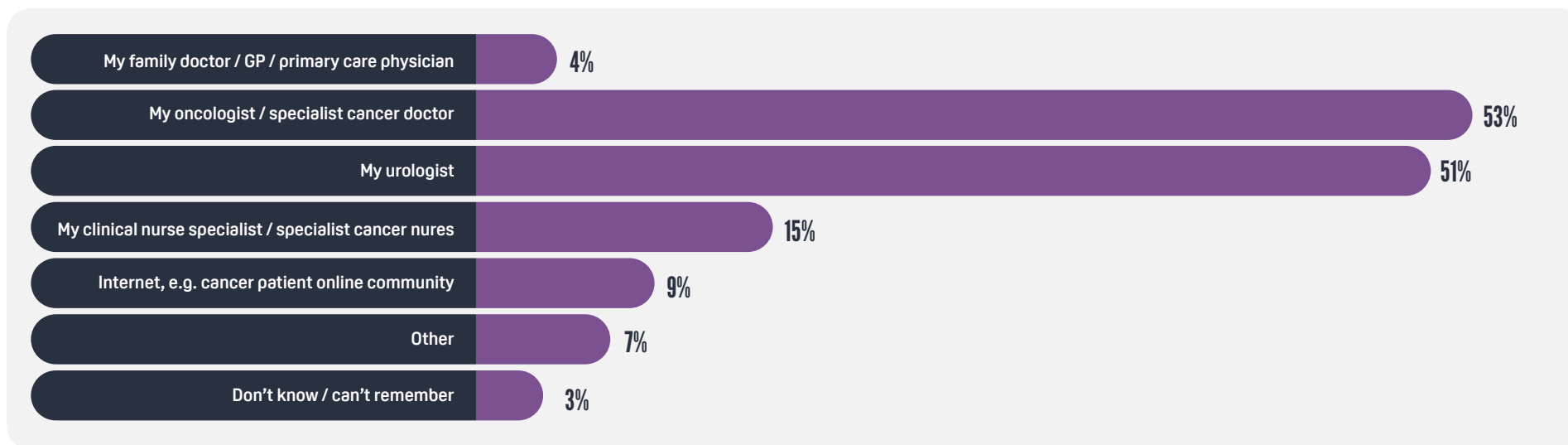


Figure 14. Who did you receive information about clinical trials from? ¹⁹

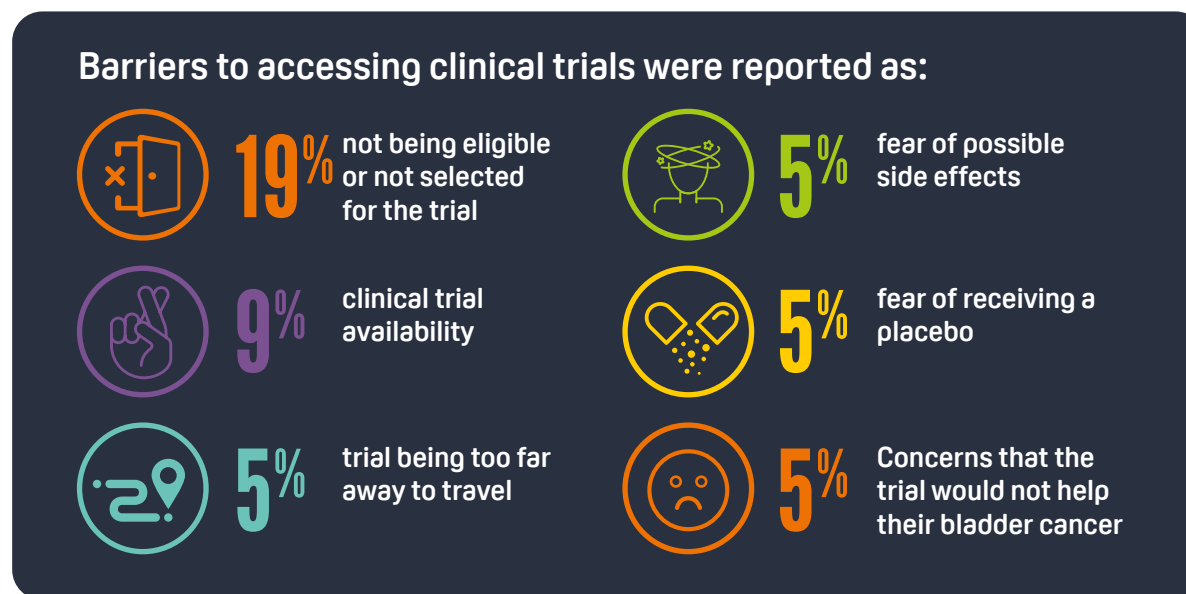


Barriers to entering clinical trials

Several barriers to accessing clinical trials were reported (Figure 15).

Metastatic and/or advanced cancer patients were less likely to experience barriers to entering clinical trials – with 70% saying there were no barriers, compared to non-muscle invasive (55%), and muscle invasive (56%) bladder cancers.

Figure 15. Barriers to accessing clinical trials ²⁰



¹⁹ This was a 'tick all that apply' question; this question was answered only by those who received information about clinical trials (16% of total).

²⁰ This was a 'tick all that apply' question

RADICAL CYSTECTOMY

This section was completed only by respondents that had a radical cystectomy. This represents 27% of the total survey respondents (n=322). When referring to 'respondents' in this chapter, we refer to only those who had a radical cystectomy (27%).

Most radical cystectomies were performed for muscle-invasive bladder cancer

70% of radical cystectomies were performed for muscle-invasive bladder cancer. It was less common for people with non-muscle invasive (24%) and advanced and/or metastatic bladder cancer (5%) to have a radical cystectomy.

Respondents with a delayed diagnosis were more likely to have a radical cystectomy

The longer it took to be diagnosed, the more likely it was for respondents to go on to have a radical cystectomy. People diagnosed in more than 6-months were most likely to have radical cystectomy (36%), compared to 3-6 months (33%), and under 3-months (26%).

Radical cystectomy was often the only treatment option presented

Nearly three quarters (74%) of people who had a radical cystectomy said that no other treatment options were discussed with them to retain their bladder (Figure 16).²¹ Despite this, most respondents still felt that enough consideration was given to other treatment options that would allow them to keep their bladder (Figure 17).

²¹ This was a 'tick all that apply' question

Figure 16. Did your surgeon discuss with you any of the following options to retain your bladder?

Response options

- No, only radical cystectomy (removal of whole bladder) was discussed
- Yes, Continued bladder instillation of chemotherapy or immunotherapy
- Yes, Radiation therapy (with / without chemotherapy)
- Yes, Partial cystectomy (i.e. surgical excision of just the tumor)
- Yes, Other

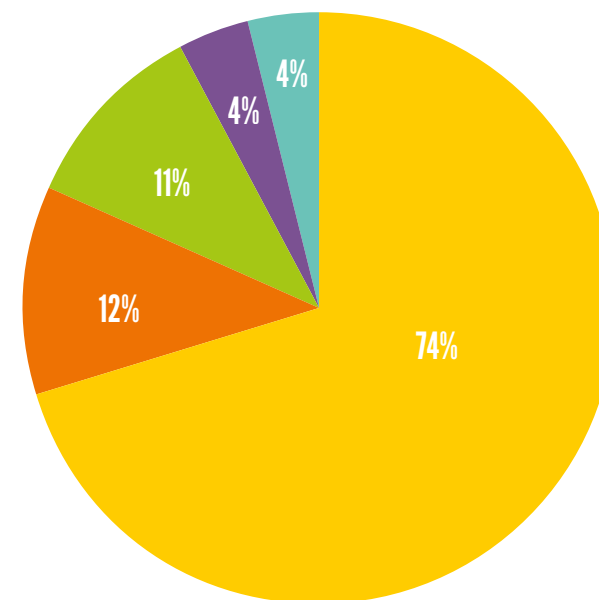
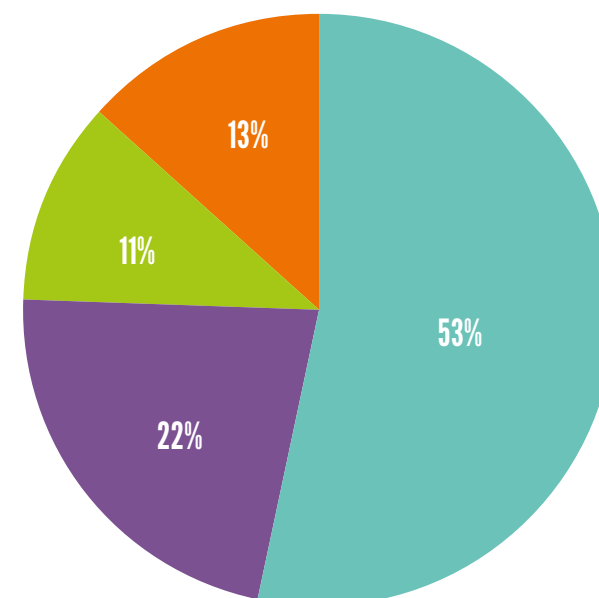


Figure 17. If you had radical cystectomy (removal of your bladder), do you feel enough consideration was given to treatments that would allow you to keep your bladder?

Response options

- Yes, definitely
- Yes, to some extent
- No
- This was not discussed with me



Urinary tract reconstruction options

The most frequently discussed reconstruction options were ileal conduit (81%) and neobladder (52%) (Figure 18).²²

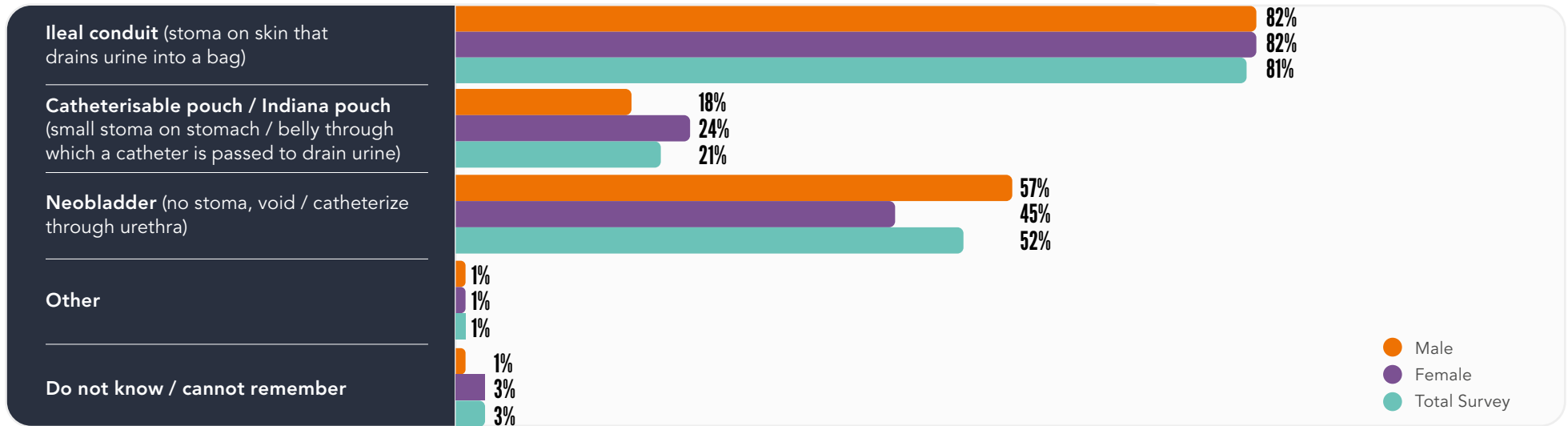


Figure 18. Which of the following urinary tract reconstruction options were discussed with you before cystectomy, even if they weren't recommended?

The most common urinary reconstructions performed were ileal conduit (70%) and neobladder (24%) (Figure 19).

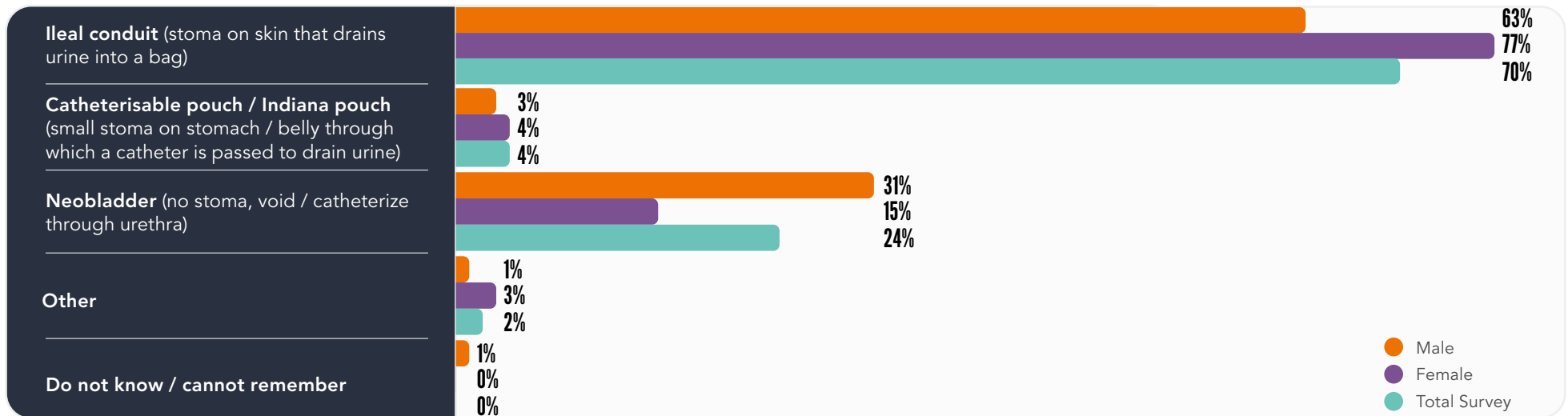


Figure 19. How was your urinary tract reconstructed?

²² This was a 'tick all that apply' question

There was significant unmet need in sexual counselling before radical cystectomy

The sexual impact of radical cystectomy is well known – with treatments directly affecting erectile ability, ejaculation, and vaginal length in women [7]. Patients undergoing radical cystectomy often experience problems with body image, sexual intimacy, and sexual enjoyment following surgery [7]. This should be managed by pre-treatment counselling and post-treatment support – however, previous studies suggest this may often be omitted [7].

“There was a dearth of information about choosing urinary diversions and what to expect as a patient during procedures, treatment, surveillance, and everyday life.”

In our survey, nearly half of all respondents (45%) were not counselled before radical cystectomy on the possible sexual side effects. Notably, males were more than three times more likely to ‘definitely’ be counselled regarding the sexual side effects of radical cystectomy (36%), compared to females (11%) (Figure 20).

Figure 20. Were you counselled before radical cystectomy about the sexual side effects?

Response options	Male	Female	Total Survey
Yes, definitely	36%	11%	25%
Yes, to some extent	34%	25%	30%
No	30%	64%	45%

There is an information ‘hurdle’ that sometimes exists for patients due to taboo topics about and treatment side effects – that are particular to bladder cancer patients.

Bladder Cancer Canada



Patient story: John* (Canada)



Once I was diagnosed with bladder cancer, the urologist went through all three urinary reconstruction options and told me to think about it. He gave me some information to take home and read about the three different procedures. I went home, and I read them all and I talked to my wife about it. I was leaning towards the neo bladder, but I wasn't completely sure. I was searching on the internet, I came across a patient organisation website, which I and I started to read and some of the information and, and it was a lot of people that had the operations that I was going to be I was going to have. It was good for me. There was a lot of good information on that site, and it helped me a lot.

My surgeon also thought that, given my situation, that I'd be a good candidate for neobladder. So, that's what I ended up going for. The first six months were horrible for me, it took me a while to build up my stomach muscles. And then of course at night, I'd have to wear a catheter. It took me a while to learn how to control my body.

Patient story: Joyce* (United Kingdom)

I thought I was just going to have my bladder removed – they took much more than just my bladder. I think there should be more information about the effects that your radical cystectomy has on you. For both men and women, it has a massive effect.

Patients need more information about treatment options and what will happen to you afterwards. I wish somebody would have taken the time to talk more to me about that and provide insight about what was going to happen to me, especially after the radical cystectomy. I wasn't prepared for what life would be like following my surgery - including the sexual side of it. Nobody tells you that part of your life is going to change, and no counselling was offered. Many women feel the same – I know this because I regularly speak to others in patient support groups, and this is a challenge many have raised.

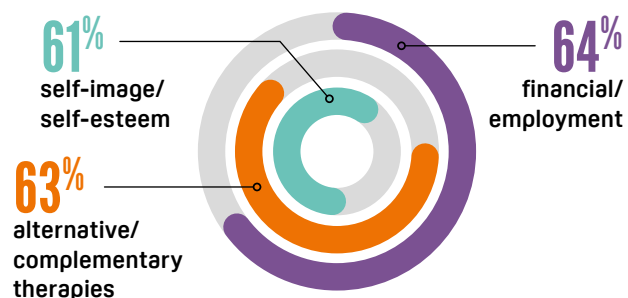
Recovery took a long time for me, I struggled with it big time. Still to this day, if I bend down to pick something I have no muscle built up in my abdomen. I wear different / loose clothes now to hide my stoma bag. It took quite some time before I spoke to somebody else with a stoma. I was happy with the support I received from stoma nurses – if I ever had any concerns or questions, I could contact the stoma nurse and they were amazing.



3.3 Findings: Supportive and complementary care

ACCESS TO SUPPORTIVE AND COMPLEMENTARY CARE

Respondents needed more help and support across many diverse areas



The areas of greatest unmet need were financial/employment issues 64%, alternative/complementary therapies (63%), and self-esteem / self-image (61%) (Figure 21).

In some cases, people paid out of pocket to access these services.²³

"I sought out my own help and support. Very little was offered at my hospital."

"I needed help with diet and nutrition, as I was having issues with my digestive system. I ended up getting it only because I paid for it myself."

Figure 21. Have you been able to get help and support for the following?

Response options		Yes, definitely	Yes, to some extent	No, and I needed it	I did not need this*
Area of support					
Diet and nutrition		23%	33%	44%	37%
Exercise and activity		19%	38%	43%	37%
Alternative and complementary therapies		13%	24%	63%	49%
Sleep problems		10%	30%	60%	44%
Sexual function relationships		11%	28%	60%	43%
Self-esteem and self-image		9%	30%	61%	49%
Depression and anxiety		12%	33%	55%	36%
Stress		12%	36%	52%	35%
Stopping smoking		32%	18%	50%	76%
Stoma care		49%	29%	22%	63%
Bowel function		18%	35%	47%	57%
Financial/employment issues		12%	24%	64%	74%

*Respondents who answered 'I did not need this' were removed from the base size of this question as the question was not applicable to the respondent's circumstances

²³ Findings from free-text questions

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

Almost all respondents (99%) wanted support from doctors throughout treatment and care. Of them, four in five (81%) received enough support from their doctor, while a fifth (19%) did not. ²⁴

"I had good GP who phoned on Friday nights to see how my family and me were doing."

"My clinician has been excellent in handling me – being professional but at the same time acting like a supportive friend. It has put me at ease throughout my treatment."

Nearly all respondents (98%) wanted support from nurses and other healthcare providers throughout treatment and care.

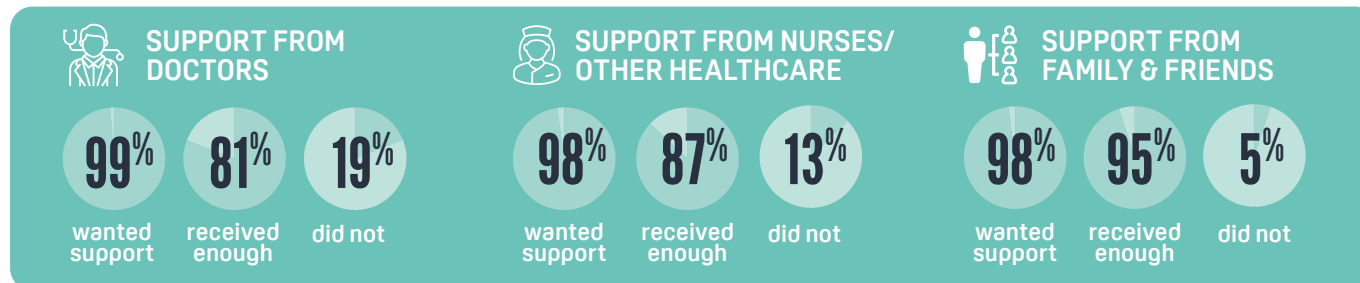
Of them, 87% received enough support, while 13% did not. ²⁵

"I was assigned to the care of a Cancer Specialist Nurse who has supported me wonderfully throughout my treatment and care."

"It was impossible to speak to the occupational doctor – they were overbooked due to COVID-19 management."

Most respondents (98%) also wanted support from family and friends. Of them, almost all (95%) received enough support, while 5% did not. ²⁶

"I live on my own and without the help of some of my family and friends I would have been lost."



Respondents wanted more practical and financial support throughout treatment and care

Most respondents (71%) wanted support with practical things – such as help with daily tasks and getting treatments. Of them, 68% received enough practical support, while 32% did not. ²⁷

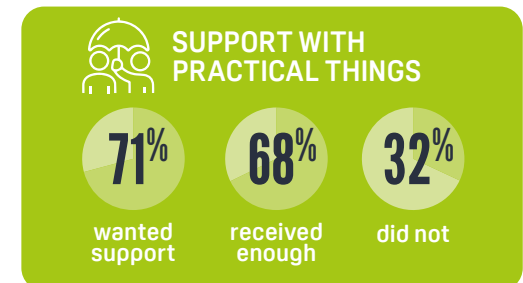
"I have a urostomy and experience leaking sometimes. I would like more support with this, as well as more practical advice, for example is it acceptable to use handicap bathrooms in public to change my appliance or is it for wheelchairs only?"

"The timing of regular consultations, check-ups, and monitoring appointments should have been considered more. I took a lot of time off to travel to and from appointments and incurred a salary loss as a result."

Additionally, 61% of respondents wanted financial support during their treatment and care.

Of them, 46% received enough financial support, while 54% did not.

"In terms of financial support, nobody is here to help and support you."



^{24, 25, 26, 27} Respondents who answered "I don't want or need support in this area" or "don't know/can't remember" were excluded from the base size.

Respondents needed closer follow-up after treatment

Following treatment, patients may experience an immense change, and have to adapt to new and sometimes distressing circumstances [1]. People may have to adapt to new toileting characteristics, new ways of being sexual and living with the lifelong treat of cancer [1].

Many survey respondents commented that after treatment, they felt alone and lacked support to manage their health. More support was needed to help with recovery and adapting to the new normal.

"I needed closer follow-up, ideally, in a physical meeting with my doctor after surgery. I have only had a phone consultation."

"Coming back home after the stoma surgery, you feel alone; support from the hospital would be nice, without us having to call them. At least to tell us that they are here and have not forgotten about us."

"I would have loved to receive adequate post-operative care, but in my case, this has been completely absent. Without the support of my patient association, it would have been impossible to move forward."

EMOTIONAL SUPPORT

Emotional support was needed, but difficult to access

Bladder cancer is known to have a significant mental health impact on those affected. One UK study found that bladder cancer patients are nearly five times more likely to take their own life than the general population and 1.6 times more likely to take their own life compared to patients with other common cancers [5].



²⁸ Please note that respondents who said "Don't know / can't remember" or "I don't want or need support in this area" were excluded from the base size.

²⁹ Please note that 36% of total respondents said that they did not need support for depression and/or anxiety and were excluded from the base size.

The emotional impact evolves and changes over time. A bladder cancer diagnosis can lead to feelings of being shocked, upset, devastated and fears about treatments [1]. Treatments can greatly impact the patient's sexuality, body image and quality of life and yet has been greatly overlooked compared to other cancer [6]. Learning how to cope with these changes can be distressing [1]. The risk of disease recurrence can impact patients cognitively and emotionally more than the actual risk itself [27].

Despite the great need for emotional support, many respondents could not access it. 58% of respondents were not offered emotional support to help them cope with their diagnosis. Almost all respondents (91%) said they needed emotional support throughout their treatment and care experience, but 30% did not receive it. ²⁸ Moreover, 55% of respondents were unable to get support for depression/anxiety, even though it was needed. ²⁹

Younger respondents (under 55) were more likely to say that they did not receive enough emotional support throughout their treatment and care experience (39%) compared to older respondents (over 74) (23%).

"I worked with a counsellor who helped me process my feelings over the various stages of treatment. I feel very fortunate to have had access to such a valuable resource."

"I contacted my hospital for psych support, but the waiting list was 6-months long, so I had to source my own."



Respondents needed emotional and mental health support most at the point of diagnosis (42%), just after diagnosis (48%) and during treatment (48%) (Figure 22).³⁰

Figure 22. When do you feel you most needed emotional / mental health support?

Response options	Male %	Female %	Total survey %
Before Diagnosis	7%	6%	7%
At the point of diagnosis	42%	44%	42%
Just after my diagnosis	49%	50%	48%
During treatment	48%	49%	48%
In the first year after my treatment	22%	23%	22%
Around appointments / check-ups	20%	31%	24%
After I've been living with bladder cancer for several years	7%	8%	7%
When in remission (no evidence of disease)	4%	6%	5%
After relapse (when bladder cancer returned)	16%	21%	18%

Patient story: Roberto* (Argentina)

The main support I got was information when I asked. I wanted to have as much information as possible to manage my disease by myself. You can only control and manage what you know about so I decided to gain all the knowledge I could on the matter. The information I got, apart from my urologist and oncologist, was mainly what I could read on different online platforms such as Mayo Clinic, cancer.org, scientific journals.

I try not to read random information, only articles from scientific sources, I find it difficult due to all the technical terminology, but it is more reliable than anything people can post on the internet. We must filter information and be cautious.

^{30, 31} This was a 'tick all that apply' question.

INFORMATIONAL NEEDS

Respondents needed more information in all areas concerning bladder cancer

Most respondents needed more information throughout their treatment and care (82%). Especially information on treatment options and duration (51%), diagnosis and what it means (39%) and side effects of treatment (37%) (Figure 23).³¹

In general, females had a greater need for more information compared to males. The only exception was for information on sexual function and fertility, where men expressed a greater need for this type of information (Figure 23).

Figure 23. Which of the following, if any, have you needed more information about?

Response options	Male %	Female %	Total survey %
Diagnosis and what it means	36%	46%	39%
Treatment options and duration	52%	52%	51%
Support for self-care	13%	19%	15%
Psychological support / counselling	19%	32%	24%
Support for my family	9%	12%	10%
Side effects of treatment	36%	41%	37%
Sexual function / fertility	29%	19%	25%
Costs	8%	9%	8%
Financial information	5%	8%	6%
Impact on work	11%	15%	13%
Travelling	12%	15%	13%
Dietary information	18%	24%	20%
Other	1%	4%	2%
I have not needed more information	20%	16%	18%

PEER-SUPPORT GROUPS AND CHARITIES

Most respondents did not receive information about peer support groups and charities

Nearly three quarters of people (73%) did not receive information about peer-support groups and charities. Often, people found these groups through their own research.

"When I found out I had bladder cancer, I did extensive independent research and wound up on BCAN where I got the very valuable information I needed."

"I found the help and support myself. I looked online on the Macmillan website and found Fight Bladder Cancer mentioned there. This literally saved my sanity! I still use the Facebook group today and I think I always will."

Half of respondents (50%) contacted a patient organisation, and/or charity for support. It was more common for people with non-muscle invasive cancer (52%) and muscle invasive cancer (49%) to contact a patient organization or charity, compared to advanced/metastatic cancer (36%).

"Joining a support group is the best way to connect with others who have been through the same experience as you, or are going through it too."

Of those who contacted a patient organisation, over half (53%) definitely received the information and support they needed (Figure 24).

Figure 24. Did you get the information and support you needed?

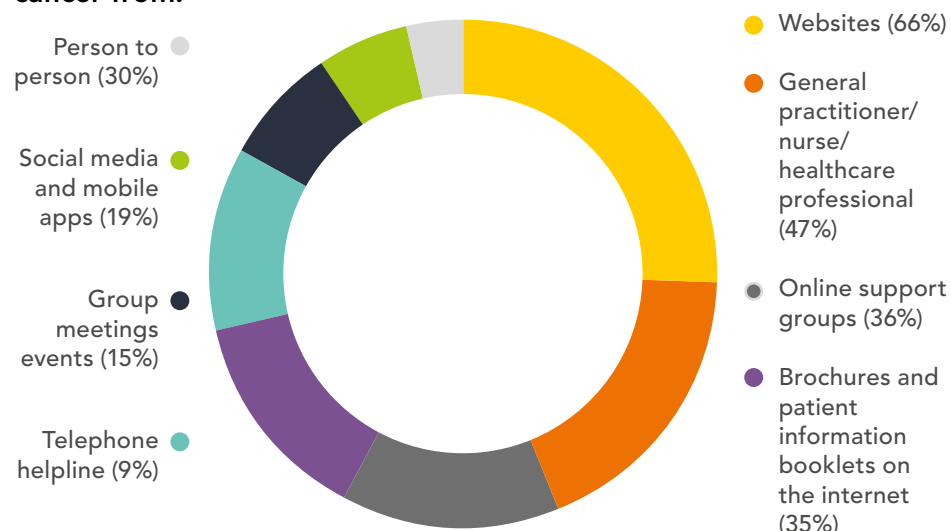


³² This was a 'tick all that apply' question.

Many respondents commented that there was a lack of local patient support groups for them to join, or that their local support groups were placed on hold due to COVID-19.

"There is good community support where I live but Covid has put a stop to my support group for stomates, which would have been helpful, and hopefully will resume soon. But there is no support I'm aware of specifically for bladder cancer 'survivors'."

Respondents preferred to receive information about bladder cancer from:³²



Patients should be receiving information and support before, during and after care. They should be put in touch with a patient organisation for help with emotional and psychological support needs; sexual problems; incontinence; bowel problems; living with life after cancer and dealing with the after-effects of treatment and stigma. Patients should also be offered a referral to a therapist to help them cope.

Action Bladder Cancer UK

Patient story: Nick* (Canada)

The surgery to treat my bladder cancer bladder cancer has had a huge impact on my day-to-day life – I mean my whole life since the diagnosis has revolved around treatment.

What I've managed to do to help cope is reach out to other people online who have had bladder cancer surgery, like me. I also found it helpful to connect with others who have a stoma, as it is difficult to find good quality information online specific to bladder cancer patients. What I have really needed more of, is information on how to resume day-to-day activities, so that would be a helpful resource to have.

I didn't realise how much of an impact bladder cancer had on my mental health. The initial diagnosis - hearing that I had bladder cancer - was quite traumatic. I didn't realise it until long afterwards. I had a lot of anxiety as a result of my diagnosis, and treatment. In hindsight, better communication about what to expect in going through the cancer diagnosis and treatment experience would have helped calm my anxiety.



Patient story: Steve* (Australia)

My advice to others is find out as much as you can and don't be afraid to ask questions. Ask for a follow-up appointment with your doctor following the diagnosis. Because by the time you've had that first conversation, you go, "oh, I didn't ask this", "What's the repercussions for that?".



I had so many un-answered questions and found value in sitting down with a patient that's gone through this process before me. I started searching Facebook for support groups and managed to eventually find a support system here in Australia. It was easy to relate to people through that support group. By the time I eventually joined, I was able to talk about what I had gone through, as I wasn't quite ready earlier in my diagnosis. The comments that were coming back to me were very supportive, but also very honest. I found others who were going through what I was experiencing, and others who were further along who guided me on what might happen next, and what I should be expecting. So that was great, as I was more prepared.

There should be more signposting to support groups in Australia. I think there should be a central repository of not only support groups, but also somewhere you can go to for financial advice, if you need assistance, psychological assistance along the way. You may not need everything all at once, but you may need certain pieces. Also, I think medical professionals should be guiding all newly diagnosed patients to support groups – as it is not something that you tend to think about when you get the news about having cancer.

3.4 Findings: Impact on daily life

FINANCIAL IMPACT

Having bladder cancer impacted people financially, to a varying degree

Financial toxicity is a concern for people with bladder cancer. Studies show that younger patients are likely to experience financial toxicity [7, 15]. People who experience financial toxicity are more likely to have delays in care (due to inability to take time off work and afford general expenses), worse physical and mental health, and poorer health related quality of life [15].

Nearly half (49%) of respondents said that having bladder cancer impacted them financially (severely, to some extent or slightly) (Figure 25). This was higher for respondents with advanced/metastatic cancer (57%), and younger respondents (68%) (under 55).

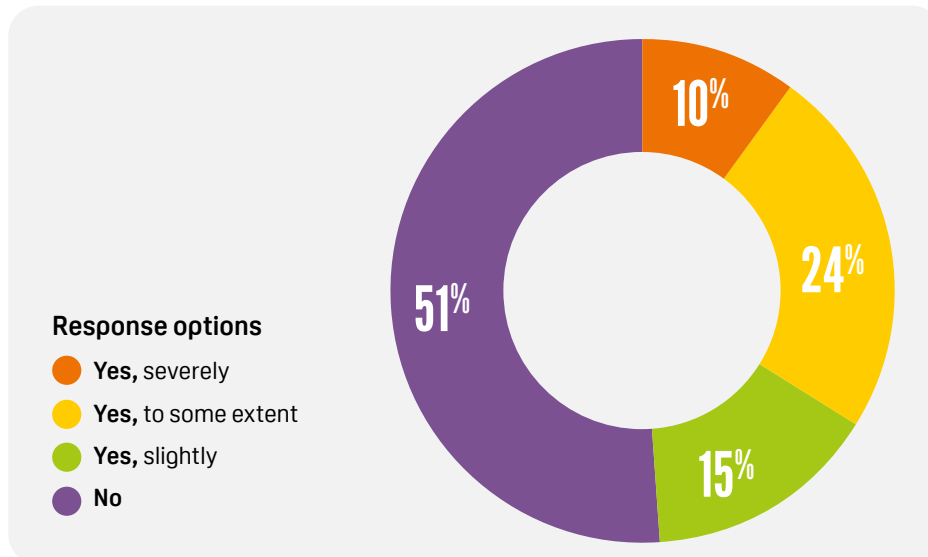
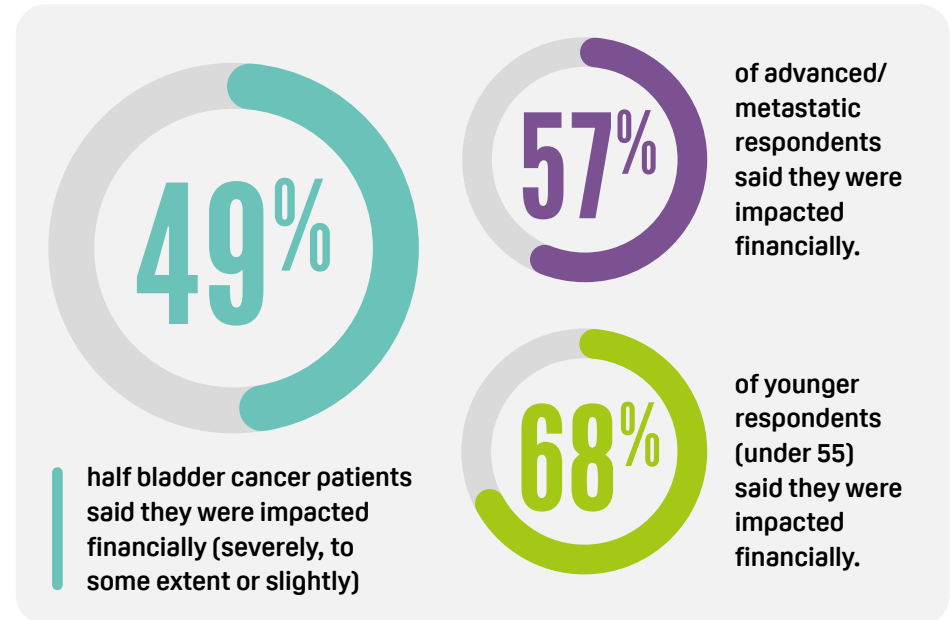


Figure 25. Has your bladder cancer impacted on your financial situation?



In the free-text comments, respondents said that additional costs due to bladder cancer created financial strain. For example, people had indirect costs, such as travel costs, hotel costs, insurance deductibles, and purchasing new supplies, etc.

Respondents also noted they paid out of pocket to access private care to speed up waiting times, and a lack of ability to get paid time off work added to financial pressures.

"I have had to give up work and the process of getting benefits is very hard."

"I spend a few hundred dollars a year on protective underwear because I now have an overactive bladder."

"Both my wife and I are fully retired. We now must save for extra expenses associated with bladder cancer treatment and ongoing support."

Changes to employment status also varied

Employment disruptions due to bladder cancer differ between treatment types [7]. Many bladder cancer patients do manual work – which is often not possible throughout treatment recovery [7].

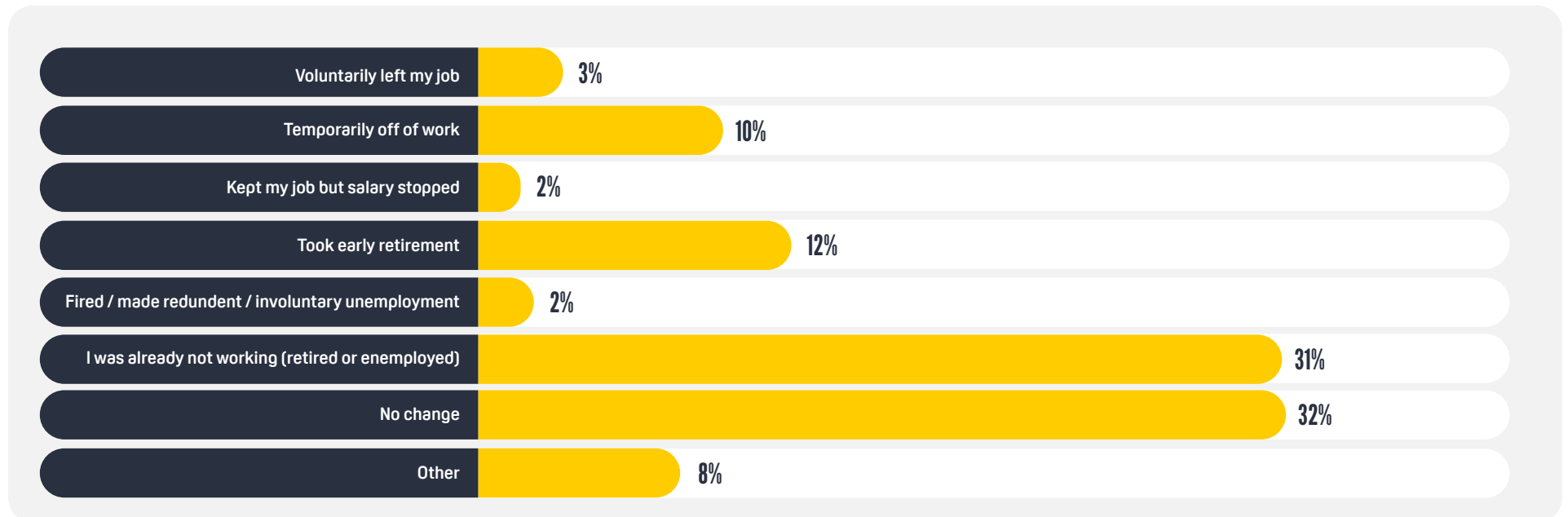
A third (32%) of respondents had no change in their employment status. Another third (31%) were already retired or unemployed when they were diagnosed with bladder cancer. However, nearly one in eight (12%) took an early retirement, and one in ten (10%) were temporarily off work (Figure 26).

“I am retired with a comfortable pension and am lucky to live in a country where treatment is free at the point of delivery.”

“After my bladder cancer treatment, I was unable to do certain jobs because I could no longer do heavy lifting.”

Advanced/metastatic respondents were more vulnerable to changes in employment status. Advanced and/or metastatic cancer patients were significantly more likely to voluntarily leave their job (19%) or take an early retirement (26%). Younger respondents (under 55) were more likely to temporarily take time off work (27%).

Figure 26. Has your employment status changed because of your bladder cancer?



THE EMOTIONAL IMPACT

The emotional impact of bladder cancer carried over into many aspects of daily life

The emotional impact of having bladder cancer was felt across many aspects of life – especially in sexual performance (36%), stress/ anxiety levels (27%), hopes for the future (26%), and ability to sleep (20%) (Figure 26). Younger respondents (under 55) were more severely impacted across nearly all aspects of life (Figure 27).

Figure 27. Has the emotional impact of your bladder cancer diagnosis affected any of the following? – Respondents answering ‘Severely’

Response options	Under 55	55-74	Over 74	Total Survey
Your relationships	16%	8%	9%	10%
Your ability to carry out day-to-day activities	18%	10%	10%	11%
Your ability to enjoy life	21%	16%	14%	17%
Your happiness	26%	17%	14%	18%
Your confidence	26%	17%	13%	18%
Stress/anxiety levels	41%	26%	19%	27%
Hopes for the future / future plans	34%	25%	20%	26%
Trouble/inability to sleep	26%	20%	14%	20%
Your body image	24%	18%	11%	18%
Sexual performance	35%	36%	33%	36%
Your work	25%	15%	9%	16%
Other	0%	16%	0%	12%

Patient story:

Roberto* (Argentina)

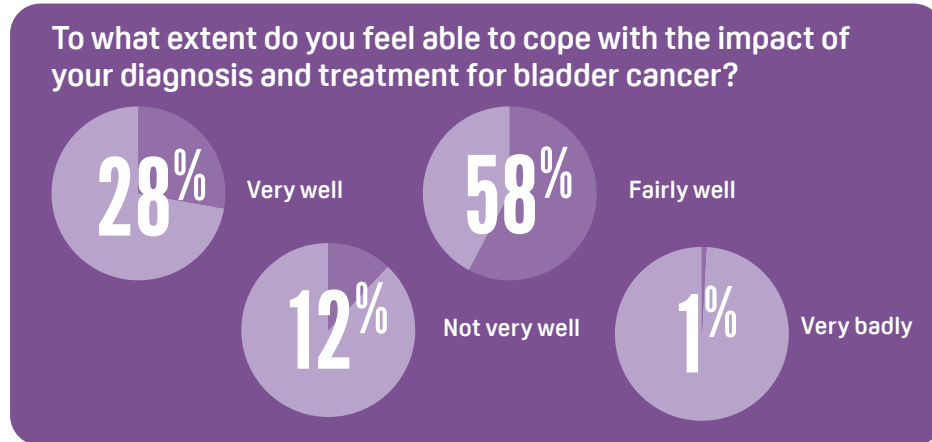
After being diagnosed and treated for bladder cancer, I have made a personal decision and I have changed some of my habits. I am only working on things that I like, what brings me joy. I have carefully selected my jobs and I am having a lot of me-time, exercising, walking, watching what I eat and all that to get ready in case a more invasive operation is required, such as a radical cystectomy. In my day-to-day life, it has made me be more aware of time, especially the time I spend on myself. I have reduced the levels of stress at work because I only do things that I like now.



Life after and with bladder cancer

Most respondents (87%) said they were able to cope with the impact of their diagnosis and treatment for bladder cancer.

However, for some, it was difficult to cope (13%).



"I still have a huge fear of death, I simply do not want to die. I have too much to live for, my wife and my child are the biggest reasons I need to live. I feel blessed that I have been clear for years. It has not been a smooth ride, but I am still alive and enjoying life."

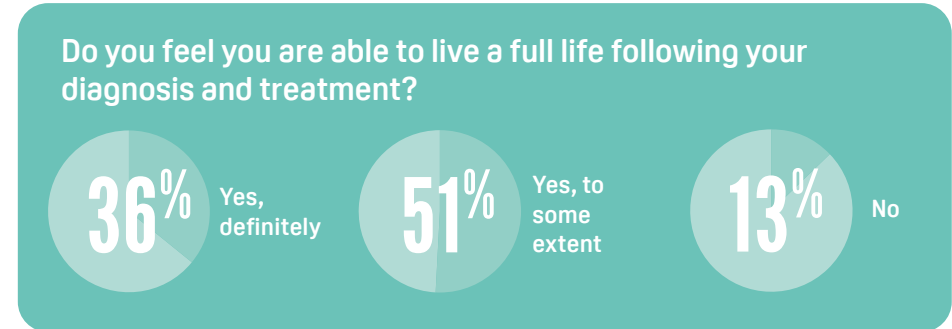
"We do not talk about the long-term effects of having bladder cancer: loss of memory, focus, loss of sleep, pains."

When asked if they felt able to live a full life, just over a third of respondents (36%) said they definitely felt able to live a full life following their diagnosis and treatment. Half of respondents (51%) said to some extent, while 13% said not at all.

"I look at things differently now. Life is a limited resource and may end sooner than we want."

"Having bladder cancer has caused me to re-evaluate what is important in my life."

Respondents with advanced/metastatic bladder cancer felt less able to live a full life – with 39% saying they could not live a full life following their diagnosis and treatment.



Patient story: Joyce* (United Kingdom)

Before I had cancer myself, I used to think that once you got rid of the cancer, then you could just move on. In reality, I found it really hard to move on from and bladder cancer had really affected me. I like to think that I am quite a strong person. After my diagnosis and treatment, I kept wanting the 'old' me back. It [bladder cancer] totally stripped me of my confidence, and I had an awful fear about it coming back. I have spoken to so many people, and realize a lot of people feel the same way. This is reassuring and comforting for me, to know that I am not the only person that is not dealing well, or coping with it.



3.5 Findings: Impact of COVID-19

The COVID-19 pandemic and bladder cancer

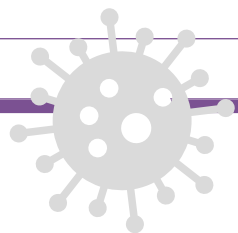
Studies show that the impact of COVID-19 on bladder cancer was significant. In bladder cancer, it led to a significant reduction in consultations during the pandemic, an increase in the presentation of high-grade and advanced tumours (in 2020, compared to 2019), increased surgery deferral and increased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

Our survey found that COVID-19 did not have a severe impact on the treatment and care of people who responded to the survey. Only 8% of respondents said that the pandemic impacted their care and treatment severely, while most (45%) said the pandemic had no impact, or the impact was slightly/to some extent (46%) (Figure 27).

"I have been extremely lucky to have a hospital that has not been badly impacted by COVID-19 and have had all my appointments, procedures and check-ups as normal."

Figure 27: To what extent has the COVID-19 pandemic impacted on your care and treatment?

Response options	
The pandemic had no impact	45%
The pandemic impacted their treatment and care experience slightly or to some extent	46%
The pandemic severely impacted their treatment and care experience	8%
Don't know / can't remember	1%



The impact of COVID-19 on survey respondents was most evident in treatment appointments being delayed or cancelled. Of the 28% of total respondents who reported delayed or cancelled treatments by their medical centre, just over a quarter (27%) of them attributed it to the pandemic alone.

"I could not start chemotherapy treatment due to lockdown; important months were missed."

Respondents also indicated they were disappointed by having to do virtual medical appointments due to the pandemic. They felt it was more difficult to have meaningful conversations with their care providers over the internet and would have preferred to have appointments in person.

"I would have preferred meeting the urologist in person, rather than over the phone because because of the pandemic. It prevented me from being more actively involved."

"The restrictions in place due to COVID-19 prevented me and my wife having any face-to-face meetings with any of the Urology Team. We did video calls, and they were wearing face masks which did not help with clarity of answers at a very worrying time. Tele-medicine is not the same as being able to see a doctor in person."

Others noted it was incredibly challenging to not be able to have family and friends visit them in the hospital or join them for medical appointments. The pandemic restrictions limited the amount of people who could attend medical facilities.

"The inability of family to visit me after treatment was hard to bear."

3.6 Findings: Caring for someone with bladder cancer

This section was completed only by carers. A total of 67 individuals completed the carer survey – this represents 6% of the total survey respondents. The findings of the carer survey are detailed in this chapter.

CARER EXPERIENCES

Most carers provided care and support to their spouse/partner (64%) or a parent (24%). The vast majority (71%) had been caring for more than a year (Figure 29, 30).

Figure 29. What is your relationship with the person you are providing care and support to?

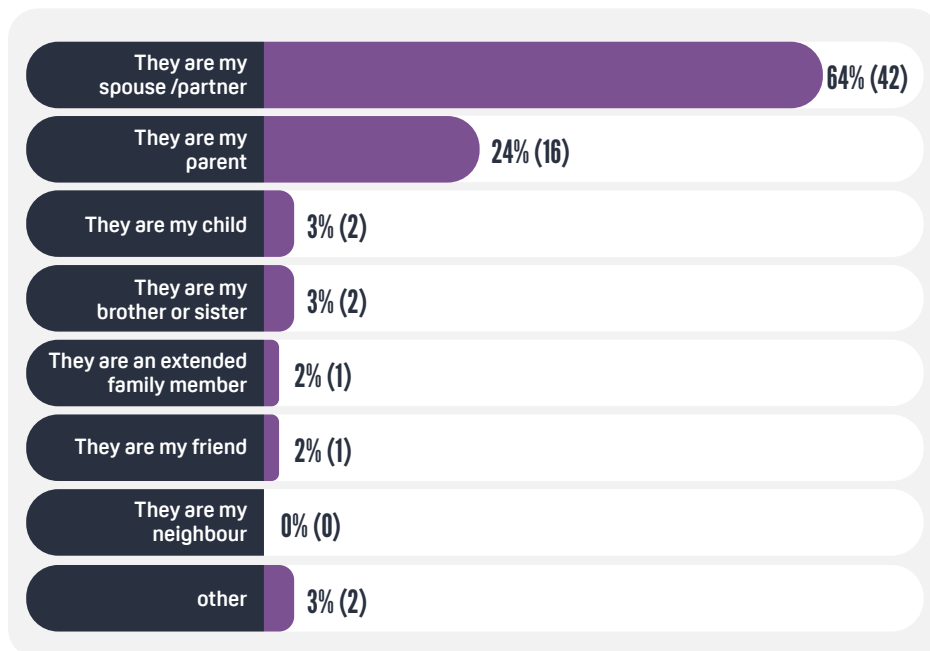
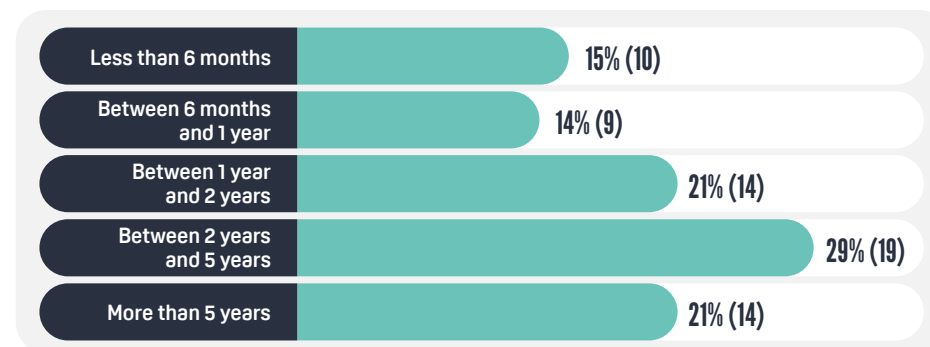


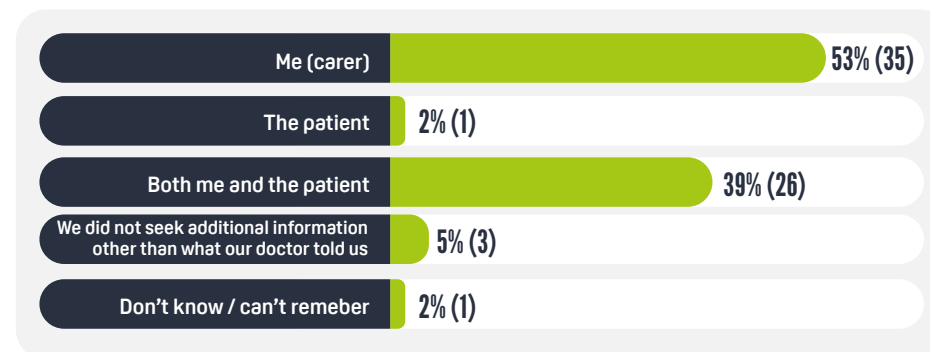
Figure 30. How long have you been providing care and support to the person with bladder cancer?



CARERS PLAYED A CRUCIAL ROLE finding information about bladder cancer

Carers played an important role in finding information about bladder cancer – with more than half (53%) seeking out this information alone on the patient's behalf (Figure 31).

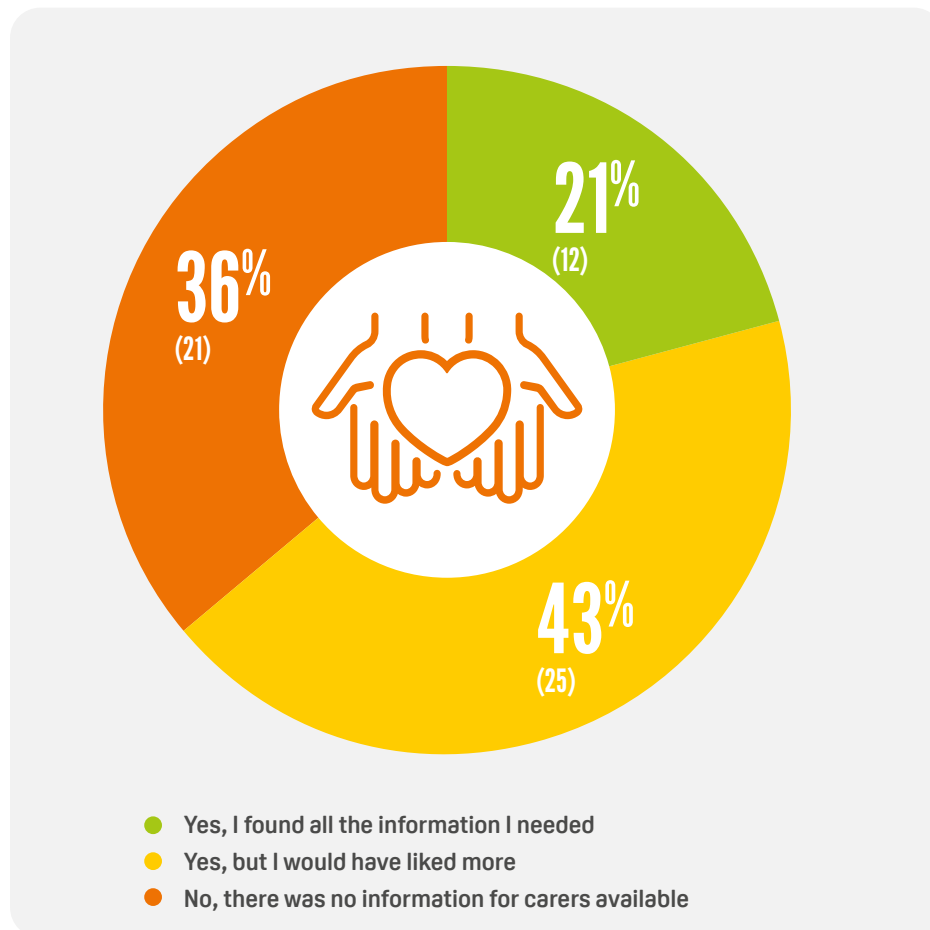
Figure 31. Following the diagnosis, who was seeking out information and details about the disease and potential treatments?



Carers needed MORE INFORMATION ON 'CARING'

Carers often lacked information on how to 'care' for a person with bladder cancer. Only a fifth (21%) found all the information that they needed on caring for someone affected by bladder cancer. The remaining, would have liked more information (43%) or could not find this information (36%) (Figure 32).

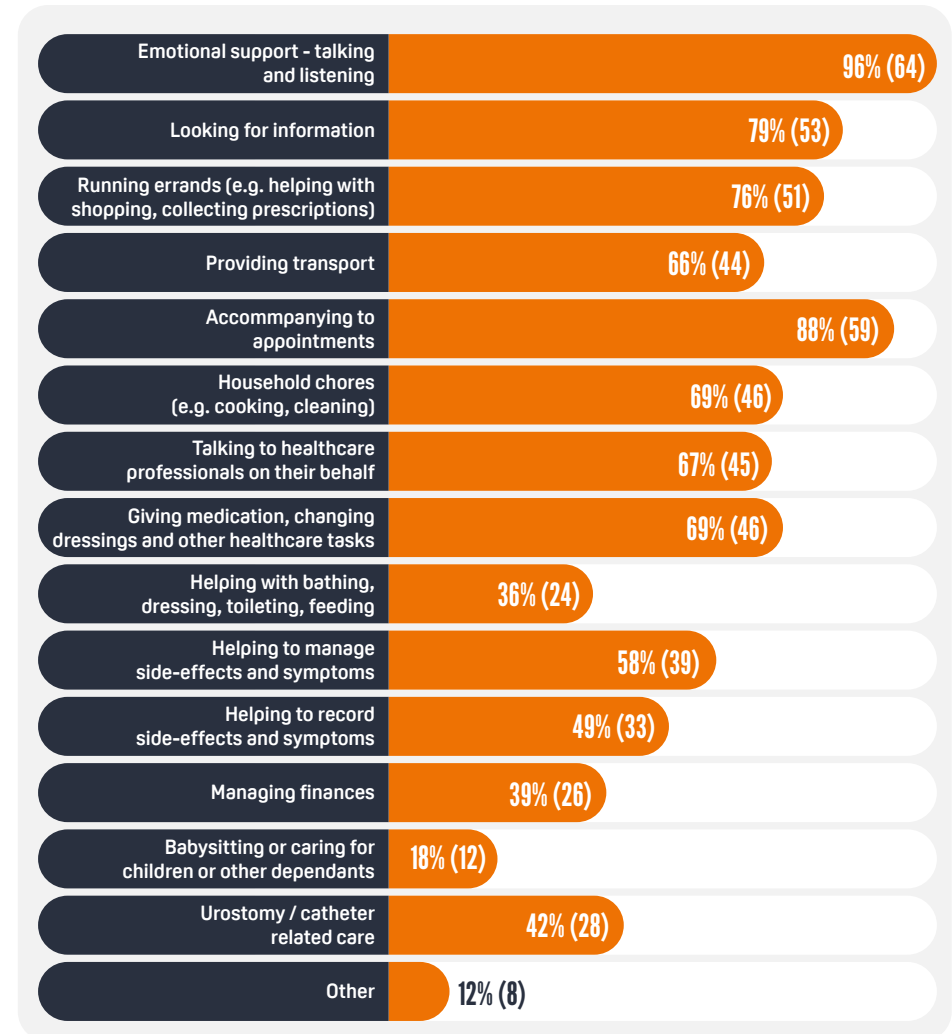
Figure 32. Were you able to find information specifically for carers of bladder cancer patients?



Carers took on MANY DIFFERENT ROLES

Carers took on many different roles when caring for someone affected by bladder cancer, the most common role was providing emotional support (96%) (Figure 33).

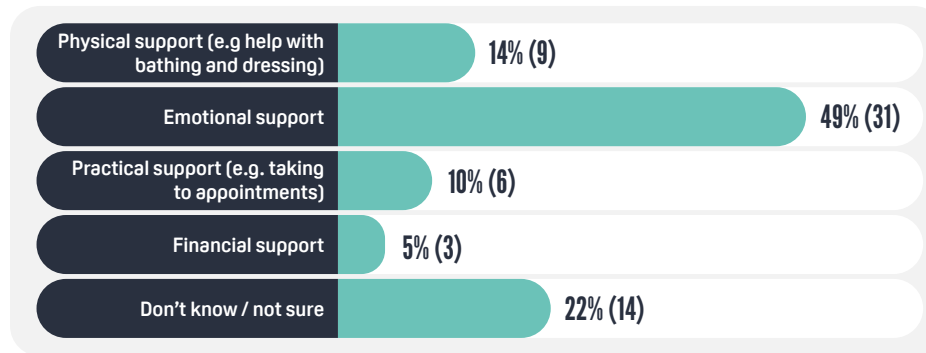
Figure 33. Please select the type(s) of care that you provide.



Carers FELT LEAST EQUIPPED TO PROVIDE EMOTIONAL SUPPORT to their loved ones

When asked about the areas of 'caring' that were most difficult to provide, carers expressed that emotional support (49%) was the most challenging (Figure 34).

Figure 34. Which ONE of the following types of care or support do you find hardest to provide?



THE ROLE OF 'CARING' AFFECTED THE CARER in many diverse ways – especially emotionally

Carers were affected by having a loved one affected by bladder cancer. The most common were feelings of fear that the person with bladder cancer will relapse (65%), experiencing emotional distress (60%), and always placing the needs of the person they were caring for ahead of their own (55%) (Figure 35).



feel that bladder cancer will relapse



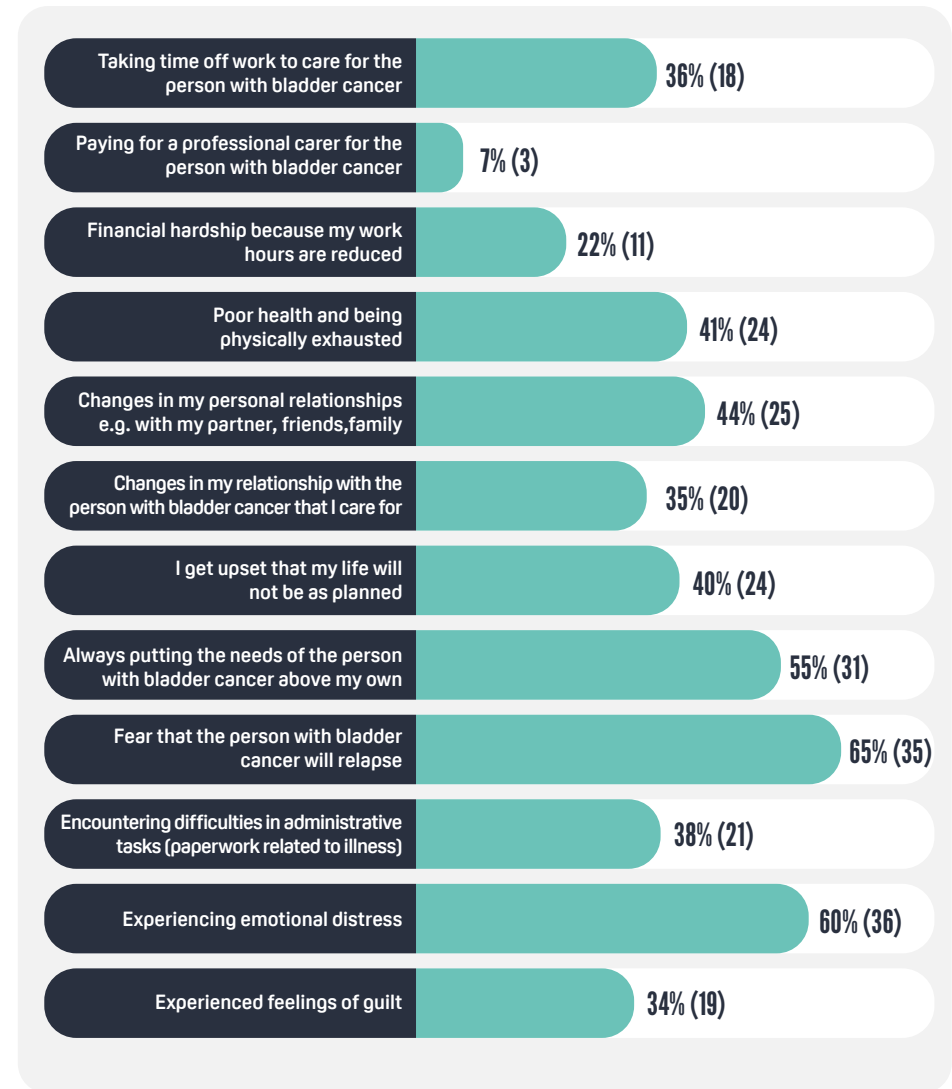
experienced emotional distress



place needs of the person cared for above their own needs

"Although a challenge at times, I perceive caregiving as what I should be doing and try to always approach it in a positive way."

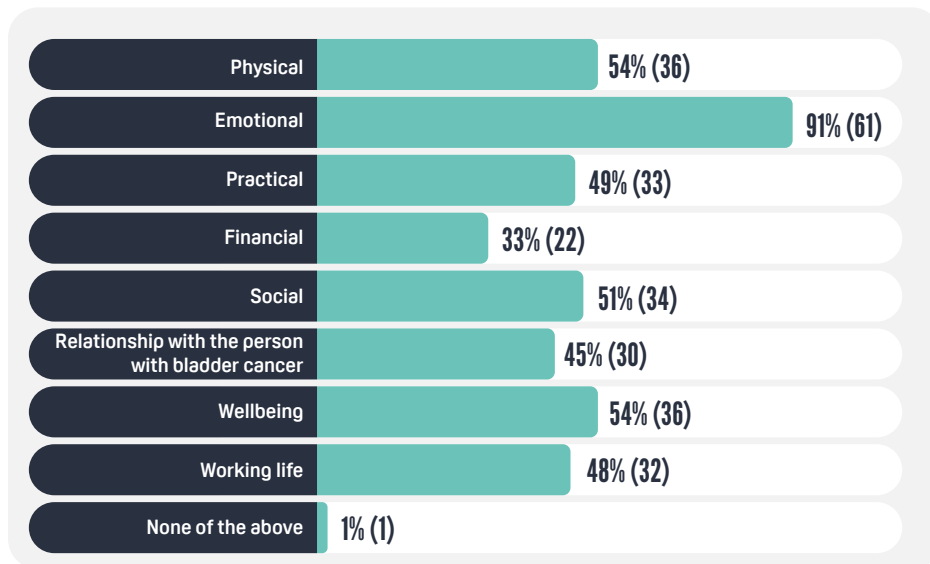
Figure 35. To what extent have each of the following issues affected you as a carer? – Respondents answering 'Often/Always'



Almost all (91%) carers said they were impacted emotionally by caring for or supporting someone with bladder cancer (Figure 36).

“There is no psychological support available for carers.”

Figure 36. Which of the following areas of your life have been impacted by caring for or supporting somebody with bladder cancer?



MORE SUPPORT WAS NEEDED FOR PARTNERS of people affected by bladder cancer

Support for partners of people affected by bladder cancer was lacking. Many respondents commented that having a partner affected by bladder cancer placed a severe strain on their relationship, and that there was a lack of support available to them to help them know how to appropriately support their loved one.

“Relationships are put under great pressure when one party becomes seriously ill. Reduced energy level, fatigue is hard to understand, also for the ill person.”

“Caring for your husband, doesn’t give you time alone to cry.”

Patient story: Sophie* (France)



Since my father was diagnosed with bladder cancer, he’s had millions of questions. So, my role has been to get him information and tell him what I find out. As soon as he has a question, I try to find the answer. But it’s true that there’s a real lack of information. For example, what a day in the life of someone with a neo-bladder is like, or what it’s like to live with a urostomy bag. He’s got a lot of questions about everything. So, I try to reassure him and, above all, to give him information.

I live hundreds of kilometres from my father (and mother), so I call every day, I ask him how he’s doing, if he’s keeping his spirits up. Financial support hasn’t yet been needed, but sometimes there are dips in morale, so you always have to reassure them. And it’s true that the appointments he has are so spread out. In fact, between each appointment – well, he got his results a month ago already, and he still has a month to go until chemo. And in fact, the more time goes on, the more he worries about the passing of time, you see. So, it’s really the wait that is difficult to manage. He’s impatient. So yeah, it’s more psychological support, shall we say.

I tell myself that I have hope that he will get better etc., and I tell myself that he is also of a certain age, that sooner or later... well, it wasn’t inevitable, of course, it isn’t inevitable that you get something like this, but I say to myself, I know that they are not that young, and I knew that it was going to happen sooner or later. So, there you go. I feel prepared, and also, I know that this cancer can be cured, so I’m fine. For the moment, I’m doing OK.



04. Methodology

04 Methodology

4.1 STUDY OBJECTIVE

The main objective of the survey was to collect the views and experiences of people with bladder cancer and their carers worldwide. By deepening and quantifying patient experiences, we hope to identify ways to improve patient experiences and patient outcomes.

4.2 LITERATURE REVIEW

A literature review was initially conducted to gather existing data on bladder cancer patient and carer experiences. A review of online databases was done using a set of search terms, including grey literature from governments, think-tanks, research organisations and charities. The search terms were *bladder cancer, patient experience, primary care, diagnosis, treatment, support, quality of life, stigma, cystectomy, and haematuria*. Articles were included if they were published from 2000-2021, in the English language, from any country of origin. The findings were summarised in a report, outlining the key themes and issues pertaining to bladder cancer, and were used to inform the development of survey questions.

4.3 MEMBER INTERVIEWS

Further to the literature review, semi-structured interviews were conducted. Interviews were completed with national bladder cancer patient organisations and charities. Interviews were conducted across 6 countries (below).

- Dr Stephanie Chisolm, Bladder Cancer Advocacy Network (USA)
- Dr Stephanie Demkiw, Bladder Cancer Awareness Australia
- Ferg Devins / Jack Moon / Tony Cornacchia / Dorothy Barrett, Bladder Cancer Canada
- Laura Magenta, Associazione PaLiNUro (Italy)
- Dr Lydia Makaroff, Fight Bladder Cancer (UK)
- Jackie O'Kelly, Action Bladder Cancer UK
- Lauren Pretorius, Campaigning for Cancer (South Africa)

The interviews were recorded, and transcripts were developed summarising key findings. Interview findings were used to inform the survey questions. Interview findings were also used to develop member organisation quotes, that are featured throughout the report.

4.4 SURVEY DESIGN AND DEVELOPMENT

The survey questions were drafted iteratively with input from member organisations and the project expert advisory committee.

As part of the process, cognitive testing was done with 7 volunteers with bladder cancer from different countries in different languages, who filled in the survey and discussed various aspects of its design. After cognitive testing, a final survey was created.

The final survey had 65 questions that covered the entire patient experience – from symptom and disease awareness, diagnosis, treatment and care, follow-up, life after cancer and COVID-19.

A section of the survey was dedicated strictly to carer experiences, and only carers were invited to complete this part of the survey. Carers were invited to complete the patient survey, on the patients' behalf. The survey was a mix between multiple choice and free text questions. During cognitive testing of the questionnaire, most volunteers stated that the questionnaire took them 15-20 minutes to complete.

4.5 FIELDWORK AND DATA COLLECTION

The survey was open for completion from 1 October 2021 to 1 February 2022 (close date). It was disseminated by WBCPC and member organisations, through their networks via websites, email, and social media. The WBCPC also conducted outreach to cancer societies and patient organisations to promote the survey in countries where a national language option was available. The survey was hosted on secure IQVIA platform, and was accessible online via the WBCPC website, in Arabic, English, French, Hindi, Italian, Japanese, Norwegian, Polish, Portuguese, Russian, and Spanish.

4.6 IN-DEPTH PATIENT INTERVIEWS

Following survey close, we conducted semi-structured interviews with patients and carers who completed the survey to contextualise the findings further. We contacted people from different parts of the world, with different stages of bladder cancer, who indicated in the survey that they would be interested in answering more questions. We interviewed 6 people with bladder cancer, and 4 carers.

The interviews were held on video calls with one done via email, by following an interview guide that explored similar themes to the survey. The specific questions varied from person to person based on their circumstances. The interview findings are presented in this report, in the format of patient and carer "stories". To retain the anonymity of the interviewees, we have not included their names and identifying details such as hospital names and dates. Any names given are pseudonyms used to protect identity.

4.7 DATA ANALYSIS AND REPORTING OF FINDINGS

Once the survey closed to the public, the data were cleaned and analysed. The following rules were applied to the data:

- For all survey questions (with the exception of those asked in the form of “tick all that apply”) the percentage responses are calculated after excluding those respondents that did not answer that particular question
- The base size for questions which have been asked in the form of “tick all that apply” is determined by the number of respondents eligible to respond. As such the missing count for a “tick all that apply” response option represents any eligible respondents who have chosen not to select that particular option. These types of questions are indicated in the footnotes
- All percentages are rounded to the nearest whole number. When added together, the percentages for all answers to a particular question may not total 100% because of this rounding
- On some questions, scores have been recalculated to exclude non-specific responses, (such as don’t know/can’t remember) or responses indicating that the question was not applicable to the participant’s circumstances. Where this has been done, it is brought to the readers’ attention using footnotes
- Results have not been weighted, meaning the numbers that you see in the findings report represent the actual response from survey respondents. The survey limitations section details what this means for interpreting the findings.

Additionally, we analysed the data according to certain respondent characteristics. These “breakdowns” help to identify patterns and trends among groups. Breakdowns were done for sex, time to diagnosis, age, geographic region (city/urban area) and bladder cancer stage (based on the stage of initial diagnosis reported by respondents).

This findings report was drafted iteratively with close input from the project expert advisory committee and WBCPC members.

The report was drafted from April – December 2022 and designed from August 2022 – March 2023.

4.8 LIMITATIONS

Our survey was distributed online, via social media and patient support organisations. The online nature of the survey means we may have excluded older patients, people without access to internet and people with disabilities. The survey was available in 11 languages and may have excluded people speaking other languages. Survey completion was voluntary, self-selected, and unpaid. As a result, it was likely respondents were directly engaged with national patient organisations and may have access to more support than the average person. Therefore, the views of respondents do not reflect the perspective of all bladder cancer patients globally.

In some instances, the survey disproportionately represented patient populations. Our survey under-represented males – 60% of responses were from males, however, males make up 75% of all bladder cancer diagnoses [21]. We also had an under-representation of patients who have progressed from one state to another, as most respondents (70%) were diagnosed within last 5-years, meaning that progression was less likely to occur within this time frame, if at all. Lastly, carers had a small base size with 67 responses, and therefore the findings may also be subject to biases towards more extreme answer options. In addition, the data cut for metastatic/advanced cancer resulted in a small base size of 28 respondents (2%), and findings may be biased towards more extreme answer options.

Our survey findings best describe the situation in the developed world. While 60% of bladder cancer cases and 50% of all deaths occur in less developed countries [21], our survey had very limited responses from low- and middle-income economies. Almost all (93%) of responses were from high-income countries, with large proportion from the UK (20%), the USA (13%), and Australia (10%). Most respondents lived in the European region (58%) or the region of the Americas (27%), where there is access to universal healthcare and patients were more likely to have better treatment and care experiences overall.



05.
Conclusion

05 Conclusion

The findings in this report represent the views and experiences of bladder cancer patients and carers from across 45 countries. While this survey was open to respondents from all countries, most responses came from high-income countries. This was a clear limitation of the study and shows the need for more engagement with patients in low- and middle- income countries. Patient organisations are vital to connecting patients to resources and representing their views and experiences, and the lack of patient organisations for bladder cancer in low- and middle- income countries is a possible reason for the low number of responses, as the survey was disseminated mainly through online communications via national patient organisations. Overall, more research is needed in low- and middle- income countries to better understand patient and carer experiences.

This survey identified clear areas needing improvement across the patient pathway. This was even though most respondents came from countries with universal healthcare, meaning the patient

experiences and access to care would have been more positive.

Awareness of the signs and symptoms of bladder cancer prior to diagnosis was low, and many did not know that blood in urine was a symptom of bladder cancer.

Women and younger respondents (under 55) had significant delays to diagnosis compared to all other respondents. Women were more than twice as likely to be misdiagnosed with a UTI compared to males.

Clinical trial access and availability was poor, with few respondents taking part in one. Nearly half of respondents were not counselled beforehand having a radical cystectomy, about sexual side-effects, and this was especially true for women. Almost all respondents needed more information throughout their bladder cancer treatment and care experience, and support was lacking in many areas – requiring people to pay for it out of pocket. The financial impact was felt among respondents to a varying degree, the burden was highest for advanced/metastatic cancer patients and younger respondents. Similarly, these

two groups were also more vulnerable to employment status changes. In general, respondents needed more support in adapting to life after cancer, from managing their condition and side effects of treatment, to being offered emotional support, and help coping with the ‘new normal’.

This survey is the first of its kind in bladder cancer patient experiences, covering the largest breadth and depth of topics and was the first global survey of bladder cancer carers. These findings represent a valuable contribution to the scientific evidence base. Going forward, these findings should form the basis of prioritising future work in bladder cancer guided by the call to action. 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 the areas of need identified by this research.

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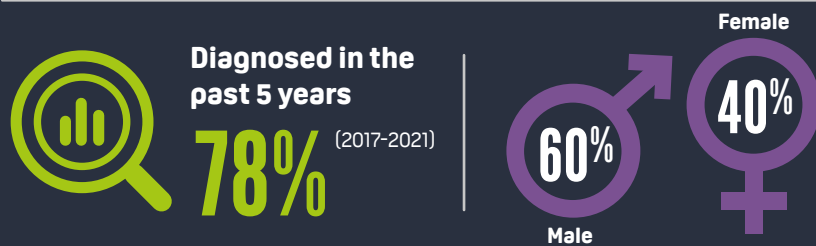
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06.
Country
Findings

AUSTRALIA

RESPONDENT PROFILE



STAGE



COUNTRY STATISTICS: AUSTRALIA

- Approximately **3,446** new diagnoses were estimated in 2020 (men = **2,648**; women = **798**; **3.5%** and **1.2%** of all new cancer incidences, respectively)
- In 2020, **1,367** deaths are estimated (men = **988**; women = **379**)
- There are **11,716** people living with bladder cancer in Australia after diagnosis of bladder cancer (men = **9,153**; women = **2,563**)



International Agency for Research on Cancer (IARC). Australia Fact Sheet Globocan 2020. Available from: <https://gco.iarc.fr/today/data/factsheets/populations/36-australia-fact-sheets.pdf>

Findings: Awareness

- 56% did not know any symptoms of bladder cancer before diagnosis.
- 37% knew that visible blood in urine was a symptom of bladder cancer.
- Compared to other common cancer types, only 27% of respondents understood the signs and symptoms of bladder cancer before diagnosis.

Findings: Diagnosis

- The most common signs and symptoms people were experience prior to diagnosis was: visible blood in urine (64%), urinating more often than usual (43%), and having to urinate many times during the night (33%).
- Upon noticing signs and symptoms of bladder cancer for the first time, 39% of respondents sought care immediately and 43% sought care within 3-months. 85% of respondents first talked to their GP about the health problem caused by bladder cancer.

- Most respondents saw their doctor once (45%) or twice (27%) before being told they needed to see a specialist about bladder cancer. Most respondents felt their symptoms were taken seriously during their first visit to a doctor (67% 'yes, definitely' and 20% 'yes, to some extent').
- Of those who delayed seeing their doctor about the signs and symptoms they had, 41% said it was because they did not think it was serious, and 45% thought it was caused by something else.
- 81% of respondents were diagnosed within 3-months of seeing their doctor about the signs and symptoms they had. 46% said the length of time it took to be diagnosed caused them concern or extra worry.
- 27% said the doctor did not clearly communicate that they were testing for bladder cancer. 65% were diagnosed with another condition before bladder cancer – the most common was a urinary tract infection (37%).
- Most respondents received their diagnosis in a face-to-face meeting (65%), while 14% received it over the phone and 13% during a medical procedure. 60% were not told they could bring a family member or friend with them.
- Most respondents understood their diagnosis (62% 'completely' and 32% 'some of it'). However, 17% did not receive all the information they needed about their diagnosis, and 18% did not have access to all their test results.

Findings: Treatment

- 12% said they wanted to be more involved in decisions about their care and treatment.
- 91% had their treatment options explained to them (completely, or to some extent).
- 21% asked for a second opinion on their diagnosis and treatment, and 18% got one.
- 82% did not have barriers stopping them from getting treatment. The most common barriers to treatment access were treatment waiting times (6%) and lack of access to treatment or drugs (e.g., BCG) (6%).
- 17% said it was difficult to travel to their treatments.

- 29% had their treatments delayed or cancelled by their medical centre at least once, and 41% said it was because of the COVID-19 pandemic.
- 92% did not receive information about clinical trials, and only 4% took part in one.

Findings: Radical Cystectomy

- Most respondents had muscle invasive bladder cancer (74%) or non-muscle invasive bladder cancer (23%) when the decision to perform a cystectomy was made.
- 69% of respondents said radical cystectomy was the only treatment option discussed to them. 14% did not think that enough consideration was given to other treatments that would allow them to keep their bladder.
- Most respondents had an ileal conduit (86%) or neobladder (9%) reconstruction.
- 58% were not counselled before surgery about the sexual side effects related to radical cystectomy.

Findings: Supportive and complementary care

- Of those who needed it, 83% received enough support from doctors, 90% received enough support from nurses and other healthcare providers and 94% received enough support from family and friends throughout their treatment and care.
- Almost all respondents (91%) needed emotional support throughout treatment and care, but 32% of them did not receive it. 60% were not offered emotional support to help cope with their diagnosis.
- Emotional support was most needed during treatment (65%), after diagnosis (55%), and at the point of diagnosis (44%).
- Over half (58%) needed financial support throughout their treatment and care, but 54% of them did not receive it.
- 63% needed practical support throughout their treatment and care, but 22% of them did not receive it.

- Respondents needed more information about treatment options and duration (54%), the side effects of treatment (47%) and diagnosis and what it means (45%).
- 81% did not receive information on peer-support groups or charities to support people with bladder cancer. Of those who contacted a support group (45%), only 8% did not get the information and support that they needed.

Findings: Impact on daily life

- 10% said their financial situation was severely impacted due to bladder cancer. 15% said they took an early retirement, 10% were temporarily off work, and 5% voluntarily left their job because of their bladder cancer.
- 27% said treatment impacted their ability to carry out daily activities (extremely, or a lot).

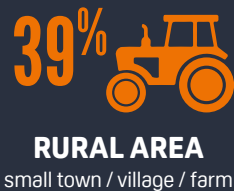
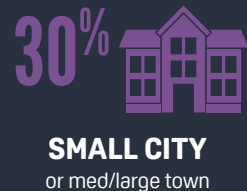
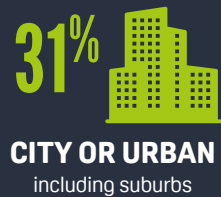
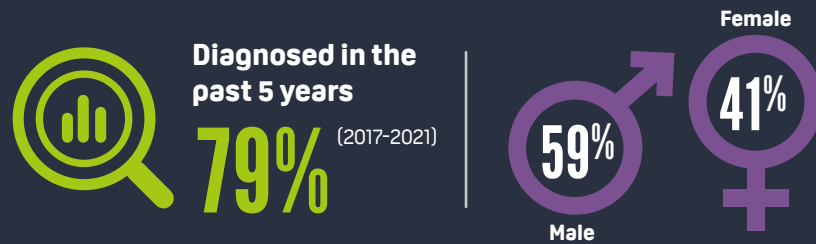
- 15% said they were not able to live a full life, and a further 14% were not able to cope, following diagnosis and treatment.
- 53% said the long-term emotional impact of treatment for bladder cancer have not been fully addressed or treated.

The emotional impact of bladder cancer impacted respondents (severely, and to some extent) in the following areas of life:

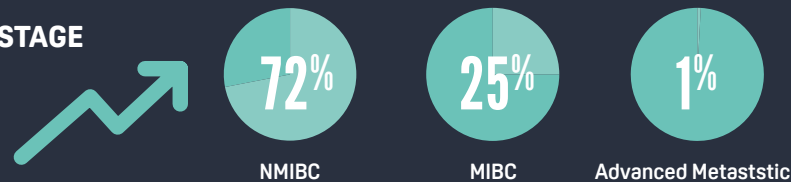


FRANCE

RESPONDENT PROFILE

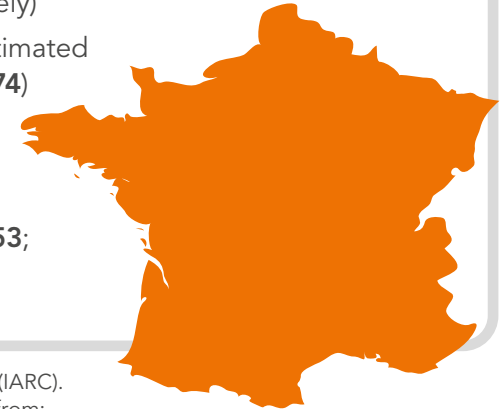


STAGE



COUNTRY STATISTICS: FRANCE

- Approximately **16,492** new diagnoses were estimated in 2020 (men = **13,321**; women = **3,171**; **5.7%** and **1.7%** of all new cancer incidences, respectively)
- In 2020, **7,713** deaths are estimated (men = **6,039**; women = **1,674**)
- There are **53,339** people living with bladder cancer in France after a diagnosis of bladder cancer (men = **43,753**; women = **9,646**)



International Agency for Research on Cancer (IARC). France Fact Sheet Globocan 2020. Available from: <https://gco.iarc.fr/today/data/factsheets/populations/250-france-fact-sheets.pdf>

Findings: Awareness

- 68% did not know any symptoms of bladder cancer before diagnosis.
- 23% knew that visible blood in urine was a symptom of bladder cancer.
- Compared to other common cancer types, only 12% of respondents understood the signs and symptoms of bladder cancer before diagnosis.

Findings: Diagnosis

- The most common signs and symptoms people were experience prior to diagnosis was visible blood in urine (60%), urinating more often than usual (32%) and feeling as if you need to go right away, even when the bladder isn't full (26%).
- Upon noticing signs and symptoms of bladder cancer for the first time, 39% of respondents sought care immediately and 41% sought care within 3-months. 73% of respondents first talked to their GP about the health problem caused by bladder cancer.

- Most respondents saw their doctor once (49%) or twice (23%) before being told they needed to see a specialist about bladder cancer. Most respondents felt their symptoms were taken seriously during their first visit to a doctor (72% 'yes, definitely' and 10% 'yes, to some extent').
- Of those who delayed seeing their doctor about the signs and symptoms they had, 42% said it was because they did not think it was serious, 29% thought it was caused by something else, and 29% were waiting to see if it would go away on its own.
- 78% of respondents were diagnosed within 3-months of seeing their doctor about the signs and symptoms they had. 85% said the length of time it took to be diagnosed caused them concern or extra worry.
- 23% said the doctor did not clearly communicate that they were testing for bladder cancer. 43% were diagnosed with another condition before bladder cancer – the most common was a urinary tract infection (22%).
- Most respondents received their diagnosis in a face-to-face meeting (77%), while 8% received it over the phone and 7% during a medical procedure. 63% were not told they could bring a family member or friend with them.
- Most respondents understood their diagnosis (65% 'completely' and 25% 'some of it'). However, 15% did not receive all the information they needed about their diagnosis, and 5% did not have access to all their test results.

Findings: Treatment

- 18% said they wanted to be more involved in decisions about their care and treatment.
- 83% had their treatment options explained to them (completely, or to some extent).
- 34% asked for a second opinion on their diagnosis and treatment, and 28% got one.
- 65% did not have barriers stopping them from getting treatment. The most common barriers to treatment access were lack of access to

treatment or drugs (e.g., BCG) (8%) and feeling that the side effects outweighed the benefits (6%).

- 9% said it was difficult to travel to their treatments.
- 33% had their treatments delayed or cancelled by their medical centre at least once, and 3% said it was because of the COVID-19 pandemic.
- 81% did not receive information about clinical trials, and only 8% took part in one.

Findings: Radical Cystectomy

- Most respondents had muscle invasive bladder cancer (83%) or non-muscle invasive bladder cancer (10%) when the decision to perform a cystectomy was made.
- 93% of respondents said radical cystectomy was the only treatment option discussed to them. 10% did not think that enough consideration was given to other treatments that would allow them to keep their bladder.
- Most respondents had an ileal conduit (45%) or neobladder (52%) reconstruction.
- 41% were not counselled before surgery about the sexual side effects related to radical cystectomy.

Findings: Supportive and complementary care

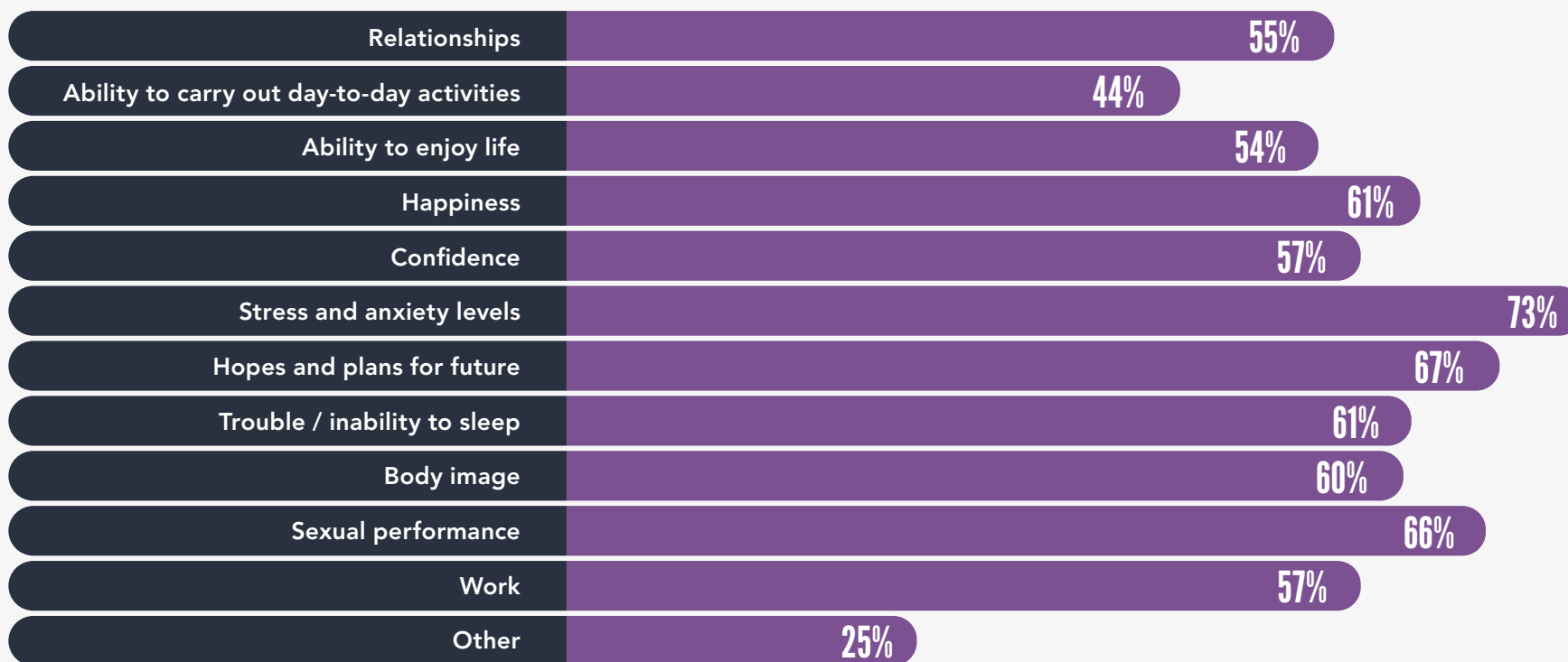
- Of those who needed it, 82% received enough support from doctors, 92% received enough support from nurses and other healthcare providers and 89% received enough support from family and friends throughout their treatment and care.
- Almost all respondents (92%) needed emotional support throughout treatment and care, but 38% of them did not receive it. 61% were not offered emotional support to help cope with their diagnosis.
- Emotional support was most needed during treatment (49%), after diagnosis (37%), and at the point of diagnosis (48%).
- 73% needed financial support throughout their treatment and care, but 70% of them did not receive it.

- 68% needed practical support throughout their treatment and care, but 76% of them did not receive it.
- Respondents needed more information about treatment options and duration (56%), the side effects of treatment (50%) and diagnosis and what it means (49%).
- 89% did not receive information on peer-support groups or charities to support people with bladder cancer. Of those who contacted a support group (55%), only 5% did not get the information and support that they needed.

Findings: Impact on daily life

- 11% said their financial situation was severely impacted. 8% took an early retirement, 15% were temporarily off work due to bladder cancer.
- 26% said treatment impacted their ability to carry out daily activities (extremely, or a lot).
- 18% were not able to live a full life following their diagnosis and treatment, and 10% were not able to cope.
- 64% said the long-term emotional impact of treatment for bladder cancer have not been fully addressed or treated.

The emotional impact of bladder cancer impacted respondents (severely, and to some extent) in the following areas of life:



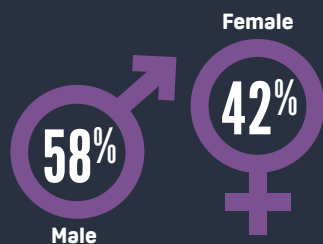
ITALY

RESPONDENT PROFILE

 **TOTAL RESPONSES = 95 Patients and 7 Carers**



Diagnosed in the past 5 years
(2017-2021)
74%



CITY OR URBAN
including suburbs



SMALL CITY
or med/large town



RURAL AREA
small town / village / farm



STAGE



COUNTRY STATISTICS: ITALY

- Approximately **25,500** new diagnoses were estimated in **2020** (men = **20,500**; women = **5,000**; **10.5%** and **3%** of all new cancer incidences, respectively)
- In 2021, **6,100** deaths are estimated (men = **4,800**; women = **1,300**)
- There are **313,600** people living with bladder cancer in Italy after a diagnosis of bladder cancer (men = **255,000**; women = **58,600**)



I Numeri del Cancro in Italia 2022, Italian Association of Medical Oncology (AIOM). Available from: https://www.aiom.it/wp-content/uploads/2022/12/2022_AIOM_NDC-web.pdf.

Findings: Awareness

- 61% did not know any symptoms of bladder cancer before diagnosis.
- 30% knew that visible blood in urine was a symptom of bladder cancer.
- Compared to other common cancer types, 51% of respondents understood the signs and symptoms of bladder cancer before diagnosis.

Findings: Diagnosis

- The most common signs and symptoms people were experience prior to diagnosis was visible blood in urine (54%), urinating more often than usual (47%) and having to get up many times in the night to urinate (36%).
- 49% of respondents first talked to their GP about the health problem caused by bladder cancer, and 51% went straight to the hospital/ specialist/emergency room.

- Most respondents saw their doctor once (71%) or twice (15%) before being told they needed to see a specialist about bladder cancer. Most respondents felt their symptoms were taken seriously during their first visit to a doctor (58% 'yes, definitely' and 14% 'yes, to some extent').
- Of those who delayed seeing their doctor initially, 34% thought their symptoms were caused by something other than bladder cancer and 26% said it was because they did not think their symptoms were serious.
- 80% of respondents were diagnosed within 3-months of seeing their doctor about signs and symptoms. 88% said the length of time it took to be diagnosed caused them concern or extra worry.
- 26% said the doctor did not clearly communicate that they were testing for bladder cancer. 58% were diagnosed with another condition before bladder cancer – the most common was cystitis (25%) and prostate problems (17%).
- Most respondents understood their diagnosis (68% 'completely' and 27% 'some of it'). However, 11% did not receive all the information they needed about their diagnosis, and 6% did not have access to all their test results.

Findings: Treatment

- 18% said they wanted to be more involved in decisions about their care and treatment.
- 81% had their treatment options explained to them (completely, or to some extent).
- 76% asked for a second opinion on their diagnosis and treatment, and 75% got one.
- 71% did not have barriers stopping them from getting treatment. The most common barrier cited was treatment waiting times (7%).
- 17% said it was difficult to travel to their treatments.
- 38% had their treatments delayed or cancelled by their medical centre at least once, and 26% said it was because of the COVID-19 pandemic.

- 76% did not receive information about clinical trials, and 17% took part in one.

Findings: Radical Cystectomy

- Most respondents had muscle invasive bladder cancer (76%) or non-muscle invasive bladder cancer (24%) when the decision to perform a cystectomy was made.
- 93% of respondents said radical cystectomy was the only treatment option discussed them. 21% did not think that enough consideration was given to other treatments that would allow them to keep their bladder.
- Most respondents had an ileal conduit (45%) or neobladder (52%) reconstruction.
- 52% were not counselled before surgery about the sexual side effects.

Findings: Supportive and complementary care

- Of those who needed it, 76% received enough support from doctors, 86% received enough support from nurses and other healthcare providers and 99% received enough support from family and friends throughout their treatment and care.
- Almost all respondents (95%) needed emotional support throughout treatment and care, but 38% of them did not receive it. 74% were not offered emotional support to help cope with their diagnosis.
- Emotional support was most needed just after diagnosis (49%), at the point of diagnosis (42%), and during treatment (40%).
- 72% needed financial support throughout their treatment and care, but 72% of them did not receive it.
- 80% needed practical support throughout their treatment and care, but 31% of them did not receive it.
- Respondents needed more information about treatment options and duration (64%), the side effects of treatment (39%) and diagnosis and what it means (48%).

- 82% did not receive information on peer-support groups or charities to support people with bladder cancer. Of those who contacted a support group (71%), everyone received the information and support that they needed (definitely, and to some extent).
- 29% said treatment impacted their ability to carry out daily activities (extremely, or a lot).
- 20% were not able to live a full life following their diagnosis and treatment, and 25% were not able to cope.

Findings: Impact on daily life

- 12% said their financial situation was severely impacted. 8% took an early retirement, 11% were temporarily off work due to bladder cancer.

The emotional impact of bladder cancer impacted respondents (severely, and to some extent) in the following areas of life:

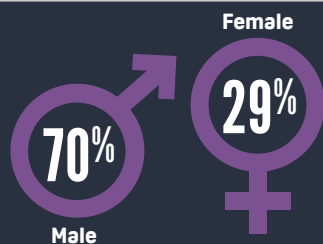


NORWAY

RESPONDENT PROFILE



Diagnosed in the past 5 years (2017-2021)
66%



CITY OR URBAN
including suburbs



SMALL CITY
or med/large town



RURAL AREA
small town / village / farm



STAGE



COUNTRY STATISTICS: NORWAY

- Approximately **1,852** new diagnoses were estimated in 2020 (men = **1,410**; women = **442**; **7%** and **3%** of all new cancer incidences, respectively)
- In 2020, **349** deaths are estimated (men = **241**; women = **108**)
- There are **15,950** people living with bladder cancer in Norway after a diagnosis of bladder cancer



Cancer Registry of Norway. Cancer in Norway 2020 - Cancer incidence, mortality, survival and prevalence in Norway. Oslo: Cancer Registry of Norway, 2021.

Findings: Awareness

- 49% did not know any symptoms of bladder cancer before diagnosis.
- 38% knew that visible blood in urine was a symptom of bladder cancer.
- Compared to other common cancer types, 29% understood the signs and symptoms of bladder cancer before diagnosis.

Findings: Diagnosis

- The most common signs and symptoms people were experience prior to diagnosis was visible blood in urine (73%), urinating more often than usual (48%) and having to get up many times in the night to urinate (32%).
- Upon noticing signs and symptoms of bladder cancer for the first time, 40% of respondents sought care immediately and a further 43% sought care within 3-months.

- 87% of respondents first talked to their GP about the health problem.
- Most respondents saw their doctor once (54%) or twice (19%) before being told they needed to see a specialist about bladder cancer. Most respondents felt their symptoms were taken seriously during their first visit to a doctor (56% 'yes, definitely' and 13% 'yes, to some extent').
- Of those who delayed seeing their doctor initially, 37% were waiting to see if it would go away on its own, and 33% thought it was caused by something else.
- 73% of respondents were diagnosed within 3-months of seeing their doctor about signs and symptoms. 58% said the length of time it took to be diagnosed caused them concern or extra worry.
- 33% said the doctor did not clearly communicate that they were testing for bladder cancer. 61% were diagnosed with another condition before bladder cancer – the most common was a urinary tract infection (29%).
- Most respondents received their diagnosis in a face-to-face meeting (52%), and 23% during a medical procedure. 83% were not told they could bring a family member or friend with them.
- Most respondents understood their diagnosis (54% 'completely' and 38% 'some of it'). However, 26% did not receive all the information they needed about their diagnosis, and 19% did not have access to all their test results.

Findings: Treatment

- 23% wanted to be more involved in decisions about their care and treatment.
- 78% had their treatment options explained to them (completely, or to some extent).
- 19% asked for a second opinion on their diagnosis and treatment, and 15% got one.
- 86% did not have barriers stopping them from getting treatment. The most common barrier cited was treatment waiting times (6%).

- 5% said it was difficult to travel to their treatments.
- 10% had their treatments delayed or cancelled by their medical centre at least once, and 20% said it was because of the COVID-19 pandemic.
- 84% did not receive information about clinical trials, and 8% took part in one.

Findings: Radical Cystectomy

- Most respondents had muscle invasive bladder cancer (74%) or non-muscle invasive bladder cancer (18%) when the decision to perform a cystectomy was made.
- 90% of respondents said radical cystectomy was the only treatment option discussed to them. 10% did not think that enough consideration was given to other treatments that would allow them to keep their bladder.
- Most respondents had an ileal conduit (72%) or neobladder (23%) reconstruction.
- 36% were not counselled before surgery about the sexual side effects.

Findings: Supportive and complementary care

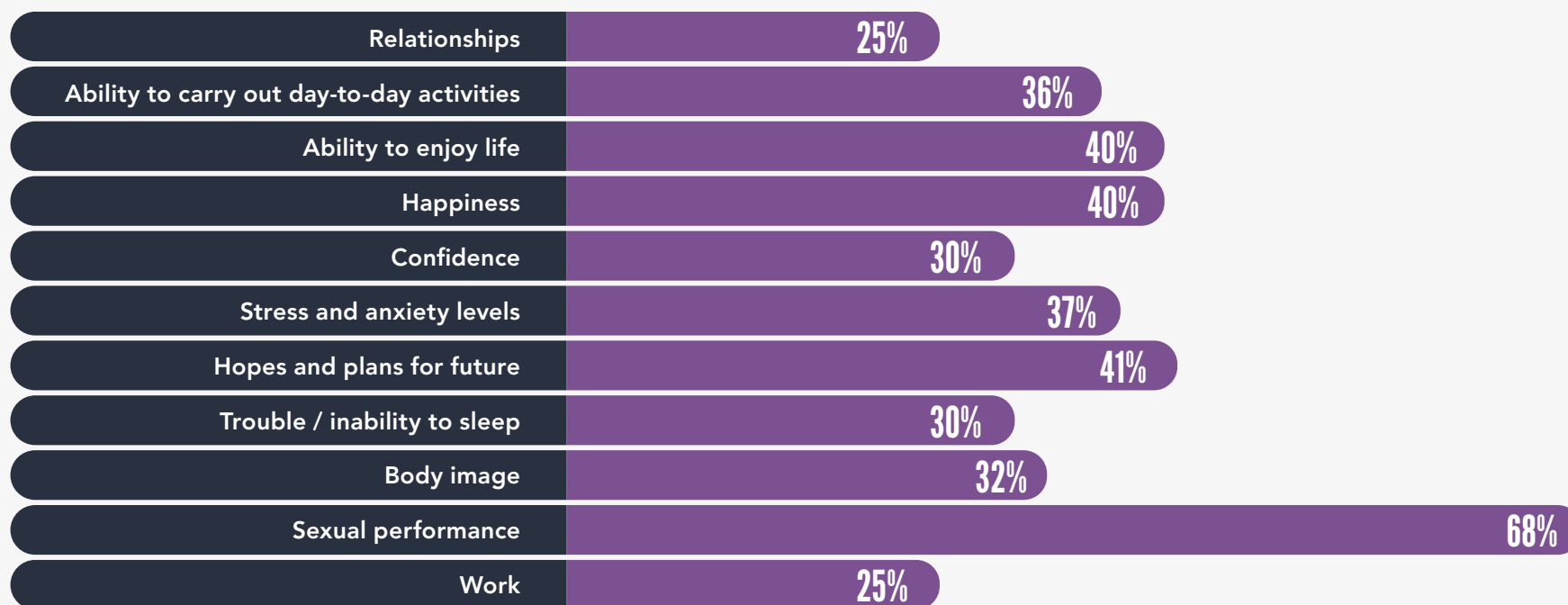
- Of those who needed it, 83% received enough support from doctors, 93% received enough support from nurses and other healthcare providers and 92% received enough support from family and friends throughout treatment and care.
- 66% needed emotional support throughout treatment and care, but 64% of them did not receive it. 77% were not offered emotional support to help cope with their diagnosis.
- Emotional support was most needed just after diagnosis (45%), at the point of diagnosis (51%), and during treatment (39%).
- 42% needed financial support throughout their treatment and care, but 53% of them did not receive it.
- 47% needed practical support throughout their treatment and care, but 44% of them did not receive it.

- Respondents needed more information about treatment options and duration (50%), the side effects of treatment (34%) and diagnosis and what it means (46%).
- 59% did not receive information on peer-support groups or charities to support people with bladder cancer. Of those who contacted a support group (66%), 96% received the information and support that they needed (definitely, and to some extent).
- 16% said treatment impacted their ability to carry out daily activities (extremely, or a lot).
- 8% were not able to live a full life following their diagnosis and treatment, and 8% were not able to cope.
- 53% said the long-term emotional impact of treatment for bladder cancer have not been fully addressed or treated.

Findings: Impact on daily life

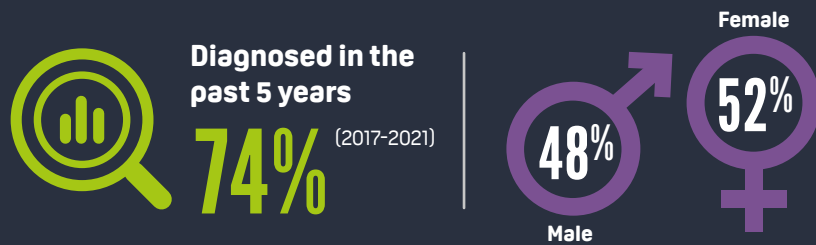
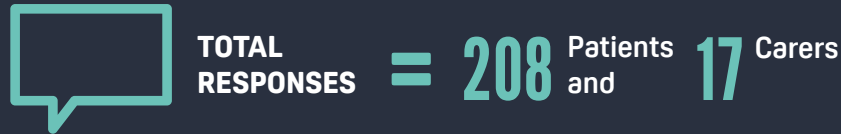
- 5% said their financial situation was severely impacted. 14% took an early retirement.

The emotional impact of bladder cancer impacted respondents (severely, and to some extent) in the following areas of life:



UNITED KINGDOM

RESPONDENT PROFILE

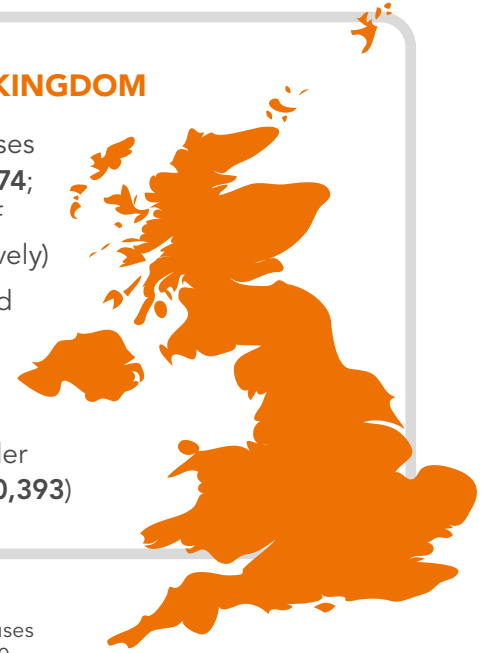


STAGE



COUNTRY STATISTICS: UNITED KINGDOM

- Approximately **12,434** new diagnoses were estimated in 2020 (men = **8,974**; women = **3,460**; **4.2%** and **1.8%** of all new cancer incidences, respectively)
- In 2020, **6,458** deaths are estimated (men = **4,460**; women = **1,998**)
- There are **41,366** people living with bladder cancer in the United Kingdom after a diagnosis of bladder cancer (men = **30,427**; women = **10,393**)



These incidence and prevalence rates are likely to be underestimated. The Global Cancer Observatory focuses on invasive bladder cancer, classified under the ICD-10 code C67. This code refers to bladder cancer that has spread beyond the bladder's lining and into the surrounding connective tissue or muscles. It does not include non-invasive types of bladder cancer, such as carcinoma in situ (ICD-10 D09.0) and neoplasms of uncertain behaviour (ICD-10 D41.4).

International Agency for Research on Cancer (IARC). United Kingdom Fact Sheet Globocan 2020. Available from: <https://gco.iarc.fr/today/data/factsheets/populations/826-united-kingdom-fact-sheets.pdf>

Findings: Awareness

- 58% did not know any symptoms of bladder cancer before diagnosis.
- 36% knew that visible blood in urine was a symptom of bladder cancer.
- Compared to other common cancer types, 31% understood the signs and symptoms of bladder cancer before diagnosis.

Findings: Diagnosis

- The most common signs and symptoms people were experience prior to diagnosis was visible blood in urine (73%), urinating more often than usual (37%) and feeling like you need to go right away even when your bladder isn't full (28%).

- Upon noticing signs and symptoms of bladder cancer for the first time, 45% of respondents sought care immediately and a further 39% sought care within 3-months.
- 87% of respondents first talked to their GP about the health problem, and 11% went straight to the hospital/specialist/emergency room.
- Most respondents saw their doctor once (52%) or twice (23%) before being told they needed to see a specialist about bladder cancer. Most respondents felt their symptoms were taken seriously during their first visit to a doctor (61% 'yes, definitely' and 12% 'yes, to some extent').
- Of those who delayed seeing their doctor initially, 31% did not think it was serious, and 42% thought it was caused by something else.
- 78% of respondents were diagnosed within 3-months of seeing their doctor about signs and symptoms. 55% said the length of time it took to be diagnosed caused them concern or extra worry.
- 40% said the doctor did not clearly communicate that they were testing for bladder cancer. 63% were diagnosed with another condition before bladder cancer – the most common was a urinary tract infection (37%).
- Most respondents received their diagnosis in a face-to-face meeting (52%), and 38% during a medical procedure. 58% were not told they could bring a family member or friend with them.
- Most respondents understood their diagnosis (57% 'completely' and 35% 'some of it'). However, 19% did not receive all the information they needed about their diagnosis, and 28% did not have access to all their test results.

Findings: Treatment

- 17% wanted to be more involved in decisions about their care and treatment.
- 88% had their treatment options explained to them (completely, or to some extent).
- 15% asked for a second opinion on their diagnosis and treatment, and 11% got one.

- 78% did not have barriers stopping them from getting treatment. The most common barrier cited was treatment waiting times (7%).
- 9% said it was difficult to travel to their treatments.
- 32% had their treatments delayed or cancelled by their medical centre at least once, and 46% said it was because of the COVID-19 pandemic.
- 90% did not receive information about clinical trials, and 5% took part in one.

Findings: Radical Cystectomy

- Most respondents had muscle invasive bladder cancer (53%) or non-muscle invasive bladder cancer (43%) when the decision to perform a cystectomy was made.
- 47% of respondents said radical cystectomy was the only treatment option discussed to them. 11% did not think that enough consideration was given to other treatments that would allow them to keep their bladder.
- Most respondents had an ileal conduit (88%) or neobladder (9%) reconstruction.
- 52% were not counselled before surgery about the sexual side effects.

Findings: Supportive and complementary care

- Of those who needed it, 73% received enough support from doctors, 80% received enough support from nurses and other healthcare providers and 95% received enough support from family and friends throughout treatment and care.
- 91% needed emotional support throughout treatment and care, but 37% of them did not receive it. 51% were not offered emotional support to help cope with their diagnosis.
- Emotional support was most needed just after diagnosis (58%), at the point of diagnosis (42%), and during treatment (46%).
- 50% needed financial support throughout their treatment and care, but 68% of them did not receive it.

- 63% needed practical support throughout their treatment and care, but 38% of them did not receive it.
- Respondents needed more information about treatment options and duration (59%), the side effects of treatment (41%) and diagnosis and what it means (48%).
- 50% did not receive information on peer-support groups or charities to support people with bladder cancer. Of those who contacted a support group (67%), 97% received the information and support that they needed (definitely, and to some extent).

Findings: Impact on daily life

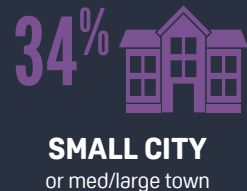
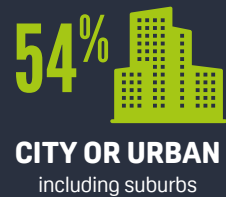
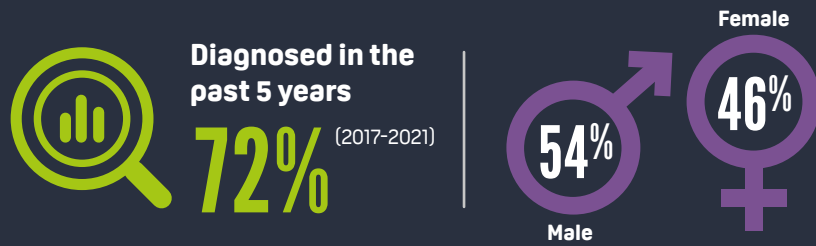
- 11% said their financial situation was severely impacted. 15% took an early retirement and 10% were temporarily off work.
- 24% said treatment impacted their ability to carry out daily activities (extremely, or a lot).
- 10% were not able to live a full life following their diagnosis and treatment, and 12% were not able to cope.
- 47% said the long-term emotional impact of treatment for bladder cancer have not been fully addressed or treated.

The emotional impact of bladder cancer impacted respondents (severely, and to some extent) in the following areas of life:

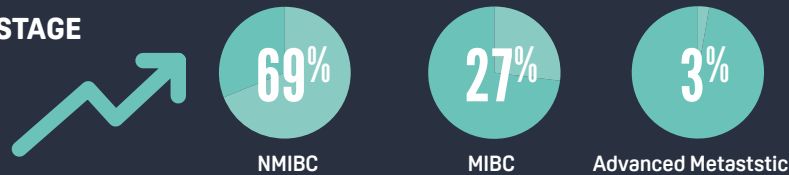


UNITED STATES

RESPONDENT PROFILE

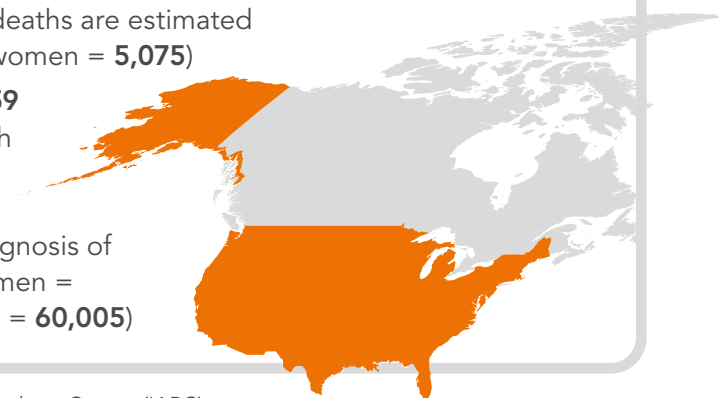


STAGE



COUNTRY STATISTICS: UNITED STATES

- Approximately **80,617** new diagnoses were estimated in 2020 (men = **61,795**; women = **18,822**; **7%** and **2.2%** of all new cancer incidences, respectively)
- In 2020, **18,130** deaths are estimated (men = **13,055**; women = **5,075**)
- There are **269,259** people living with bladder cancer in the United States after a diagnosis of bladder cancer (men = **209,254**; women = **60,005**)



International Agency for Research on Cancer (IARC). United States Fact Sheet Globocan 2020. Available from: <https://gco.iarc.fr/today/data/factsheets/populations/840-united-states-of-america-fact-sheets.pdf>

Findings: Awareness

- 54% did not know any symptoms of bladder cancer before diagnosis.
- 30% knew that visible blood in urine was a symptom of bladder cancer.
- Compared to other common cancer types, 32% understood the signs and symptoms of bladder cancer before diagnosis.

Findings: Diagnosis

- The most common signs and symptoms people were experience prior to diagnosis was visible blood in urine (73%), urinating more often than usual (45%), having to get up many times in the night to urinate (29%), and feeling as if you needed to go right away even when your bladder isn't full (29%).

- Upon noticing signs and symptoms of bladder cancer for the first time, 39% of respondents sought care immediately and a further 43% sought care within 3-months.
- 63% of respondents first talked to their GP about the health problem, 35% went straight to the hospital/specialist/emergency room.
- 77% of respondents were diagnosed within 3-months of seeing their doctor about signs and symptoms. 54% said the length of time it took to be diagnosed caused them concern or extra worry.
- 25% said the doctor did not clearly communicate that they were testing for bladder cancer. 65% were diagnosed with another condition before bladder cancer – the most common was a urinary tract infection (39%).
- Most respondents received their diagnosis in a face-to-face meeting (61%), and 17% during a medical procedure. 46% were not told they could bring a family member or friend with them.
- Most respondents understood their diagnosis (66% 'completely' and 27% 'some of it'). However, 21% did not receive all the information they needed about their diagnosis, and 7% did not have access to all their test results.

Findings: Treatment

- 89% had their treatment options explained to them (completely, or to some extent).
- 55% asked for a second opinion on their diagnosis and treatment, and 51% got one.
- 78% did not have barriers stopping them from getting treatment. The most common barrier cited was treatment waiting times (5%).
- 6% said it was difficult to travel to their treatments.
- 28% had their treatments delayed or cancelled by their medical centre at least once, and 14% said it was because of the COVID-19 pandemic.
- 77% did not receive information about clinical trials, and 9% took part in one.

Findings: Radical Cystectomy

- Most respondents had muscle invasive bladder cancer (71%) or non-muscle invasive bladder cancer (24%) when the decision to perform a cystectomy was made.
- 68% of respondents said radical cystectomy was the only treatment option discussed to them. 8% did not think that enough consideration was given to other treatments that would allow them to keep their bladder.
- Most respondents had an ileal conduit (68%) or neobladder (24%) reconstruction.
- 54% were not counselled before surgery about the sexual side effects.

Findings: Supportive and complementary care

- Of those who needed it, 84% received enough support from doctors, 86% received enough support from nurses and other healthcare providers and 93% received enough support from family and friends throughout treatment and care.
- 97% needed emotional support throughout treatment and care, but 15% of them did not receive it. 55% were not offered emotional support to help cope with their diagnosis.
- Emotional support was most needed just after diagnosis (52%), at the point of diagnosis (39%), and during treatment (57%).
- 66% needed financial support throughout their treatment and care, 30% of them did not receive it.
- 78% needed practical support throughout their treatment and care, but 14% of them did not receive it.
- Respondents needed more information about treatment options and duration (52%), the side effects of treatment (39%) and diagnosis and what it means (31%).

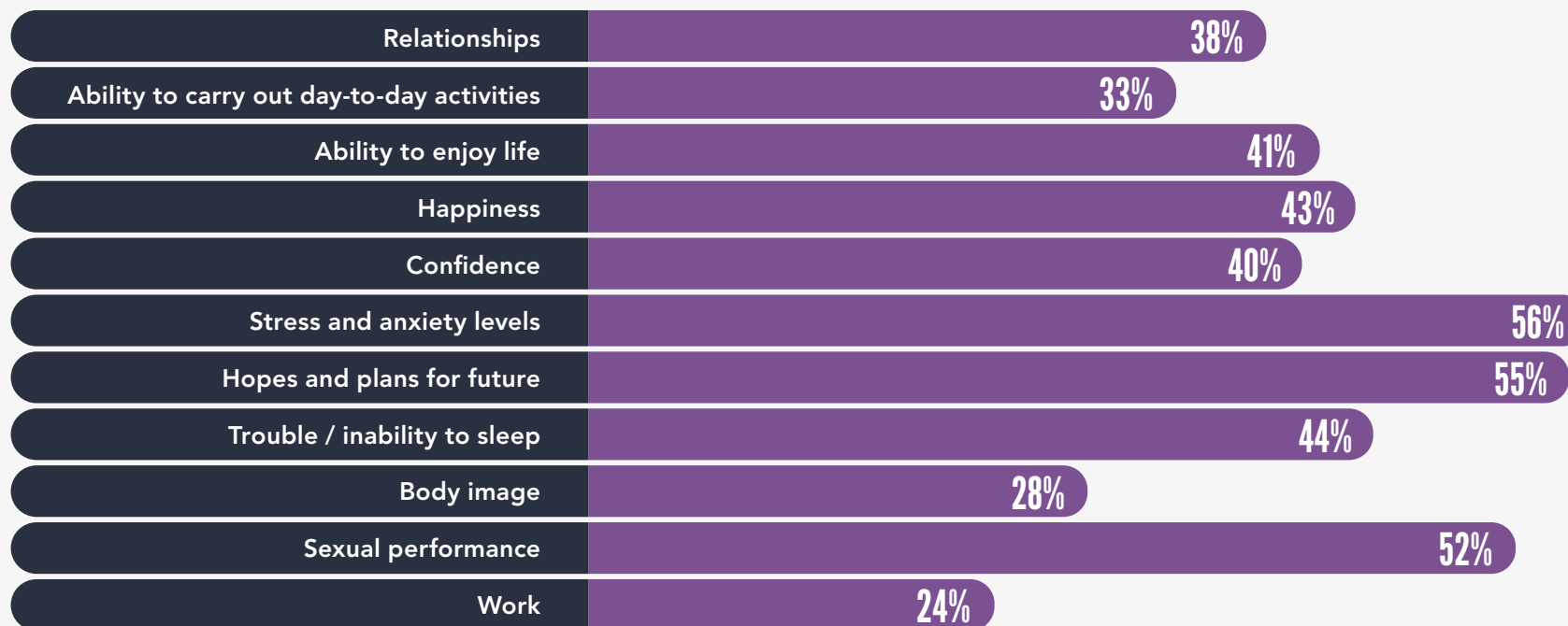
- 73% did not receive information on peer-support groups or charities to support people with bladder cancer. Of those who contacted a support group (50%), 93% received the information and support that they needed (definitely, and to some extent).

- 39% said the long-term emotional impact of treatment for bladder cancer have not been fully addressed or treated.

Findings: Impact on daily life

- 21% said treatment impacted their ability to carry out daily activities (extremely, or a lot).
- 12% were not able to live a full life following their diagnosis and treatment, and 10% were not able to cope.

The emotional impact of bladder cancer impacted respondents (severely, and to some extent) in the following areas of life:



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