BCAN
Bladder Cancer Advocacy Network

# THE NEW FACES OF BLADDER CANCER

2026

**BCAN is grateful to our generous sponsors of the New Faces of Bladder Cancer survey.**

FERRING
PHARMACEUTICALS

Johnson&Johnson

UroGen®
Pharma

# TABLE OF CONTENTS:

# EXECUTIVE SUMMARY

For two decades, the Bladder Cancer Advocacy Network (BCAN) has championed bladder cancer research, education, and advocacy. In celebration of our 20th anniversary, BCAN launched the New Faces of Bladder Cancer 2025 Survey—the most comprehensive patient-centered research initiative in our organization's history. With over 1,100 completed responses from individuals across 49 U.S. states and Puerto Rico, this landmark study captures the complete spectrum of bladder cancer experiences, from pre-diagnosis symptoms through long-term survivorship, revealing both remarkable progress in care delivery and persistent gaps that demand attention. We are grateful to our partners, Ferring Pharmaceuticals, Inc., Johnson & Johnson and UroGen for their support of this critical initiative.

## Survey Demographics and Representation

Survey respondents represent a diverse clinical experience across all bladder cancer stages: 47% were initially diagnosed with non-muscle invasive bladder cancer (NMIBC) or carcinoma in situ (CIS; 23%), 22% with muscle-invasive disease (MIBC), and smaller proportions with advanced, metastatic, or upper tract urothelial carcinoma (UTUC). Geographically, participants came from urban (86%), suburban (7%), and rural (6%) communities, with the median age of 70 at survey completion and 66 at diagnosis—closely mirroring national epidemiologic patterns.

The sample was predominantly male (61%) and White (95%), with high educational attainment (74% holding college degrees or higher) and relatively high household incomes (52% earning over $100,000 annually). Nearly all respondents had health insurance, primarily Medicare (68%) and private coverage (49%). While this profile aligns with typical bladder cancer demographics, the significant underrepresentation of racial and ethnic minorities, rural residents, and economically disadvantaged populations highlights critical limitations and points to broader equity challenges in both research participation and care access.

# Two Decades of Progress: A Changing Landscape

The data reveal transformative improvements in bladder cancer care over the past 20 years. Patients diagnosed within the past decade experienced a fundamentally different care environment compared to those diagnosed earlier:

**Enhanced Treatment Options and Shared Decision-Making:** Recently diagnosed patients were far more likely to receive multiple treatment options across all disease stages, reflecting rapid therapeutic advances including novel intravesical therapies, immunotherapies, and targeted agents. Shared decision-making has strengthened considerably—only 34% of recently diagnosed patients reported their treatment goals were not discussed, compared to 42% diagnosed over a decade ago.

**Improved Patient Education and Information Access:** Pathology report comprehension has improved dramatically, with patients consistently noting that "pathology reports are more readable now" and expressing gratitude for BCAN resources that demystified complex medical terminology. Written materials, internet resources, and BCAN-specific educational tools were all more commonly utilized and understood by recently diagnosed patients (28% vs. 25% for written materials; 40% vs. 30% for internet resources; 14% vs. 6% for BCAN resources).

**Expanding Clinical Trial Awareness:** Clinical trial awareness and participation increased substantially, with 33% of recently diagnosed patients looking into trials compared to only 23% diagnosed over a decade ago. This reflects both expanded trial availability and improved patient education about research opportunities.

**Growing Recognition of Supportive Care Needs:** Mental health support recognition has strengthened, with 91% of recent patients acknowledging its importance compared to 83% diagnosed earlier. While gaps persist, recently diagnosed patients were more likely to be offered mental health resources (59% vs. 52%).

**Technological Advances in Diagnosis:** Modern flexible cystoscopes have dramatically improved the procedural experience, with several long-term survivors noting that contemporary equipment is "far easier to tolerate than the straight steel tubes of the past, which were excruciating."

# Persistent Challenges: Unmet Needs Across the Care Continuum

Despite progress, bladder cancer remains a profoundly disruptive illness with substantial room for improvement. Systemic gaps persist across diagnosis, treatment, and survivorship.

## *Diagnostic Delays and Sex-Based Disparities*

**Women face systematic disadvantages** throughout the diagnostic journey. Nearly half of women (45%) were treated for urinary tract infections before diagnosis compared to only 15% of men, often cycling through repeated antibiotics rather than receiving timely urologic evaluation. Women were less likely to seek care immediately (53% vs. 66% of men), almost twice as likely to wait 1-2 months, and significantly more likely to first see primary care or gynecology rather than urology (22% saw urology first vs. 39% of men). Critically, those with UTI histories were diagnosed with muscle-invasive disease more frequently, demonstrating how misdiagnosis leads to later-stage detection with worse outcomes.

**Younger adults face unique challenges,** with 41% of those under 50 reporting they would have liked more time to discuss treatment goals, and 52% receiving no mental health resources despite facing disrupted fertility, careers, and long-term life plans.

## *Inadequate Supportive Care Services*

**Mental health support remains woefully insufficient.** Despite 90% of respondents rating mental health resources as important, 41% were never offered any support by their clinical teams. Among those who did receive offers, only 14% utilized them, often due to insurance limitations, lack of cancer-focused counseling, or difficulty accessing services. Many described the additional burden of financial stress—"My stress is the stress of money"—highlighting how economic insecurity compounds emotional distress.

**Survivorship care planning is haphazard rather than systematic.** Despite 86% rating survivorship care plans as important, 57% were never offered one. Many had never heard of the concept until completing this survey but strongly wished they had structured guidance for follow-up testing, side effect management, and long-term health monitoring.

**Sexual function and continence support are severely underutilized.** Only 27% of patients who valued sexual function were offered relevant resources, and 30% of neobladder patients received no assistance with continence despite its profound impact on quality of life. Patients structured entire routines around bathroom access, experienced sleep disruption, and avoided social activities—yet help was seldom offered.

**Genetic testing remains uncommon** (12% of respondents), with many patients unaware such testing existed, unable to afford it, or receiving results without actionable guidance on treatment implications.

## *Financial Toxicity and Economic Barriers*

**Financial burden affected 20% of participants,** rising to 28% among women and 41% among those diagnosed before age 50. Most concerning, some patients explicitly stated that financial hardship directly influenced treatment decisions, describing delaying or declining recommended care due to cost. Only 6% recalled being told about drug-company assistance programs, and just 24% of those identifying cost as a barrier were offered any financial resources—representing a critical gap in patient navigation and support.

Hidden costs compounded the burden: travel, lodging, unpaid time off work, copays for repeated surveillance, and long-term supply needs (catheters, ostomy materials, incontinence products) were rarely reimbursed but profoundly affected patients' economic stability and treatment adherence.

## *The Emotional Weight of Recurrence*

**Fear of recurrence defined the survivor experience** for 79% of respondents, rising to 86% among women, 91% among those under 50, and 87% among those who still had their bladder. Patients described persistent "scanxiety," hypervigilance around bodily changes, and the challenge of "living with the reality of recurrence without it taking control." While many found strategies to coexist with this fear—through faith, support groups, daily gratitude practices, and peer connection—the data underscore that emotional support for this chronic anxiety remains inadequate.

# Call to Action: From Progress to Equity

Twenty years of BCAN leadership have yielded meaningful advances in bladder cancer treatment options, patient education, and community support. Yet this survey reveals that progress has been uneven, with persistent disparities by sex, age, geography, and socioeconomic status.

We must eliminate sex-based disparities in symptom recognition, diagnostic pathways, treatment discussions, and supportive care access. We must standardize mental health support, survivorship planning, genetic testing, fertility preservation discussions, and continence/sexual health counseling as core components of bladder cancer care rather than optional extras. We must address financial toxicity through systematic patient navigation, assistance program education, and policy advocacy. We must expand research participation to include rural, diverse, and economically disadvantaged populations whose voices remain underrepresented.

This report will guide BCAN's strategic priorities and inform the broader bladder cancer community's efforts to improve patient experiences. The voices captured here—resilient, hopeful, hurting, and determined—demand our continued commitment to advancing research, improving clinical practice, strengthening support services, and ensuring that all bladder cancer patients receive excellent medical care alongside comprehensive, equitable support throughout their journey. The progress of the past 20 years proves that transformation is possible; the persistent gaps documented here prove that our work is far from finished.

# ACKNOWLEDGMENTS

We gratefully acknowledge the bladder cancer patients who shared their experiences and perspectives in the New Faces of Bladder Cancer Survey. Your voices are vital to helping us understand the real-world impact of bladder cancer—across all types, stages, and experiences. Your input helps us create more meaningful programs and resources, advocate for patients' needs, and guide future research efforts.

This survey marks twenty years of BCAN’s commitment to serving the bladder cancer community. We are proud to document the evolving needs of patients and reaffirm our dedication to ensuring that every person facing bladder cancer has access to the information, education, and support they deserve.

Special thanks go out to the Survivor to Survivor support program volunteers who reviewed the survey drafts to ensure the questions reflected the most relevant issues facing our community. We also extend our appreciation to the team at Vital Statistics Consulting for their expertise in data analysis and interpretation.

We recognize the leadership of BCAN for identifying the need to document how the bladder cancer journey has evolved over the past 20 years, and for championing patient-centered research that continues to shape the future of bladder cancer care.

> ***“BCAN is the laymen’s best teacher and support system for making this journey.”***

# BACKGROUND AND PURPOSE

For two decades, the Bladder Cancer Advocacy Network (BCAN) has stood as the leading national organization dedicated to advancing bladder cancer research, patient education and support, and advocacy. Yet despite significant advances in treatment options and clinical understanding, the patient experience of navigating bladder cancer care remains inadequately documented and understood. In celebration of our 20th anniversary, BCAN launched the most ambitious patient-centered research initiative in our organization's history: the New Faces of Bladder Cancer 2025 Survey.

## A Landmark Investigation

The New Faces of Bladder Cancer survey represents the most extensive patient-reported data collection effort in BCAN's history, with over 1,000 completed survey responses incorporating both quantitative and qualitative data elements. This comprehensive, large-scale, mixed-methods study captures experiences, challenges, and unmet needs across the complete spectrum of bladder cancer—from non-muscle invasive disease through muscle invasive and metastatic cancer, including rare forms and upper tract urothelial carcinoma.

What sets this survey apart is its breadth and depth. Unlike clinical studies that focus on specific treatments or outcomes, this investigation examines the entire patient journey from pre-diagnosis symptoms through long-term survivorship. The 74-question survey explores not only medical experiences but also psychosocial challenges, financial impacts, support service access, and quality-of-life concerns that profoundly affect patients and their families.

## The Critical Need for Patient Voice

Bladder cancer represents a significant public health challenge, with the American Cancer Society estimating approximately 84,870 new cases in 2025 in the U.S.—over 75% of cases (65,080) among men.[1] This makes bladder cancer among the most common cancers, yet these patients have historically been underrepresented in comprehensive patient experience research.

Approximately 2.1% of men and women will be diagnosed with bladder cancer at some point during their lifetimes, based on 2018–2021 data, with men significantly more likely to be affected than women.[2]

Despite affecting hundreds of thousands of Americans, most existing data focuses on clinical outcomes and survival metrics, leaving crucial gaps in understanding the lived experience of diagnosis, treatment decision-making, side effect management, and long-term survivorship.

The healthcare landscape has evolved dramatically since the founding of BCAN in 2005. New treatment options, including novel intravesical therapies and immunotherapies, have expanded the therapeutic arsenal. Simultaneously, healthcare delivery has become increasingly complex, with patients navigating multiple care settings, insurance challenges, and evolving support services. These changes necessitate a comprehensive reassessment of patient experiences to identify both progress achieved and persistent gaps requiring attention.

## Amplifying Patient Voices for Systemic Change

The primary purpose of this landmark survey is to amplify the voices of those who have or have had bladder cancer, transforming individual experiences into actionable insights for systemic improvement. By documenting patient experiences across diverse geographic regions, cancer types, and care settings, this research provides the evidence base needed to drive meaningful changes in clinical practice, healthcare policy, and advocacy priorities.

This initiative is particularly timely as the bladder cancer community grapples with questions of care equity, treatment access, and quality-of-life support. The COVID-19 pandemic highlighted existing disparities in cancer care,[3] while rapid advances in treatment options have created new challenges in patient education and decision-making support. Understanding how patients experience these evolving challenges is essential for developing effective solutions.

# Looking Forward: From Data to Action

This report represents the first comprehensive analysis of patient voices that will guide BCAN's strategic priorities and inform the broader bladder cancer community's efforts to improve patient experiences.

By systematically analyzing patient experiences, identifying disparities, and developing actionable insights, this survey serves as a catalyst for the systemic changes needed to ensure that all bladder cancer patients receive not only excellent medical care but also comprehensive support throughout their cancer journey.

# METHODOLOGY

This mixed-methods research was conducted via an online survey using SurveyMonkey. The survey consisted of 74 questions, most of which were multiple choice but included free text boxes for respondents to share additional details. The survey was in English.

The *New Faces of Bladder Cancer 2025 Survey* was promoted with a multi-channel outreach strategy to ensure broad participation across the bladder cancer community. BCAN leveraged its *Inspire* online community of 50,000+ members,[4] posting a call to action that encouraged members to share their experiences and perspectives. The survey was also promoted through BCAN's social media channels, including four targeted posts on Facebook resulting in a reach of 1,790 accounts and through a dedicated email blast to 28,298 recipients on BCAN's mailing list. More than 500 participants in the monthly Female Focus support group were also encouraged to complete the survey. This coordinated approach helped reach both long-time bladder cancer survivors and new patient/survivor voices in the bladder cancer space.

We began with a total of 1,323 survey responses. We excluded responses from people residing outside the U.S. (n=52), missing key demographics (10 missing sex, 1 with implausible age, and 119 without an age at diagnosis or implausible diagnosis age), yielding a final analytical sample of 1,141 observations. Of participants who opened and initiated the survey, 65% completed the survey and the average completion time was approximately 45 minutes.

Quantitative analyses were conducted using R statistical software, and qualitative analyses were performed using dual coding and augmented by Copilot AI. For the questions with a text box for free response, we developed a series of codebooks that arose from the common themes throughout the questions' answers. Copilot AI was used to support the development of qualitative codebooks from functional formulas in Google Sheets. Additionally, Copilot AI helped troubleshoot any formula errors and REGEX logic.

Through iterative interaction, Copilot AI facilitated the development of BYROW/LAMBDA formulas capable of multi-label coding, ensuring that survey responses were consistently coded according to the established codebook. This process enhanced efficiency, reduced technical barriers, and contributed to the rigor and reproducibility of the qualitative data analysis. Minor grammar and spelling errors in participant quotes have been corrected throughout this document for readability.

Rurality was coded by cross-referencing respondent ZIP codes to Rural-Urban Commuting Area (RUCA) classifications.[5] ZIP codes were first mapped to Census tracts using the HUD-USPS ZIP Code Crosswalk files with residential address ratio weighting to account for ZIP codes spanning multiple tracts based on information from the 2010 decennial census and 2006-10 American Community Survey. Census tract identifiers were then linked to RUCA codes from the USDA Economic Research Service. RUCA codes were collapsed into three categories: urban (codes 1-3, representing metropolitan areas), suburban (codes 4-6, representing micropolitan areas), and rural (codes 7-10, representing small town and rural areas).

Insurance is complicated. Respondents were asked to select all types of health insurance they currently had. Throughout this report, we considered all respondents who selected a particular type of insurance – therefore, it was possible that respondents may be double-counted if they were covered by multiple types of insurance. Though there was not a specific question on the survey for veteran status, we defined veterans as either those who reported being in the military before or after the Vietnam War, or those who were using VA insurance. Respondents selected all types of bladder cancer they had ever been diagnosed with.

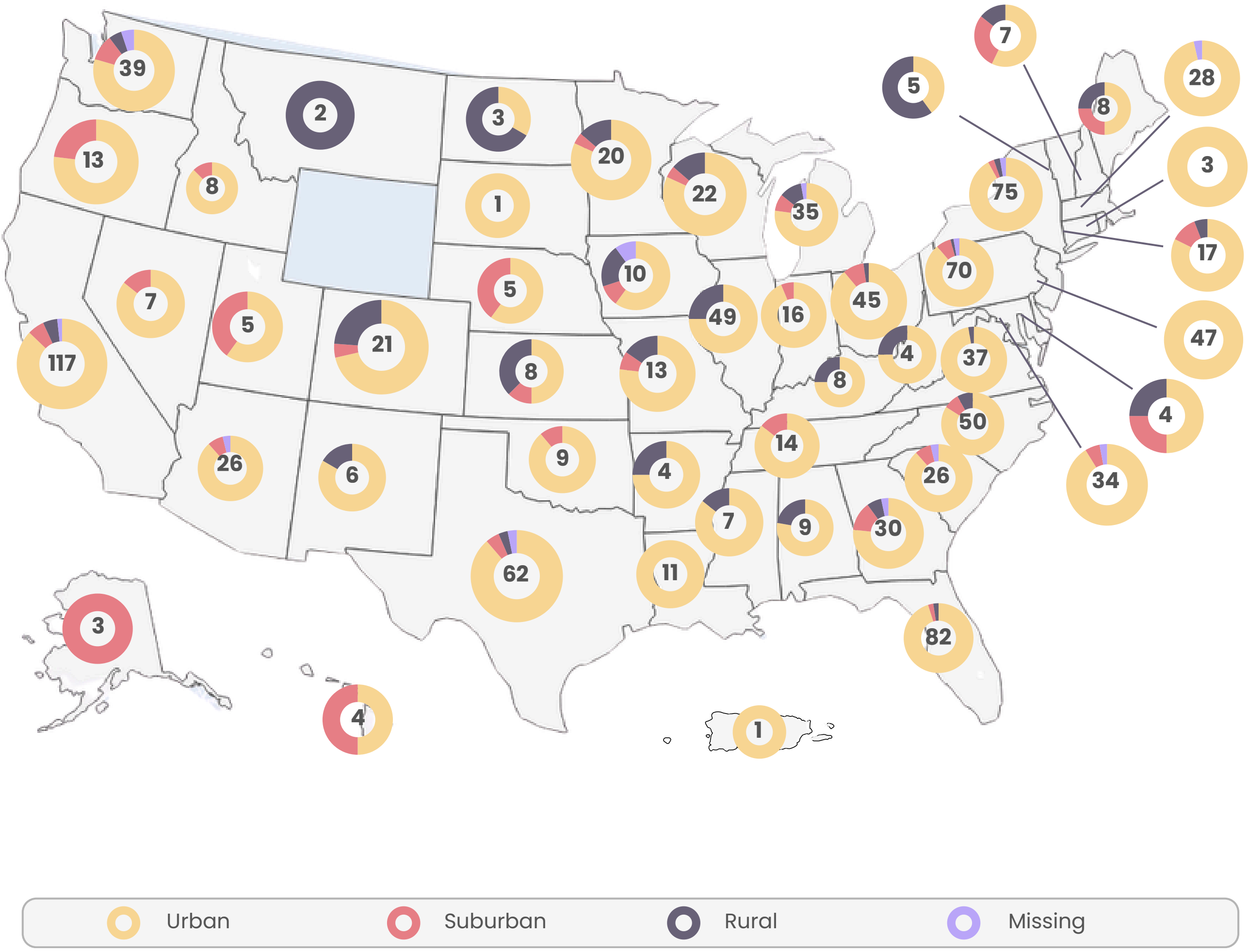
In analyses, we used a hierarchy of CIS < NMIBC < MIBC < advanced stage < metastatic to define their presumed lowest or first stage as well as their highest stage. UTUC and rare cancers were included as separate categories and not included in this hierarchy. The breadth of the survey reduced some respondents' completion of certain survey questions; for each analysis, we used a complete-case approach where we only analyzed trends among respondents who answered the relevant questions of interest.

# RESPONDENT CHARACTERISTICS

## Sociodemographic

### *Geography*

Geographically, the survey represents participants from 49 US states and Puerto Rico, with representation from urban (86%), suburban (7%), rural residents (6%), and the remainder whose zip code did not map to a residence type. This urban predominance is consistent with national cancer surveillance data, which show that bladder cancer incidence is highest in metropolitan regions.



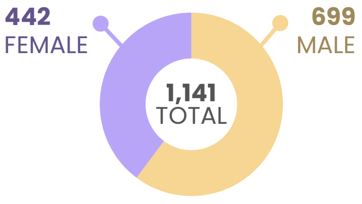
## *Race and Ethnicity*

The survey lacked racial and ethnic diversity, with 95% identifying as White, followed by <2% of Black/African American, Hispanic or Latino, Asian or Asian American, and less than 1% identified as other racial and ethnic groups. A SEER-Medicare***** analysis of 6,044 patients with muscle-invasive bladder cancer reported that 89.5% were White, 5.8% were non-Hispanic Black/African American, 1.4% were Hispanic, and 3.3% identified as other races.[6] The study also highlighted geographic disparities: Black/African American patients were concentrated in Louisiana (19%), New Jersey (18%), and Georgia (18%), and had up to twice the risk of bladder cancer–specific mortality compared to White individuals, particularly among those with stage T2 bladder cancer.[6] Compared with these national registry data, the survey sample over-represents White respondents while underrepresenting Black/African American, Hispanic/Latino, and other racial and ethnic groups. This underscores the need for continued efforts to engage with diverse participants and investigate the social and geographic factors that shape disparities in bladder cancer outcomes.

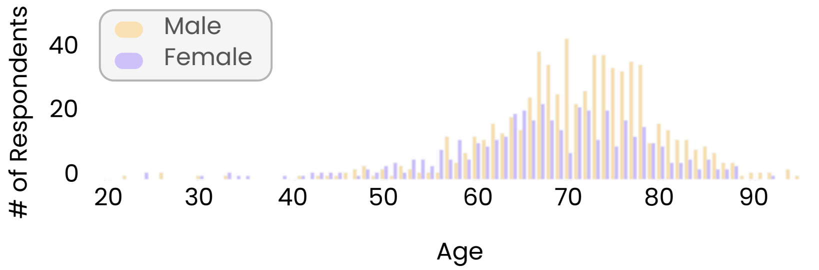
## *Sex and Age*

In the survey, 61% of respondents were male and 39% were female–a smaller male predominance than typically observed in bladder cancer epidemiology. In reality, men are diagnosed with bladder cancer 3-4x more frequently than women, yet women tend to present with more advanced disease and experience higher cancer-specific mortality.**[7,8]** The relatively higher proportion of female respondents to this survey may reflect greater engagement of women within the bladder cancer community, or differences in sampling. Regardless, it provides an opportunity to examine sex-specific experiences and outcomes in greater depth.

**SEX DISTRIBUTION**



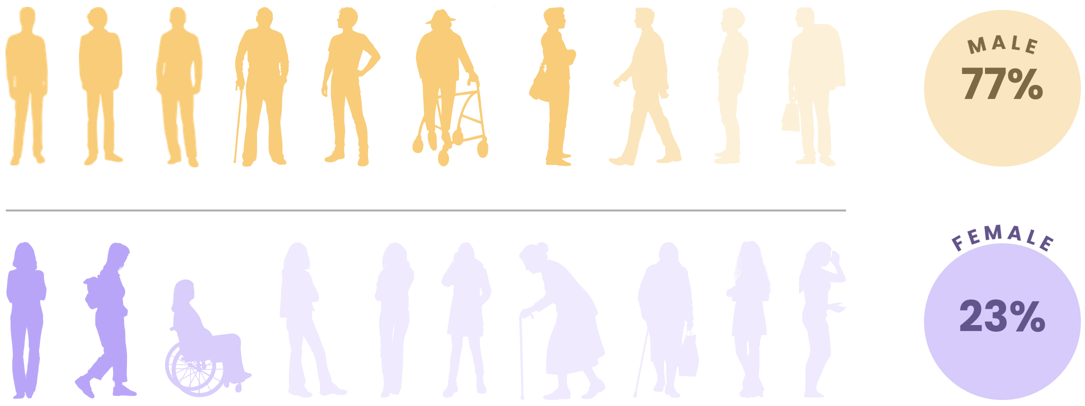
**AGE DISTRIBUTION AT TIME OF SURVEY**



---

*****SEER-Medicare refers to a linked database that combines cancer registry data from the National Cancer Institute's Surveillance, Epidemiology, and End Results (NCI SEER) Program with Medicare beneficiary data.

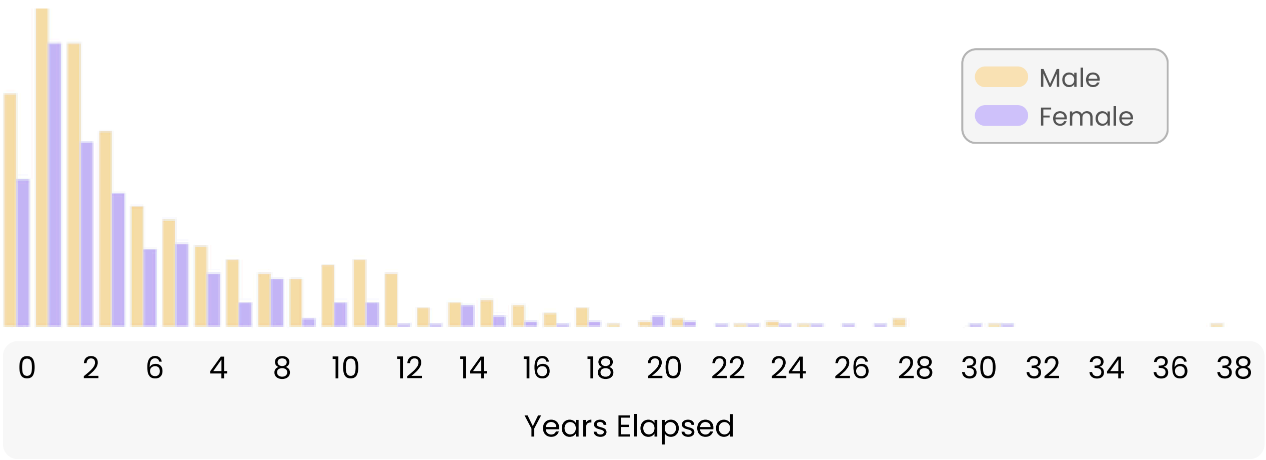
## NATIONAL ESTIMATES OF BLADDER CANCER PREVALENCE



Recent estimates suggest that males are **3-4x more likely** to be diagnosed with bladder cancer than females, yet women present with more advanced disease.[7,8]

The median respondent age at the time of the survey was 70 [range: 22-95], with a median age at diagnosis of 66. This skews only slightly lower than the national estimated average age of 73 at diagnosis, though bladder cancer can be diagnosed at any age. In SEER specifically, nearly 60% of patients were aged 70 years or older, underscoring the predominance of disease in older adults.[2] Overall, the survey's recruitment aligns closely with the broader epidemiological profile of bladder cancer in the U.S. as represented by national SEER data, in which most individuals with bladder cancer are older, White, and male.

## YEARS SINCE DIAGNOSIS



## *Education, Income, and Insurance*

The majority of respondents had a high level of educational attainment. Nearly half (43%) held a graduate or professional degree, and 31% had completed college or trade school. An additional 18% reported having some college experience, while 7% had finished high school or earned a GED. A small proportion (0.6%) reported some high school education, and 0.5% did not provide a response. Nationally, about 38% of U.S. adults aged 25 and older have completed college or higher, whereas 74% of respondents in this sample reported finishing college, trade school, or earning a graduate or professional degree.[9] Compared to national data, this sample is more highly educated.

Among all respondents, 15% reported annual household incomes below $50,000, 32% reported $50,000–$99,999, 23% reported $100,000–$149,999, and 29% reported $150,000 or higher. In comparison, national 2024 data show that 30% of U.S. households earned below $50,000, 27% earned $50,000–$99,999, 17% earned $100,000–$149,999, and 26% earned $150,000 or more. This sample, therefore, represents a higher-income population overall, with nearly half (52%) reporting annual incomes above $100,000, compared to 43% nationally.[10]

Nearly all respondents had health insurance, predominantly Medicare and private coverage. Among those earning under $50,000, 79% had Medicare, 31% had private coverage, and 13% had Medicaid, with smaller percentages reporting military/veteran coverage (8%) or ACA plans (1%). Medicare and private insurance remained dominant in higher income brackets, with 58% and 56%, respectively, among those earning ≥$150,000.

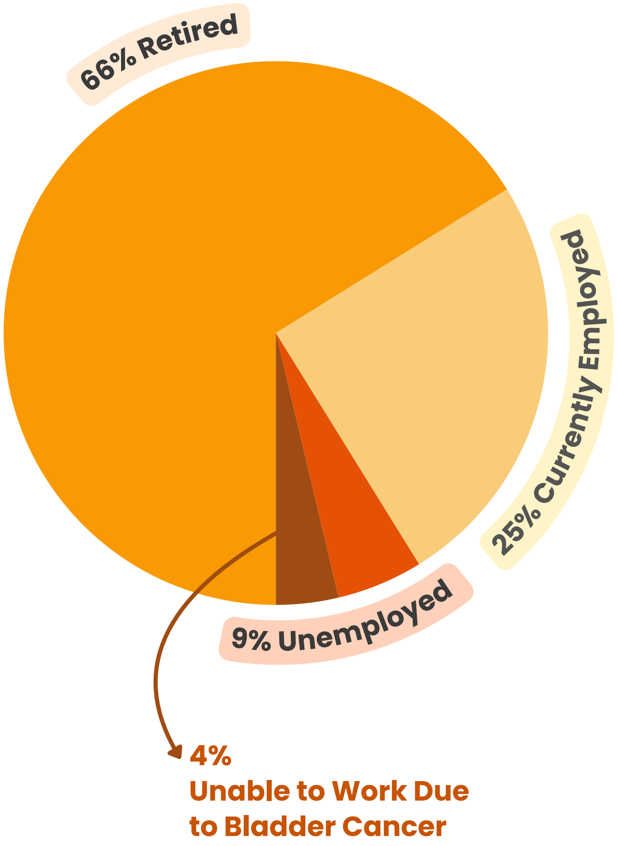
This sample showed substantially higher insurance rates than national averages. Nationally, about 92% of Americans had coverage in 2024, with private insurance covering 66% and public programs (Medicare 19%, Medicaid 18%) covering 35%.[11] In contrast, fewer than 1% of survey respondents were uninsured.

The sample's demographics explain these coverage patterns. Most respondents were 60 or older, with the largest concentration between ages 70 and 80, consistent with bladder cancer's typical age distribution. This older population naturally led to higher Medicare enrollment compared to the general U.S. population, while limited Medicaid coverage reflected a largely older, privately insured group rather than one dependent on public assistance.

Nationally, rural Americans remain more reliant on public insurance programs such as Medicare, Medicaid, and ACA Marketplace plans. According to the U.S. Department of Health and Human Services, one in ten rural adults under 65 is enrolled in Marketplace coverage, one in six is enrolled in Medicaid, and one in three is enrolled in Medicare, compared with lower enrollment rates in urban areas.[12] These trends mirror the survey data, in which rural participants were more likely to report public coverage than private insurance.

## Employment Status

Most respondents were retired (63%), which aligns with the typical age of bladder cancer patients, though several noted that they retired earlier than planned due to their diagnosis and treatments. "I retired five years earlier than was my plan because of my bladder cancer," one patient reflected, while others described ongoing challenges that prevented a return to work: "I lost my job because of the surgery. I had complications that prevented me from lifting," and "I'm on short-term disability for now and have some cognitive issues since having immunotherapy. This worries me as far as going back to work…"



Among the 42 respondents who stopped working due to bladder cancer, the mean age at diagnosis was 57 years. Most (83%) were under 65, representing substantial potential losses in income and employment-related benefits. Several participants specifically highlighted the physical and emotional toll of treatment.

> ***"I was unable to do my job both physically... and mentally because all my focus was on whether or not I was going to have an accident, and the ability to make it to the bathroom to change if I did."***

Disease severity was a major factor in work disruption. Those unable to work tended to have higher-grade disease, metastatic progression, or recurrence, and some had rare or aggressive histologic variants, such as small cell neuroendocrine, plasmacytoid, or squamous cell carcinoma. Cases also included mixed tumor grades or upper tract urothelial carcinomas (UTUC). Some were able to return to work in modified roles, though not all found this support sustainable: "After my RC/Neo*****, I was on long-term disability until they fired me and told me that it would be an 'undue hardship' for the organization to continue to accommodate my leave." Even for those still employed, bladder cancer affected job performance and focus. These experiences illustrate that bladder cancer can have profound impacts on employment, particularly for those diagnosed at younger ages or with more aggressive disease.

---

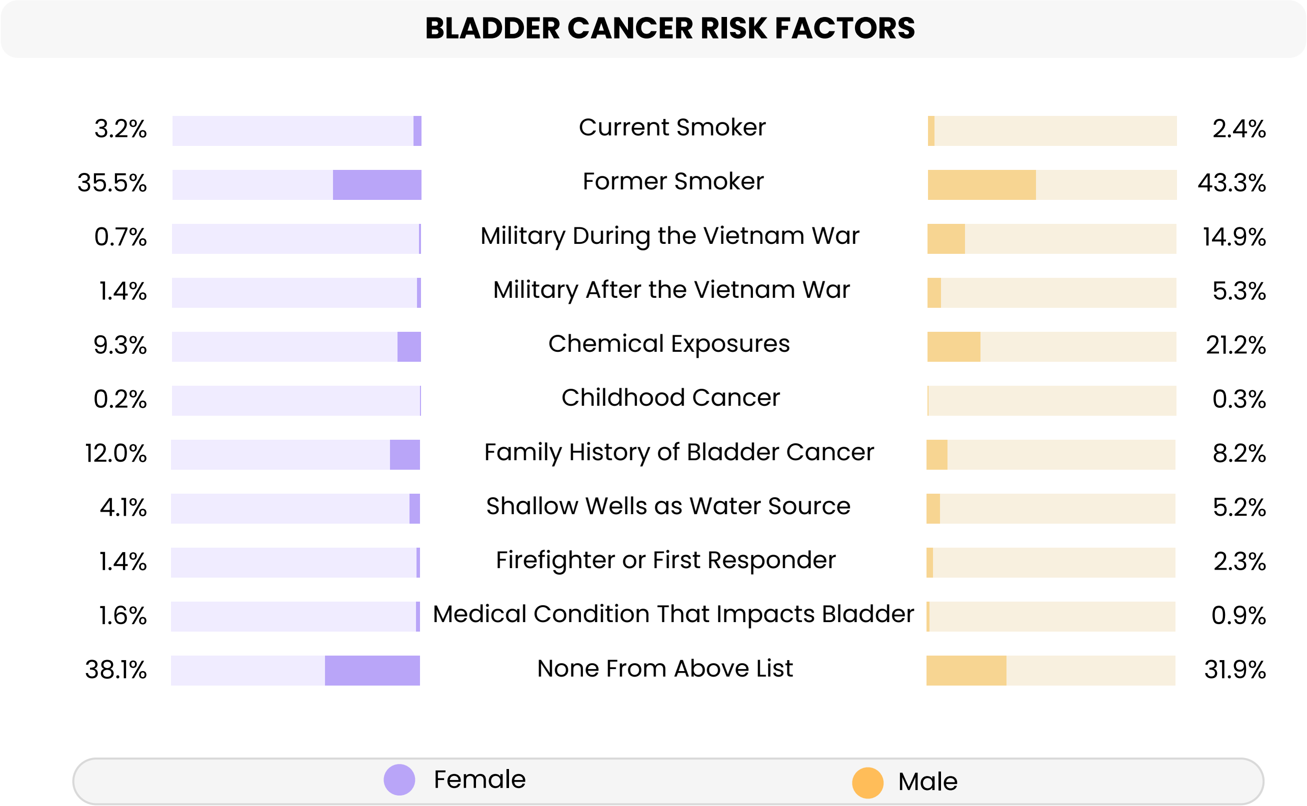
*****RC/Neo refers to a radical cystectomy (bladder removal) with the creation of a neobladder (Neo), which is a urinary diversion created from the patient's intestine.

# Clinical

## *Risk Factors*

Bladder cancer is linked to several well-established risk factors, including cigarette smoking, chemical exposures, and environmental conditions. Participant-reported risk factors largely reflected these known exposures. Overall, current or former smoking was reported by 491 (43%) of respondents, and second-hand smoking was by far the most commonly cited risk factor in the free-text responses.

Reported exposures differed by sex. Current smoking was slightly more common among women (3%) than men (2%), whereas former smoking was more common among men (43%) than women (36%). Military service during the Vietnam War was reported by 9% of respondents (15% of men and <1% of women), with an additional 4% serving in the military after the Vietnam War. Chemical exposures were reported by 17% overall, and were more than twice as common among men (21%) than women (9%).



Among men, commonly reported risk factors included farm and industrial chemicals, and environmental contamination related to military or occupational settings—reflected in comments such as "Was stationed on an island in Alaska that was heavily fined by the EPA" and "I worked in an auto parts factory that produced plastic parts." Respondents frequently mentioned exposures to substances such as Agent Orange, asbestos, solvents, paints, plastics, and contaminated water (e.g., Camp Lejeune, Army bases, and community wells). A few men also noted nuclear or radiation-related exposures, including work in nuclear medicine or living near nuclear processing sites.

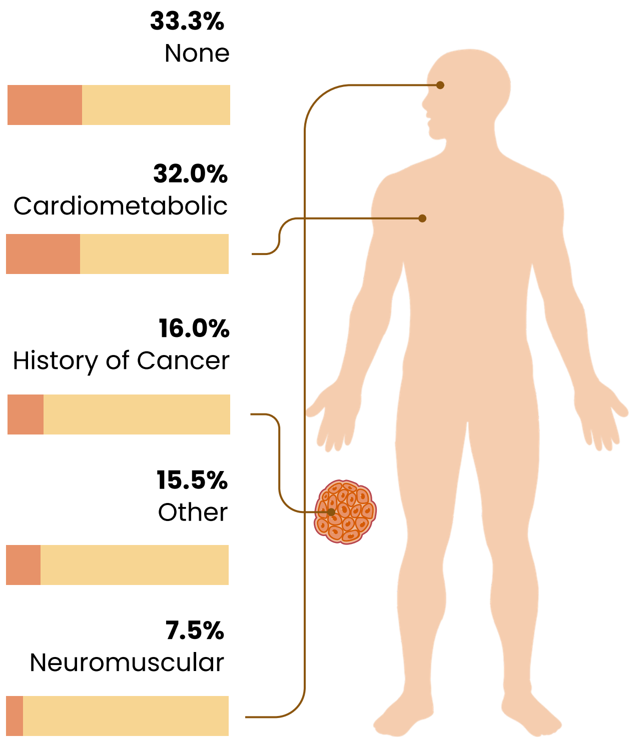
Among women, frequently cited factors included the use of certain medications (e.g., Zantac, Actos) and potential exposures from personal care products or hair treatments. Several women described chronic bladder or urinary tract problems, prior gynecologic or urologic surgeries, or previous cancer diagnoses (primarily breast and cervical). Environmental concerns were also raised, including comments like "Grew up in a paper mill town" and "[I was] exposed daily to black soot and fumes in my government workspace from a fire not properly cleaned up and suffered irreversible sinus damage from surgeries/endometrial cancer/sick migraines and subsequent sick-building syndrome and chemical allergies ever since."

Overall, risk factor patterns differed by sex, with more men likely to report chemical or military exposures and women more likely to report medical or environmental factors. Yet while many bladder cancer risk factors are well established, much remains unknown about why some individuals develop the disease and others do not. This uncertainty was reflected in the free-text responses, with many respondents listing any possible exposure, condition, or abnormality—anything that might help explain what they themselves could not.

## *Comorbidities*

A systematic review by Williams et al. found that patients undergoing radical cystectomy who had both high comorbidity and poor performance scores faced up to a sevenfold greater risk of non-cancer mortality compared with those who were otherwise healthy.[13] The authors emphasized that quantification of comorbidity through measures like the Charlson Comorbidity Index is a powerful predictor of perioperative and long-term outcomes, reflecting how advancing age compounds health risks beyond the cancer itself. In the context of these data, the increased burden of comorbid conditions among older respondents is expected but underscores the importance of integrating structured comorbidity assessments into the management and treatment of bladder cancer patients.

**RESPONDENT COMORBIDITIES**



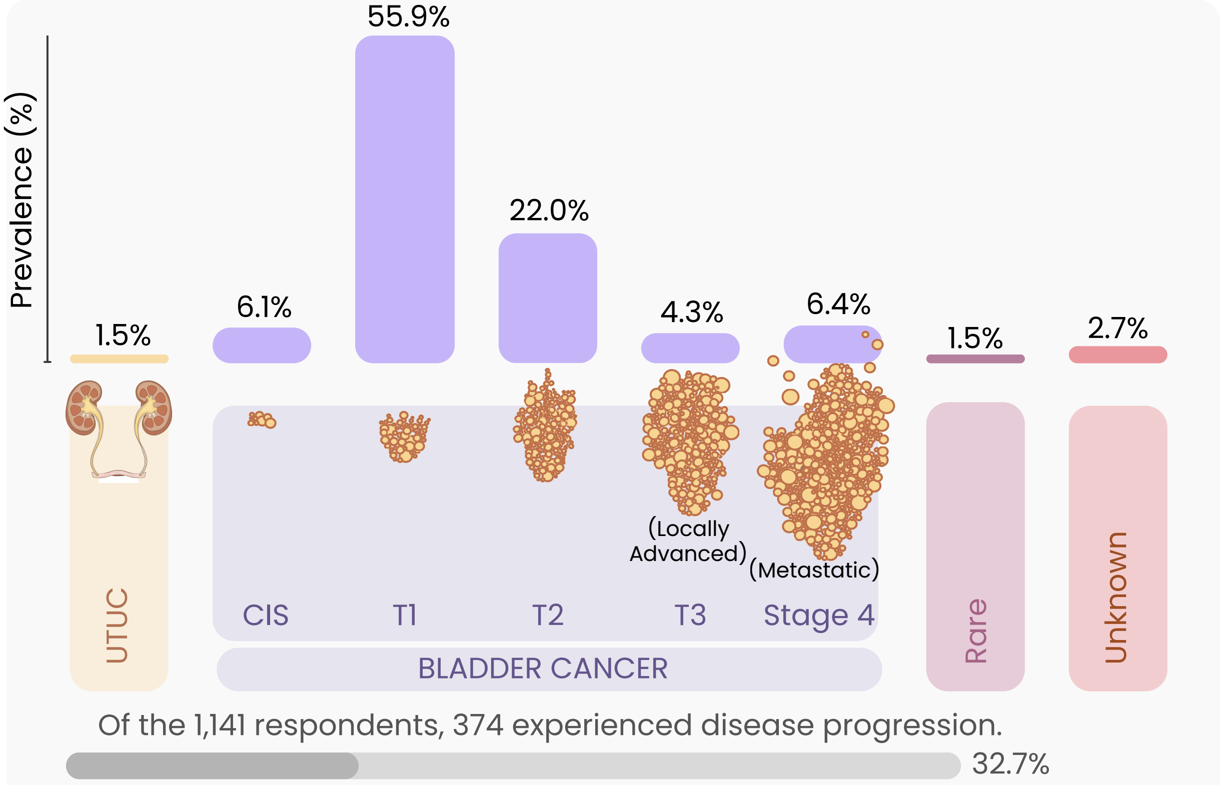
**Comorbidities <5%**

| | |
|---|---|
| GI | Respiratory |
| Renal/Urologic | Autoimmune |

Overall, only 1 in 3 respondents reported that they didn't have any other medical conditions aside from their bladder cancer. Comorbidities such as hypertension and cardiovascular disease were reported more frequently among older participants, which aligns with published evidence showing that comorbidity burden rises with age, especially in those with bladder cancer. Cardiometabolic conditions were far more common in men (35%) than women (28%) and among veterans (41%). Neuromuscular conditions were more common in females (10%) and veterans (9%). Respiratory and autoimmune conditions were more common in females, but overall rare (5% and 4%, respectively).

## *Most Advanced Bladder Cancer Stage*

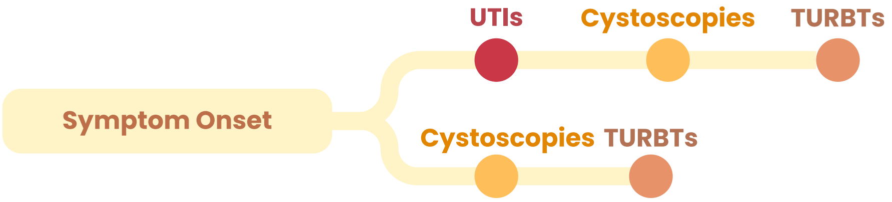
Respondents selected all the bladder cancer stages with which they had been diagnosed. Here, we summarized them by their highest stage. Non-muscle invasive bladder cancer was the most advanced diagnosis for approximately half of the respondents, though all stages were represented. Additionally, about one third experienced disease progression from an initial lower stage to a more advanced stage, consistent with Lotan et al., who found that among 5,490 high-risk NMIBC patients in the SEER-Medicare database (2007-2020), recurrence (33.6%) was the most frequent long-term event, followed by MIBC progression (15.9%) and distant metastasis (16.7%) at 10 years,[14] underscoring the disease's chronic and recurrent nature in an aging, Medicare-insured population.



This distribution also aligns with national patterns. In one study of 349,326 primary bladder neoplasms in SEER, over half were localized at diagnosis, about one-quarter locoregional, and fewer than one-fifth metastatic.[15] Representation across all disease stages is critical for survey validity, and our sample composition–dominated by NMIBC but inclusive of MIBC and metastatic cases–positions this survey to accurately reflect the experiences of patients across the full spectrum of bladder cancer diagnoses while mirroring the broader U.S. bladder cancer population.

# THE JOURNEY TO DIAGNOSIS

## Symptoms



UTI diagnoses and treatment can slow down the process of bladder cancer diagnosis and treatment

Early warning signs and diagnosis are key in the outlook of surviving and thriving with bladder cancer. Visible blood in the urine was the most commonly reported pre-diagnosis symptom, affecting nearly half of participants (48%). When including episodes of intermittent hematuria (27%) and microscopic hematuria (21%), the majority of individuals experienced some form of bleeding prior to diagnosis. Frequent urination (32%) and urinary urgency (16%) were also commonly reported, reflecting early bladder irritation.

> ***"Blood in urine…once."***

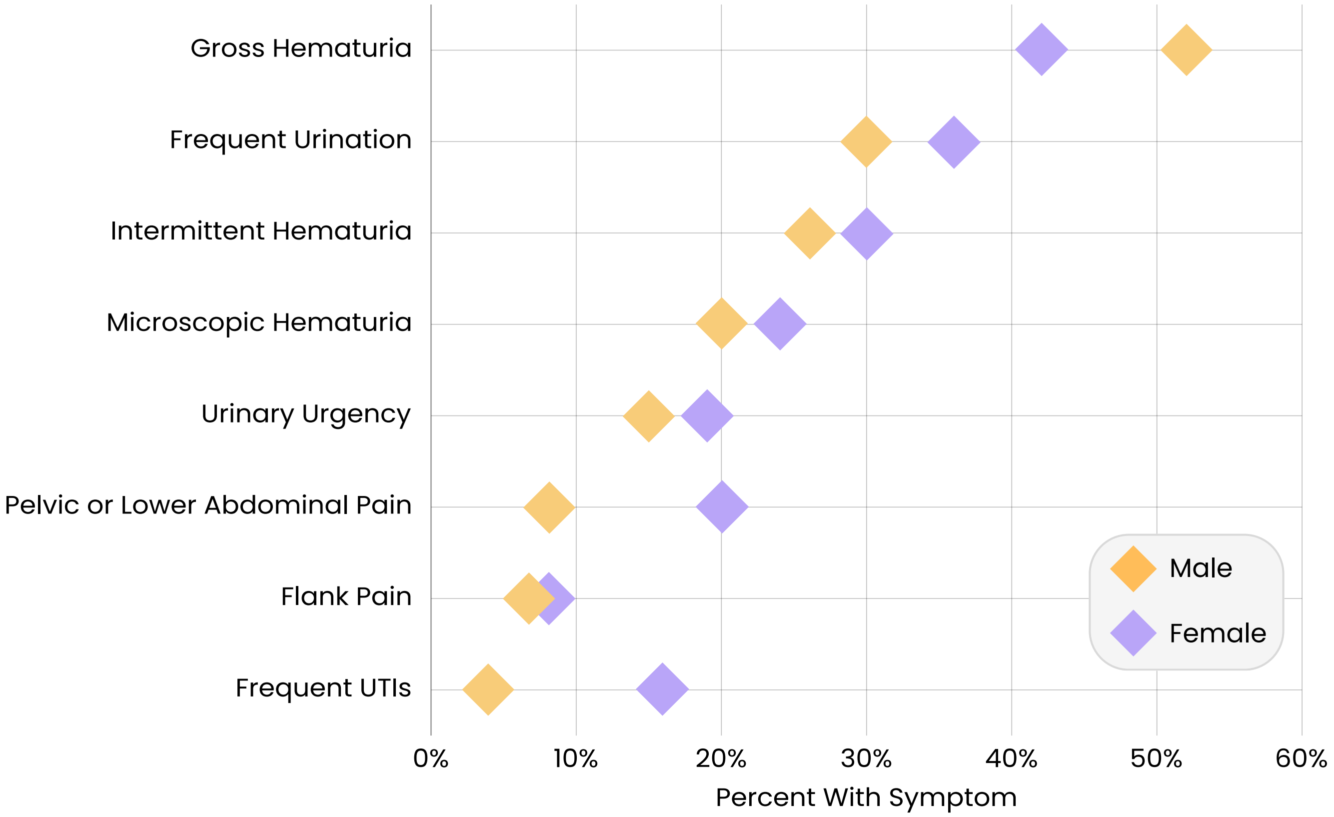
> ***"I went to urinate and all that came out was blood."***

Symptom presentation varied by sex. With the exception of gross hematuria, the remaining symptoms were all more common in women than men. This indicates that female patients may present more often with less specific symptoms that can be misattributed to benign urinary conditions. Overall, hematuria remains a critical early sign, yet a substantial subset of patients present with nonspecific urinary or pain symptoms that may delay timely evaluation. In general, patients diagnosed within the past 10 years were more likely to report each symptom than those diagnosed more than 10 years ago. This may be a reflection of improved recognition of bladder cancer warning signs, or it could be attributed to recall bias, as individuals diagnosed over 10 years ago may not recall their initial symptoms as clearly. A small portion of respondents (7%) indicated their cancer was detected incidentally through routine testing, highlighting that some cases remain asymptomatic before diagnosis.

> ***"First, spotting, blood clots in urine. Then, urine was completely bright red."***

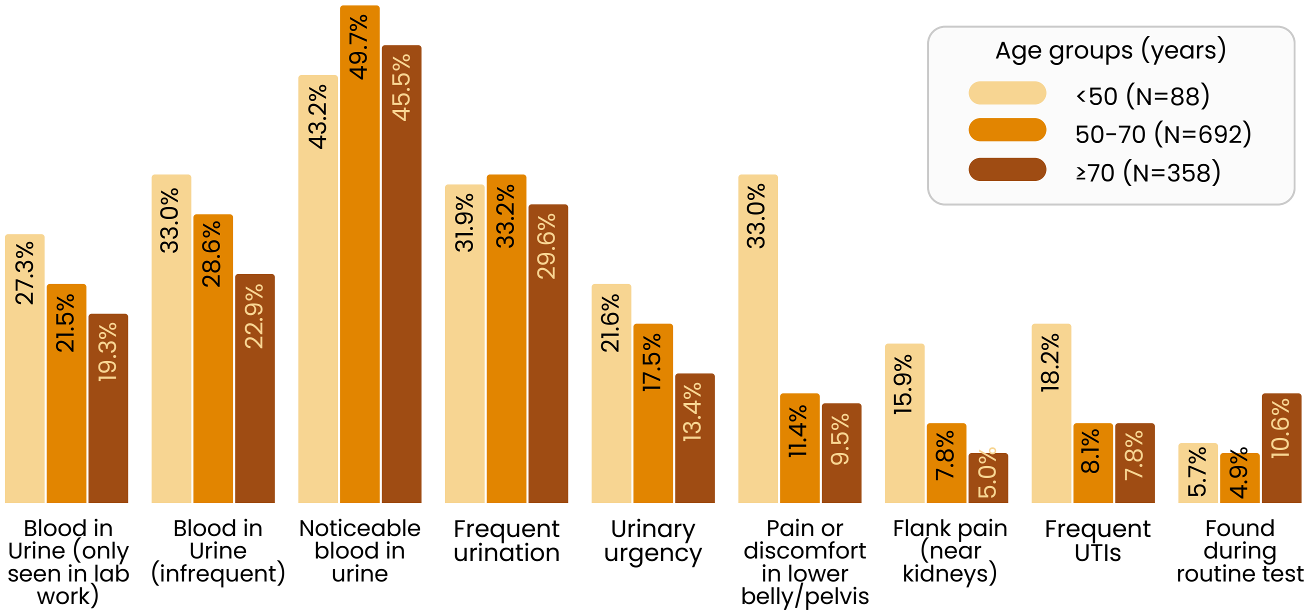
> ***"...little bit of blood in urine, 2 mornings in a row and then never again."***

## BLADDER CANCER SYMPTOMS BEFORE DIAGNOSIS BY SEX



Symptom patterns differed by age at diagnosis. Visible blood in urine was consistently the most common symptom across all age groups, affecting 45–50% of individuals, though younger adults (<50) reported slightly lower rates (43%). Younger respondents were notably more likely to experience pelvic pain (33%) and flank pain (16%) compared with older adults, which may reflect differences in tumor location or delays in diagnostic evaluation due to attribution to non-cancer causes. Frequent UTIs were also more common in those diagnosed before age 50 (18%), suggesting misdiagnosis may be more prevalent in younger patients who are not considered high-risk for bladder cancer. Conversely, individuals ≥70 years old were more frequently diagnosed incidentally through routine testing (11%), likely reflecting more consistent medical surveillance and screening for comorbidities. These differences highlight the importance of maintaining clinical suspicion for bladder cancer even in younger adults, particularly when symptoms persist or recur. This is echoed in recent data showing that young patients frequently present with hematuria and high-grade disease yet face aggressive progression when diagnosis is delayed.[16]

**SYMPTOMS BY AGE AT DIAGNOSIS**



## UTIs as a Setback

Many respondents–especially women–were treated for urinary tract infections (UTIs) in the months or years leading up to their bladder cancer diagnosis. Nearly half of women (45%) reported at least one UTI compared with only 15% of men, reflecting how often women's early bladder cancer symptoms may be dismissed as "just another infection," or as one participant recalled being told, an "old lady issue." Younger women described this pattern even more sharply, suggesting that those perceived to be at lower cancer risk may be more likely to have their symptoms misattributed or untreated.

These UTIs shaped where patients first sought care. Women with UTI histories were far more likely to start in primary care, and often received repeated antibiotics rather than a timely referral to urology. As one patient shared, "I was treated with multiple types of antibiotics and multiple rounds–even after I told the NP that I didn't think I had a UTI." Several described years of cycling through treatments: "For over 4 years, I was treated for supposed UTIs…the antibiotics seemed to get rid of the blood in my urine, but it kept coming back." One participant outlined a long cascade of negative tests: "10 days of Macrobid…then amoxicillin…negative culture…negative FISH*…then `suspicious` cytology" before their cancer was ultimately identified.

---

*Fluorescence In Situ Hybridization (FISH) test

UTI diagnoses were slightly more common among those within the past 10 years (28%) compared to 22% of those diagnosed over 10 years ago, and among rural residents (38%). Though not statistically significant differences, these patterns highlight an area where clinical pathways still need improvement. Ultimately, the pattern of misdiagnosis and delayed diagnosis carry consequences. Individuals with UTI histories were diagnosed with MIBC more often than those without. This is consistent with larger studies, showing that when symptoms are repeatedly labeled as an infection, bladder cancer tends to be found later and at a more advanced stage.[17]

> ***"Not being referred right away prolonged my diagnosis."***

## Seeking Care

Most respondents (61%) sought medical care as soon as symptoms appeared, and another 17% did so within 1-2 months. This pattern was similar for those diagnosed recently as compared to those diagnosed more than a decade ago, suggesting that patient-driven delays have not changed much over time. However, important differences emerged across key groups. Women were less likely than men to seek care immediately (53% vs. 66%) and almost twice as likely to wait 1-2 months. Younger adults (<50 years of age at symptom onset) also tended to delay longer, sometimes waiting more than six months–mirroring a lower perceived bladder cancer risk at younger ages.

Symptom type and severity influenced urgency as well. People with gross hematuria were more likely to seek immediate care (63% compared to 55% of those without), often describing it as an unmistakable alarm: "I called my GP and was told there were no appointments for weeks–until I said 'blood in my urine'. Suddenly, it was 'Tomorrow morning, 9 o'clock." In contrast, those with non-specific urinary symptoms often waited longer or were treated for benign conditions.

When respondents described barriers that delayed diagnosis, access issues (12%) and testing delays (6%) were the most common. Some struggled to secure appointments. “It was during the pandemic and difficult to get in,” one person said. Others weren’t sure which specialist to see. As one explained, “Like many of us, I didn’t know what I didn’t know… I found a urologist who had an opening three weeks later, so I took it.”

> ***“When my PCP said no appointments were available, I figured if they didn’t think it was urgent, than neither did I.”***

Overall, primary care was the most common first point of contact (51%), followed by urology (32%). However, patient sex influenced these care pathways: 15% of women first saw a gynecologist, and women were less likely to see a urologist first compared to men (22% vs. 39%). Around 10% of women and 11% of men sought care at an urgent care or ED first.

One woman shared the difficulty of even accessing gynecologic care: “Finding a gynecologist who would accept a new Medicare patient was impossible…I finally had gross hematuria that looked like I was peeing raspberry juice and went to urgent care.” Age and geography also influenced pathways. Older adults were more often referred directly to urology, and rural respondents relied heavily on primary care due to fewer specialists. In total, these patient experiences underscore how easily delays can accumulate due to both patient uncertainty and systemic barriers.

# DIAGNOSIS

Bladder cancer presents a wide spectrum of disease severity, ranging from non–muscle invasive tumors to metastatic disease. Understanding the distribution of stage at diagnosis is critical for contextualizing patient experiences, treatment decisions, and outcomes. Among survey respondents, over two thirds (70%) were initially diagnosed with non–muscle invasive bladder cancer (NMIBC). Of those, 23% were specifically diagnosed with Carcinoma in situ (CIS), while approximately one in five (22%) had muscle-invasive disease (MIBC; **Table 1**). A small minority reported locally advanced (1%) or metastatic disease (2%), and upper tract urothelial carcinoma (UTUC) was reported by 1.0% of respondents. These patterns broadly reflect U.S. epidemiology, where approximately 70% of bladder cancers are diagnosed at non–muscle invasive stages, and 30% present as muscle-invasive at initial diagnosis.[18]

**Table 1.** Cancer Stage at Diagnosis

| | CIS | NMIBC | MIBC | Locally Advanced | Metastatic | UTUC |
|---|---|---|---|---|---|---|
| **Overall** | 263 (23%) | 539 (47%) | 252 (22%) | 13 (1%) | 24 (2%) | 11 (1%) |
| **Years Since Diagnosis** | | | | | | |
| **<10 Years** | 197 (21%) | 467 (49%) | 216 (23%) | 10 (1%) | 22 (2%) | 10 (1%) |
| **≥10 Years** | 66 (37%) | 70 (39%) | 36 (20%) | 3 (2%) | 2 (1%) | 1 (<1%) |
| **Sex** | | | | | | |
| **Male** | 175 (25%) | 320 (46%) | 155 (22%) | 9 (1%) | 13 (2%) | 5 (<1%) |
| **Female** | 88 (20%) | 219 (50%) | 97 (22%) | 4 (<1%) | 11 (2%) | 6 (1%) |
| **Age at Diagnosis (Years)** | | | | | | |
| **<50** | 23 (26%) | 43 (49%) | 17 (19%) | 2 (2%) | – | – |
| **50-70** | 169 (24%) | 314 (45%) | 145 (21%) | 11 (2%) | 21 (3%) | 7 (1%) |
| **>70** | 71 (20) | 180 (50%) | 90 (25%) | – | 3 (<1%) | 4 (1%) |
| **Insurance** | | | | | | |
| **Medicare** | 203 (26%) | 349 (45%) | 172 (22%) | 7 (<1%) | 14 (2%) | 8 (1%) |
| **Medicaid** | 4 (13%) | 21 (66%) | 5 (16%) | – | -- | – |
| **Private** | 123 (22%) | 276 (49%) | 124 (22%) | 7 (1%) | 10 (2%) | 5 (<1%) |
| **VA** | 18 (23%) | 41 (53%) | 15 (20%) | – | 1 (1%) | – |

*Percentages represent row totals.*

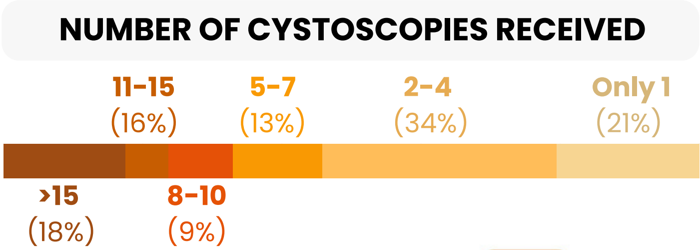
Stage at diagnosis varied modestly by time since diagnosis. Respondents diagnosed over 10 years ago were slightly more likely to report CIS or NMIBC and less likely to report metastatic disease. These differences may reflect changes in staging practices, earlier detection, or evolving treatment strategies over time. Stage distributions did not differ by insurance type in this survey.

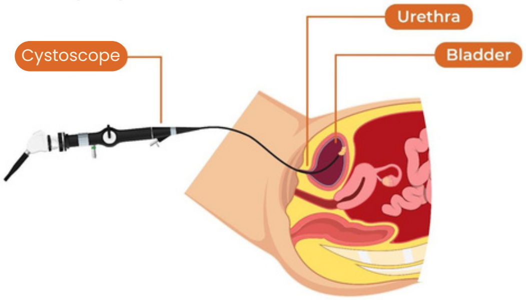
Men and women showed similar proportions of NMIBC and MIBC, though women reported a slightly higher proportion of metastatic presentations (2.5% vs. 1.9%). This aligns with broader evidence that women often experience delays in diagnosis due to differences in symptom recognition and clinical evaluation,[19] underscoring the importance of improving early detection in women.

Age at diagnosis demonstrated a clearer association with stage. Older adults (≥70 years) were more likely to be diagnosed with MIBC compared to younger patients (25.1% vs. 19.3% in the <50-year group), while younger respondents were more frequently diagnosed with CIS/NMIBC. These observations are consistent with SEER-based analyses showing that patients ≥75 years are more likely to present with advanced disease and experience higher bladder cancer–specific mortality. Nevertheless, contemporary cohorts treated with BCG for NMIBC suggest that age >70 is not independently associated with worse progression or cancer-specific outcomes, suggesting that effective treatment can offset many of the risks typically attributed to advancing age.[20]

# Cystoscopy

Cystoscopies are a critical tool for both diagnosing bladder cancer and monitoring for recurrence. Frequency varied widely across various characteristics, and unsurprisingly, 56% of respondents diagnosed over 10 years ago noted they had over 15 cystoscopies throughout their bladder cancer journey, compared to only 10% of those diagnosed in the past 10 years.


NUMBER OF CYSTOSCOPIES RECEIVED



Overall, among those who were not diagnosed with advanced or metastatic bladder cancer at the outset, only 20% reported having just one cystoscopy, while nearly half underwent five or more procedures over time (44%), reflecting the chronic nature of bladder cancer and the need for ongoing monitoring. Notably, 17% reported more than 15 cystoscopies, highlighting the long-term surveillance burden many patients experience.

Stage at diagnosis was a major determinant of surveillance intensity. Among patients with CIS—a high-risk subset of NMIBC that is often more difficult to visualize on cystoscopy—the long-term surveillance burden was greatest: 30% underwent more than 15 cystoscopies. This elevated burden reflects both the challenges of detecting CIS and guideline-directed high-risk NMIBC follow-up. Across the broader NMIBC group, cystoscopy use remained high (19% with >15 procedures), underscoring that CIS contributes disproportionately to overall NMIBC surveillance intensity. In contrast, individuals diagnosed with MIBC largely clustered in the one-to-four procedure range (86% total), reflecting that definitive treatments (e.g., cystectomy) generally eliminate the need for long-term bladder surveillance—a pattern consistent with literature showing that extended TURBT-based follow-up is required primarily for NMIBC rather than for patients treated definitively for invasive disease.[21]

Access patterns varied slightly by geography: patients in urban areas tended to have more cystoscopies (18% with >15)—potentially reflecting greater access to urology care—compared to suburban and rural respondents with slightly lower procedure counts. Cystoscopy frequency did not vary by insurance with the exception of a higher proportion of VA-insured patients in the >15 procedure category (26%).

***"My urologist warned me, 'This is going to feel like going the wrong way down a one-way road.'"***

Experiences with cystoscopies ranged widely from "very easy" to "the worst pain I've ever experienced." Two factors consistently explained the gap: effective numbing and pain management, and empathetic, communicative providers. The majority of negative experiences occurred during the first few cystoscopies, when patients felt unprepared for what the procedure would feel like and unclear on what to expect afterwards. As one respondent put it, "Doctors are technicians...their information is different to me than resources like BCAN or other patients." Another added, "Once you've had a couple, your experience is the best teacher...everyone's experience is unique," highlighting the importance of patient-to-patient guidance and support.

Empathy and communication shaped the cystoscopy experience. Patients who felt their clinician was rushed, communicated bluntly, or left them feeling exposed and vulnerable felt far more distress. By contrast, other respondents consistently praised providers who explained each step in the process, warned them before painful moments, and treated them with respect. “The nurse preparing you is the most important in determining if you have a good or bad experience,” one patient shared, while another noted that “the procedure and environment fade when the nurse and doctor are kind.”

When numbing agents were applied correctly and given time to work, many described the cystoscopy as “uncomfortable, but not painful” and “pretty quick.” Several individuals diagnosed over 10 years ago noted that modern, flexible scopes were far easier to tolerate than the “straight steel tubes of the past, which were excruciating.” Despite the range of experiences, most recognized the importance of the procedure.

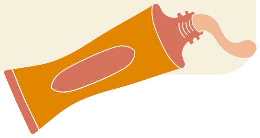
> ***“It needs to be done. Don’t be afraid. It’s part of saving your life.”***

Overall, patients made clear that the cystoscopy does not have to be traumatic. With adequate pain management, careful technique, clear explanation, and genuine empathy, the procedure becomes manageable–routine, even. But when those elements are missing, that same procedure can feel “barbaric,” “embarrassing,” and profoundly distressing, underscoring how deeply the clinical approach shapes the patient experience.

## KEY ADVICE FOR PROVIDERS

**Explain everything clearly. Let the patients see the screen if they want.**

**Use numbing gel and allow it time to work. Go slow and be gentle.**



**Maintain privacy and dignity. Empathy matters.**

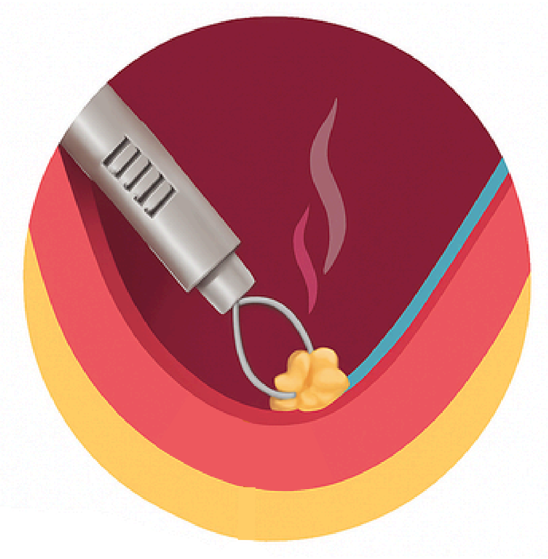
**For patients: choose your provider carefully.**

### *Blue Light Cystoscopy*

In the U.S., blue light cystoscopy received FDA approval for surveillance of NMIBC in 2018 and improves surveillance and early bladder cancer detection. However, it can be very expensive due to the need for specialized equipment, and it may yield false-positive results in settings with increased inflammation from BCG treatments.[22] As a newer procedure, these survey data indicate it is still relatively uncommon. In fact, only 15% of those diagnosed with NMIBC or MIBC received blue light cystoscopy, and even fewer reported narrow-band imaging. Utilization was consistent across urban and suburban areas, and while only 9% of rural residents reported receiving blue light cystoscopy, the sample size was too small to determine whether this truly reflects a meaningful disparity. There was minimal variation in uptake by insurance status, especially between Medicare enrollees and those with private insurance. Although blue light cystoscopy improves tumor detection and reduces recurrence, real-world adoption remains low.

## TURBTs

A transurethral resection of bladder tumor (TURBT) is the primary procedure used to diagnose and remove visible bladder cancer tumors, and many patients require multiple TURBTs over time due to recurrence or ongoing surveillance. Among respondents in our survey who were initially diagnosed with a non-advanced stage of bladder cancer, 62% underwent at least 2 procedures, while only 38% had a single TURBT. The most common experience was 2-3 TURBTs (42%), underscoring the relapsing nature of bladder cancer and the procedural burdens that accompany long-term disease management. A smaller subset of respondents reported seven or more TURBTs (7%), including 3% with over 10 TURBTs.

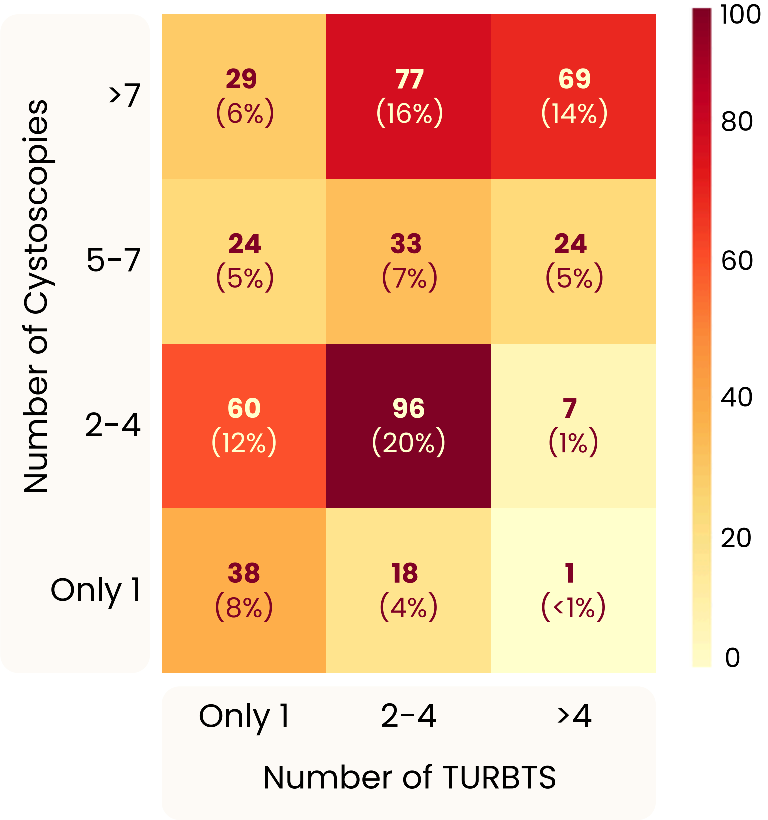


> ***"A TURBT is what it is... necessary."***

TURBT frequency understandably varied by stage at diagnosis. Individuals initially diagnosed with CIS/NMIBC experienced the highest recurrence-related burden, with many requiring multiple resections. In contrast, patients with MIBC typically underwent fewer TURBTs, with 70% of these respondents noting only a single TURBT, consistent with care pathways that prioritize definitive treatments like radical cystectomy over repeated resections. Time since diagnosis was strongly correlated with the number of TURBTs a respondent had received. Those diagnosed over 10 years ago were far more likely to have undergone more than ten procedures compared to those diagnosed within the last 10 years (13% vs. 2%), reflecting prolonged surveillance needs over the course of their survivorship. Among the 539 respondents initially diagnosed with NMIBC, most had undergone multiple procedures (typically 2-4 cystoscopies and 1-3 TURBTs) at the time of the survey—a strong representation of the intensive surveillance and treatment cycle that characterizes early-stage bladder cancer care. Beyond the variance described above, no meaningful differences in TURBT frequency were observed by patient insurance type or geography, aside from a slight trend toward higher TURBT utilization in urban settings.

Persistent treatment pattern variation, including the underutilization of cystectomies among eligible patients,[23] highlight how care decisions shape patients' procedural experiences and underscores the importance of clear communication and shared decision-making. Overall, these data emphasize the substantial and often prolonged procedural burden faced by people with early-stage bladder cancer. Reducing recurrence through optimal intravesical therapy, better risk stratification, and emerging biomarkers may help limit repeat TURBTs over the course of bladder cancer survivorship.[24, 25]

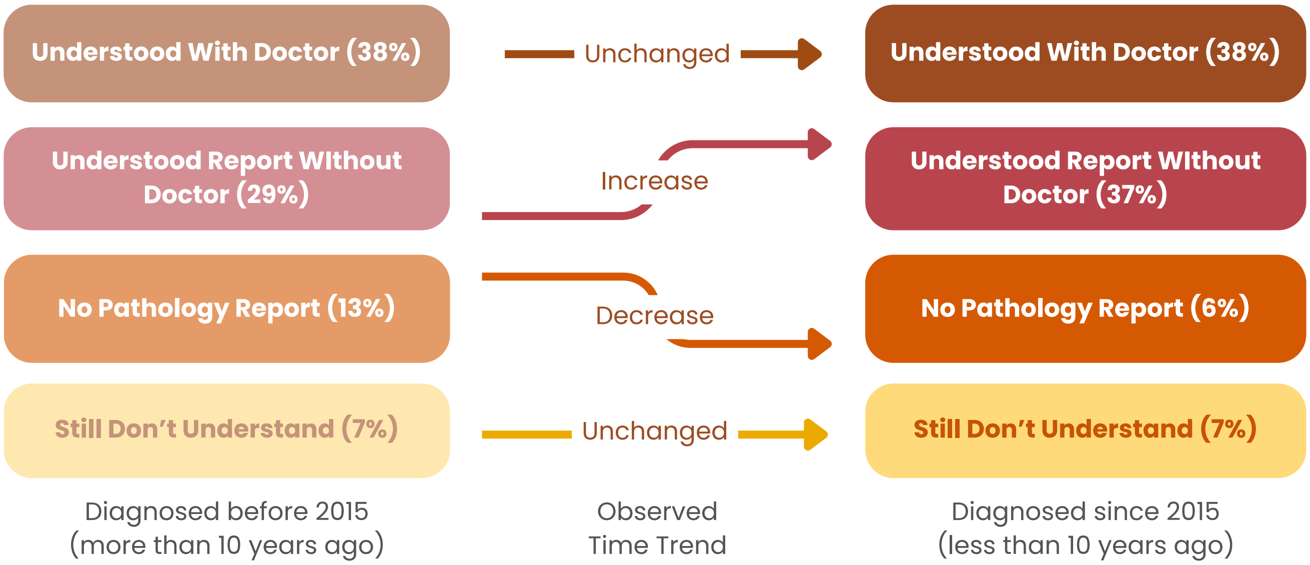
**DIAGNOSIS & TREATMENT PATTERNS IN THOSE WITH NMIBC**



Across the 712 respondents initially diagnosed with NMIBC or MIBC, 45% reported receiving a restaging TURBT, including 52% of those initially diagnosed with NMIBC and 29% diagnosed with MIBC. Rates were similar regardless of when they were diagnosed, where they lived, or the type(s) of insurance held, suggesting restaging practices are relatively consistent across sociodemographic factors. Among those who had a restaging TURBT, 24% reported either present cancer, recurrence, or progression. These utilization patterns align with the literature showing that restaging TURBT identifies residual tumor in up to 40–50% of NMIBC patients and upstages as many as 15%,[26] reinforcing why high-risk NMIBC requires frequent cystoscopy and repeat resections to ensure complete tumor control. However, for others, the restaging TURBT was a sigh of relief: “I was all clear!”

## *TURBT Pathology Report*

After their TURBT, almost all respondents reported receiving a pathology report, with only 13% of those diagnosed over 10 years ago stating they did not receive a report, compared to 6% of those diagnosed within the past 10 years. Report comprehension is still a challenge, but the landscape has improved significantly. Among respondents with NMIBC or MIBC, 37% understood their pathology report on their own, and another 38% understood after a doctor or nurse reviewed it with them. Only 7% stated they still didn’t understand the report after the explanation. Those with a high school education or less were slightly more likely to report difficulties.



| Diagnosed before 2015 (more than 10 years ago) | Observed Time Trend | Diagnosed since 2015 (less than 10 years ago) |
|---|---|---|
| **Understood With Doctor (38%)** | Unchanged → | **Understood With Doctor (38%)** |
| **Understood Report Without Doctor (29%)** | Increase → | **Understood Report Without Doctor (37%)** |
| **No Pathology Report (13%)** | Decrease → | **No Pathology Report (6%)** |
| **Still Don’t Understand (7%)** | Unchanged → | **Still Don’t Understand (7%)** |

Many respondents described the reports as inherently technical. As one patient put it, “docspeak is hard for anybody to understand that hasn’t gone to medical school.” The reports could be intimidating and overwhelming, especially when they appeared in the patient portal before the clinician had a chance to review them. Several people said they had to read the report “several times and look up words”, delayed opening the document because “pathology is intimidating”, or avoided reading the document altogether because it “just causes anxiety.” One person recalled not receiving any explanation from their first doctor and only learned that a second TURBT was needed after doing their own research and pushing for clarification.

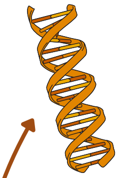
A common theme in free-text responses was that interpretability has improved substantially, driven by clearer explanations from clinicians and wider availability of patient-friendly resources. Several credited BCAN specifically: “BCAN helped me understand the pathology report,”, I came to a full understanding after detailed information on the BCAN app”, and “I understood thanks to information I learned from the BCAN website and pamphlets.” Another described the importance of combining online resources with clinician conversations: “I understood because of research and pages on the BCAN website, but I appreciated hearing it again from my doc.”

> ***“As much as you can be [an] informed patient, your doctor has to put lab results into perspective.”***

Taken together, the findings show that while pathology reports remain dense and often written above the 10th-grade reading level,[27] patients today have far more support than they did even ten years ago–from educational tools to clinician practices to peer-developed resources. Many respondents explicitly noted that “pathology reports are more readable now” and that explanations are more consistently offered. Continued improvements in clarity, layout, and clinician time walking through results could further strengthen comprehension, confidence, and shared decision-making. Overall, the trend is clear: although understanding pathology is difficult, the network of support has expanded dramatically, and patients now have more pathways than ever to make sense of this crucial information.

# Genetic Testing

Genetic testing is becoming increasingly important in bladder cancer care, especially as urine-based tumor DNA tests and molecular profiling can guide treatment choices and predict bladder cancer recurrence.[28] Yet only 12% of respondents had genetic testing for their bladder cancer, and many said they "didn't know this was available", that it was "never discussed" or that "it was not offered and I didn't know to ask." Several noted that when they were first treated, "tumor genetics [were] in [their] infancy," highlighting the recent technological advancement.



20 of these people had to pay out-of-pocket for the costs

**Responded to Question: 965**

**119 had genetic testing performed**

**Of those who remembered the results, 76 had at least one genetic mutation**

**Most common genetic mutations were:**

- ERBB2 (HER2) (6)
- FGFR3 (5)
- TP53 (5)
- Nectin-4 (4)

Cost was a major barrier. One in six patients tested paid out of pocket because insurance would not cover the testing. Some were still in appeals, saying "insurance denied the claim…" or avoided testing altogether because "my insurance didn't cover a lot of lab work; forget genetic testing." Despite these challenges, a few respondents emphasized its value: "I can't remember if I paid out of pocket, but I would have," and others pursued testing through clinical trials when not covered by their insurance.

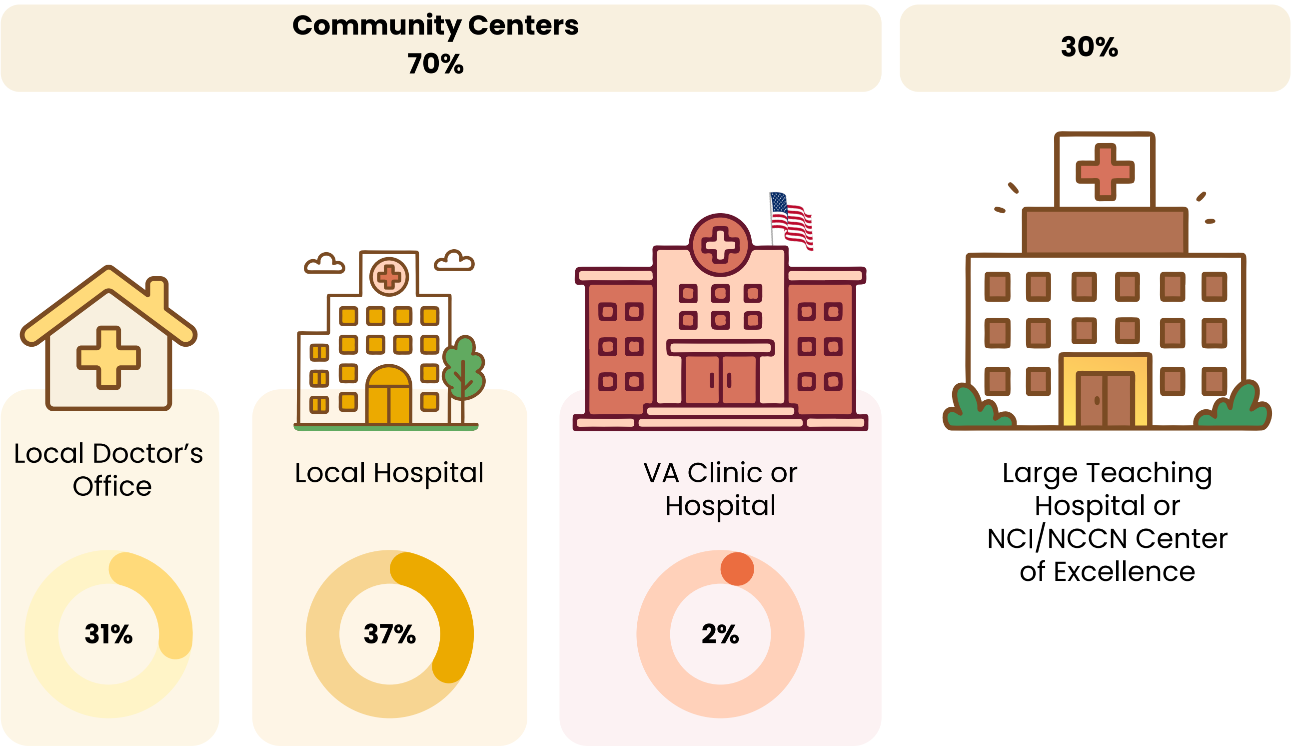
Even among those tested, many couldn't recall their results or were still waiting for them. Only 21 respondents remembered discussing with their provider how their tumor's genetic changes might guide treatment, and one person described the disappointment when their clinical center "would not discuss genetics or these potential treatments with me at all."

As bladder cancer continues to shift towards personalized, mutation-informed treatment–including FGFR3 inhibitors, immunotherapy selection, and biomarkers of progression–these findings highlight a key gap. Genetic testing remains underutilized, underexplained, and unevenly accessible, leaving many patients without information that could meaningfully improve their bladder cancer outcomes.

# TREATMENT

## First Treatment Setting

Respondents were asked which type of care they first sought for treatment. The majority of patients were seen at community centers, defined as local doctors' offices, local hospitals, or VA clinics or hospitals. The remaining 30% were seen at a large teaching hospital or a NCI/NCCN Center of Excellence*****. We asked respondents how far they traveled for their first treatment, defining very short as less than 10 miles or under 15 minutes; short as 10-30 miles or 15-30 minutes; moderate as 31-75 miles or 30-90 minutes; and long as over 75 miles or over 90 minutes. Overall, 40% of respondents traveled a short distance, while 42% of participants traveled a moderate distance.



**Community Centers**
**70%**

**30%**

Local Doctor's Office
**31%**

Local Hospital
**37%**

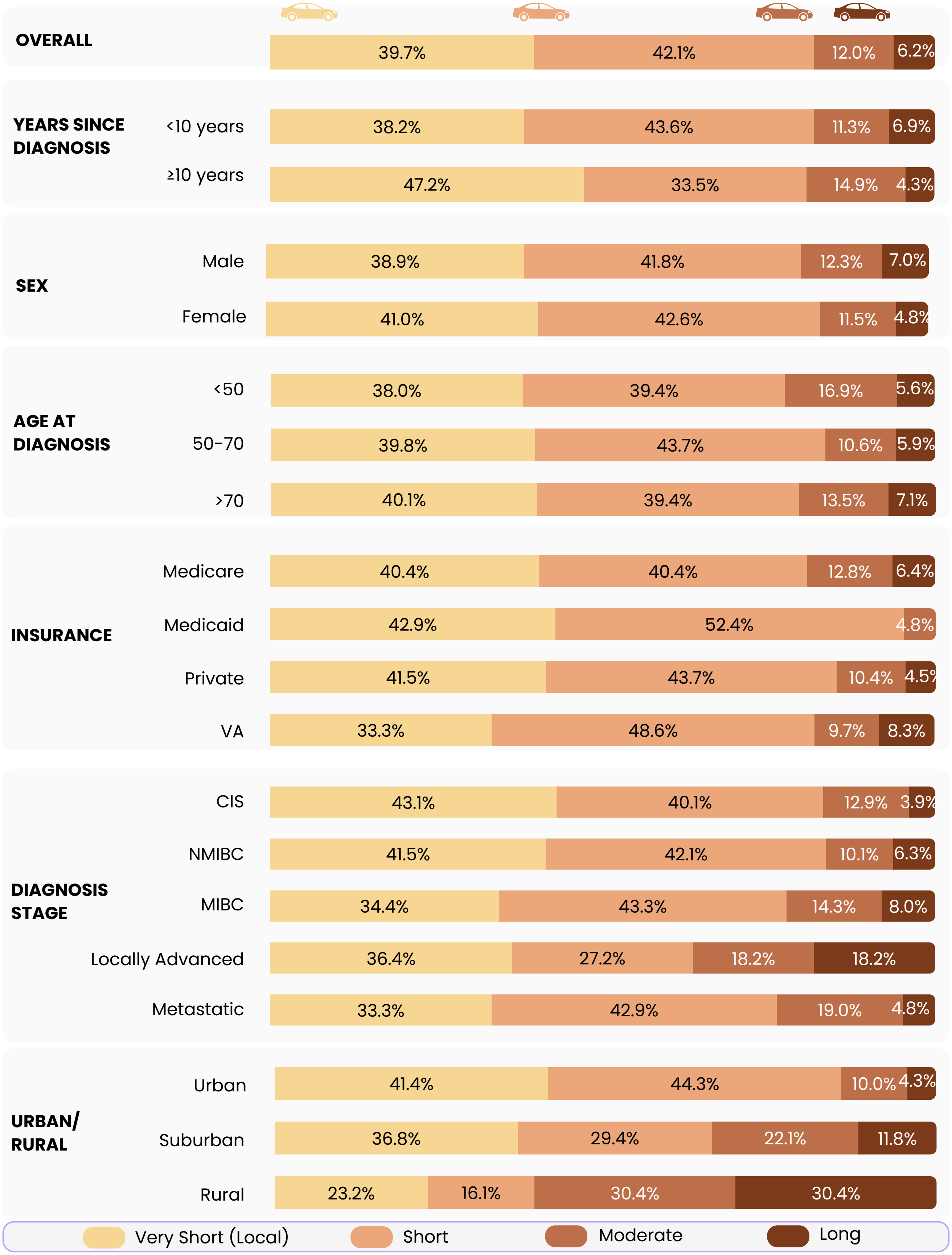
VA Clinic or Hospital
**2%**

Large Teaching Hospital or NCI/NCCN Center of Excellence

---

*****A National Cancer Institute (NCI)/National Comprehensive Cancer Network (NCCN) Center of Excellence is a designation for a healthcare organization that meets rigorous performance measures to provide high-quality cancer care.

## DISTANCE TRAVELED TO FIRST TREATMENT FACILITY

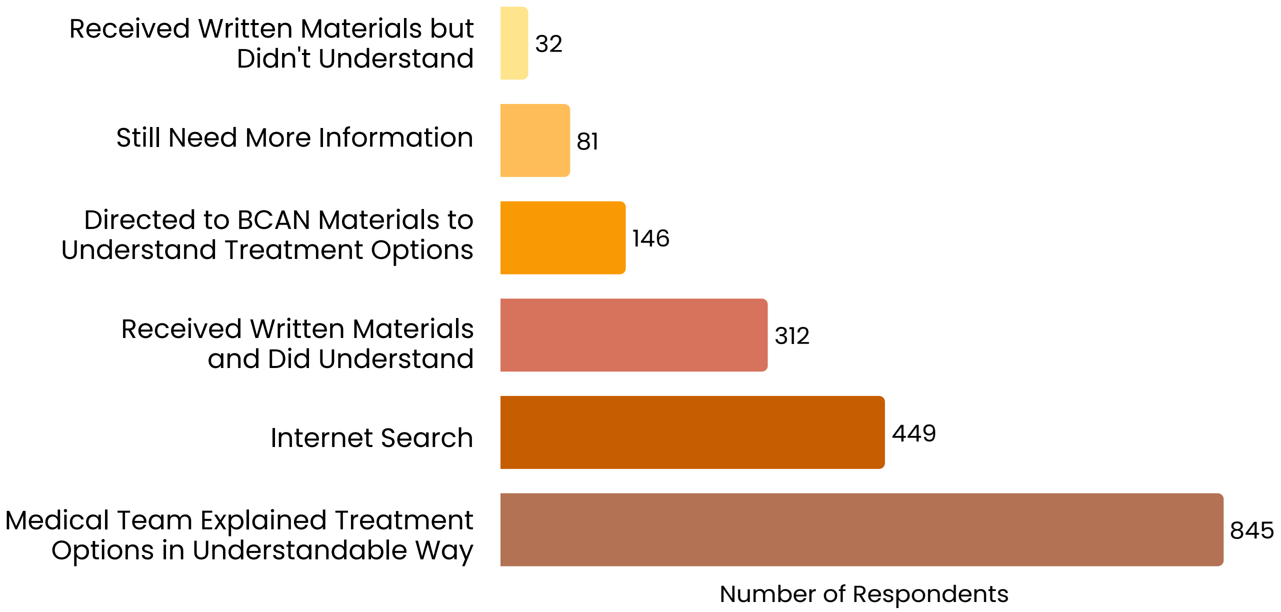


# Understanding of Treatment Options

Most respondents (84%) felt that their treatment options were explained clearly and in a way they understood. To learn more, patients turned to a mix of sources, including internet searches (45%), written materials (31%), and BCAN resources or videos (15%).

Some differences emerged in how well certain groups understood their treatment options. For example, men were more likely than women to say their treatment options were explained in an understandable way (78% vs. 70%) and to receive written materials they understood (31% vs. 22%). Understanding also varied by age: only 69% of patients diagnosed before age 50 reported receiving information that they understood, compared to 78% of those over 70 years old at the time of their diagnosis. Education played a modest role as well. Those with graduate or professional degrees were slightly more likely to understand both their treatment options (77% vs. 70%), and written materials (30% vs. 24%) compared to those with less than a college degree. Use and understanding of other resource types were similar across education levels, and no differences emerged by rural, urban, or suburban residence status. Finally, patients diagnosed within the past 10 years were more likely to have understandable written materials and other resources compared to those diagnosed more than a decade ago, reflecting expanded access to patient-centered information (written materials: 28% vs. 25%; internet: 40% vs. 30%; BCAN: 14% vs. 6%).

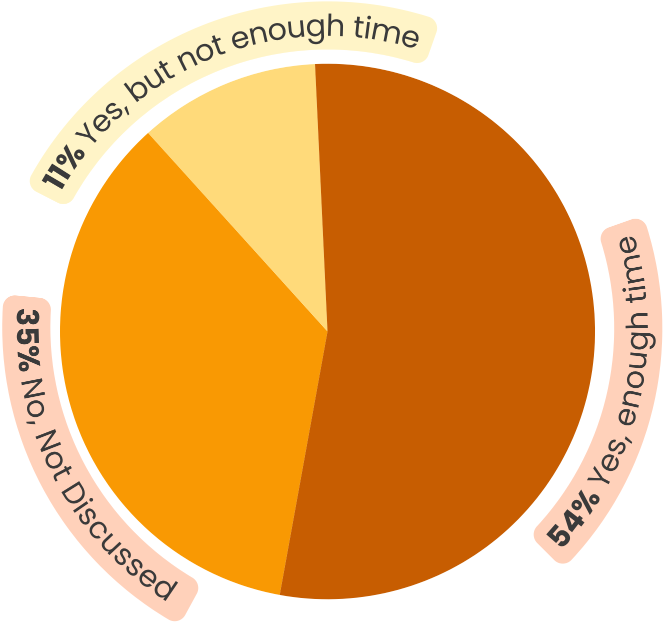
**RESOURCES USED TO UNDERSTAND TREATMENT OPTIONS**



Shared decision-making means that patients and clinicians work together to choose the treatment that best fits the patient's medical needs and personal priorities. For people with bladder cancer, this process helps match treatment options to what matters most-preserving quality of life, understanding risks and benefits, managing side effects, and respecting goals such as maintaining independence, sexual function, or minimizing time away from work or family. It ensures that decisions reflect both the best evidence and the patient's own values and wishes.

Over 1 in 3 respondents did not discuss their wishes and goals regarding their bladder cancer treatment with their provider. Among those diagnosed over 10 years ago, 42% reported not being asked about their goals and wishes, compared to 34% of those diagnosed within the past 10 years, suggesting a gradual trend toward greater uptake of shared decision-making in the treatment journey. Conversations also varied by sex: 69% of men reported having a conversation with their provider compared to 58% of women. Of those who did discuss their treatment goals, 15% of men and 20% of women said they would have liked more time to discuss their treatment goals and preferences.

**DISCUSSED TREATMENT GOALS WITH PROVIDER**



Patient experiences highlight both positive and negative aspects of these conversations. Some respondents felt their goals were acknowledged and respected: "We spoke a few times about options and had Q&A time. The team were more than happy to answer all our questions and explain so... we could make an informed decision moving forward", and "yes... we brainstormed together." Others, however, reported feeling disregarded or pushed towards a specific treatment: "...they did not seem to care what I wanted and kept trying to push me to do radical surgery" and "I never felt that they were interested in what was important to me or provided more details on the various options and issues that I would need to deal with."

Some patients were clear about their priorities and how these influenced treatment discussions: "It was made clear to me that the goal was long-term survival–that is, a cure, not just a treatment that would fend off the inevitable for a while," and "I expressed to them that I wanted to keep my prostate and bladder if at all possible." In other cases, patients' preferences were overruled or ignored, leading to outcomes that were not aligned with their goals: "Vaginal preservation [is] important to me, told the doctor several times, after surgery he said he felt that removing part of it gave extra long-term protection."

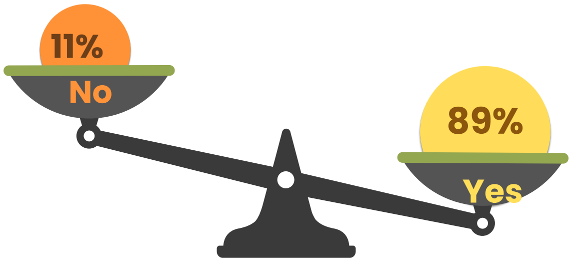
Together, these responses illustrate that while shared decision-making is increasingly recognized, there is still considerable variability in how well patient goals and preferences are elicited, acknowledged, and incorporated into treatment planning.

> ***"We talked about survival and continuity of my current lifestyle."***

## Risks and Benefits

The vast majority of respondents (89%) stated that they had a conversation with their provider about the risks and benefits of the treatment(s) that were offered to them. The frequency of these discussions were consistent regardless of years since diagnosis and were similar across stages at first diagnosis, although those initially diagnosed with MIBC reported slightly higher levels of discussion (93%). Conversations were also more common among men (91%) and veterans (95%). Among the smaller group who did not receive information about the risks and benefits of their treatment, respondents were more often female (15%) or on Medicaid (26%). One patient simply noted: "I can't say enough about how lucky I am to have [my doctor]."

**DISCUSSED RISKS AND BENEFITS OF TREATMENT(S)**

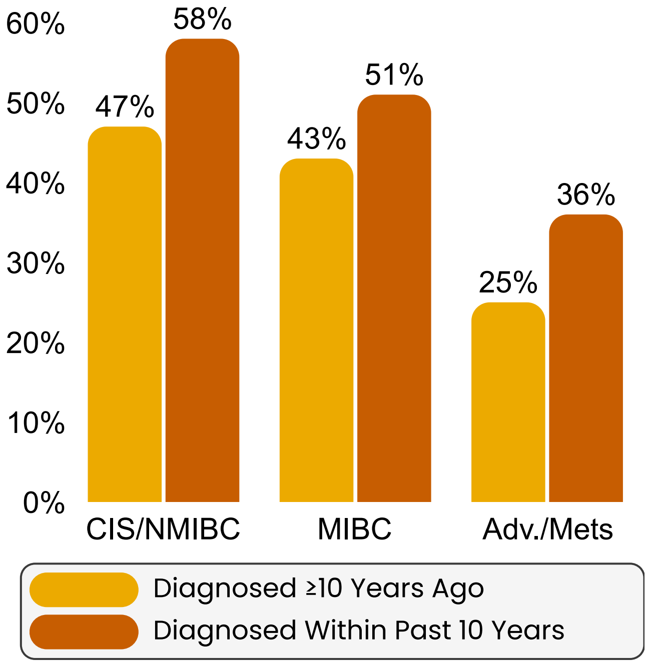


Even with these provider-led conversations, many patients sought information elsewhere, underscoring how essential patient-to-patient advocacy and lived experience were in shaping treatment decisions. Respondents consistently turned to resources that connected them to others who had "been there," whether through BCAN, online communities, or direct survivor conversations. One person described reading extensively, including about "how other patients felt about their decisions," while another reflected on the experience of "[talking] to a survivor who had the same cancer type as I did." Others relied on BCAN's Survivor-to-Survivor program or online groups to better understand life after urinary diversion surgeries: "I watched BCAN videos… I read people's accounts… I spoke directly to people who were living with my diversionary methods." Many turned to Google, YouTube, and Facebook communities, and one patient mentioned they used AI to help formulate questions they should ask their doctor. Together, these experiences show that while most patients received core information from their providers, many ultimately relied on peer voices, survivor stories, and patient-oriented resources to fully understand their choices–often viewing shared wisdom of other patients as just as important as the clinical information offered to them in the exam room.

## Multiple Treatment Options

When asked whether respondents were offered multiple treatment options, a clear pattern emerged: patients diagnosed within the past 10 years were far more likely to receive choices than those diagnosed over a decade ago, and this was consistent across all stages of diagnosis. This shift reflects the rapid expansion of evidence-based treatments and clinical discoveries in bladder cancer over the last decade, but it also highlights how limited the landscape once was for many long-term survivors.

**MULTIPLE TREATMENT OPTIONS OFFERED BY PROVIDER**



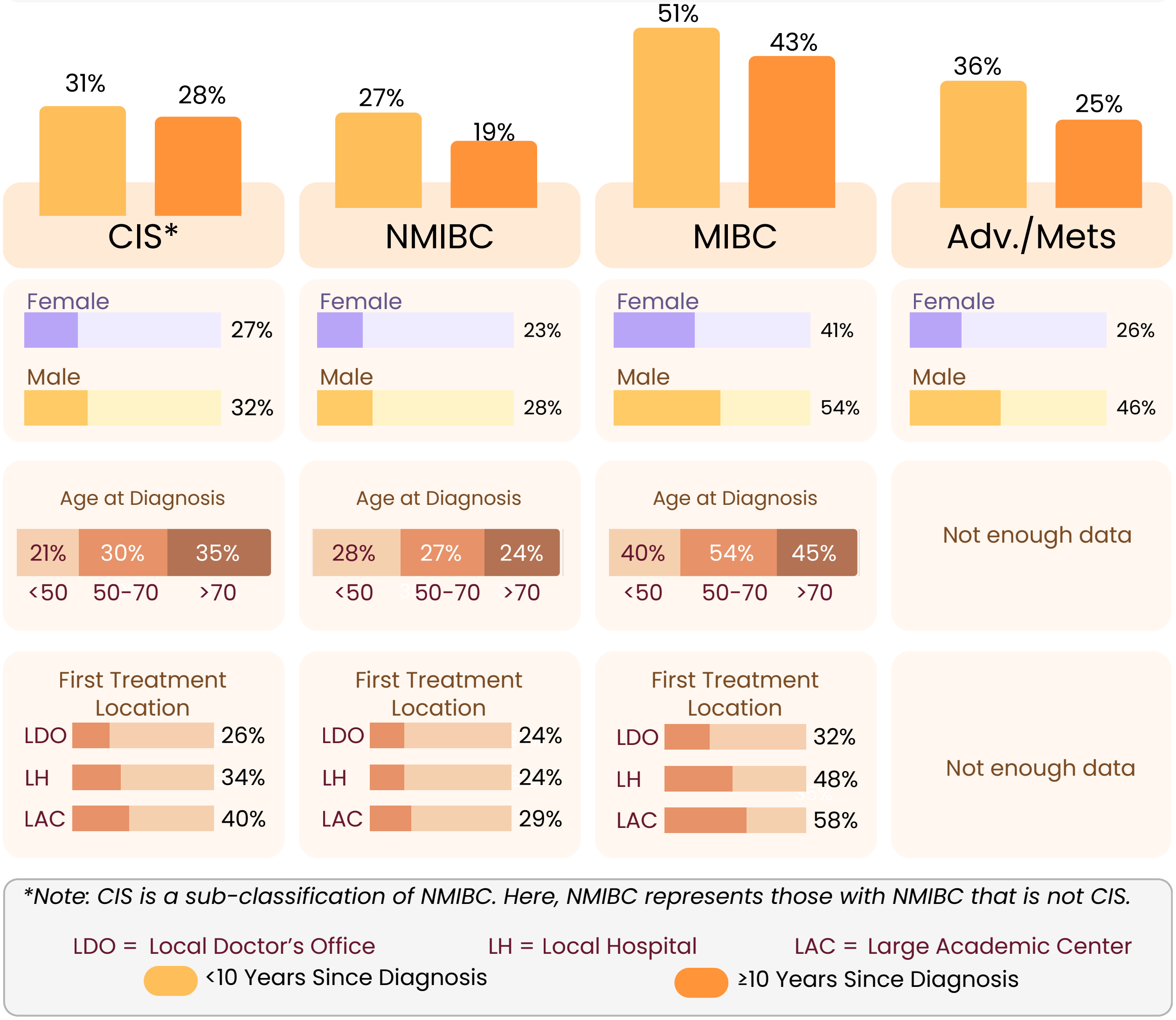
Even today, the experience of being offered options varies widely. Men were more likely than women to report receiving multiple treatment options across CIS/NMIBC, and MIBC. In contrast, women with more advanced or metastatic disease were more likely to receive multiple treatment options than men. Age also played a role: individuals diagnosed before age 50 were consistently less likely to be offered more than one path forward. Access mattered as well. Patients treated at large academic centers described far more choice than those whose first treatment occurred in a local office or community hospital. For example, among patients with CIS—a high-risk subset of NMIBC—40% of those treated at a major academic center reported having multiple options, compared with only 26% at a local doctor's office. Similar gaps appeared across the broader NMIBC group (29% vs. 24%) and MIBC (58% vs. 32%). It is difficult to discern whether patients were offered multiple treatment options based on the location of their first treatment or whether the treatment they chose influenced where they first sought care.

However, behind the numbers are deeply personal experiences of choice–or the absence of it. Some patients trusted their clinicians even when only one path was presented: "No choices given, but I highly trust my urologist's judgment." Others emphasized a collaborative process, even when the recommendation was clear: "While I was given multiple options, I did ask what my doctor recommended," and "My doctor gave me clear and full information about treatment options…But he emphasized that the choice was mine." For others, the standard of care felt predetermined: "We discussed 'choices,' but it was clear that given my symptoms and findings, there was a [single] clear, research-based standard of care that my doctors recommended and followed." External factors also shaped whether options were, in reality, available. Many patients noted the global BCG shortage as a limiting force–and sometimes the only reason that their range of options was narrowed. For those affected, the shortage reshaped the definition of "choice".

Across all these experiences, one theme stands out: while treatment options have expanded dramatically in recent years, many patients still face constraints based on when, where, and with whom they begin their treatment journey. And for some, having any sort of real choice remains the exception rather than the norm.

> ***"My 'choices' were a) BCG or b) a radical cystectomy. Not much of a choice, really."***

**% OFFERED MULTIPLE TREATMENT OPTIONS BY PRESUMED STAGE AT DIAGNOSIS**



**Note: CIS is a sub-classification of NMIBC. Here, NMIBC represents those with NMIBC that is not CIS.*

LDO = Local Doctor's Office
LH = Local Hospital
LAC = Large Academic Center

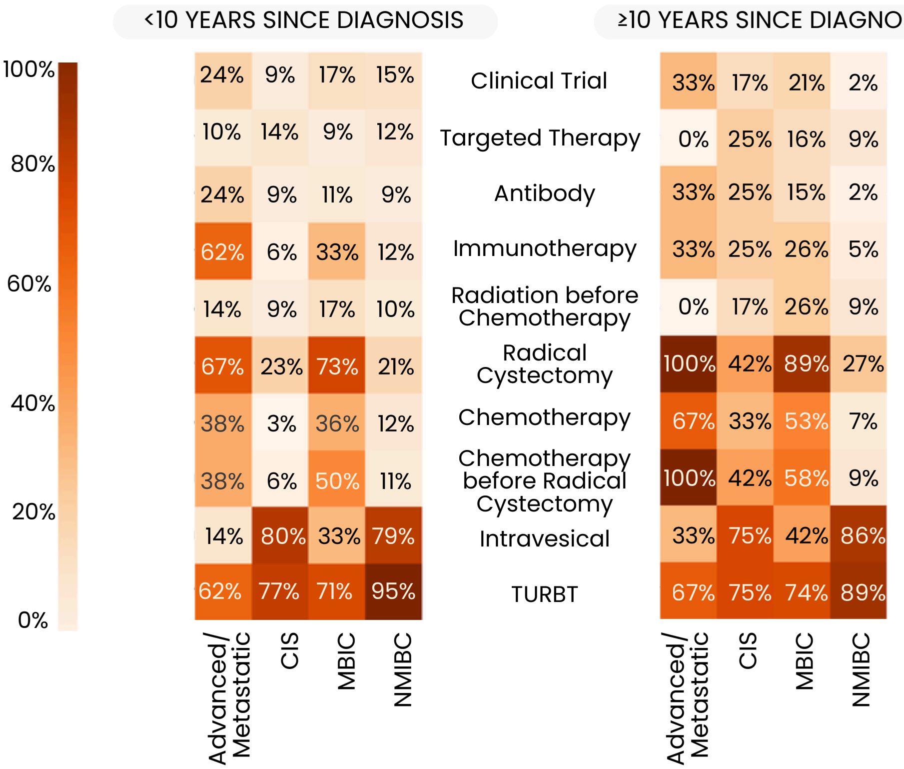
# The Power of a Second Opinion

Overall, 43% of respondents stated that they sought a second opinion on their treatment options. Second opinions were much more common among urban and suburban residents (44%) compared to rural residents (26%), among those diagnosed before the age of 50 (63%), and among those with more advanced stages of bladder cancer (54-61%). For the vast majority of patients, second opinions were an empowering experience that instilled confidence that patients were receiving the correct treatment for their situation. One patient said, "My doctor arranged a meeting for my family and me with him and [other] cancer specialists." Another who received a second opinion did not have such a positive experience: "...the head of bladder oncology told me it was too late, that he couldn't do anything for me and was told to go home and get my affairs in order."

# Treatments Received

Among patients who did not report disease progression, we sought to describe the treatments they received and identify trends among those diagnosed within the past 10 years compared with those diagnosed over a decade ago. Notable changes were observed. For example, among those diagnosed with NMIBC, radical cystectomies were more common among those diagnosed over 10 years ago. At the same time, other treatment modalities, such as clinical trials, immunotherapies, and targeted therapies, emerged with greater prevalence in the last decade. Similarly, among those diagnosed with MIBC, nearly all reported a radical cystectomy, compared to the past 10 years, when fewer patients reported a radical cystectomy, and immunotherapy and chemotherapy were more common.

**PERCENT OF PATIENTS EVER RECEIVING EACH TREATMENT BY DIAGNOSIS**



<10 YEARS SINCE DIAGNOSIS

| | Advanced/ Metastatic | CIS | MBIC | NMIBC |
|---|---|---|---|---|
| Clinical Trial | 24% | 9% | 17% | 15% |
| Targeted Therapy | 10% | 14% | 9% | 12% |
| Antibody | 24% | 9% | 11% | 9% |
| Immunotherapy | 62% | 6% | 33% | 12% |
| Radiation before Chemotherapy | 14% | 9% | 17% | 10% |
| Radical Cystectomy | 67% | 23% | 73% | 21% |
| Chemotherapy | 38% | 3% | 36% | 12% |
| Chemotherapy before Radical Cystectomy | 38% | 6% | 50% | 11% |
| Intravesical | 14% | 80% | 33% | 79% |
| TURBT | 62% | 77% | 71% | 95% |

≥10 YEARS SINCE DIAGNOSIS

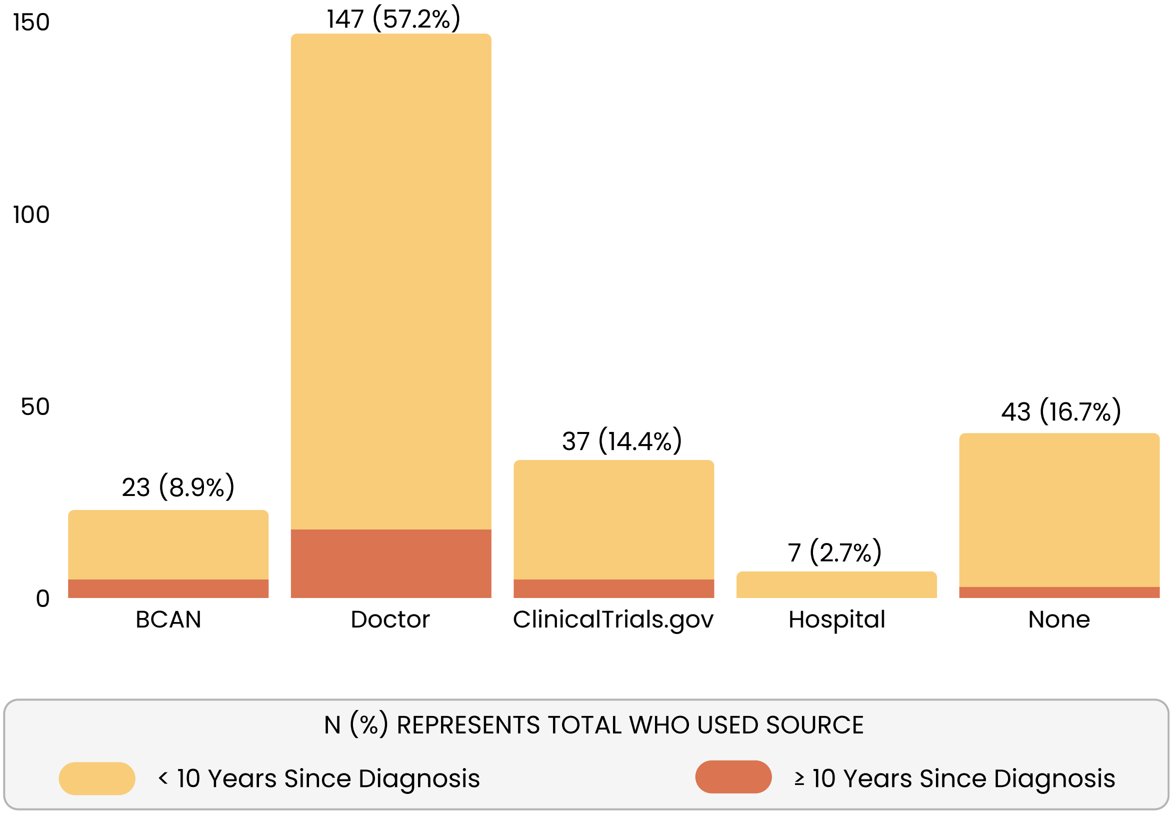
| | Advanced/ Metastatic | CIS | MBIC | NMIBC |
|---|---|---|---|---|
| Clinical Trial | 33% | 17% | 21% | 2% |
| Targeted Therapy | 0% | 25% | 16% | 9% |
| Antibody | 33% | 25% | 15% | 2% |
| Immunotherapy | 33% | 25% | 26% | 5% |
| Radiation before Chemotherapy | 0% | 17% | 26% | 9% |
| Radical Cystectomy | 100% | 42% | 89% | 27% |
| Chemotherapy | 67% | 33% | 53% | 7% |
| Chemotherapy before Radical Cystectomy | 100% | 42% | 58% | 9% |
| Intravesical | 33% | 75% | 42% | 86% |
| TURBT | 67% | 75% | 74% | 89% |

# Clinical Trials

Overall, about 1 in 3 respondents have looked into a clinical trial for their bladder cancer, while approximately half reported that they had never even thought about a clinical trial. Another 13% said they either did not want to be in a trial or their doctor discouraged it. Patterns differed by time since diagnosis. Among those diagnosed within the last 10 years, approximately 33% looked into a trial and 48% didn't consider it. This is in contrast to those diagnosed over 10 years ago, where only 23% looked into a trial and 60% didn't consider, suggesting expanding awareness and availability of trials in more recent years.

Nearly 50 patients reported difficulties finding a suitable trial, which was echoed by one who remarked that they "Haven't found one that I qualified for and haven't been contacted about any for which I applied." Most patients who sought information on clinical trials relied on their doctor, though ClinicalTrials.gov and BCAN.org were also important sources. Several respondents first encountered trial information on these sites despite not previously considering clinical trials, reinforcing that these platforms serve as meaningful and manageable entry points for patients interested in learning more information.

**SOURCES OF CLINICAL TRIAL INFORMATION AMONG THOSE WHO PARTICIPATED**



Among those who were actively in a clinical trial, experiences varied widely. A subset of respondents described difficult or impersonal experiences. One participant shared, “The clinical trial was very documentation driven…You are a piece of meat that they are experimenting on.” Another reflected on their treatment trajectory, stating “…I honestly felt like I was wasting my time.” Others emphasized factors that kept them from joining. Concerns about placebos were common: “[The] purpose of [the] trial was explained, but there was a 50% chance I might receive the placebo and I didn’t want to go through that.” For some, the trial design conflicted with personal priorities and autonomy. With regards to the type of surgery the respondent would receive, one individual said: “I didn’t participate because it would have affected the only decision I had control over…” Others cited logistics such as long travel distances and urgency: “I did not have time for a trial. My focus was survival. Time was critical.”

Despite these concerns, the vast majority of individuals who were clinical trial participants had positive experiences. Patients described reassuring aspects of clinical trials, noting that “currently in trial… feels like [the] best possible option for treatment” and “Being in the trial kept everything in line. All the testing had to be done and documentation was a part of it. It was reassuring to know nothing was going to be missed.” Another said “The trial gave me an added level of care with the research team reaching out.” Many expressed openness to future participation under the right circumstances: “I would consider a clinical trial if my bladder cancer were to advance.” At the same time, the comments make clear that patients often lack crucial information about how clinical trials are designed–especially the role of placebos. Several respondents declined trials because of fear of “getting a placebo”, even though in many bladder cancer trials, the placebo arm may be the current standard of care rather than “nothing”. These quotes point to a broader need for clearer and more accessible explanations of trial structures, comparison groups, and what participation realistically involves, so patients can make informed decisions rooted in understanding and empowerment rather than uncertainty or misconceptions.

Building on these experiences, we asked respondents what researchers could do to improve the decision-making process for patients considering clinical trials. Their feedback highlights several clear recommendations:

## KEY RECOMMENDATIONS FOR RESEARCHERS

### Provide Clear and Complete Information Up Front

- Preliminary data and inclusion/exclusion criteria
- Explanation of trial steps, schedule, commitment, and expectations
- Written materials provided prior to consent meeting

### Transparency Around Risks, Benefits, and Unknowns

- Clearly outline the pros vs. cons
- Discuss potential side effects
- Be honest about what is and is not known about the treatment

### Communication Matters

- Use clear, plain language
- Give patients examples of helpful questions they may ask
- Check for understanding throughout the process and not just at the end

### Strengthen the Researcher-Clinician Interface

- Hold seminars or briefings so clinicians are aware of and understand the trial
- Ensure consistency in how trial information is presented

### Ongoing Patient Support and Follow-Up

- Provide a clear contact for questions throughout the study
- Offer post-consultation support and aftercare, as appropriate
- Maintain regular communication so patients don't feel abandoned

### Honor Patient Autonomy and Motivations

- Respect that patients have different motivations for joining trials
- Ensure decisions are informed and not rushed

# PATIENT SUPPORT AND EMPOWERMENT

A bladder cancer diagnosis can bring emotional stress, financial pressures, and physical challenges that impact daily life. Support and empowerment mean giving patients the tools, resources, and encouragement they need to cope with anxiety or depression, manage treatment costs, and adapt to changes in energy, mobility, or urinary function. Over the past 20 years, greater awareness, improved patient education, stronger advocacy, and expanded support networks have transformed how these challenges are recognized and addressed, helping people feel more informed, supported, and confident throughout their care.

## Mental Health and Self-Confidence

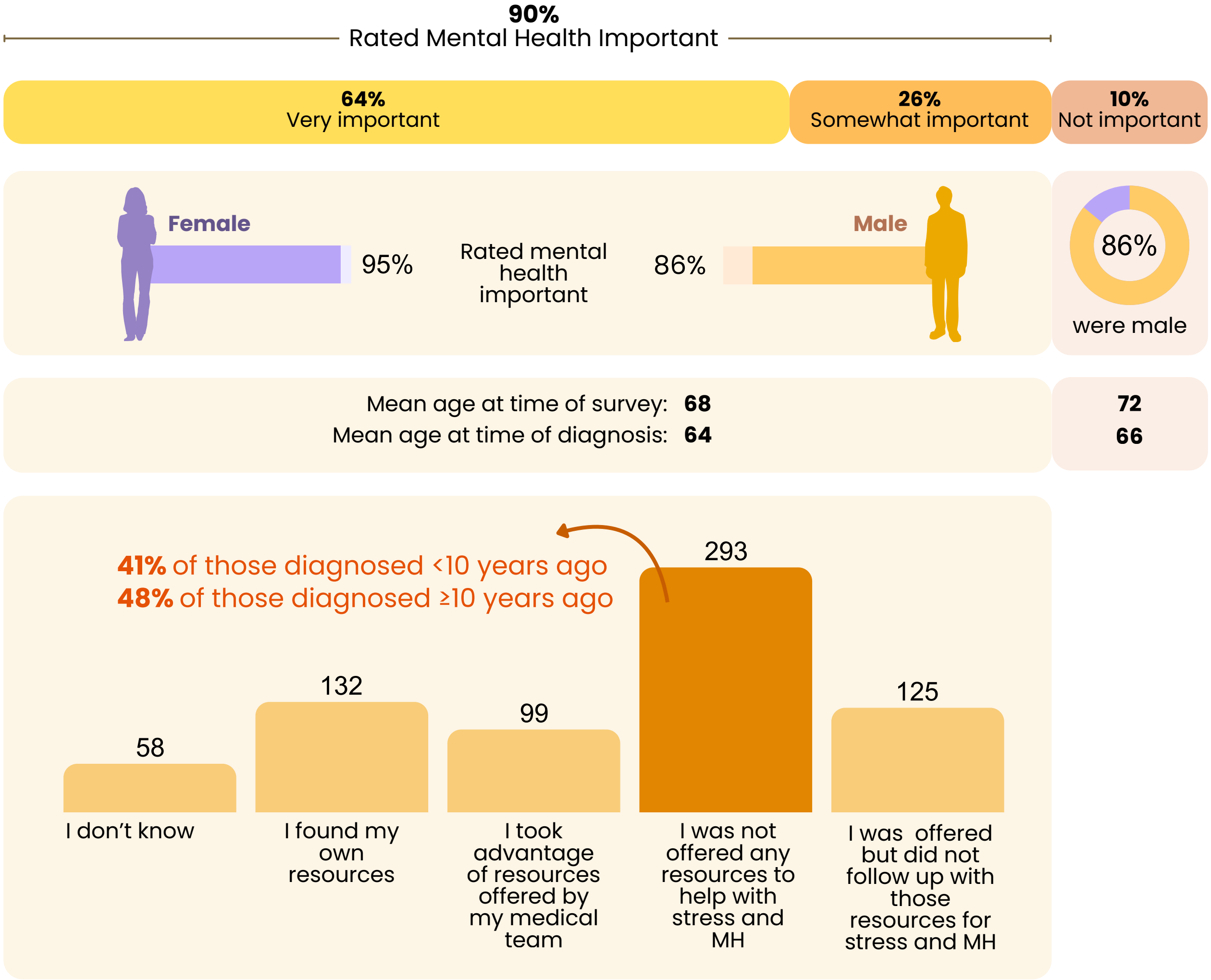
Decades of research across oncology consistently show that mental health support is a critical component of cancer care. Emotional distress, anxiety, depression, and uncertainty about the future affect medical decision-making, treatment adherence, and overall quality of life. Bladder cancer is no exception—patients face not only the physical demands of surgery, surveillance, and long-term management, but also the psychological impact of a disease that is recurrent, stigmatized, and often life-altering. Our findings reinforce what is already well documented: access to mental health resources is not a “nice to have,” but an essential part of comprehensive cancer care.

When asked about the importance of having resources to help manage the stress and mental health impacts of bladder cancer, 90% of respondents rated these resources as important. This was true for 86% of males and 95% of females, and more common among those diagnosed within the past 10 years (91%) compared to those diagnosed over 10 years ago (83%). Respondents who considered mental health resources important had a mean age of 68 at the time of the survey (mean age 64 at diagnosis).

The 79 people who reported that mental health resources were not important tended to differ in several ways. Among this group, 83% were male, the mean age at survey was 72 (66 at diagnosis), and a slightly higher proportion were veterans (14%). They were also somewhat more represented among those initially diagnosed with CIS (14%) compared to MIBC (8%), or advanced/metastatic disease (11%).

Despite variation in perspectives, many respondents highlighted the universal emotional strain of bladder cancer. As one person shared, “Bladder cancer is life changing, so stress and anxiety go along with that change. This can affect the mental health of any individual going through this disease.”

**RESOURCES FOR STRESS AND MENTAL HEALTH (N=786)**



## *Gaps in Mental Health Support*

Among participants who said mental health support was important, 41% reported that they were not offered any resources by their clinical team. These gaps did not differ by sex but showed only modest improvement over time: 41% of those diagnosed within the past 10 years were not offered resources compared to 48% of those diagnosed over 10 years ago. Access also varied by age at diagnosis. Of those diagnosed before age 50, 52% did not receive mental health resources, compared to 41% of those diagnosed between 50–70, and 44% of those diagnosed at age 70 or older. Differences were also evident by disease stage. Half of those initially diagnosed with NMIBC were not offered resources, compared to 21% diagnosed with MIBC. No meaningful differences emerged by veteran status or insurance type.

Many respondents described the consequences of facing cancer without emotional support. One wrote, “Sometimes I wondered what was worse—the disease itself or the effect on your mental state.” Another shared, “18 months of ongoing appointments, treatment, surgeries… it’s exhausting. I feel like I only exist to go to doctors. I would like my old life back.”

## *Utilization of Offered Mental Health Resources*

Only 14% of all respondents used the mental health resources offered by their clinical team. Utilization was slightly higher among females than males (16% vs. 13%), and among those diagnosed within the past 10 years (15%) compared to those diagnosed earlier (13%). People diagnosed between ages 50–70 were the most likely to use resources (16%), compared to only 10% of those diagnosed younger than 50 or older than 70. Patients initially diagnosed with MIBC used mental health support most frequently (21%), compared to those with CIS/NMIBC (12%). Veterans used services at a slightly lower rate (12%) than non-veterans (15%). A number of respondents emphasized how crucial these resources were when available. As one patient explained, “I had horrific anxiety… but I was able to work through it with psychotherapy, medication for sleep, and exercise.” Another said, “Support groups and mental health counseling—I've needed and used all the tools in my toolbox.”

## *A Search for Support*

Because many were not offered resources through their clinical team, 20% of respondents reported finding mental health support on their own. Those with at least a college education were more likely to do so (21%) than those without (14%). Patients described searching for support groups, online communities, therapists, or peer mentors who understood bladder cancer specifically. But as one person noted, “Resources should be easily accessible; you shouldn’t have to find them yourself.” Another emphasized, “Talking to a therapist with bladder cancer experience—not just any therapist—made a huge difference.”

## *The Compounding Stress of Financial Strain*

In addition to the emotional weight of cancer itself, respondents frequently described the financial and insurance-related stress that accompanied their diagnosis and treatment. These pressures often intensified feelings of anxiety, fear, and uncertainty. Several individuals described the relief that came from secure coverage—“Knowing I wasn’t alone, and that my insurance would cover any treatment indicated, helped me deal much better with recovery.” Others conveyed the opposite experience: “My medical cost-sharing plan didn’t cover any mental health help… It was frustrating and a substantial expense.”

For some, financial worries eclipsed the disease itself: “My stress is the stress of money and my inability to contribute to my wife,” and “If I didn’t have Medicare and a good supplemental plan, my stress level would be very high.” Others struggled with access rather than affordability. “I tried a virtual therapist that was not helpful, and I couldn’t afford another,” one patient shared. Another described desperately searching for local support groups without success.

Collectively, these experiences underscore a broader reality: the mental health impact of bladder cancer is shaped not only by the disease, but by the systems that surround it—insurance, clinical communication, resource availability, and financial security.

## *The Emotional Reality*

Throughout the free-text responses, patients emphasized that emotional support is not optional—it is central to coping and to healing. Many described bladder cancer as a profoundly lonely experience: “Cancer is a lonely place. Every person needs support, encouragement, and love to make it through it,” and “I’m a strong person, but dealing with bladder cancer can bring you down quick,” and “There can be some really dark days… I am sympathetic to those who need external support.”

Despite the challenges, many also highlighted the value of hope, connection, and community. As one respondent put it, “Knowing I was one of many helped significantly. Online resources helped.” Another shared, “Support systems—my husband, family, friends—have been invaluable. But support groups with people going through the same thing were essential.”

Taken together, these findings reinforce a consistent message from the broader literature: mental health support is an essential—yet often underprovided—component of bladder cancer care. Access to emotional, psychological, and peer-based resources remains uneven, and structural barriers such as insurance limitations continue to shape patients’ experiences. Strengthening mental health support across the care continuum represents a critical opportunity to improve the quality of life and overall well-being of people living with bladder cancer.

## *Physical Impacts on Self-Confidence*

Patients described profound and wide-ranging shifts in how they view their bodies after bladder cancer treatment. Many reported a loss of confidence rooted in feelings of physical unpredictability—particularly around continence, ostomy management, and changes in bodily function.

Participants described constant vigilance over leakage, visibility of appliances, or sudden urinary needs, with one individual summarizing: “I am no longer in control of my body.” This sense of diminished control often led to avoiding social situations, heightened self-consciousness, and a feeling of being “broken.”

Concerns about appearance were also a recurring theme. Scars, weight changes, muscle loss, abdominal disfigurement from repeated surgeries, and ostomy appliances contributed to feeling less attractive or less like their “former self.” Some framed it as part of rapid aging—“I feel like I aged much faster”—while others spoke to a profound rupture in identity, such as former athletes who now struggle with basic bodily functions. For several respondents, the emotional impact was stark: “I used to love my body. Now I hate my body.”

At the same time, a number of patients highlighted adaptation, resilience, and reoriented priorities. Some noted that being older shifted their focus toward functionality over appearance, while others described finding confidence through improved health behaviors or personal growth during survivorship. A few emphasized the body’s unexpected strength and capacity to recover, sharing that their confidence improved as they learned to “listen to [their] body” and witness its “amazing recuperative powers.”

Patients living with a urostomy offered specific reflections on the daily realities of adjusting to and managing an appliance. These experiences encompassed everything from choosing clothing to navigating social stigma and embarrassment, such as during airport screenings. For some, the ostomy represented a visible reminder of illness; for others, it was an accepted part of moving forward.

Together, these accounts illustrate that body-related changes after bladder cancer treatment can deeply affect self-confidence—shaping how patients move through the world, how they see themselves, and how they believe others see them. Feelings ranged from grief, loss, and frustration—to acceptance, gratitude, and newfound strength. Despite the significant physical and emotional burdens, many patients expressed a continued determination to adapt, advocate for themselves, and reclaim confidence in bodies that, while altered, have carried them through cancer and into survivorship.

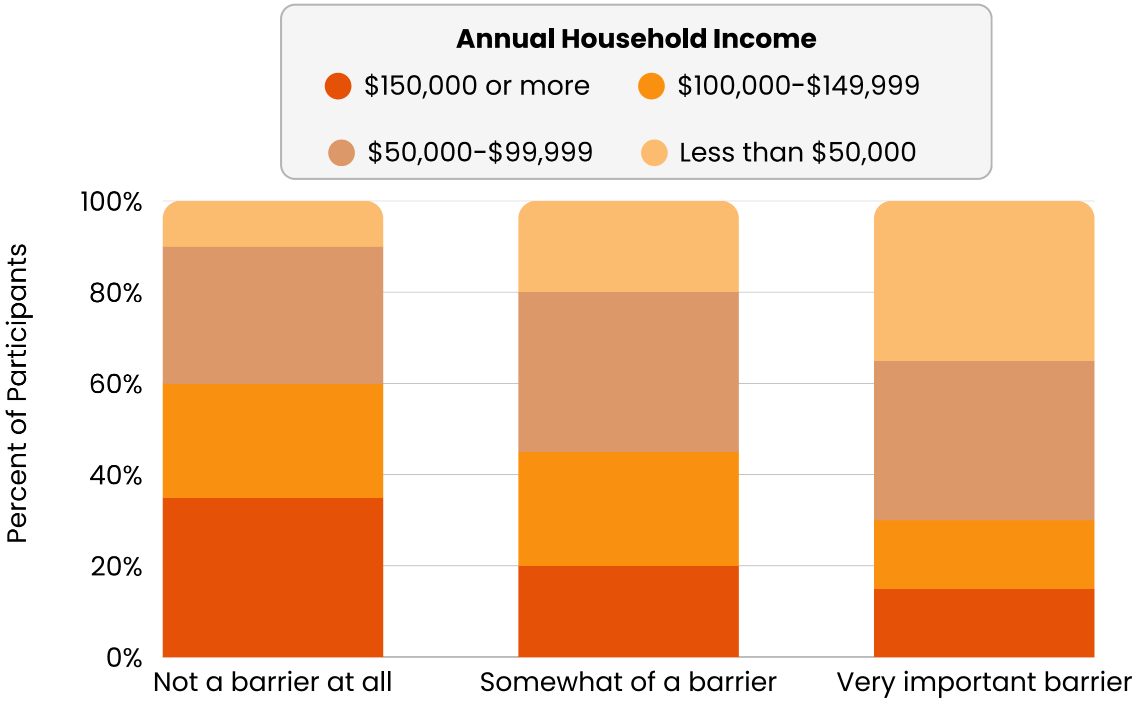
# Financial Burdens and the Hidden Costs of Bladder Cancer

Financial strain emerged as a significant barrier to care for many respondents. Overall, 20% of participants reported that cost had been somewhat or very much a barrier, and these individuals tended to have lower household incomes. Yet only 24% of those who identified cost as a barrier recalled being offered any type of financial resources or assistance program—regardless of whether they ultimately used them—highlighting a substantial gap in financial guidance within clinical settings.

## *Burden*

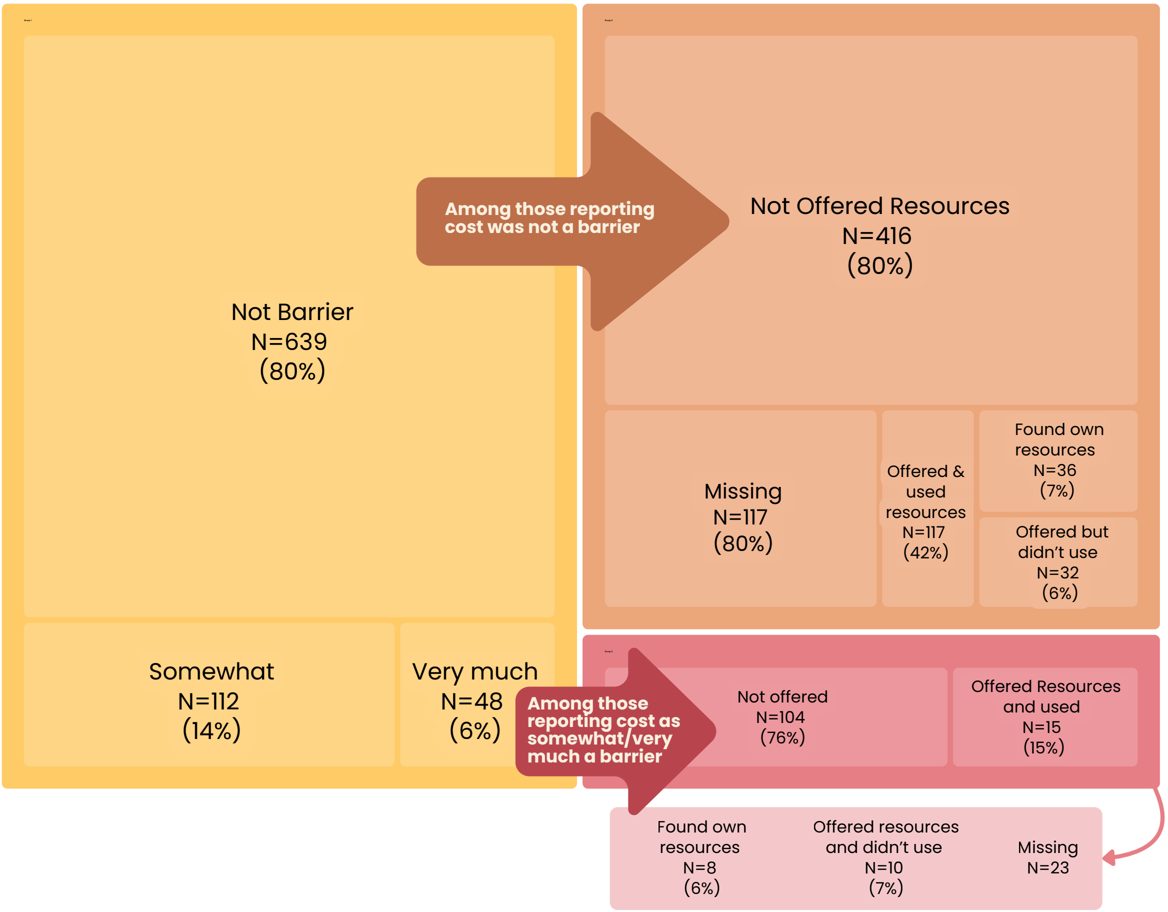
Financial burden was more common among people diagnosed within the past decade (21% vs. 13% diagnosed more than 10 years ago), reflecting the rising costs of newer treatments and the evolving insurance landscape in the U.S. Women were nearly twice as likely as men to report financial strain (28% vs. 15%), and younger patients faced the steepest financial challenges, with 41% of those diagnosed before age 50 reporting cost-related barriers.

**COST OF BLADDER CANCER TREATMENT AS A BARRIER BY INCOME LEVEL**



The severity of the disease also mattered. Reports of financial hardship increased with higher stage upon diagnosis, suggesting that more intensive or complex treatment pathways lead to greater financial exposure. While the sample size limited robust comparisons by insurance type, preliminary patterns showed that 23% of privately insured respondents reported cost as a burden compared to 14% of those on Medicare, though the free-text data reveal a more nuanced reality.

**FINANCIAL RESOURCES OFFERED BY WHETHER TREATMENT COSTS WERE BARRIER**



## *The Patchwork Reality of the U.S. Insurance System*

Patients described vastly different experiences depending on their insurance coverage. Many Medicare beneficiaries emphasized how essential supplemental plans were—"I have Medicare and pay for a high-quality supplement. Many people can't afford one," one person noted. Others described high-deductible private plans that left them unable to access major cancer centers or needing to take on substantial debt simply to initiate treatment. As one respondent wrote, "I had to put $99,000 on several credit cards before I could receive treatment… My credit rating took a hit."

For veterans, the VA system provided a lifeline. A number of respondents explicitly credited VA care with eliminating the financial burden of treatment. One wrote, "I am a Vietnam/Agent Orange vet, so if my insurance did not cover anything I could go to a VA facility." Another responded simply: "No cost from the VA." For these individuals, eligibility for VA care dramatically reduced financial stress—an option not available to many other survey respondents.

### *Hidden Costs*

Although most respondents reported that their primary treatment costs were at least partially covered by insurance, many stressed that the most burdensome expenses were not the treatments themselves, but the surrounding costs rarely reimbursed by insurance. These included travel, lodging, unpaid time off work, copays for repeated procedures, and long-term supply needs (e.g., catheters, lubricant, ostomy materials, incontinence products). For some, travel was a particular hardship. Patients living in rural areas or far from major cancer centers often faced repeated long-distance trips. One person explained, "I went to [an Academic Center] 12 hours from home… lodging, gas, and food were all out-of-pocket." Patients described a cascade of ongoing expenses, such as: "Travel to and from was costly and I had to stay in hotels some," to "We had to board the dog," to "All the problems with incontinence for a year cost over $800 in products." Income loss was another major theme. Respondents described taking unpaid leave, relying on short-term disability, or depleting retirement savings. "Missed a lot of work without pay," one wrote. Another shared, "Cashed out retirement."

### *Medical Decision-Making Shaped by Costs*

Perhaps the most concerning finding was the number of patients who said that financial hardship directly influenced their treatment choices. A few respondents explicitly described delaying or declining recommended care because of cost: "I'm trying to keep costs down by not pursuing other treatment options," and "Cost… dictates my plan of care." These responses reveal the bleak reality: for some patients, the care they received was not determined by what was medically best, but by what they could afford. This stands in stark contrast to goals of equitable, patient-centered cancer care.

### *Cost Assistance Programs*

Only 6% of respondents recalled being told about drug-company assistance programs for out-of-pocket costs. Nearly all who learned about such programs were diagnosed within the past decade, suggesting increasing awareness over time but still substantial missed opportunities. Of the 53 individuals who did receive information, most were Medicare recipients (36%) or privately insured (25%), with very few using Medicaid and only one using VA insurance. Income did not appear to determine who was told about these programs. Still, these resources were not universally available or sufficient. As one respondent described, “Treatment was covered, but prescriptions were not always covered or had a large copay.” Others waited on grants to offset expenses or struggled to secure approvals for tests and imaging.

## Living With the Possibility of Recurrence

Given the nature of bladder cancer and its high likelihood of returning, fear of recurrence was a defining part of the patient experience. Nearly four in five respondents (79%) reported worrying about their cancer coming back or becoming worse. This concern was especially pronounced among people diagnosed in the past decade (82%), women (86% vs. 74% of men), and younger respondents—91% of those under age 50 reported fear of recurrence, with worry gradually declining as age increased. These emotions were also more common among individuals who still had their bladders (87%) compared with those who had undergone a radical cystectomy (66%). Worry was strongest among people first diagnosed with NMIBC and among those who had already experienced disease progression (79%).

Participants described this fear as a persistent presence—a low hum in the background of daily life. Several described "scanxiety," the dread leading up to surveillance scans, noting that "scanxiety is real" and that for many, the thought of recurrence was "always on my mind." One participant shared that "any time my bladder is off, I worry about it coming back," while another noted, "I am focused on THIS round of cancer and treatment."

For some respondents, the fear was tempered by age or perspective. "I do not worry about it at my age," one participant wrote, while another reflected on having already lived far beyond their initial prognosis, saying, "I've so far exceeded my life expectancy it's mind-boggling… I put a lot of emphasis on the positive and try to annihilate the negative."

Many framed their emotional response as a daily balancing act—staying vigilant without letting worry take over. One participant explained, "My challenge is how to live with the reality of recurrence without it taking control." Others described strategies they relied on: turning to faith, practicing daily affirmations, keeping busy, or focusing on gratitude. One wrote, "Instead of focusing on it coming back, we give thanks for every day that it has not." Another emphasized the importance of mental grounding, saying, "If I slip into the 'what ifs,' I try to refocus on things that bring me joy—my son, my art, my garden."

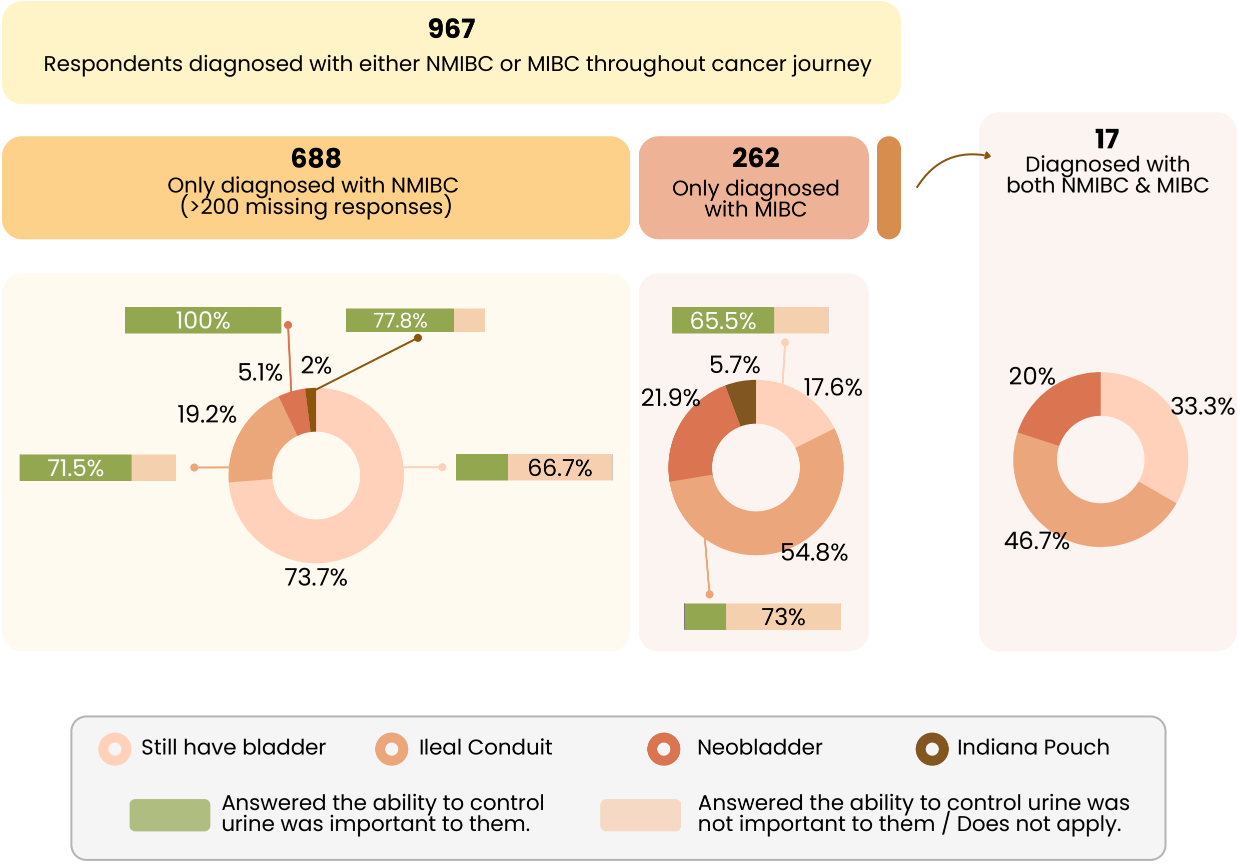
Several respondents described a deep sense of hypervigilance, especially around bodily changes. One participant shared, "I think about it most every time I pee," while another reported, "I worry EVERY time I pee that I will see blood." This vigilance often intensified around routine surveillance: "I get anxious leading up to my quarterly cystoscopy."

For some individuals, the emotional burden was intertwined with life circumstances. A widow with three children wrote, "I'm terrified it's going to kill me." Others reflected on earlier conversations with clinicians—"The doctor told me, 'We cannot cure this, but we can control it…it will recur.' I believed him." Yet even with this knowledge, many still expressed determination to keep moving forward: "I try to enjoy life. I do enjoy life." Despite the diversity of experiences, a clear theme emerged: the worry never fully disappears, but many find ways to coexist with it—through faith, routines, support systems, and a focus on gratitude and daily life.

# Continence

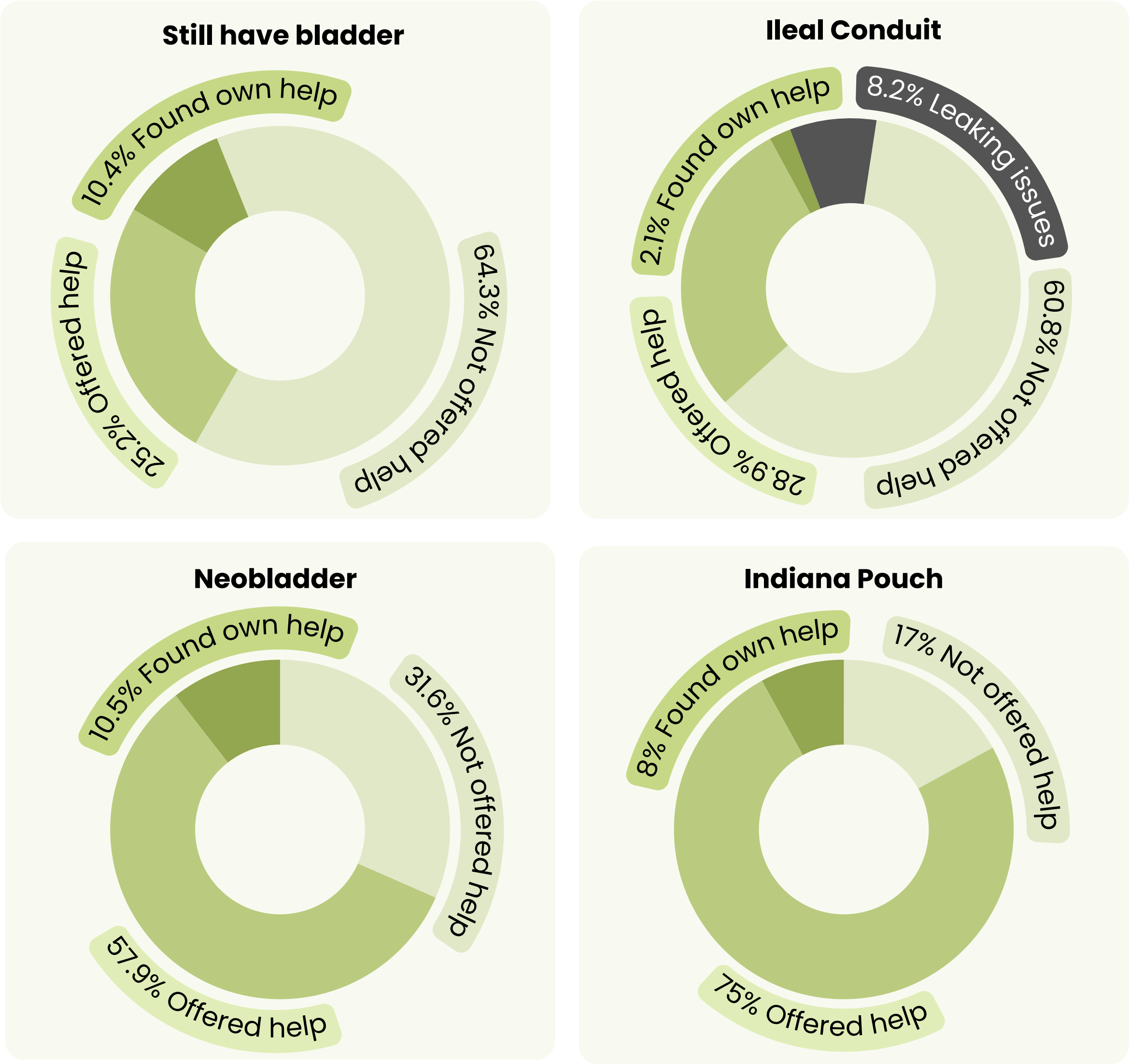
Across the 967 respondents with NMIBC or MIBC, post-treatment urine control was a major priority. About two-thirds of participants said continence was important to them, especially those who still had either their bladder or a neobladder. The reasons were deeply personal: fears of smelling like urine, anxiety about public accidents, the burden of constant bathroom trips, and major disruptions to activities of daily life. Many described structuring their entire routines, travel, and social activities around access to a bathroom.

## IMPORTANCE OF URINE CONTROL BY RADICAL CYSTECTOMY



Continence experiences, challenges, and support offered varied by urinary diversion reconstruction type. Patients with neobladders reported continence as most important, yet 30% said they were not offered any help despite common issues like nighttime leakage, urgency, and frequent accidents. A small number of patients with Ileal conduits struggled with leaking ostomy bags, and about 59% of those with an Ileal conduit were not offered any help. Approximately three quarters of patients with Indiana Pouches or patients who received BCG reported they were not offered assistance with urine control. Across all groups, the picture was similar: help and assistance were rare, even when continence issues deeply shape patients' quality of life.

## AMONG THOSE WHO SAID URINE CONTROL WAS IMPORTANT



**Still have bladder**

**Ileal Conduit**

**Neobladder**

**Indiana Pouch**

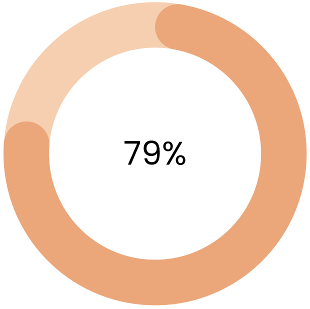
Among those who did receive support or found their own support, several types of resources stood out as common themes:

- Pelvic floor physical therapy, particularly for those with a neobladder
- Pads, shields, diapers, external catheters, and mattress protection
- Ostomy nurses and guidance on urostomy bag management
- Catheterization instructions and advice on timing, techniques, and building continence over time
- Medications (such as Flomax) for symptom management
- Peer support, especially from others with the same type of urinary diversion.

Patients repeatedly emphasized that practical, hands-on guidance, whether through exercises, ostomy coaching, or everyday types, made a meaningful difference in their day-to-day lives.

## Intimacy and Sexual Function

Sexual function and intimacy are critical components of quality of life for many individuals living with bladder cancer. In this survey, 79% of respondents reported that sexual function was important to them. This importance was slightly higher among men (83%) than women (69%) and inversely correlated with age: 92% of respondents diagnosed under age 50 rated it as important, compared to 72% of those over 70.



**Patients who said sexual function was important to them*

The perceived importance was consistent across patients who had undergone radical cystectomy and those who retained their bladder. Notably, respondents initially diagnosed MIBC were slightly more likely to report sexual function as important (84%), reflecting the profound impact treatments for MIBC can have on sexual health.

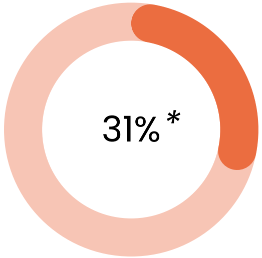
Despite the high importance placed on sexual function, only 27% of respondents who identified it as important reported being offered support or resources. Support was more commonly offered to men, those diagnosed over 10 years ago, patients who underwent radical cystectomy, and individuals initially diagnosed with either NMIBC or MIBC. This gap highlights both the clinical and psychosocial barriers to discussing sexual health, as well as discomfort or stigma around the topic.

Patient narratives underscore the critical nature of sexual health within the bladder cancer experience. One respondent noted, "The concern over erectile dysfunction (ED) was not discussed enough. There was a point that I just wanted this cured at all costs. I wish I had spent more time discussing ED." Another highlighted the technical aspects of preserving sexual function after surgery, stating, "If a prostate has to be removed, sparing the nerve bundle is critical so that a man can function physically—sexually and achieve an erection—not only to have children but to continue having a healthy physical relationship with their partner." These accounts illustrate the deep personal impact of sexual dysfunction and the importance of timely, open communication with care teams.

The findings suggest that while sexual function remains a high priority for most patients, the provision of supportive resources and counseling is limited. Integrating sexual health discussions into routine care, offering specialized counseling, and proactively addressing potential treatment-related effects are essential steps toward improving overall quality of life for bladder cancer patients.

## Reproductive Health

For younger patients facing bladder cancer, questions about fertility carried profound weight. Among the 35 respondents under age 50 who answered the question, 11 (31%) indicated that the ability to have children in the future was



**Among the 35 patients <50 years old at diagnosis* important to them. Seven were female and four were male; all but two were initially diagnosed with NMIBC. However, eight of these 11 patients were not offered any fertility preservation options.

One patient reflected on the careful deliberations before treatment: "It was definitely something that I thought about when I made [treatment] plans… what I could live with, what did I need… It was a good exercise in figuring out what treatments I was prepared to accept."

> ***"I am at the point in my life where I want to try for kids, but I can't and it hurts."***

The outcomes varied dramatically. One patient shared their loss: "My husband and I decided after my initial diagnosis of bladder cancer that we would not have children." Another described an unexpected pregnancy after being advised to wait. Another expressed straightforward hope: "I simply want to start a family one day." When fertility preservation was discussed, it made a tangible difference. One patient noted: "Fortunately, I was told to freeze sperm. I now have 2 kids!" Another described alternative measures: "Due to high risk of metastasis…we were unable to freeze eggs. We are doing Zoladex injections to help protect the ovaries."

However, discussions about fertility preservation were not always handled with appropriate sensitivity and care. One patient recounted a deeply distressing experience: "When I relayed to [my local oncologist] the costs to engage in fertility preservation, she acted very annoyed. I left the appointment in tears."

## Survivorship Planning

As one respondent noted, "Survivorship care plans are important as [they] provide a road map on how to navigate life after bladder cancer." It is intended to provide guidance on the frequency of follow-up and testing, side effect management, staying healthy, and keeping track of things to monitor in the future. When asked about the importance of having such a plan, 86% of respondents said it was somewhat or very important. Yet, despite this strong desire for structure and guidance, 57% of respondents reported that they had not been offered a survivorship care plan. Many shared that they had never even heard of the concept until taking this survey, but strongly wished they had one.

> ***“Knowledge is power. [A survivorship plan] removes much of the mystery and fear of the unknown.”***

This sense of being left without direction came through repeatedly. “The aftercare is almost as important as the medical care. They go in hand in hand,” one respondent wrote, while another emphasized how overwhelming the transition can be without support: “I want to live and sometimes all of this is so overwhelming… Care plans keep me focused.” Another noted the importance of self-advocacy: “This was not part of my clinical trial. I have had to try to figure this out within the VA system. You usually have to ask.”

## Roles and Relationships

Respondents described a wide spectrum of ways bladder cancer reshaped their family dynamics, social interactions, and workplace experiences. Their reflections ranged from feeling burdensome or invisible, to finding deeper connection and even a sense of purpose in supporting others.

### *Burden and Fragility*

Many respondents expressed a deep awareness of how their illness shifted roles within their families. Several described guilt, dependency, or the sense that loved ones had taken on new emotional responsibilities:

- “I feel like my kids are now placed in the role of worrying about my future and care that may be needed.”
- “Sometimes I feel guilty because of the time it takes away from others.”
- “I feel a burden to my family.”

Others noted that they were treated differently, even when they felt unchanged inside:

- “It makes everyone tip-toe around me and I feel like a charity case.”
- “Family treated me fragile—then when I found out I was in remission, back to normal!”
- “I try hard not to let it affect my roles and relationships, however I believe it has changed others’ relationship with me. I am treated differently than I was.”

The workplace, for some, was an even more isolating environment: “People at work have acted like I'm either no longer here or like cancer is contagious.”

## *Strengthening of Family Bonds and Social Connections*

Alongside these challenges, many respondents shared that their relationships grew stronger, grounded in gratitude and mutual support:

- “It has strengthened my relationships with close family and friends.”
- “Stronger bonds and more appreciation for every day.”
- “My husband and I are closer than ever.”
- “We seemed to have gotten closer.”

Several described a more thoughtful or compassionate perspective toward others:

- “I believe I try to be more understanding of what people go through.”
- “I realized how much and how many people actually care about me.”

One respondent captured the complex duality well “It’s a conscious effort to stay positive, and some days, difficult.”

## *Role of Friends and Family*

Patients overwhelmingly described the critical role that family, friends, and broader social networks played in navigating bladder cancer treatment. Support took many forms, ranging from practical assistance to emotional sustenance, with recurring themes emerging around caregiving, advocacy, companionship, and the power of connection.

Practical and logistical support was a major source of relief. Many patients highlighted family and friends helping with transportation to appointments, surgeries, and chemotherapy sessions, as well as assisting with daily tasks such as meal preparation, household chores, and childcare. One respondent described their experience as: “Right after surgery, people brought meals for a few weeks. I was gifted a blanket to use in my recliner chair. A friend cleaned my patio. We experienced so much love! That was key to recovery and moving forward.”

Emotional support and advocacy emerged as equally critical. Patients described partners, children, and close friends providing a consistent presence during treatment, attending medical appointments, and offering reassurance during moments of fear or uncertainty.

One participant reflected: “My wife was a rock of support. She did everything from managing appointment schedules to advocating for quicker appointments… She never seemed to mind any of the accidents with bodily fluids during chemo or post-surgery.” Others emphasized the importance of listening, validating emotions, and allowing patients to process their experiences at their own pace: “Allowed me to talk when needed and to allow me to deal with this in my own way and in my own time.”

Community and peer support, including online networks and connections with other bladder cancer patients helped patients navigate aspects of the disease that family and friends could not fully understand. Patients described the reassurance and practical guidance they gained from support groups and survivors: “Online bladder cancer support groups (like on Facebook) or reading other folks’ journeys on BCAN helped. I felt like I could better cope by connecting with people who have been through similar situations.”

Spiritual and motivational support were also commonly cited, with many patients relying on prayer, faith, and messages of encouragement from their social network to maintain hope and resilience. One respondent noted: “My family and friends are very supportive. They inquire on how I am doing and offer help if I need it. I lean on my faith and am grateful for those praying for me.”

While the majority of patients reported positive experiences with support, some highlighted challenges, including friends or coworkers who struggled to engage or relate: “It’s been very difficult. People ignore me, stopped talking to me or dropped out of my life. Others ask how I am doing but no one asks if they can help.” This contrast underscores the profound value of consistent, compassionate engagement from both close and extended social networks.

Overall, the data indicate that a strong network of support—ranging from immediate family to friends, online communities, and faith-based resources—is a cornerstone of coping with bladder cancer. Patients relied on this support not only to manage the practicalities of treatment but also to sustain emotional well-being, foster resilience, and reclaim a sense of normalcy and agency during a profoundly disruptive experience. The narratives underscore the enduring power of human connection to transform the bladder cancer journey from one of isolation and stress to one of empowerment and hope.

## *Maintaining Identity and Seeking Community*

Some emphasized that, despite major life changes, their core identity remained intact: “I'm the same person with my ‘bladder’ on the outside.” For a few, openness and community–particularly within peer groups–provided relief that general relationships could not: “I find it helpful to belong to an ostomy group on Zoom where we can freely talk about our health and challenges.”

## *Empowerment and New Sense of Purpose*

A notable subset of respondents framed their experience as a source of empowerment, a way to help others or advocate for earlier diagnosis:

- “I have been more active in providing my experience to others who contact me.”
- “I continue to be a cheerleader for early diagnosis and treatment.”

Overall, respondents’ reflections reveal that bladder cancer reshapes roles and relationships in complex and often contradictory ways—introducing feelings of burden and vulnerability while also strengthening bonds, deepening appreciation, and inspiring many to support others facing similar challenges. Patients emphasized both the emotional weight of being treated differently and the empowerment that comes from connection, understanding, and shared experience. Together, these insights highlight the importance of recognizing the social and relational dimensions of survivorship, ensuring that support extends beyond medical care to the full network of relationships that shape a patient's life.

## Future Life Goals

Bladder cancer reshaped how many respondents understood themselves and imagined their future. Overall, 57% said their diagnosis had changed how they see themselves and their life goals—a shift felt more strongly by women (65%) than men (52%). These impacts grew with disease severity: while roughly half of those diagnosed with NMIBC reported changes in their identity or long-term plans, the proportion climbed sharply among patients with MIBC, locally advanced, or metastatic disease. For example, 74% of individuals with metastatic bladder cancer said their view of themselves and their future had fundamentally changed. Younger adults—particularly younger women—carried the heaviest emotional burden, navigating disrupted plans at a stage in life when goals often feel most forward-looking.

Yet within these difficult realities, respondents shared stories that were raw, honest, and often unexpectedly hopeful. Many wrote about learning to live in the present, saying things like "None of us know how long we will live… we just know we have today—and it's not over." Others described how cancer forced a painful recalibration of what their future might hold: "I can't look further down the road… one day at a time is what I think about." Travel plans were postponed, careers reshaped, and identities redefined. One person reflected, "I was a go-getter at work, now… I'm more comfortable where I am," while another acknowledged the vulnerability that came with illness: "I feel vulnerable and highly aware of my own mortality."

For others, this loss opened the door to clarity, gratitude, and purpose. Many spoke of a newfound commitment to daily joy—"My priorities have changed and I try to enjoy each day"—and of discovering inner strength: "I realized I was a lot stronger than I ever thought… I refused to give in." Several respondents described their journey as a calling to help others: "I feel I was given bladder cancer to share my story and help others," wrote one teacher who now mentors newly diagnosed patients. Others leaned on faith, family, and community, finding grounding in what mattered most: "I live my life differently—more kind, more deliberate."

Still, not all reflections were uplifting. Some wrote with painful honesty about the losses that feel impossible to ignore. "It's the new norm… diapers at night. No sex. I don't feel like a man anymore." For others, hope was fragile but present, held up by the people who mattered most: "I would give up except for my wife and family. Support helps me keep going."

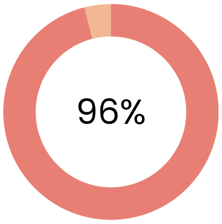
Taken together, these voices reveal the profound duality of living after a bladder cancer diagnosis: the bleak realities of uncertainty, altered bodies, and disrupted futures, alongside the resilience, gratitude, and meaning that many find in the aftermath. Lives change—sometimes in devastating ways—but many respondents also described a hard-won sense of clarity about what matters, and an enduring determination to keep moving forward.

## EMR & Telehealth

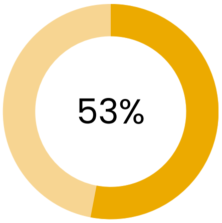
Electronic medical records and telehealth have become essential parts of bladder cancer care. They make it easier for patients and clinicians to share information, track test results, monitor symptoms, and stay connected between visits. These tools support faster decisions, better coordination, and more convenient access to care—especially during treatment and long-term surveillance.

By far, Epic was the most commonly used type of electronic medical record (EMR), and this did not vary by urban or rural residence. Additionally, 53% of respondents stated they had used telehealth or remote monitoring to communicate with their medical team (53% who lived in urban areas, 46% of those in suburban areas, and 51% of those who lived in rural areas). Surprisingly, telehealth use did not vary by respondent age (the mean age of telehealth users was 68 compared to the mean age of 70 among non-users). Telehealth use varied slightly by insurance type–55% of those with private insurance used telehealth compared to 51% of Medicare users.

Electronical Medical Record (EMR) Users



Telehealth Users



*"I learned these things:*

1. ***About 25% of [bladder cancer] diagnoses are incorrect or understaged, which can change treatment protocol and outcome, so get a 2nd or 3rd opinion.***
2. ***There are oncologists who specialize in bladder cancers and that's who we need to see.***
3. ***Go to the best doctors you can find.***
4. ***Advocate for yourself.***
5. ***Find resources to help you through your journey.***
6. ***Talk about it. Help bring bladder cancer out of the shadows. Increase awareness."***

# CHARTING THE PATH FORWARD

The New Faces of Bladder Cancer 2025 Survey represents the collective voice of over 1,100 individuals whose experiences illuminate both how far we've come and how far we must go. Through their stories—of resilience, frustration, hope, and determination—we see a landscape transformed by two decades of progress, yet still marked by inequities that demand urgent attention.

The data reveal undeniable achievements. Patients today have access to more treatment options, better educational resources, and improved diagnostic technologies than ever before. Shared decision-making has strengthened. Clinical trial awareness has expanded. The bladder cancer community, anchored by BCAN's leadership, has built networks of support that transform isolation into connection and confusion into clarity.

Yet these advances have not reached everyone equally. Women continue to face diagnostic delays that lead to later-stage detection. Younger patients navigate disrupted life plans with insufficient support. Rural residents encounter access barriers. Financial toxicity forces some to choose between recommended care and economic stability. Mental health support—rated as essential by 90% of respondents—remains unavailable to nearly half who need it.

Most critically, this survey reveals that excellence in medical treatment alone is insufficient. Patients need comprehensive support that addresses the emotional weight of recurrence fear, the practical challenges of continence and sexual function, the financial burden of hidden costs, and the profound identity shifts that accompany survivorship. They need pathology reports they can understand, survivorship plans that provide direction, and healthcare teams that see them as whole people rather than disease sites.

As BCAN enters its next chapter, these findings will guide our strategic priorities. We will advocate for systematic changes in clinical practice—from standardized mental health screening to routine fertility preservation discussions for younger patients. We will push for policy reforms that address financial toxicity and insurance gaps. We will expand our educational resources and peer support programs, ensuring they reach rural, diverse, and economically disadvantaged populations whose voices remain underrepresented. And we will continue amplifying patient experiences to drive research priorities and shape clinical guidelines.

The transformation documented in this report proves that meaningful change is possible. The patients who shared their experiences have given us a roadmap. Now it is our collective responsibility—as advocates, clinicians, researchers, and community members—to ensure that every person facing bladder cancer receives not just treatment, but truly comprehensive, equitable, patient-centered care. The next 20 years must be defined not by whether we can improve outcomes, but by our commitment to ensuring those improvements reach everyone, regardless of sex, age, geography, or socioeconomic status.

The voices in this survey remind us that behind every statistic is a person navigating one of life's most challenging journeys. They deserve nothing less than our full commitment to transforming their experiences from isolation to support, from confusion to clarity, and from survival to thriving.

# REFERENCES:

1. Key Statistics for Bladder Cancer. American Cancer Society. January 22, 2025. https://www.cancer.org/cancer/types/bladder-cancer/about/key-statistics.html
2. National Cancer Institute. SEER Cancer Stat Facts: Bladder Cancer. National Cancer Institute. https://seer.cancer.gov/statfacts/html/urinb.html
3. Association of Community Cancer Centers. Achieving Health Equity in Bladder Cancer Care. ACCC Buzz. May 26, 2022. https://www.accc-cancer.org/acccbuzz/blog-post-template/accc-buzz/2022/05/26/achieving-health-equity-in-bladder-cancer-care
4. Inspire. Bladder Cancer Advocacy Network. https://www.inspire.com/groups/bladder-cancer-advocacy-network/
5. U.S. Department of Agriculture, Economic Research Service. Rural-Urban Commuting Area (RUCA) Codes. https://www.ers.usda.gov/data-products/rural-urban-commuting-area-codes
6. Freudenburg E, CY Yang, JH. et al. Geographic Distribution of Racial Differences in Bladder Cancer Mortality for Muscle-Invasive Disease. Bladder Cancer. 2020;6(3):317–328. doi:10.3233/BLC-200517.
7. Dobruch J, Daneshmand S, Fisch M, Lotan Y, Noon A, Resnick MJ, et al. Gender and bladder cancer: A collaborative review of etiology, biology, and outcomes. Eur Urol. 2016;69(2):300-310.
8. Liu Z, Zhang H, Luo R, Wang B, Li T, Zheng B. Clinical characterization and prognostic modeling of bladder cancer patients with a history of prior tumors: a SEER database analysis. Transl Cancer Res. 2025;14(2):1111-1123.
9. Hanson M. Educational Attainment Statistics. Education Data Initiative. January 14, 2025. https://educationdata.org/education-attainment-statistics
10. Kollar M, Scherer Z. Income in the United States: 2024 (Report P60-286). United States Census Bureau; September 9, 2025. https://www.census.gov/library/publications/2025/demo/p60-286.html
11. Bunch LN, Ketema H. Health Insurance Coverage in the United States: 2024 (Report P60-288). United States Census Bureau; September 9, 2025. https://www.census.gov/library/publications/2025/demo/p60-288.html
12. Turrini G, Branham DK, Chen L, Conmy AB, Chappel AR, De Lew N, Sommers BD. Access to Affordable Care in Rural America: Current Trends and Key Challenges. Washington, DC: U.S. Department of Health & Human Services, Office of the Assistant Secretary for Planning and Evaluation; July 9, 2021. https://aspe.hhs.gov/sites/default/files/documents/09e40880648376a13756c59028a56bb4/rural-health-rr.pdf
13. Williams SB, Kamat AM, Chamie K, et al. Systematic Review of Comorbidity and Competing-Risks Assessments for Bladder Cancer Patients. Eur Urol Oncology. 2018;1(2):91-100.
14. Lotan Y, Bhattacharya R, Fang H, et al. Assessing real-world recurrence in high-risk (HR) non-muscle-invasive bladder cancer (NMIBC) treated with bacillus Calmette-Guérin (BCG) in the United States through a recurrence algorithm: A SEER-Medicare study. J Clin Oncol. 2025;43(16_suppl):4601. doi:10.1200/JCO.2025.43.16_suppl.4601

15. Han J, Lee H, Kaushish A, Baralo B, Paul AKR. Primary sarcomas of urinary bladder: A SEER analysis. J Clin Oncol. 2025;43(5_suppl):878. doi:10.1200/JCO.2025.43.5_suppl.878
16. Agarwal M, Panwar VK, Mittal A, et al. Changing Clinical Spectrum and Disease Progression in Young Patients With Bladder Cancer: A Retrospective Observational Study. Cureus. 2024;16(1):e82516. doi:10.7759/cureus.82516
17. Liedberg F, Gårdmark T, Hagberg O, et al. Treatment Related to Urinary Tract Infections Is Associated with Delayed Diagnosis of Urinary Bladder Cancer: A Nationwide Population-based Study. Eur Urol Oncol. 2025;8(1):119-125. doi:10.1016/j.euo.2024.07.008
18. Sun M, Trinh QD. Diagnosis and Staging of Bladder Cancer. Hematol Oncol Clin North Am. 2015;29(2):205-218, vii. doi:10.1016/j.hoc.2014.10.013
19. Pignot G, Barthélémy P, Borchiellini D. Sex Disparities in Bladder Cancer Diagnosis and Treatment. Cancers. 2024;16:4100. doi:10.3390/cancers16234100
20. Lin W, Pan X, Zhang C, et al. Impact of Age at Diagnosis of Bladder Cancer on Survival: A Surveillance, Epidemiology, and End Results-Based Study 2004-2015. Cancer Control. 2023;30:10732748231152322. doi:10.1177/10732748231152322
21. Mebroukine S, Klein C, Yacoub M, et al. Utility of restaging transurethral resection in patients with primary high-grade Ta bladder cancer. World J Urol. 2025;43:387. doi:10.1007/s00345-025-05778-z
22. McElree IM, Steinberg RL, Mott SL, et al. The role of blue light cystoscopy and additional operative evaluations during first surveillance after induction therapy for high-risk NMIBC. Bladder Cancer. 2025;13:23523735251324318. doi:10.1177/23523735251324318
23. Zheng Y, Ye Y, Chen J, Wei Z, Liu Z, Yu K, Zhang X. Prevalence and outcomes of transurethral resection versus radical cystectomy for muscle-infiltrating bladder cancer in the United States: A population-based cohort study. Int J Surg. 2022;103:106693. doi:10.1016/j.ijsu.2022.106693
24. Shindo T, Hashimoto K, Tanaka T, et al. Therapeutic options to reduce intravesical recurrence in newly diagnosed Ta high-grade bladder cancer according to risk stratification: A multicenter retrospective study. Int J Urol. 2021;28(11):1136-1142. doi:10.1111/iju.14657
25. Griebsch I, Shrestha S, Lotan Y, et al. The Impact of Intravesical Instillations on Quality of Life in Patients with Non-Muscle-Invasive Bladder Cancer: A Systematic Review. Oncol Ther. 2025;13:895-918. doi:10.1007/s40487-025-00375-x
26. Shkolyar E, Zhou SR, Carlson CJ, et al. Optimizing cystoscopy and TURBT: enhanced imaging and artificial intelligence. Nat Rev Urol. 2025;22:46-54. doi:10.1038/s41585-024-00904-9
27. Mossanen M, Calvert JK, Wright JL, et al. Readability of urologic pathology reports: The need for patient-centered approaches. Urol Oncol. 2014;32(8):1091-1094. doi:10.1016/j.urolonc.2014.04.011
28. Chaudhuri AA, Pellini B, Pejovic N, et al. Emerging Roles of Urine-Based Tumor DNA Analysis in Bladder Cancer Management. JCO Precis Oncol. 2020;4:806-817. doi:10.1200/PO.20.00060

BCAN
Bladder Cancer Advocacy Network

4520 East West Highway | Suite 610 | Bethesda, MD 20814