

July 27, 2020

NCCN Guidelines Panel

Thomas W. Flaig, MD, Chair

Dear Bladder Cancer Guidelines Panel,

The Bladder Cancer Advocacy Network (BCAN) was founded in 2005 and is the only national advocacy organization devoted to advancing bladder cancer research and supporting those impacted by the disease. BCAN is on the front-lines advocating for greater public awareness and increased funding for research to identify effective treatments and eventually, a cure for bladder cancer.


We commend the committee for their thorough analysis of the evidence and development of these guidelines. We respectfully request the NCCN Bladder Cancer Guidelines Committee review the suggestions provided by our patient research advocates related to potential gaps in the Version 5.2020 of the Bladder Cancer NCCN Evidence Blocks.

These gaps include:

1. **Urinary diversion options** are not fully highlighted in the radical cystectomy segments. Continent Cutaneous Pouchor CCP (Indiana Pouch) and Neobladder are not mentioned anywhere in the document. [Radical cystectomy first appears on page BL-5. Also on BL-7, BL-B. Ileal conduit is mentioned one time on BL-H. CCP is no where in the document and neobladder is also not included. All three are viable urinary diversion options and should be explained to patients.]
2. **Bladder preservation** (using trimodal therapy) is neither included nor explained as a viable treatment option in most of the recommendations. [Bladder preservation is first mentioned in the footnotes of BL-5 and 7. Trimodality therapy does not show up until BL-B. It is not offered as an actual treatment option anywhere. Bladder preserving options are included in the [Treatment of Non-Metastatic Muscle-Invasive Bladder Cancer: AUA/ASCO/ASTRO/SUO Guideline \(2017\)](#)]
3. **Best supportive care** – starts on BL-6 and is mentioned throughout, yet it is not defined. NCCN has numerous (12) guidelines on supportive care, including palliative care. We recommend at least mentioning them early in the document. [[Pain](#), [Antiemesis](#), and [Palliative Care](#) are three examples that can be mentioned/linked]
4. **Managing common side effects**, such as those experienced by patients having BCG treatments, are not addressed, and should be. There is an [NCCN patient guideline for managing IO side effects](#) that could be referenced if you feel it is appropriate. Many bladder cancer patients experience *recurrent urinary tract infections* as a side effect during their treatment journey and well into survivorship.
5. The current document does not address **environmental or occupational risk factors** (including those for military personnel or first responders) that may be significant in disease development or progression. [Smoking is listed as risk factor on BL-1, [Veterans and Agent Orange: Update 2014](#) changed the categories of association with exposure to the herbicides sprayed in Vietnam for three health effects. **Bladder cancer** was moved from “inadequate or insufficient” evidence of association up to “limited or suggestive” evidence of association. The VA has yet to make a formal statement about bladder cancer as a presumptive condition as a result of Agent Orange exposure though. Current [VA Burn Pit Registries](#) are attempting to document the impact of this environmental/occupational exposure on the health of veterans of modern warfare.]
6. Recently approved treatment options focusing on genetic mutations present a need for patients to understand and consider **genomic testing** to allow for more treatment or clinical trial options, should they experience disease progression. This first appears on page BL-8 and should be suggested earlier in disease staging.
7. **Clinical Trials** – the message on page 5 is important, but is lost as a footnote and not positioned as a treatment option in the remaining document. Please consider listing clinical trials as a viable treatment option throughout, or *somehow making the recommendation more prominent than a mere footnote*.
8. Clearly assessing patient goals of care as an element of the guidelines, would help bridge the divide between treating a tumor and treating the patients living with the disease. Perhaps adding a statement to the introduction will help to highlight this for clinicians.

We appreciate both the work of the Guidelines Panel as well as your attention to our recommendations. Thank you for working to improve this comprehensive set of guidelines.

Sincerely,

A handwritten signature in cursive script that reads "Stephanie Chisolm".

Stephanie Chisolm, PhD

BCAN Director of Education and Research, along with patient advocates: Jerome Freedman, Christine Griner, Bill Russell, Karl F. Popp, R. Ph., Jerome Ward, Nancy Lindsey, John Pitzer, Carlos Glender, Theodore Lehmann, Andrew Archuleta, Gail Dykstra, Tom Reed, Ralph Ullman, and Karen Saches.