

REPORT

# 5 strategies to close gaps in bladder cancer care

Reducing variations in treatment and promoting guideline-concordant bladder cancer care

This strategy report outlines five actionable priorities to improve bladder cancer care across health systems. It also focuses on patient education, care coordination, referral pathways, provider knowledge, and program measurement. The report addresses the challenges posed by high recurrence rates, complex patient populations, and evolving therapies, highlighting the need for standardized, guideline-concordant care.

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- Hospitals and health systems

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## Methodology

This project examined key strategies to improve bladder cancer care. To support this work, Advisory Board conducted eight hour-long interviews with bladder cancer care providers, including an oncodermatologist, a clinical pharmacist, and an oncology nurse, each representing eight health systems across the East Coast and Midwest United States. Participating organizations included academic medical centers and nonprofit multispecialty health systems.

The following pages summarize key insights from the research team’s comprehensive literature review and interviews. For each strategy, the team outlines key insights, supporting evidence, additional resources, and guidance to help bladder cancer programs improve quality of care.

# The challenge



## Section takeaways

- 1 Bladder cancer's high prevalence, particularly among older men, and high recurrence rate make it difficult to treat.
- 2 Despite rapid development of new treatments, many therapies carry adverse events that complicate oncologists' management strategies.
- 3 The long-term and complex nature of treatment strategies places a significant economic burden on both patients and the healthcare system.

Bladder cancer is a complex disease that requires ongoing management across multiple care settings, particularly in its regional and metastatic forms. It is the ninth most common cancer globally and the sixth most common among men.<sup>1</sup> Regional bladder cancer accounts for about 7% of cases with a five-year survival rate of around 40%, while distant metastatic bladder cancer comprises 6% of cases and carries a survival rate of just 9%.<sup>2</sup> These advanced stages often emerge after recurrence and are rarely curable, shifting treatment toward life-extending therapies.<sup>2</sup>

### Disparities exist across age, gender, and race

Bladder cancer disproportionately affects older adults, with a median age at diagnosis of 73 and the highest incidence among individuals aged 65 to 74.<sup>3</sup> Patients often present with complex comorbidities and chronic conditions that complicate care planning. Providers often conduct additional assessments, including evaluations of frailty, cognitive function, and treatment tolerance. These assessments can delay treatment decisions and contribute to variation in first-line treatment when patients are considered too vulnerable for standard therapies.

Bladder cancer is more common in men, who are nearly four times more likely to be diagnosed than women.<sup>3</sup> However, women often present with more advanced disease and experience poorer outcomes.<sup>4</sup> Racial and socioeconomic disparities further compound the burden. Black patients are less likely to receive guideline-concordant care and more likely to experience delays in diagnosis and treatment compared to white or Hispanic patients.<sup>4</sup>

### High recurrence rates complicate treatment

Recurrence is a defining characteristic of bladder cancer and a critical factor in shaping care strategies. Recurrence rates can reach up to 50% among patients who initially respond to treatment, whereas recurrence rates of 5% are considered high for many other cancers.<sup>5</sup> These recurrences often happen within the first four years.<sup>5</sup>

Recurrence increases patient volume and heightens demand for follow-up care, coordination, and long-term monitoring.<sup>5</sup> Patients may also experience increased emotional burden as they navigate decisions between extending life and maintaining quality of life.

4x

More common in men than women<sup>3</sup>

50%

Recurrence rate<sup>5</sup>

## Evolving therapies and increasing prevalence of adverse events

New treatments have been accompanied by a rise in adverse events (AEs), including skin reactions, peripheral neuropathy, and nephritis. These events complicate clinical management and may lead to inappropriate treatment discontinuation.<sup>6</sup> This challenge is compounded by rapid changes in treatment guidelines and the continuous emergence of new therapies and clinical trials. General oncologists must stay current across multiple tumor types while also maintaining awareness of a wide range of potential adverse events and appropriate management strategies.

## Bladder cancer carries a high financial impact on patients and the overall healthcare system

The economic impact of bladder cancer is considerable. Total annual costs exceed \$6.5 billion, driven by direct medical expenses, indirect costs, and productivity losses.<sup>7</sup> Among cancers, bladder cancer ranks among the highest in lifetime treatment costs because of its high recurrence rate and the need for ongoing surveillance.<sup>8</sup> Care teams may coordinate proactively to prevent costly and resource-intensive hospitalizations and emergency department visits.

Financial toxicity is also a significant concern for bladder cancer patients, particularly in later stages when complex treatment regimens, frequent appointments, and multiple providers contribute to high costs.<sup>7</sup> This challenge is amplified by Medicare coverage gaps, including limitations for newer drugs and high out-of-pocket costs under Medicare Part D.<sup>7</sup>



**\$6.5B**

In total economic  
impact<sup>6</sup>

# 5 strategies to improve bladder cancer care

Bladder cancer places a burden on the health system because of its high recurrence rates and complex patient population.<sup>5</sup> The disease often affects older adults with multiple comorbidities, who typically fall outside the standard clinical trial model, making treatment planning and care coordination more challenging.

Health systems should prioritize key areas where care varies from guideline-concordant practice. Incorporate the following five strategies into bladder cancer programs to ensure patients receive timely, comprehensive, and equitable care.

**01**      **Standardize patient education without overburdening the care team**

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**02**      **Create a care journey map to better monitor and coordinate care**

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**03**      **Facilitate care team coordination to boost internal communication**

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**04**      **Enhance referral pathways to manage treatment and adverse events**

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**05**      **Address knowledge gaps to prepare for new research and therapies**

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# 01 Standardize patient education without overburdening the care team



## Section takeaways

- 1 Given the complexity of the care journey, oncologists and patients can build trusting relationships that support patient engagement in treatment plans.
- 2 Health systems can develop a standardized checklist of topics oncologists should cover with patients at diagnosis, before treatment, during treatment, and after treatment.
- 3 Each care team can take on specific educational and logistical roles to help patients receive comprehensive support and remain engaged in their health.

Oncologists should build trust with patients from the onset of diagnosis through treatment completion given the complex care journey and high recurrence rate of bladder cancer. A key step is to standardize patient education at specific timeframes during the care journey. This helps ensure that every patient understands their treatment plan, is aware of risk factors, and feels comfortable sharing concerns about side effects and complications that may arise during the treatment plan.

## Tailor patient education to key milestones of the care journey

*At each point in the patient care journey, make a checklist of key topics to cover so that every patient receives the same education.*

### 01 At diagnosis



- Plain-language overview of bladder cancer
- Treatment options
- What to expect during care journey

### 02 Pre-treatment



- Focused education on side effects
- Logistics of scheduling
- Appointment support services

### 03 During treatment



- Reinforce key points of symptom management (i.e., dose changes are normal)
- Address adverse events (AEs)
- Discuss treatment timeline changes

### 04 Post-treatment



- Long-term monitoring (i.e., timeline of scans)
- Lifestyle guidance
- Recurrence risk education



### Patient check-in questionnaire or electronic Patient-Reported Outcomes

To encourage patients to raise concerns early and consistently, use a questionnaire at pre-determined points in the care journey. To develop these questionnaires, brainstorm the most common patient milestones and side effects and prioritize them based on typical patient experiences. For example, a questionnaire for the first month check-in might focus on medication side effects and the patient's emotional well-being. Consider what the milestones are for subsequent visits and how the patient-reported outcomes can be collected electronically.

Sample of patient-reported outcomes for bladder cancer patients include:<sup>9</sup>

- Abdominal pain
- Constipation
- Diarrhea
- Decreased appetite
- Fatigue
- Insomnia
- Nausea
- Neuropathy
- Rashes
- Shortness of breath
- Swelling
- Urinary symptoms

### Delineate roles and responsibilities across the care team

In a setting of high patient volumes and unique care needs, it can be difficult to make sure every patient receives an equal level of education during their bladder cancer care journey. To mitigate missed steps and bias, delineate role responsibilities among the care team. This will also ensure that no individual is overburdened with the task of education or follow-up questions. Clearly define each team member's role and responsibilities so that every patient's education is comprehensive and works in tandem to reinforce critical information throughout the care journey.



### Example care team responsibilities



#### Oncologist

Explains diagnosis, treatment rationale, and clinical decision-making



#### Nurse

Reinforces initial information and explains treatment plan



#### Care navigator

Manages appointment logistics and contact for offline questions



#### Clinical pharmacist

Educates medication adherence and side effect management

Additionally, consider the role of non-clinical staff. What is their responsibility, and at what points during the care journey is that responsibility important? For example, a social worker or financial counselor will address needs related to social drivers of health, such as transportation to appointments and filing insurance claims correctly.



### Key performance indicators for patient education

- Patient-reported outcomes (PROs): Track symptoms, functional status, and treatment side effects
- Quality of life (QoL): Physical, psychological, and economic well-being
- Patient satisfaction: Net promoter score (NPS) or other satisfaction surveys

## 02 Create a care journey map to better monitor and coordinate care



### Section takeaways

- 1 Health systems should create a care journey map specific to their system to guide each patient through the treatment process and prevent them from falling through the cracks.
- 2 The care journey map should follow evidence-based guidelines, coordinate care transitions, and provide ample opportunities for patients to communicate with providers.
- 3 A care navigator, or someone with similar role responsibilities, can support continuity of care and provide a personalized point of contact for patients.

Patients often feel overwhelmed by the complexity of bladder cancer care, which involves tracking numerous appointments, tests, and treatment decisions. In addition to patient education sessions, care teams should also guide patients through each phase of care to reduce delays, minimize variation, and ensure timely interventions.

To keep patients on track, care teams should help them meet critical milestones and avoid missing appointments. Creating a patient journey map allows care teams to visualize the care path with patients, coordinate effectively, and ensure no patient falls through the cracks.

### Care journey map

A care journey map allows providers to better track patients across key milestones and promotes standardization of treatment selection and continuation. The journey map should reflect the unique needs of a hospital or health system and should be updated as recommendations evolve to promote guideline-concordant care. This approach helps providers consistently select appropriate first-line therapies and maintain alignment with evidence-based standards. The following offers a foundation to build a care journey map within bladder cancer care, along with key considerations for each phase of treatment.





### Real-time tracking can monitor patient progress and flag opportunities for intervention

Teams should embed integrated tracking mechanisms within the standardized care journey framework to monitor patient progression, identify delays in care delivery, and assess adherence to treatment protocols.

Tracking patient milestones through digital platforms and integrated patient portals enables timely identification of critical transitions in bladder cancer care. Key milestones include initial diagnosis, referral to appropriate specialists, and initiation of treatment. By embedding structured data fields and alerts online, care teams can monitor progress and flag overdue actions — such as delayed referrals, missing consults, no-show appointments, or uninitiated therapies. Automated prompts and dashboards can highlight gaps in care and ensure that patients are not lost between stages.



## Foundations of a care journey map

Phase of treatment	Sample stakeholders	Sample responsibilities	Key considerations
Awareness & diagnosis 	<ul style="list-style-type: none"> <li>❖ Urologist</li> <li>❖ Medical oncologist</li> <li>❖ Nurse</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Identification of disease</li> <li><input type="checkbox"/> Treatment plan creation</li> <li><input type="checkbox"/> Patient education</li> </ul>	<ul style="list-style-type: none"> <li>✓ What is the transition plan between primary providers?</li> <li>✓ Who owns patient education at this phase?</li> </ul>
Staging & initial treatment 	<ul style="list-style-type: none"> <li>❖ Medical oncologist</li> <li>❖ Surgical oncologist</li> <li>❖ Nurse</li> <li>❖ Clinical pharmacist</li> <li>❖ Financial coordinator</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Start of therapy</li> <li><input type="checkbox"/> Treatment planning</li> <li><input type="checkbox"/> Dosage management</li> <li><input type="checkbox"/> Insurance processes</li> <li><input type="checkbox"/> Patient education</li> </ul>	<ul style="list-style-type: none"> <li>✓ Therapy anchored in evidence-based guidelines?</li> <li>✓ How is the care team staying coordinated?</li> <li>✓ What materials and portals are available for patient questions?</li> <li>✓ What are the insurance needs?</li> </ul>
Monitoring & adverse event management 	<ul style="list-style-type: none"> <li>❖ Medical oncologist</li> <li>❖ Nurse</li> <li>❖ Clinical pharmacist</li> <li>❖ Specialists (e.g., neurologist, dermatologist)</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Dose modification</li> <li><input type="checkbox"/> Adverse event management</li> <li><input type="checkbox"/> Referrals</li> <li><input type="checkbox"/> Patient education</li> </ul>	<ul style="list-style-type: none"> <li>✓ What are the specialist referral pathways?</li> <li>✓ How is the care team staying coordinated?</li> <li>✓ What are the appointment availability and scheduling needs?</li> </ul>
Survivorship & palliative care 	<ul style="list-style-type: none"> <li>❖ Nurse</li> <li>❖ Specialists</li> <li>❖ Social worker</li> <li>❖ Financial coordinator</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Referrals</li> <li><input type="checkbox"/> Patient education</li> <li><input type="checkbox"/> Care-setting change</li> <li><input type="checkbox"/> Insurance</li> </ul>	<ul style="list-style-type: none"> <li>✓ What is the transition plan to palliative?</li> <li>✓ What are the insurance needs?</li> <li>✓ What lifestyle changes should be considered?</li> </ul>

## Dedicated care navigators promote continuity and personalized support

Assigning dedicated care navigators to each oncologist is a targeted strategy to enhance continuity and personalized support throughout the bladder cancer care journey. These navigators are responsible for tracking patient referrals and follow-ups, coordinating diagnostic testing and appointments, and serving as a contact point for patients for education and concerns.

By embedding navigators into the care team, organizations can proactively identify delays or gaps in care — such as missed consults or uninitiated therapies — and intervene before they impact outcomes. Dedicated care navigators can use the care journey map and real-time tracking to promptly identify patients who fall behind in their care pathway. They can investigate the underlying cause — such as missed appointments due to transportation barriers — and connect patients with appropriate support services, like arranging transportation, to resolve the issue and restore continuity in care.

This role supports operational efficiency by streamlining communication across specialties and ensuring that patients remain engaged and informed. Care navigators serve as a consistent point of contact, helping patients navigate complex care pathways and reinforcing adherence to guideline-concordant treatment plans.



### Key performance indicators for patient journey mapping

- Missed appointment rate: Serves as an indicator of potential access barriers or patient engagement challenges.
- Treatment plan adherence: Measures completion of recommended therapies and consistency in following prescribed care.

# 03 Facilitate care team coordination to boost internal communication



## Section takeaways

- 1 The multitude of specialists and support staff involved in bladder cancer care can make it difficult for the care team to ensure consistent and timely coordination.
- 2 Building standardized and direct lines of communication among the care team, particularly with clinical pharmacists, may be key to facilitating coordinated care.
- 3 The most advanced model to enhance care coordination is the establishment of a permanent, on-site care team, but this strategy requires greater investment.

Bladder cancer care involves a wide range of specialists and support staff who each contribute to different aspects of the treatment journey. Coordinating care across these roles can present challenges. Providers and care teams often struggle to collaborate consistently and share timely updates, making it difficult to monitor patient progress and maintain clear communication throughout the continuum of care.

To reduce delays and friction, care teams should establish sustainable communication structures that support real-time information exchange. These systems enable teams to work together more effectively and ensure that the patient journey map functions as intended.

### Build communication frameworks and protocols

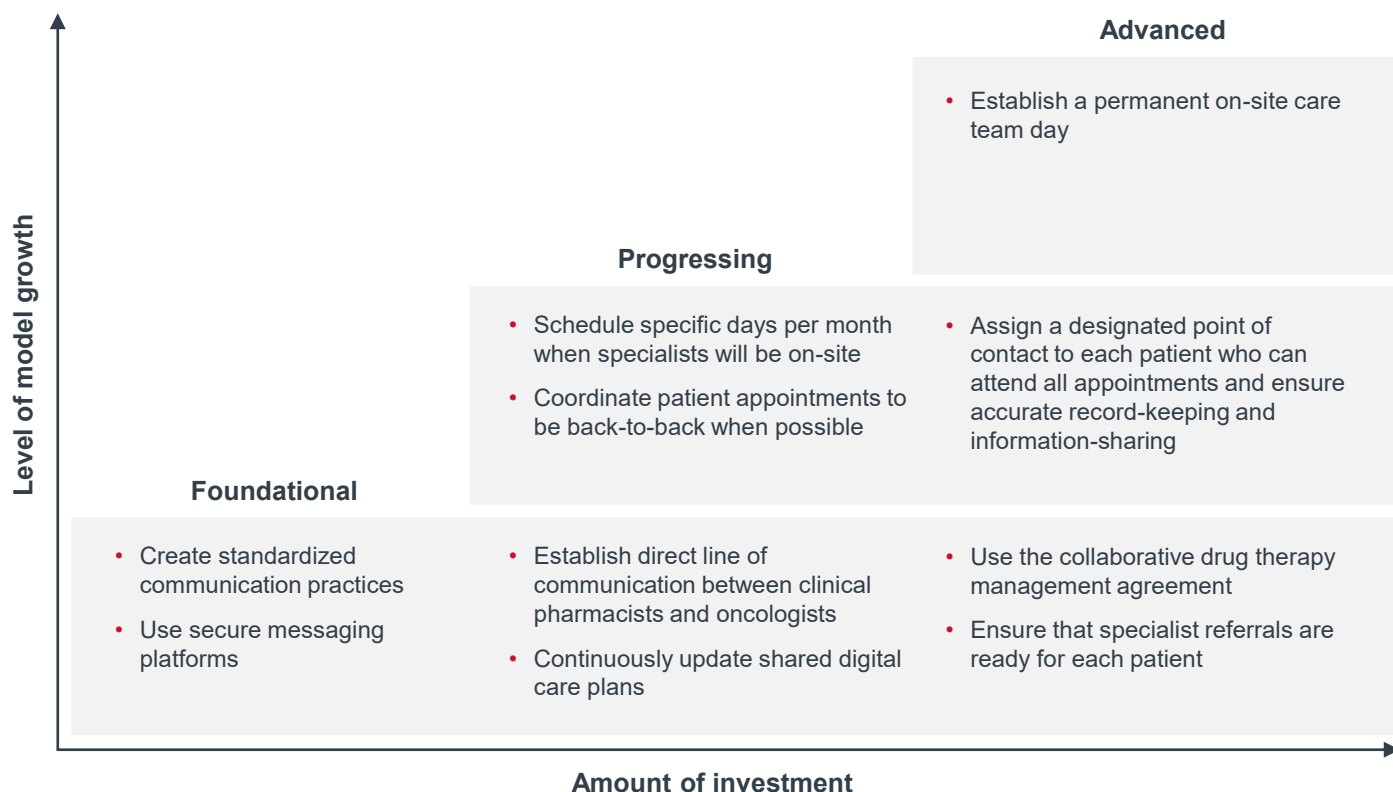
A multidisciplinary team communication framework can improve real-time collaboration among providers involved in bladder cancer care. Standardized communication protocols can include the use of shared digital care plans that are continuously updated and accessible to all team members, enabling quick visibility into patient status and treatment progress. Care teams use secure messaging platforms to relay timely updates on treatment changes, referrals, and diagnostic results, helping reduce delays and miscommunication across specialties. Embedding these tools into routine workflows ensures that every care team member has a clear and efficient way to communicate with one another at any point in the patient's treatment journey.

### Collaborate with clinical pharmacists

Clinical pharmacists play a critical role in bladder cancer management by developing individualized treatment plans, optimizing dosing strategies, and anticipating potential side effects. Establishing a direct line of communication between the provider and clinical pharmacist can help ensure timely updates to the treatment plan as the oncologist communicates the need for changes.

Consider using collaborative drug therapy management (CDTM), a formalized agreement between clinical pharmacists and providers. Recognized in all 50 states and authorized in 46, CDTM enables pharmacists to manage treatment within defined protocols, including ordering labs and adjusting medications based on patient response. This formal agreement can help reduce delays in treatment adjustments and promote more coordinated medication management.

### Multidisciplinary bladder cancer clinic model



#### Key performance indicators for care team coordination

- Treatment plan adherence: Measures completion of recommended therapies and consistency in following prescribed care.
- Wait times: Tracks the duration from referral to first appointment and from diagnosis to treatment initiation, reflecting system efficiency and responsiveness.

# 04 Enhance referral pathways to manage treatment and adverse events



## Section takeaways

- 1 Health systems should have robust referral infrastructure to categorize the severity of adverse events and trigger referrals to specialists promptly depending on the urgency.
- 2 Developing an effective referral infrastructure starts with identifying the key milestones in the patient's care journey and where a specialist may typically need to step in.
- 3 The oncology practice can work to establish consistent points of contact and build relationships with local and virtual specialists.

The introduction of newly approved therapies into national guidelines creates new opportunities for patient treatment but also may increase adverse events. Hospitals and health systems need robust referral pathways that allow them to quickly adapt to new therapies and adverse events that their bladder cancer patients are experiencing.

### Consider a decision tree to manage adverse events

Adverse events (AEs), particularly those related to infusion therapies, are common during a bladder cancer patient's treatment journey. Lack of effective AE management can lead patients to delay or discontinue care.<sup>6</sup>

A decision tree standardizes the management of common AEs, which can allow care teams to efficiently triage. To create this decision tree, first identify common AEs (such as rash, diarrhea, fatigue, or neuropathy)<sup>6</sup> for the first line therapies of bladder cancer. For each AE, create a severity scale identifying the symptoms that bucket it into a low, medium, or high priority. Depending on the priority rating, identify moments to trigger referrals to specialists that have been pre-identified as equipped to manage the AE within the hospital or health system. Include the referral specialists in the creation of the decision tree to gain buy-in for appointment priority.

### Build a network of specialist providers

Bladder cancer patients have a large care team that can include the medical oncology team, the urologist who identified the initial abnormality, and specialists who treat severe adverse events during treatment. While time intensive, a concerted effort to create a network of trusted specialists associated with the oncology practice may help improve patients' treatment management and overall outcomes. Create and maintain a curated list of local and virtual specialists that the medical oncology team can lean on regularly.



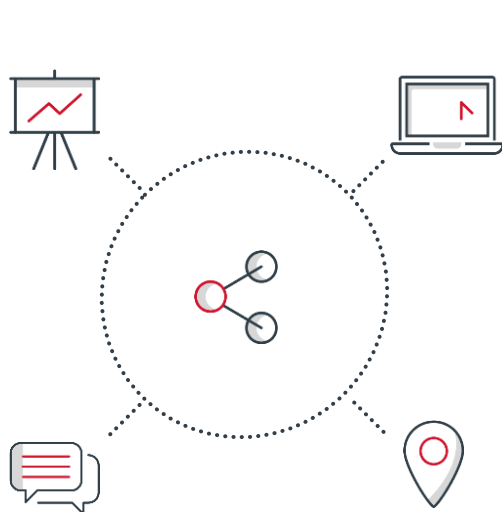
## Oncoderm Referral System

To ease the burden of access for cancer patients in need of dermatology care, a large health system created an e-mail listserv that enables oncologists to directly refer patients.<sup>10</sup> The health system identified that cancer patients were not receiving timely dermatologic follow-up care due to digital platform related communication gaps and long appointment wait times. Creating this e-mail listserv specific to the oncodermatology referral pathway within the health system significantly improved scheduling efficiency.

A retrospective analysis showed:

- A decrease in average referral-to-scheduling time from 19 to 4 days.<sup>10</sup>
- A decrease in referral-to-appointment time from 51 to 22 days.<sup>10</sup>

## How to build a specialist network



### Conduct retrospective study

Determine the treatment journey that may include non-oncology visits and pre-diagnosis treatment for a 50-patient study group.



### Connect trends

Gather data to connect dots for future patients using an EMR system or email pathway.



### Establish clear communication

Establish main point-of-contacts between oncologists and specialists' offices.



### Proactive outreach

Proactively reach out to local office with corresponding insurance coverage.



## Key performance indicators for enhancing referral pathways

- Emergency department visits/preventable admissions: Especially within 30 days of treatment
- Referral timeliness: Time from primary care or urology referral to specialist consultation

# 05 Address knowledge gaps to prepare for new research and therapies



## Section takeaways

- 1 Due to the rapid changes in therapies and clinical guidance, clinicians may struggle to remain informed and may not have access to timely, succinct updates.
- 2 Health systems can assign one clinician the responsibility of curating important information, create a centralized resource hub, and encourage peer collaboration.
- 3 Relying on pharmaceutical liaisons may be particularly useful to ensure accurate and efficient communication between providers and drug manufacturers.

Improving the dissemination of clinical guidance and therapy updates is essential to ensure that all providers, including general oncologists who treat bladder cancer infrequently, deliver guideline-concordant care. Given the rapid evolution of bladder cancer therapies, numerous clinical trials, and frequent updates to care guidelines, clinicians may struggle to stay current amid their busy patient schedules. Four opportunities to equip providers with timely, digestible access to evolving clinical information include:

### Create a physician champion model

A physician champion can be a dedicated physician or a rotating role charged with curating and sharing updates. This allows for other providers to receive timely, digestible information on evolving therapies and clinical guidance. Dissemination channels may include monthly article club summaries, biweekly email digests, and short internal video explainers.

Some organizations use a population health staff member dedicated to oncology. This individual curates information on new therapies, evolving care guidelines, and real-world treatment patterns, ensuring that frontline providers remain informed and aligned with best practices.

### Use a centralized resource hub

A digital repository — such as a SharePoint site — can house key resources, including summaries of new therapies, decision trees for patient case management, and FAQ-style guidance documents. This hub enables providers to access up-to-date clinical information in a streamlined format, reducing reliance on fragmented or outdated materials. Regular updates aligned with evolving guidelines ensure that the content remains current and supports guideline-concordant care.

## Encourage peer to peer collaboration

Peer-to-peer collaboration can help improve clinical consistency and knowledge-sharing across bladder cancer care teams. A formal network connects specialists, such as those involved in clinical trials or research with generalist providers, to help bridge gaps in guideline adherence and therapeutic awareness. This model supports the dissemination of real-world insights and emerging data. Collaboration models may already exist at the health system for other cancer types or diseases; consider applying the similar models to bladder cancer.

## Establish a pharmaceutical liaison

A pharmaceutical liaison role strengthens the connection between providers and drug manufacturers. This liaison serves as a centralized contact point for reaching out to the drug manufacturer's drug representatives and medical science liaison (MSL). The MSL can provide more in-depth information about therapies like guidance on dosing for non-clinical trial patient profiles and rare treatment toxicities.

In addition to clinical insights, the pharmaceutical liaison can proactively request tear-away pages or quick-reference materials from drug reps for newly approved therapies that may be relevant to patients. A one-pager summarizing the drug's package insert is easier for patients to digest — making it a valuable tool for care team coordination and patient education.



### Key performance indicators for addressing knowledge gaps

- Adherence to treatment plans: Including achievement of therapeutic milestones.
- Use of guideline-concordant care:
  - Percentage of eligible patients receiving 1st-line (1L) therapy.
  - Percentage receiving 1L maintenance therapy when indicated.

# Measure progress of bladder cancer programs

To narrow the areas of opportunity, assess the following key performance indicators (KPIs) within the bladder cancer program. Identify the KPIs with the highest need for improvement, align to a strategic priority outlined in this report, and bring the need to leadership teams to improve care gaps.

## Key performance indicators outlined in this report:

- Patient-reported outcomes (PROs): Track symptoms, functional status, and treatment side effects.
- Quality of life (QoL): Physical, psychological, and economic well-being.
- Patient satisfaction: Net promoter score (NPS) or other satisfaction surveys.
- Missed appointment rate: Serves as an indicator of potential access barriers or patient engagement challenges.
- Treatment plan adherence: Achievement of therapeutic milestones and consistency in following prescribed care.
- Wait times: Tracks the duration from referral to first appointment and from diagnosis to treatment initiation, reflecting system efficiency and responsiveness.
- Emergency department visits/preventable admissions: Especially within 30 days of treatment.
- Referral timeliness: Time from primary care or urology referral to specialist consultation.
- Adherence to treatment plans: Including completion of recommended therapies.
- Use of guideline-concordant care:
  - Percentage of eligible patients receiving 1st-line (1L) therapy.
  - Percentage receiving 1L maintenance therapy when indicated.

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