



# Patient Engagement in Research

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FRED HUTCHINSON CANCER CENTER



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## What We'll Cover...

1. Patient advocacy in research
2. History of patient advocates in BCAN
3. How (and why) to get involved!



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## Patient Advocacy

The Worlds of Patient Advocacy



© PAIR: Patient Advocates In Research



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### Patient-Centered Outcomes Research



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### Patient-Centered Outcomes Research

- “Given my personal characteristics, conditions, and preferences, what should I expect will happen to me?”
- “What are my options, and what are the benefits and harms of those options?”
- “What can I do to improve the outcomes that are most important to me?”
- “How can the healthcare system improve my chances of achieving the outcomes I prefer?”



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### Comparative Effectiveness Research

Direct comparison of existing interventions to determine which:

- Work best for which patients
- Pose greatest benefits/harms



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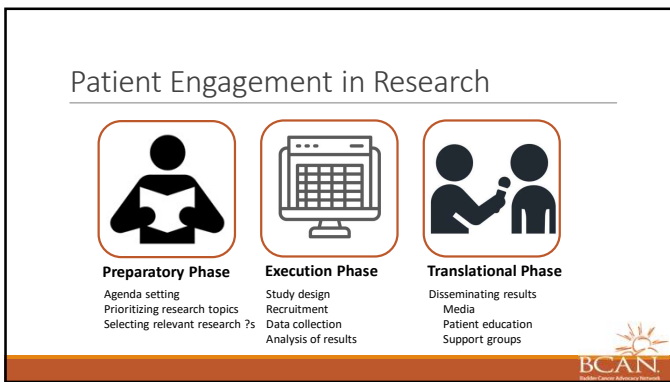
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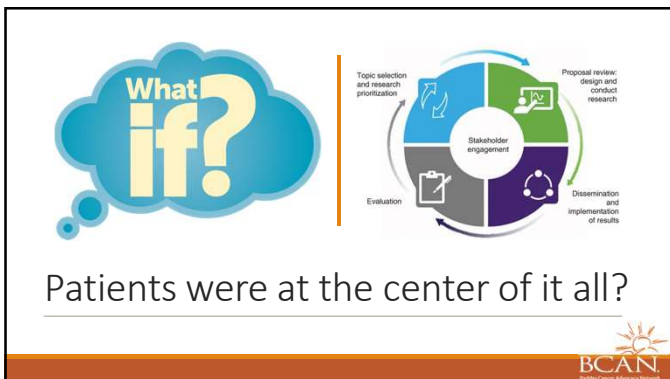
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“Would researchers be helped to do more relevant research if the public became more involved in planning and promoting research?”

~Sir Iain Chalmers, BMJ 1995



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Engage patients with bladder cancer and their caregivers in research question prioritization

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1. Recruit Patients and Caregivers to join the BCAN Patient Survey Network



PCORI Contract 1089; Smith, et al. Cancer 2018



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## 2. Generate Research Questions



PCORI Contract 1089; Smith, et al. *Cancer* 2018



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## 3. Prioritize Research Questions



- Survey sent to the BCAN Patient Survey Network
  - Asked to rank questions/disease stage
  - Free text research questions
- Stakeholder conference calls

PCORI Contract 1089; Smith, et al. *Cancer* 2018



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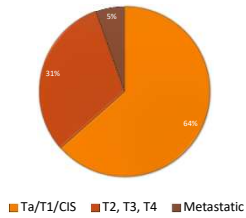
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## 3. Prioritize Research Questions: BCAN Patient Survey Network



- 2 rounds of surveys
  - 2015
    - 660 participants Round 1
    - 361 participants Round 2
  - 2016
    - 1000 participants
    - Stratified by stage of disease



PCORI Contract 1089; Smith, et al. *Cancer* 2018



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3. Prioritize Research Questions:  
BCAN Patient Survey Network 

NMIBC (591 respondents)

1. How can patients and providers make decisions about the need for radical cystectomy and what is the best timing?
2. What are the best treatments for patients whose cancer returns or worsens after BCG treatment?
3. What are the best biomarkers for predicting response to bladder treatments?
4. What are the best ways to decrease pain and discomfort from cystoscopy and procedures such as placing a bladder catheter?
5. What are the best ways to increase quit rates among patients who are smoking at the time of a bladder cancer diagnosis?

PCORI Contract 1089; Smith, et al. *Cancer* 2018 

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3. Prioritize Research Questions:  
BCAN Patient Survey Network 

MIBC (314 respondents)

1. How does a patient with invasive bladder cancer choose between preserving the bladder (with radiation and chemotherapy) and removing the bladder (radical cystectomy)?
2. How does a patient undergoing bladder removal (radical cystectomy) choose between different urinary diversions (such as ileal conduit and neobladder)?
3. Which patients benefit most from chemotherapy before bladder removal?
4. What recovery programs best improve sexual health for patients who undergo treatment for invasive bladder cancer?

PCORI Contract 1089; Smith, et al. *Cancer* 2018 

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3. Prioritize Research Questions:  
BCAN Patient Survey Network 

Metastatic (91 respondents)

1. How do new treatments for metastatic bladder cancer compare to others?
2. In what order should treatments be given for patients with metastatic bladder cancer?
3. What are the best ways for a patient to find out about new clinical trials for metastatic bladder cancer?
4. How can caregivers of patients with metastatic bladder cancer reduce their burdens?

PCORI Contract 1089; Smith, et al. *Cancer* 2018 

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### 4. Disseminate Research Questions

Patient Survey Network  
BCAN  
Funding Agencies  
Researchers (Abstract, Papers)



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### Cancer

*Bladder Cancer | View topic brief*

- What is the comparative effectiveness of treatments (including various intravesical agents, cystectomy or bladder-preserving alternatives to cystectomy) in patients with intermediate or high-risk non-muscle invasive bladder cancer who have failed first-line induction intravesical therapy with BCG or other agents? Proposed studies should be large-scale (preferably an RCT) and should include patient-centered outcomes such as mortality, progression to muscle invasive bladder cancer, side effects, and quality of life.



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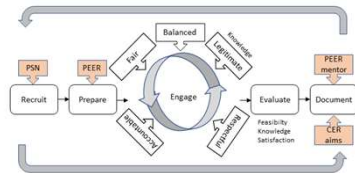
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### Overview of BCAN Engagement Projects

- Engagement Award 1:**  
Patient Survey Network (PSN)
- Engagement Award 2:**  
Patient Empowerment in Engagement Research (PEER)
- Engagement Award 3:**  
Promoting Implementation of Patient Engagement (PIPE)



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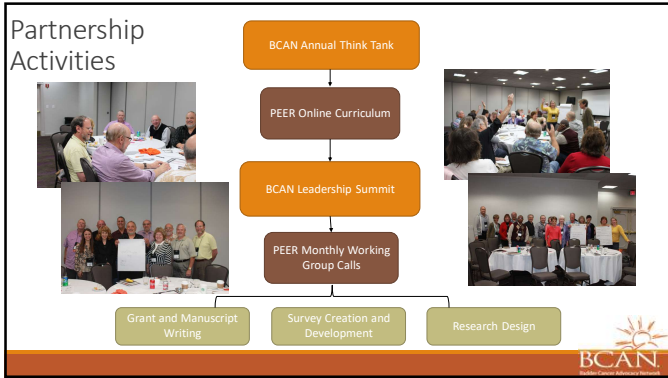
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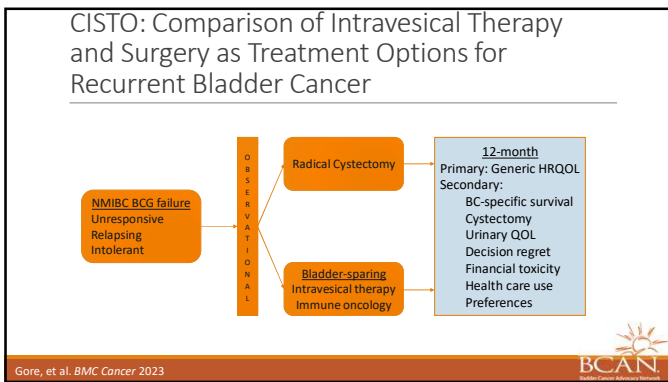
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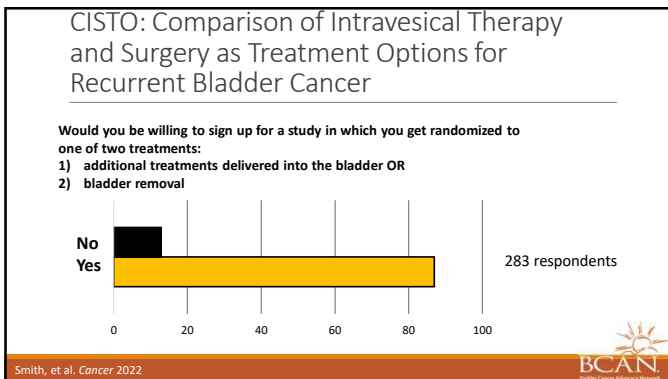
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### CISTO: Comparison of Intravesical Therapy and Surgery as Treatment Options for Recurrent Bladder Cancer

"Most people with non-muscle invasive bladder cancer would not choose to have their bladder removed, but the risks of doing so ... need to be better quantified so informed decisions can be made."


"...I'm going through BCG treatment right now and it is getting more difficult to handle. I wish I [could make] the choice based on experience of others!"

"Having ... bladder cancer that is not responsive to BCG ... is a very precarious situation. Making the decision to have a radical cystectomy or try another treatment ... is very confusing and a 'gamble' at best. A clinical trial that examines the outcomes of the various options AND how the patients arrived at their decisions would be very valuable to patients."

"A clinical trial that examines the outcomes of the various options AND how patients arrived at their decisions would be very valuable to patients down the road when they have to make similar decisions."

"...what are the financial implications of the direction that I choose - that affects [me and my husband] in our retirement?"

Smith, et al. *Cancer* 2022




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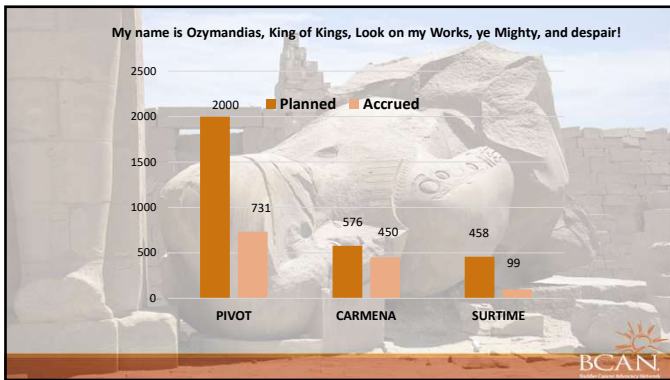
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### Patient Engagement in Research




**Preparatory Phase**  
Agenda setting  
Prioritizing research topics  
Selecting relevant research topics



**Execution Phase**  
Study design  
Recruitment  
Data collection  
Analysis of results



**Translational Phase**  
Disseminating results  
Media  
Patient education  
Support groups




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**CISTO** Comparing Intravesical Therapy & Surgery as Treatment Options

Home | Team | Locations | Resources | Contact

Bladder cancer is the fourth most common cancer in men and the tenth most common cancer in women. In 2022, over 77,000 Americans were diagnosed with bladder cancer, about three-quarters of whom had a type called non-muscle-invasive bladder cancer (NMIBC), in which the cancer is limited to the inner layer of the bladder. NMIBC is usually treated with a combination of a procedure that removes the tumor while leaving the bladder in place and application of a medicine called BCG (Bacillus Calmette-Guérin) injected directly into the bladder.

Unfortunately, NMIBC tumors frequently return or worsen. This choice is not an easy one, selecting between these options involves weighing the risk of bladder cancer progression and the loss of a window of potential cure with intravesical therapy against the risk of morbidity and impact to quality of life with bladder removal.

Much remains unknown about the comparative effectiveness of these two treatment options. There is also very little information about how patient preferences and quality of life factor into the decision. The CISTO Study aims to fill an critical evidence gaps in order to facilitate personalized, patient-centered care. The results from CISTO may provide other evidence about the clinical and quality of life outcomes so that future patients, their caregivers, and their providers can make more informed treatment decisions.

**BCAN**  
Bladder Cancer Action Network

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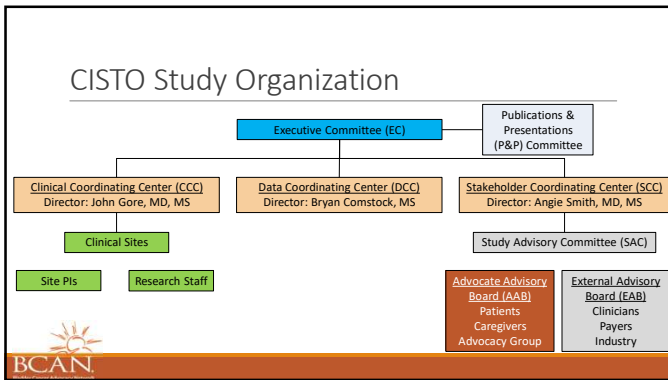
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**TURBT Get the Facts**

Two versions of the 'TURBT Get the Facts' brochure are displayed side-by-side. The brochures contain detailed information about TURBT procedures, risks, and benefits. The BCAN logo is at the bottom right.

**BCAN**

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## TURBT Expert Explanation

Detailed information about TURBT for patients

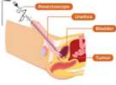
- Written by Yair Lotan (EAB)
- Reviewed by AAB

June 8, 2022

### Understanding TURBT: Bladder Tumor Removal Surgery

What is a TURBT?

Generally, after the diagnosis of a bladder tumor, the urologist will suggest that the patient have an outpatient surgical procedure in the hospital to remove the bladder tumor. The doctor may refer to this procedure as a TURBT (transurethral resection of a bladder tumor). The TURBT will allow the doctor to examine the bladder more completely under anesthesia (general or spinal). To see inside the bladder, they use a resectoscope. Like the cystoscope, the resectoscope is introduced through the urethra into the bladder.



BCAN  
Bladder Cancer Adjuvant Network

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## TURBT Treatment Talk Webinar

- Yair Lotan (EAB)
- Lori Roscoe (AAB)

47 live attendees; 404 total views online

Now available at BCAN.org:  
<https://bcan.org/trans-urethral-resection-of-the-bladder-tumor-turbt/>



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## NMIBC That Returns after BCG

What You Should Know About Non-Muscle Invasive Bladder Cancer (NMIBC) that Returns after BCG Treatment

What does it mean to have NMIBC return after BCG Treatment?

What are some of the treatment options when NMIBC returns after BCG Treatment?

NON-SURGICAL TREATMENTS	SURGICAL TREATMENT
<ul style="list-style-type: none"> <li>Immunotherapy</li> <li>Photodynamic Therapy</li> <li>Topical Chemotherapy</li> <li>Hyperthermia</li> </ul>	<ul style="list-style-type: none"> <li>Radical cystectomy</li> <li>Bladder-sparing cystectomy</li> <li>Bladder-sparing cystectomy with penile prostheses</li> <li>Bladder-sparing cystectomy with urinary diversion</li> <li>Bladder-sparing cystectomy with urinary diversion and penile prostheses</li> <li>Bladder-sparing cystectomy with urinary diversion and penile prostheses and pelvic lymph node dissection</li> </ul>

BCAN  
Bladder Cancer Adjuvant Network

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## Influence of Partnership & Patient Advocates

### Funding

- CISTO – Comparing bladder preservation vs. cystectomy for BCG-unresponsive NMIBC
- Cystoscopy discomfort
- CROCUS – Comparing cystectomy vs. chemoradiation for MIBC

### Patient Representation

- Grant review (e.g. CDMRP, BCAN)
- Industry (e.g. Pharmaceutical advisory boards)
- Pre-clinical trials
- Clinical Trials Committees (e.g. SWOG)

### Dissemination to other sites

- Replicating the process in multiple GU cancers, including kidney and prostate

### Potential value for patients immense

- Research focused on patient-centered priorities
- Design addresses most important outcomes
- Dissemination done effectively to medical community



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Being a patient advocate in research has given me the opportunity to transform vulnerability into strength, uncertainty into hope, and isolation into unity. It was an opportunity to use my voice as an impetus for change, my experience as a motivator for progress, and has given me hope for a promising, more patient inclusive future in healthcare.

Being an AAB Patient Advocate has given me a way to use my personal experience with bladder cancer to inform decision-making for other patients. The long-term method of this study provides an in-depth opportunity to reach a variety of patients and to gather meaningful data. It has been my privilege to be a part of CISTO.

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## How to Get Involved!

- Learn about research patient advocacy (next slides)
- Become a research patient advocate
  - Review for grants (e.g. CDMRP, BCAN)
  - Industry (e.g. Pharmaceutical advisory boards)
  - Pre-clinical trials
  - Clinical Trials Committees (e.g. SWOG)
  - Volunteer to join a research team
- Join the Patient Survey Network



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Learn More About...

- Engaging in Clinical Trials → <https://bcan.org/engaging-in-clinical-trials/>
- Joining BCAN PSN → [https://unc.az1.qualtrics.com/jfe/form/SV\\_3wnylIA22wi9Pu](https://unc.az1.qualtrics.com/jfe/form/SV_3wnylIA22wi9Pu)
- Engaging w/ Pharma as a Patient → <https://bcan.org/engaging-with-pharma-wet>

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