



Patient Engagement in Research

ANGELA B. SMITH, MD, MS, FACS

PROFESSOR, VICE CHAIR FOR ACADEMIC AFFAIRS
UNIVERSITY OF NORTH CAROLINA, DEPARTMENT OF UROLOGY
LINEBERGER COMPREHENSIVE 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



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Patient engagement is the blockbuster drug of the century.

-Farzad Mostashari

BLOCKBUSTER®

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Comparative Effectiveness Research

Direct comparison of existing interventions to determine which:

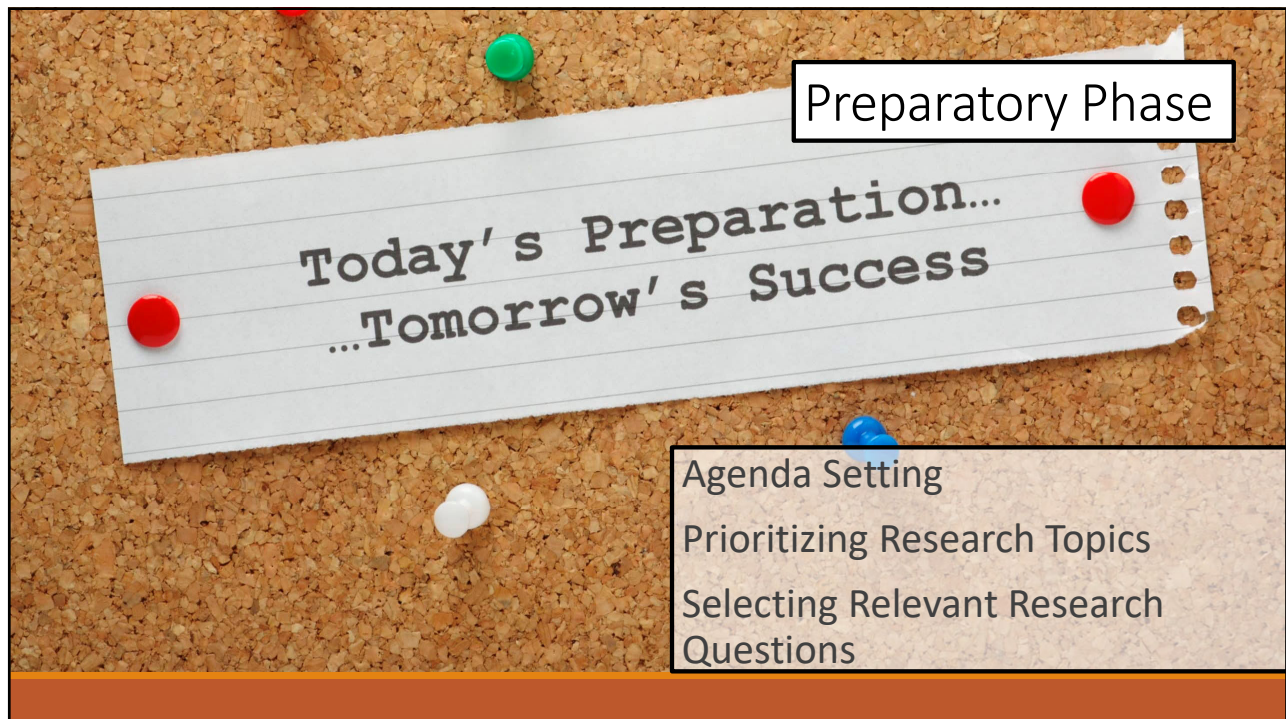
- Work best for which patients
- Pose greatest benefits/harms

The image shows a golden scale of justice, a symbol of balance and comparison, set against a dark blue background. The scale is positioned on the right side of the slide, with its two pans hanging from a central beam. The background is a solid dark blue, and the scale is rendered in a metallic gold color.

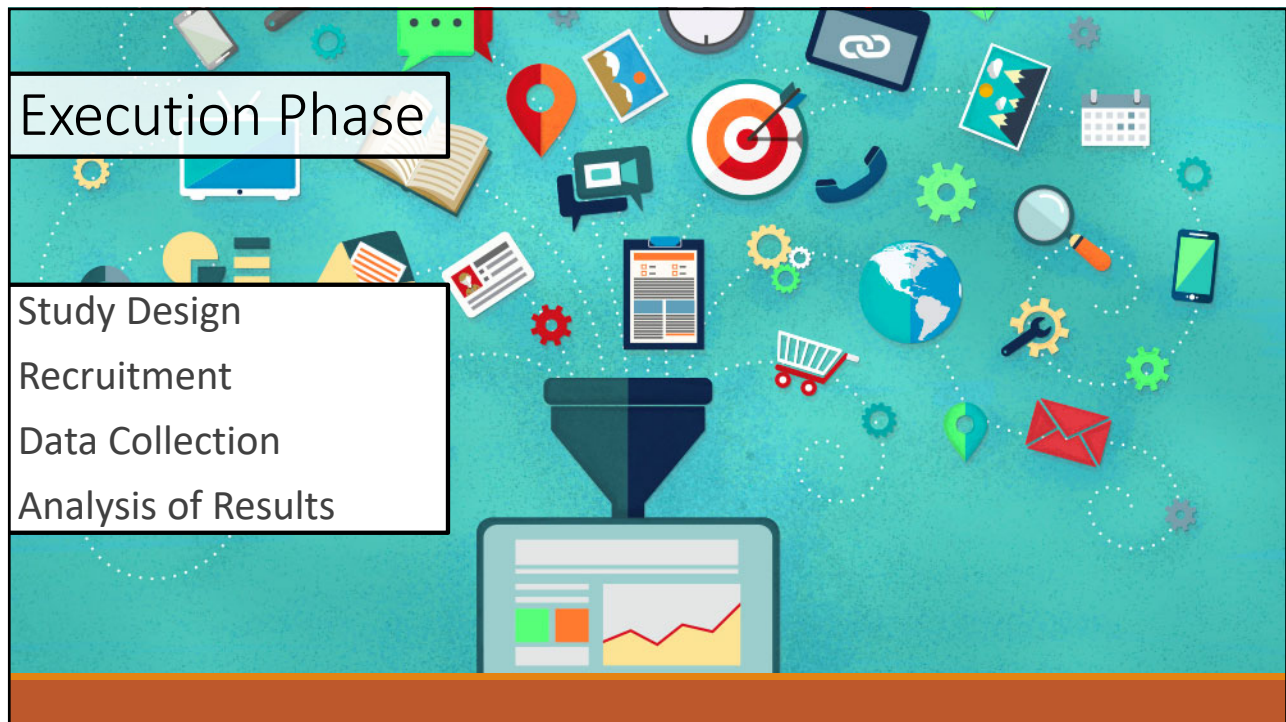
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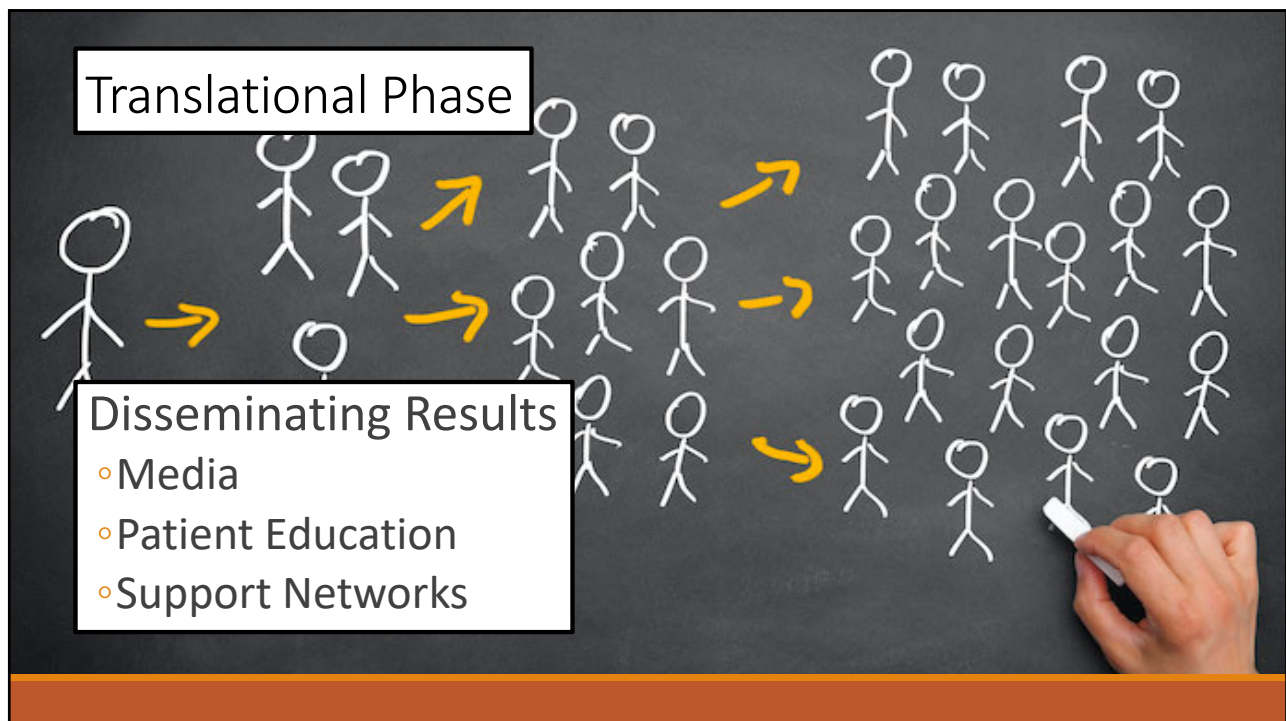
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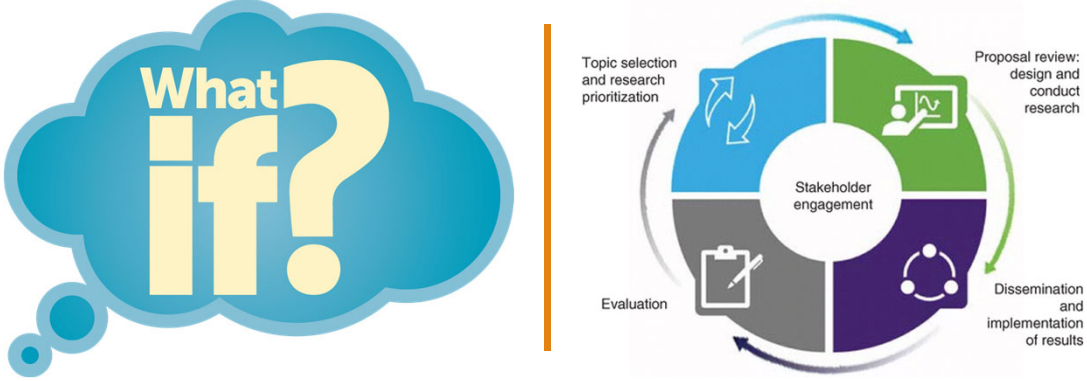
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What if?

Topic selection and research prioritization

Proposal review: design and conduct research

Stakeholder engagement

Dissemination and implementation of results

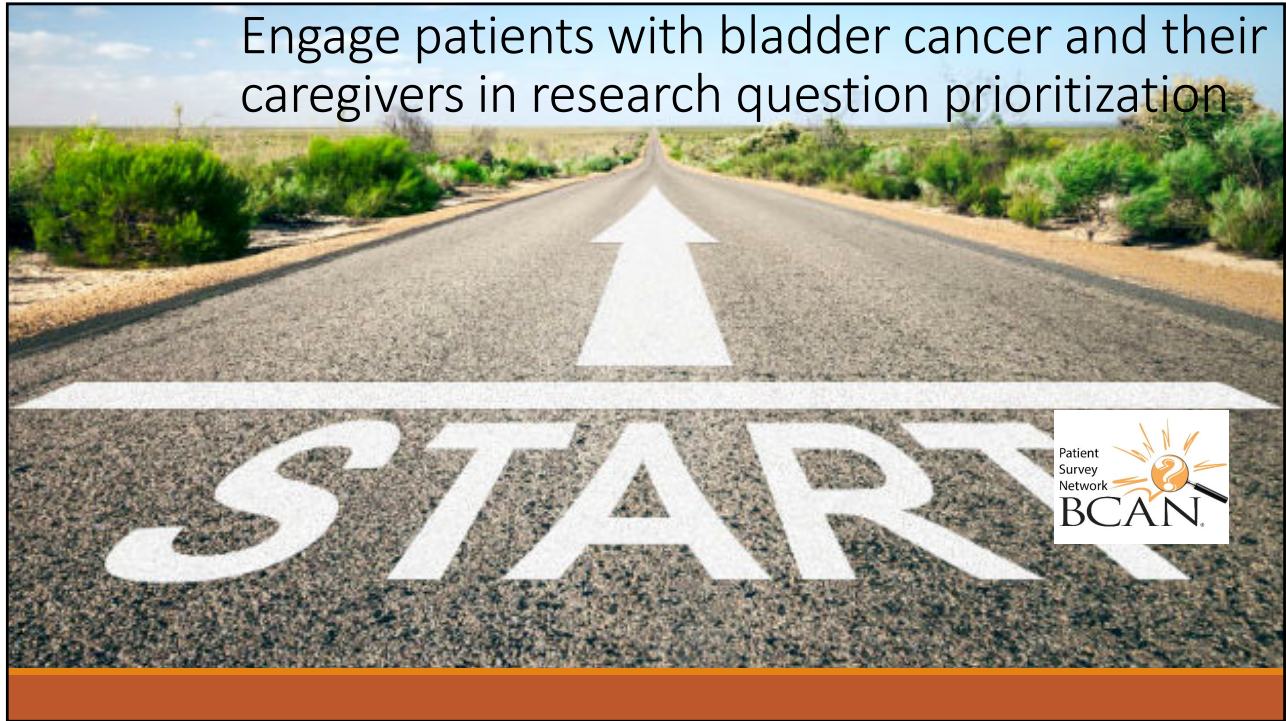
Evaluation

Patients were at the center of it all?

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Recruit patients and caregivers to join the Patient Survey Network

Bladder Cancer Advocacy Network
www.bcan.org
info@bcan.org
800-901-BCAN

Join us for our Patient Insight Webinar
Be Heard! Join the Patient Survey Network
On Friday, March 27th | 1am-12pm EST

Bladder Cancer Advocacy Network
Leading the way in awareness and action
Bladder Cancer Advocacy Network
Bladder cancer support group and discussion community

Inspire has
686,033
Members
14,912
of which are part of
this community.
Join today
EXPLORE COMMUNITIES

Bladder Cancer Advocacy Network
New guest blog post @angasmith_uni @JLUNCology on patient survey network "We want you! To tell us what to research" bcan.org/want-666-65-4...


PATIENTS AND CAREGIVERS IMPACTED BY BLADDER CANCER:
BCAN has received funding from the Patient-Centered Outcomes Research Institute (PCORI) to actively engage bladder cancer patients and caregivers in the research prioritization process.

<p>Project Mission</p> <p>Traditional research has relied on medical researchers and funding agencies to determine important research questions in bladder cancer. This project aims to turn this approach on its head by instead asking bladder cancer patients and caregivers about research questions that are important to them.</p>	<p>How will we do this?</p> <p>Through a joint effort between BCAN and PCORI, a patient survey network (PSN) will be created which includes BOTH PATIENTS AND CAREGIVERS. We will conduct workshops through the entire BCAN network as well as through focus groups at BCAN's offices and medical centers throughout the United States.</p>	<p>Who is funding this?</p> <p>PCORI has awarded a contract to BCAN to establish a patient survey network (PSN) through the Bladder Cancer Advocacy Network (BCAN) framework. Award winners, which encompass active involvement of patients, caregivers, clinicians, and other healthcare stakeholders as integral members of the research process.</p>
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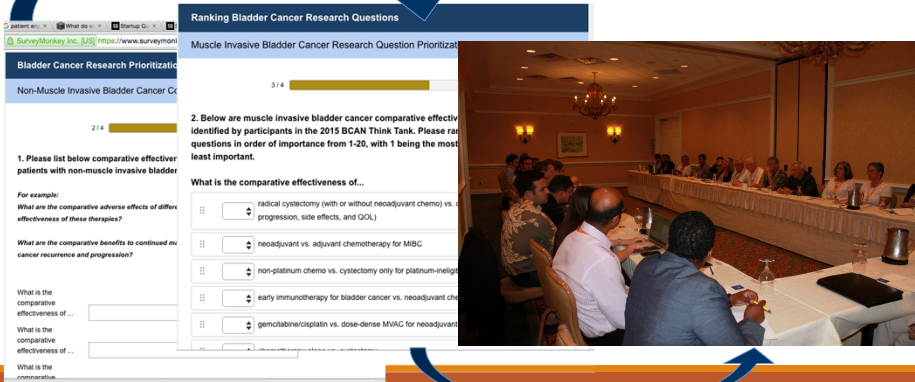
How and when can I get involved?
In February or March we will send an email to all members of the BCAN online community. This will include a link to participate. You can join at any time. You don't have to join online if you would prefer to call (301-215-9099). Once we have research and caregiver input, we plan to meet with a survey in the fall. We will also ask for research ideas and questions from our community.

Where can I get more information about the Patient Survey Network?
Visit this link: <http://www.bcan.org/research/join-patient-survey-network/>
Email: PSN@bcan.org Call 301-215-9099 ext. 203


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Generate research questions



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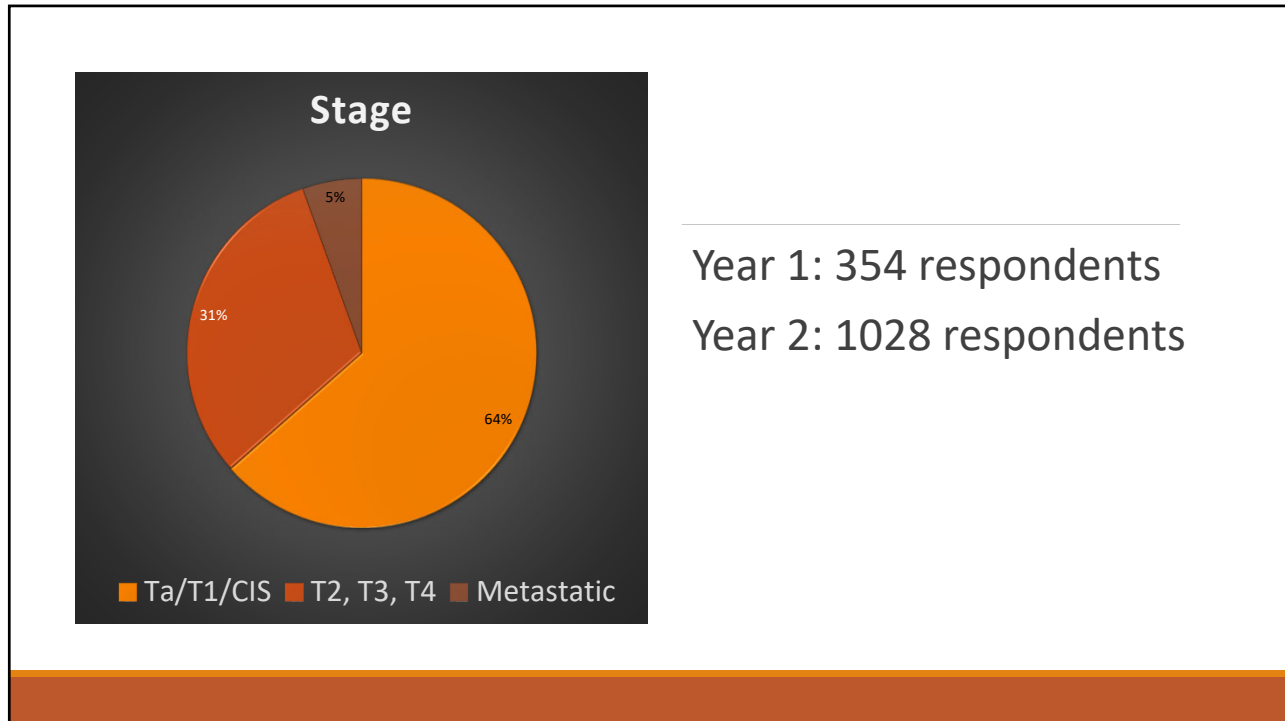
Prioritize research questions

Survey sent to the BCAN Patient Survey Network

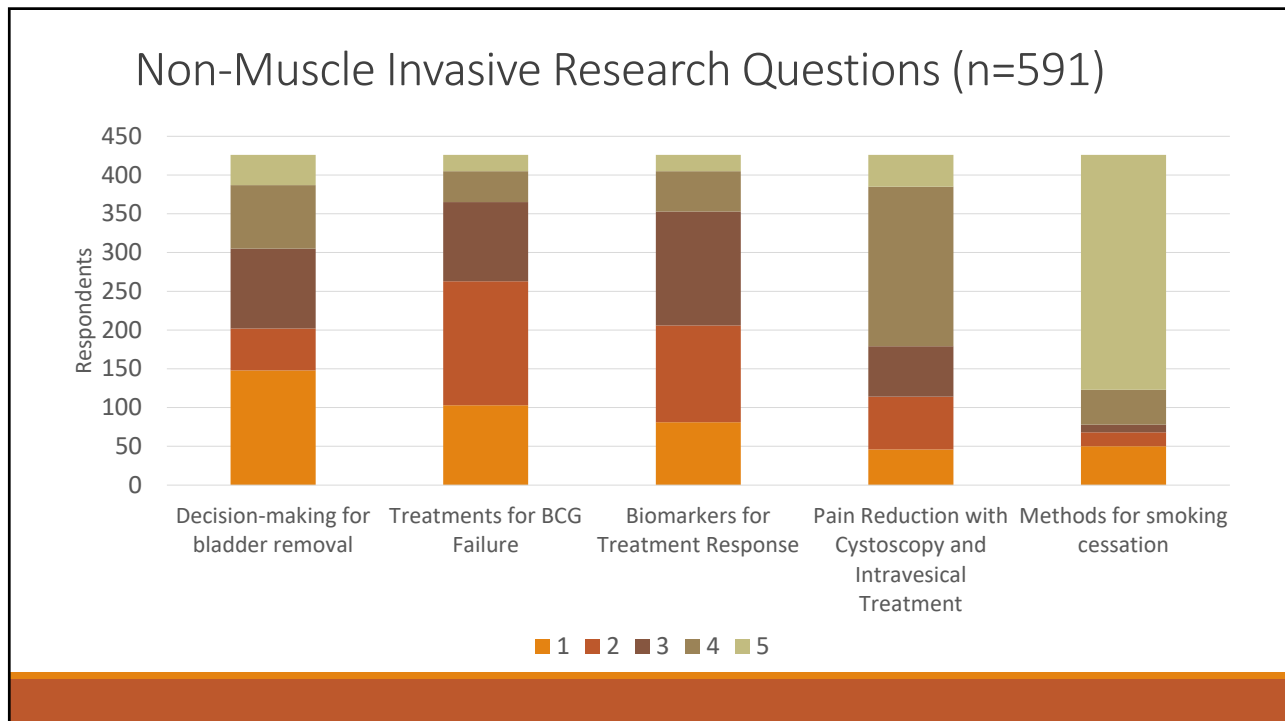
- Asked to rank questions/disease stage
- Free text research questions

Stakeholder conference calls

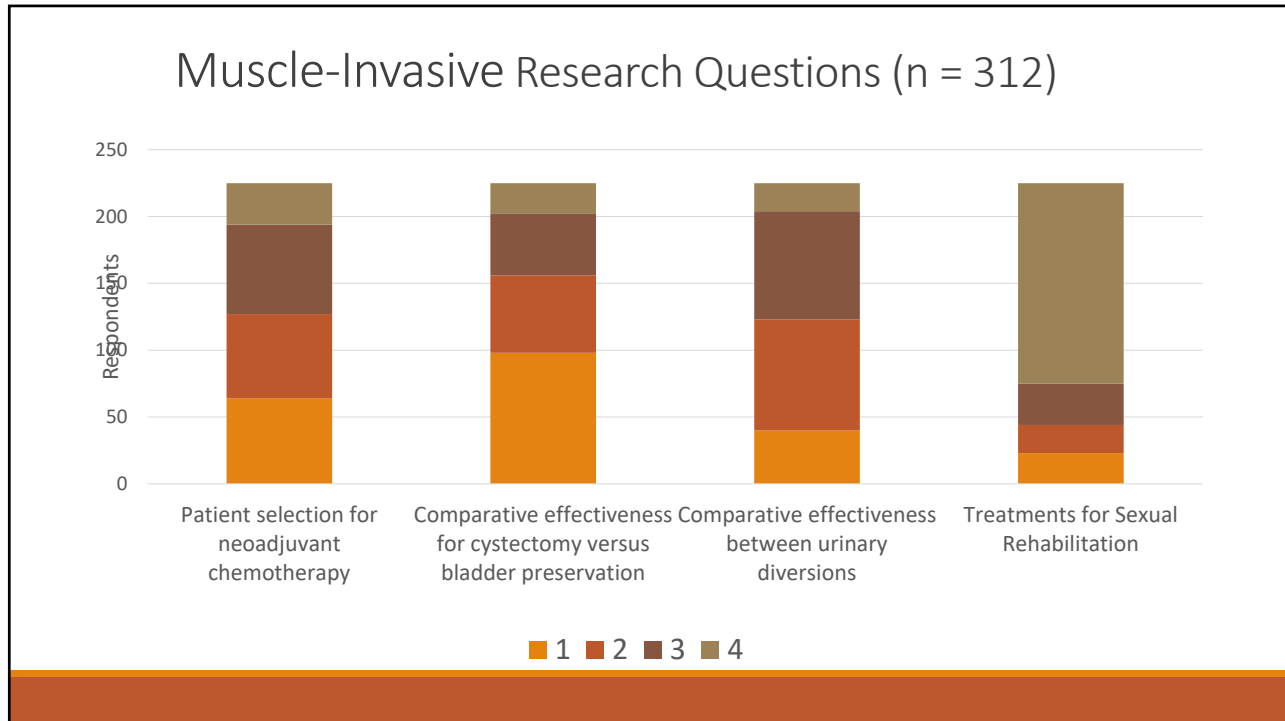
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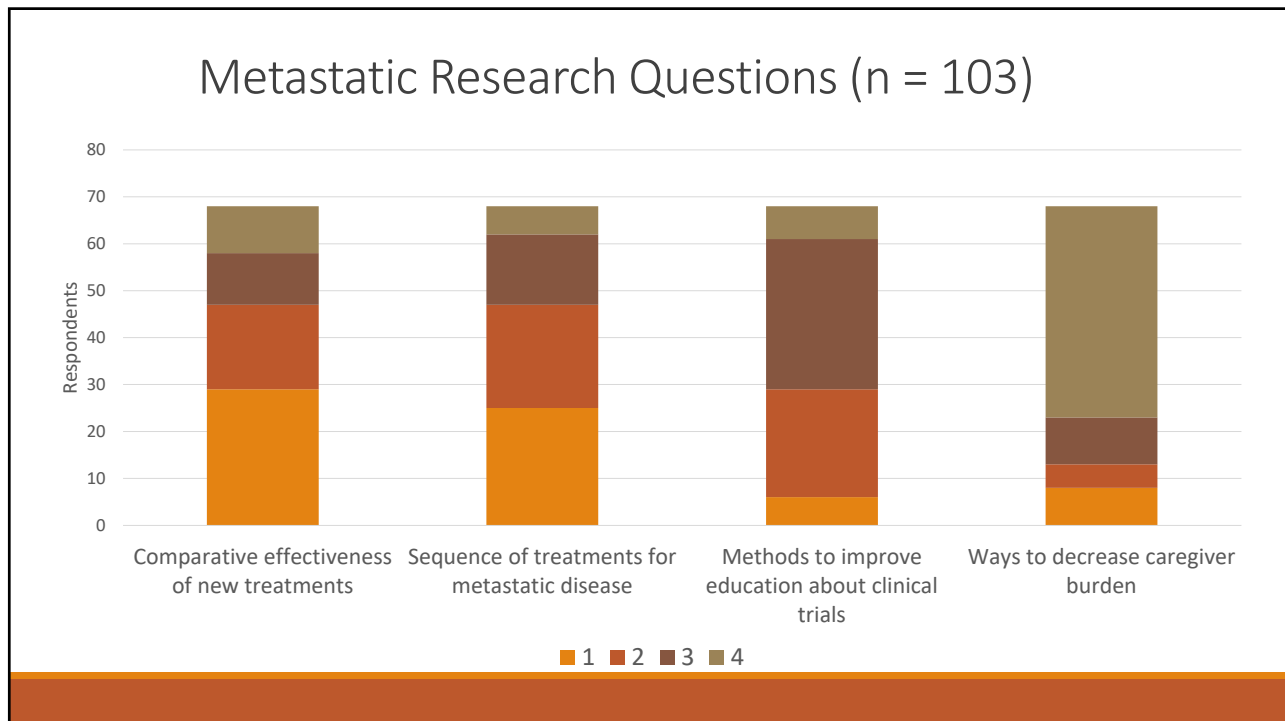
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Disseminate Research Questions

Patient Survey Network


BCAN

Funding Agencies

Researchers (Abstract, Papers)



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Priorities

PCORI 2017 Pragmatic Funding Announcement

- 1
- 2
- 3

2. Studies of patients with non-muscle invasive bladder cancer (NMIBC) who failed first-line treatments.

 - 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 NMIBC 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 MIBC, side effects, and quality of life.

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Overview of BCAN Engagement Projects

Engagement Award 1:

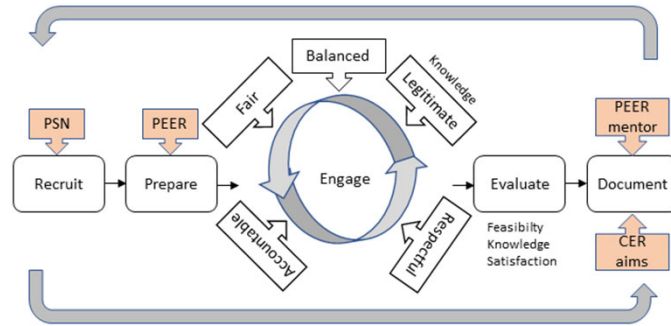
Patient Survey Network (PSN)

Engagement Award 2:

Patient Empowerment in Engagement Research (PEER)

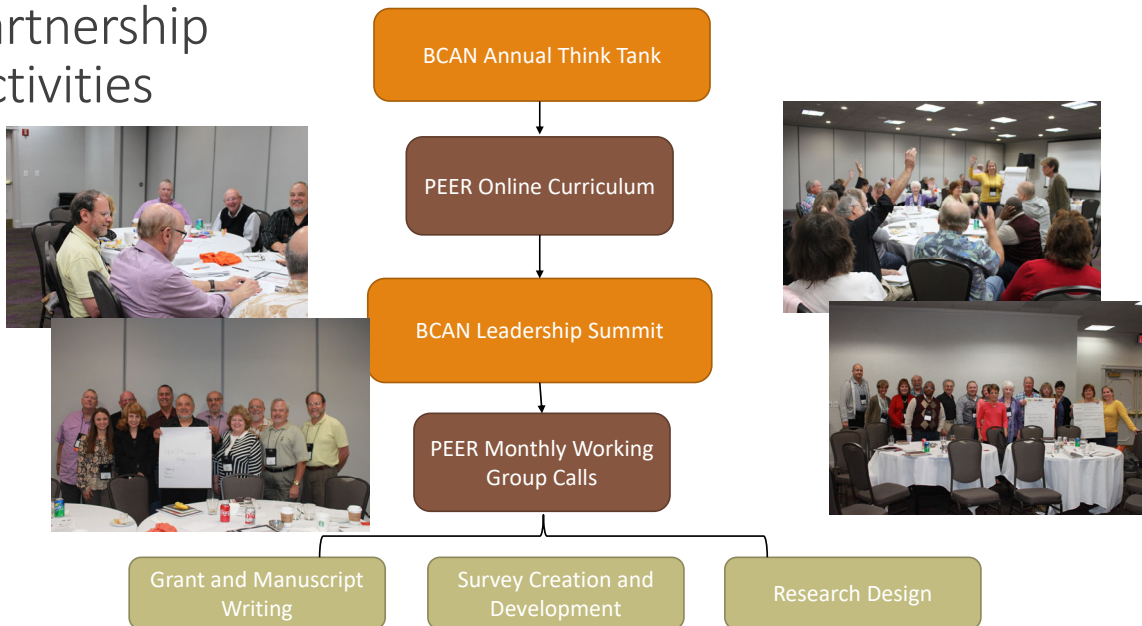
Engagement Award 3:

Promoting Implementation of Patient Engagement (PIPE)



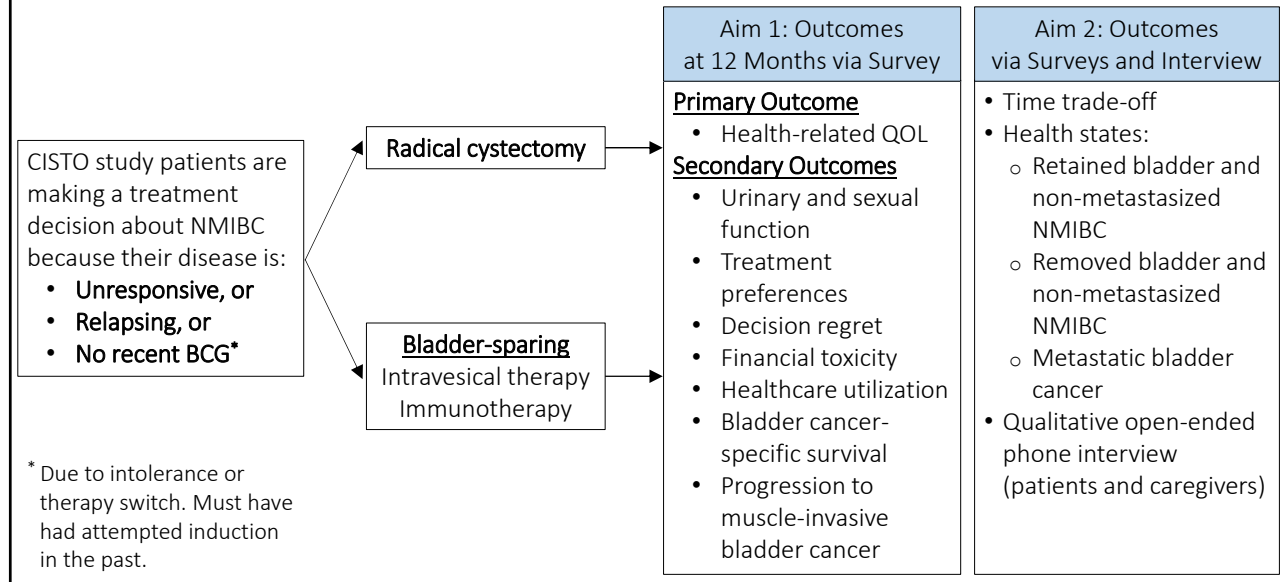
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Partnership Activities



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CISTO: Pragmatic Observational Study



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CISTO: Comparing Intravesical Therapy & Surgery as Treatment Options



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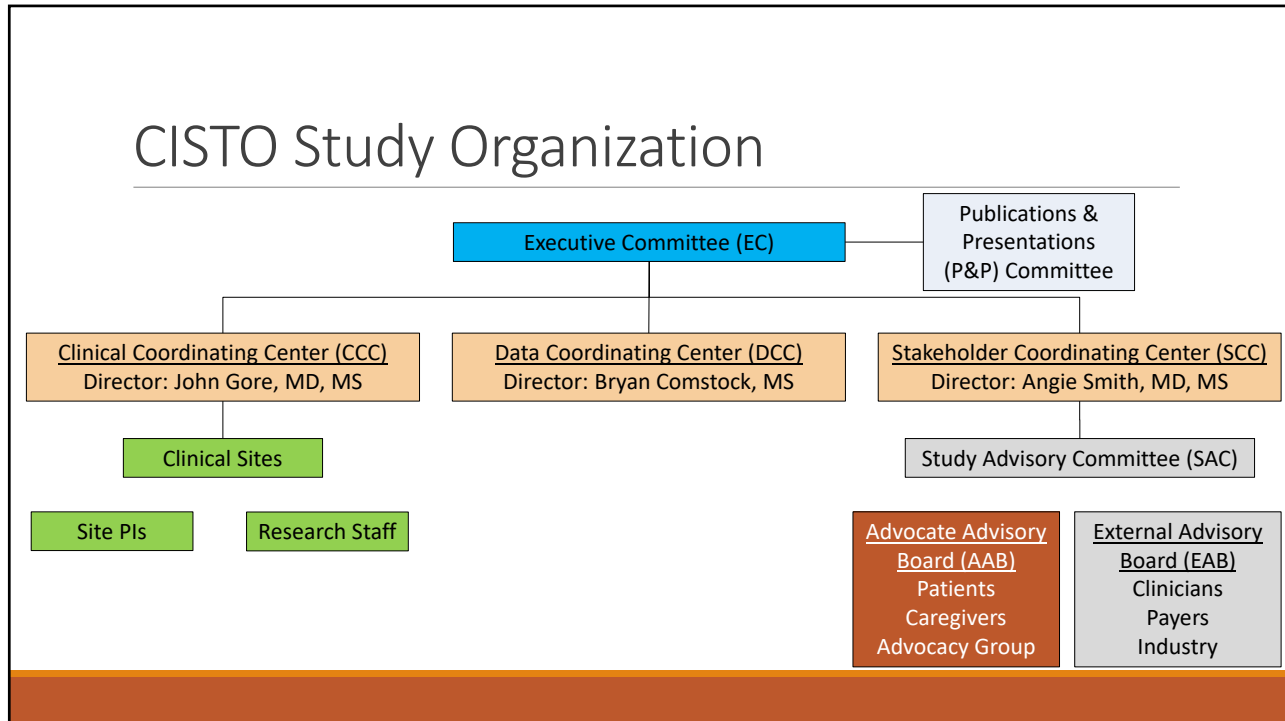
Bladder cancer is the fourth most common cancer in men and the tenth most common cancer in women. In 2017, over 77,000 Americans were diagnosed with bladder cancer, about three-quarters of whom had a type called non-muscle invasive bladder cancer (NMIBC), in which the cancer is limited to the inner layers 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 Bacillus Calmette-Guérin (BCG) inserted 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.

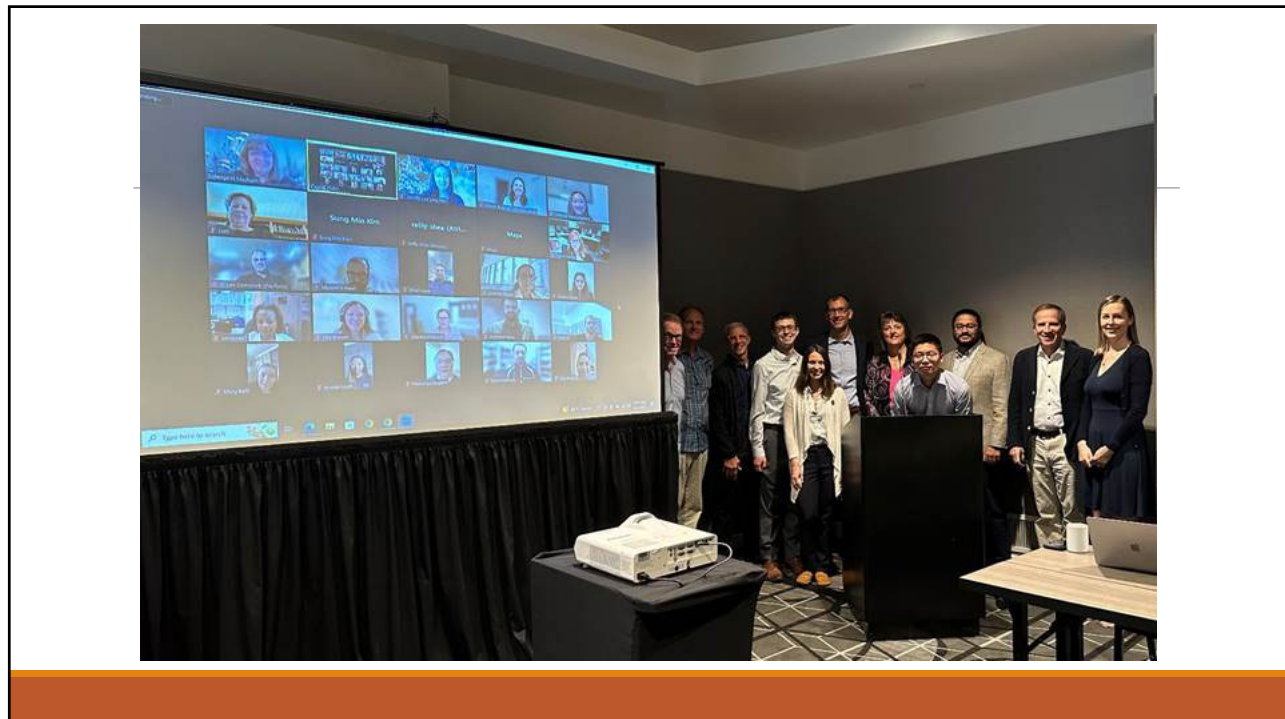
Much remains unknown about the comparative effectiveness of these two treatment options. There is also very little information about how patient preferences and quality of life factor into the decision. The CISTO Study aims to fill in critical evidence gaps in order to facilitate personalized, patient-centered care. The results from CISTO may provide

etter evidence about the clinical and quality of life outcomes so that future patients, their caregivers, and their providers can make more informed treatment decisions.

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TURBT Get the Facts

BLADDER CANCER ADVOCACY NETWORK GET THE FACTS

TURBT

What is TURBT?

A transurethral resection of the bladder tumor (TURBT) is a surgical procedure used to diagnose and treat visible bladder cancer tumors. TURBT is often an outpatient procedure done in the hospital. Most patients go home the same day, but some may stay in the hospital overnight because of their medical conditions or the extent of the tumor resection.

How is TURBT done?

The doctor inserts a resectoscope through the urethra to examine the bladder more completely while the patient is under anesthesia (general or spinal). The doctor then uses a small, electrified loop of wire attached to the resectoscope to remove bladder tumor tissue. A pathologist looks at that tissue to determine the stage and grade of the bladder cancer.

Your doctor may add a chemotherapy drug directly into the bladder after a TURBT to reduce the chances of future tumor recurrence.

ASK YOUR HEALTHCARE TEAM

- What will the results of the TURBT tell you?
- How long does the TURBT take?
- Will I likely need any other treatments when I go home?
- Will you give me any other treatments with the TURBT?
- How long should it take for me to recover after the TURBT?
- When will you know the results of the pathology report? How will you share those with me?
- What is your experience with the TURBT procedure?
- Will you be using enhanced cystoscopy during my TURBT?

Always consult a 3rd degree

BLADDER CANCER ADVOCACY NETWORK GET THE FACTS

TURBT

TERMS TO KNOW

- Anesthesia:** Loss of pain and other sensation, using medication.
- Biopsy:** The examination of tissue removed from the body to discover the presence, cause, or extent of a disease.
- Catheter:** A flexible tube inserted through a narrow opening into a body cavity, particularly the bladder, for removing fluid.
- Chemotherapy:** The treatment of cancer disease using chemical substances.
- Cystoscopy:** Examine the bladder and urethra using a thin, lighted instrument (called a cystoscope).
- Intravesical:** Within the bladder.
- Pathology:** The laboratory examination of samples of body tissue for diagnostic purposes.
- Pathologist:** A doctor who identifies diseases by studying cells and tissues under a microscope.
- Resection:** To cut out tissue or part of an organ.
- Resectoscope:** A thin, tube-like instrument used to remove tissue from inside the bladder with a light and lens for viewing.
- Stage:** The extent of cancer within the body.
- Urethra:** The tube through which urine empties from the bladder.

WHAT YOU SHOULD KNOW: Advice from bladder cancer patients who have experience with TURBT

BEFORE A TURBT

Bring a friend or family member to take notes on what the doctor tells you. Ask your doctor what type of anesthesia you will receive for your TURBT and ask if there is anything you should do before your TURBT procedure. Ask your doctor about any pre-operative testing you may need, and where and when that testing will happen. Find out where your TURBT will take place and what to expect on the day of your procedure.

DURING A TURBT

The doctor cuts visible tumor(s) away from the lining of your bladder with using instruments inserted through the resectoscope. Once a tumor has been removed, bleeding is prevented or reduced by using a mild electric current to cauterize (sear) the area where the tumor was. Tissue from the tumor will be sent to pathology to be evaluated.

AFTER A TURBT

Once the TURBT is over, you will be taken to the recovery room to allow the anesthesia to wear off. Your nurses will encourage you to drink plenty of water. Drinking water helps flush out your bladder. When you wake up after your TURBT, you may have a catheter in your bladder to allow your bladder to empty. Fluid may be added to wash out blood and debris from your bladder. A catheter may need to be kept in for several days if bleeding is persistent. If you are sent home with a catheter, make sure you understand how to use it and when it should be removed. Before going home, you will get instructions on post-TURBT recovery and you may also get prescriptions for medicines to take. Side effects of the TURBT may include painful urination, bladder infection, frequency and bladder spasms, medications and soothing gels can help. Ask your doctor what he or she recommends. Blood in your urine and passing blood clots from where they took out the tumor's can continue for a few weeks. Pads or protective underwear can help people who experience urine leakage after the treatment. Plan to rest and take it easy for a few days after your TURBT. Drink lots of fluids to help flush out debris and clots in your bladder. Call your medical team if you have questions or something seems wrong. Be sure to ask for a copy of your pathology report, keep this with your medical record information.

NEXT STEPS:

- Your doctor will help you decide what additional treatment you might need based on what the pathology report says.
- You may need to have a repeat TURBT in 2-4 weeks to completely remove the tumor or to get a stronger biopsy sample for the pathologist to examine.
- If you have small, low-grade tumors that have not invaded the lining of your bladder, a TURBT may be the only treatment you need. If you will still need regular cystoscopies to make sure there is no recurrence.
- If the tumor has invaded the muscle wall, your doctor may recommend surgery or other treatments.
- It can be helpful to talk to someone who has experienced TURBT. Call the BCAN Survivor 2 Hour program to connect with a volunteer who knows about having TURBT. (weekdays, 9am-5pm) 888-761-BCAN

Visit www.bcan.org/bladder_cancer_turbt for more information.

The Bladder Cancer Advocacy Network (BCAN) BCAN's mission is to increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community.

www.bcan.org 888-761-BCAN (2226)

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TURBT Expert Explanation

Detailed information about TURBT for patients

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

Understanding TURBT: Bladder Tumor Removal Surgery

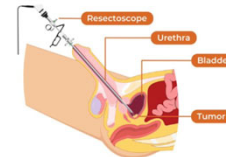
VIDEO

June 6, 2022

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.



This anatomical diagram illustrates the location of the bladder and urethra, and the path of the resectoscope during a TURBT procedure.

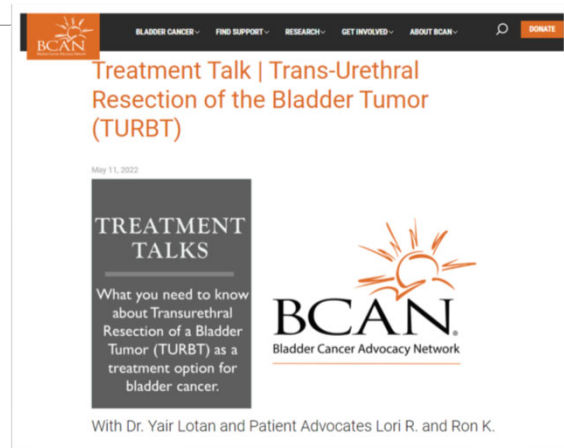
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TURBT Treatment Talk Webinar

- 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

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?

NMIBC is a cancer that grows on the lining of the bladder. This type of cancer does not grow into the deeper muscle layer of the bladder. It is often treated with BCG, a medicine that is instilled directly into the bladder. This treatment is given once a week for several weeks in your doctor's office. If the cancer returns after BCG treatment, the risk of the cancer spreading can increase. New treatment options must then be considered. Your doctor might call this BCG "unresponsive" or BCG "refractory" NMIBC.

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

There are many ways to treat bladder cancer that returns after BCG. Treatment options depend on your health, medicine tolerance, lifestyle, and type of disease. Treatment options may include:

NON-SURGICAL TREATMENTS	SURGICAL TREATMENT
<ul style="list-style-type: none"> • Intravesical Treatments <ul style="list-style-type: none"> - BCG - Chemotherapy • Systemic Immunotherapy • Chemoradiation 	<ul style="list-style-type: none"> • Radical Cystectomy, which includes: <ul style="list-style-type: none"> Removal of the bladder Removal of the prostate in some men Removal of the uterus, ovaries, and part of the vagina in some women Removal of lymph nodes in the pelvis Construction of a reservoir to contain urine, using the bowel

NMIBC THAT RETURNS AFTER BCG

SURGICAL TREATMENT

➤ **Radical cystectomy is a surgical treatment. It is the treatment most likely to cure you of bladder cancer. It includes:**

- Removal of the bladder
- Removal of the prostate in some men
- Removal of the uterus, ovaries, and part of the vagina in some women
- Removal of lymph nodes in the pelvis
- Construction of a reservoir to contain urine, using the bowel

How does a patient choose the best treatment if bladder cancer returns?

It can be hard to choose between different treatments. There are no studies that have directly compared treatment options. Talk with your doctor to understand the benefits and risks of each treatment option you have. It can also be helpful to hear stories from patients who had bladder cancer that returned after BCG. You can do that at this free link: <https://bcan.org/decision-making-webinar>.

Are there clinical trials available for NMIBC that returns after BCG?

Some hospitals participate in clinical trials for NMIBC that returns after BCG. One study, called CISTO (Comparison of Intravesical Therapy and Surgery), was designed by patients and for patients to compare treatments when NMIBC returns after BCG treatment. BCG refractory patients are eligible to enroll in CISTO. In this study, patients answer surveys about their experience with the treatment they choose. Participating helps future patients who face the same decision about choosing between treatment options.

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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.
- Engaging w/ Pharma as a Patient → <https://bcan.org/engaging-with-pharma-web>



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THANK YOU TO OUR INCREDIBLE, ENGAGED PATIENTS!



pcori
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Bladder Cancer Advocacy Network
BCAN
Leading the way to awareness and a cure

UNC SCHOOL OF MEDICINE

W