


ENGAGING PATIENTS ON TEAMS: PATIENT PERSPECTIVE

Robert Lipman
BCAN Patient Research Advocate




Bob Lipman: Starting in 2003 and over the course of two years, I had tumors removed several times, I had BCG, which failed. Then we switched to BCG and interferon which also failed. Then the choice was between having my bladder removed or to continue with the treatment, which is exactly the question that's being answered by the CISTO study. At that time, in 2005, when I was making that decision, there really wasn't any data from a patient perspective of how to make that decision. There was no information about what the impact of that decision would be. Certainly, the doctor could tell me, one way or the other, is the success of either of us their course of treatment, but there really wasn't anything from a patient perspective. I continued the treatment and I've been cancer free since 2005. I continue with BCG and interferon maintenance treatments and now I get a yearly cystoscopy. I've been volunteering with BCAN since 2005 and in terms of patient engagement, it's really about research that's carried out with or by members of the public, rather than to, or about or for them. We think of maybe doctors doing research studies and they want to do something to you. This is really research being carried out with the public and by different patients. You've heard Angie mentioned some of these PCORI-funded projects. I urge you to go to the PCORI website, so you can read them more about their overall goals. I'm going to talk a little bit more



PATIENT BACKGROUND

- Diagnosed with NMIBC high-grade CIS in 2003
- Three TURBTs
- BCG failed (intravesical immunotherapy)
- BCG plus Interferon also failed
- Choice between bladder removal surgery or continue treatment
 - No data on patient outcomes for impact of the decision
 - Current CISTO study seeks to provide that data
- Continued treatment, cancer-free since 2005



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from my involvement with these efforts. These aren't really sequential, some of them are taking place in parallel. All of these projects are in collaboration with BCAN.

Bob Lipman: As Angie mentioned, in the Patient Empowerment and Engagement Research project known as PEER, we developed online training modules, so that we could learn more about clinical trial basics, and more about bladder cancer. Not everybody knows all aspects of bladder cancer depending on what you might have been diagnosed with. Then we also measure the effectiveness of that training and how the patient advocates felt, how good that was, and how to improvement. Then, as also mentioned, the Patient Survey Network prioritized several research questions. One of the questions was, is a cystoscopy a major source of discomfort and anxiety for bladder cancer patients? If you've had a cystoscopy, you know what I'm talking about.

PATIENT EMPOWERMENT IN ENGAGEMENT RESEARCH (PEER)

- Online training modules
 - Clinical trial basics
 - Bladder cancer
- PSN prioritized several research questions
 - Is cystoscopy a major source of discomfort and anxiety for bladder cancer patients?
 - Developed survey used by the PSN
 - ~460 responses, analyzed results
 - Possible PCORI funding for a pragmatic trial

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A survey was developed for use by the Patient Survey Network. It asked various questions about the level of your discomfort and anxiety, whether it has changed between your first cystoscopy and your most recent cystoscopy and if there was any type of measures that you used, or the doctor suggested, that might alleviate that discomfort and pain, such as a warm blanket, being able to visualize or see the inside of your bladder while this cystoscopy is going on, whether music helped. We had about 460 responses, results were analyzed. There's possibility of PCORI

funding for pragmatic trial, clinical trial that's going to look at those issues, so that we can measure those things that alleviate the discomfort and anxiety and measure them in a clinical setting and provide some results.

We heard about Promoting Implementation of Patient Engagement or PIPE. Majority of this took place at the recent BCAN Leadership Summit. One of the activities for PIPE at the

PROMOTING IMPLEMENTATION OF PATIENT ENGAGEMENT (PIPE)

- 2019 BCAN Leadership Summit
- How to connect trained research advocates to research teams
 - Promote patient engagement in research
 - Involve BCAN research advocates in research and clinical trial teams
 - Disseminate results of patient-centered outcomes in bladder cancer research

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summit, was how to connect trained research advocates like myself to research teams. We had brainstorming sessions, to gather ideas about these three different questions, how to promote patient engagement in research. We've heard to Patty some ways that patients can be involved in the clinical trials and involve those research advocates in research and clinical trial teams and how to get those results out, whether it's through a website, or social media, or publications, and journals, but how to make sure that all that information gets out to the people who need to have that information.

Angie, talked a little bit about CISTO. I won't go over the details of it. She did a pretty good job of that since she's running that study. Some of the important aspects of it is that, this is a pragmatic clinical trial. It's comparing the effectiveness of the treatment and the outcome in a real world patient experience. It's not about, which drug is better or which treatment is better? The treatment is still selected by the patient. We're going to be surveying the patients and some of the caregivers about how things are going over the next several years, what's their quality of life and various other questions.

COMPARING INTRAVESICAL THERAPY & SURGERY AS TREATMENT OPTIONS (CISTO)

- Pragmatic clinical trial looks at treatments and outcomes of real-world patient experience
- Treatment is selected by the patient
- CISTO is enrolling patients whose bladder cancer has returned despite standard treatments
 - Choosing between having their bladders removed and receiving more medicine into the bladder
 - Deciding on which treatment to choose after bladder cancer has returned is a challenging problem for patients and clinicians

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COMPARING INTRAVESICAL THERAPY & SURGERY AS TREATMENT OPTIONS (CISTO)

- Compare the impact of the treatment options of bladder removal and additional medicine into the bladder on patients' quality of life and on the clinical outcomes that patients have rated as being most important
- 900 patients, 25 caregivers, 28 sites
- Strict criteria for who qualifies as a patient
- cistostudy.org
- Advocate Advisory Board (AAB)
 - Part of the Stakeholder Coordinating Center (SCC)

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Bob Lipman: Again, this is comparing the impact of the treatment options. As part of the trial, they're looking to enroll 900 patients and 25 caregivers. There are 28 sites across the country where they're going to be enrolling those patients. That process is just beginning in terms of certifying the sites where patients will be enrolled, and there are very strict criteria of who qualifies as a patient. We need an even bigger pool of the 900 patients to see who really qualifies and there's a split between the patients who are continuing their medical treatment

or intravesical therapy, versus the patients who have elected to have their bladder removed. You can go to the study website, cistostudy.org. Angie showed a little diagram of the makeup of all the different components of the study. **I'm on the Advocate Advisory Board**, which is part of the Stakeholder Coordinating Center.

What are the roles of the Advocate Advisory Board? These statements here were taken directly from an onboarding welcome packet and to roll out to the advocates what we would be doing. Not all of these things are taking place at the same time. These will be taking place at different times over the course of the study. Of course as patients, we want to provide our perspective on the healthcare experience. What has our experience been in terms of intravesical therapy, of having more treatment with medicine, versus having our bladders removed? On the Advocate Advisory Board, we have both different types of patients. Some of the things that we've been doing is reviewing the study protocol and the patient workflow.



CISTO AAB ROLES

- Provide the patient perspective on the healthcare experience
- Ensure research is patient-centered through review of study protocol and patient workflow processes
- Refine educational materials
- Participate in operational committees as warranted
- Make binding recommendations on all phases of study conduct
- Participate in crafting blog posts, brief reports, and tweet chats
- Participate in manuscript development and presentations at national meetings
- Advise on improvements for patient engagement in research




CISTO AAB QUALITIES

- Share insights and experiences in productive ways
- See beyond their own personal experiences
- Respect diversity and differing opinions
- Are good listeners
- Collaborate on solutions
- Are passionate about enhancing the health-care experience



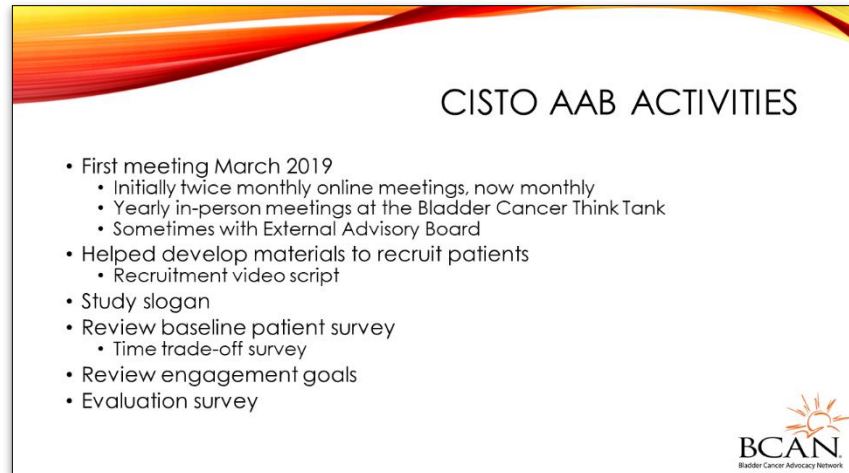
Most important is one of the qualities of someone who's on the Advocate Advisory Board. I'd like to focus on the second one. All of us, advocates, who are patients, our bladder cancer stories really define us. We've been through a lot. Some people they might have had bladder cancer and had tumors

removed once and some BCG and that's it. Other people who have had their bladders removed, it's a much longer process and people have different various stages and ranges, grades of bladder cancer. Their experiences are either routine, or there might be outliers, but we really have to look at it beyond our own personal experiences, and what is our experience to help for the greater good.

Some of the activities that we've done so far and so our first meeting was in March of this of last year. Initially, we had twice monthly online meetings. Now they are monthly and we've had a

variety of issues to discuss. I've known some of these other people on the advisory board from other activities. We're very compatible group of people. We have very lively discussions. Everybody's opinion is welcomed. Everything is recorded for further review by the stakeholder committees. We also have yearly in-person meetings at the Bladder Cancer Think Tank. The online meetings

are held with the External Advisory Board. We get some cross pollination of ideas between the people who are external to the study and the advocates. Some of the practical things that we've done is, we helped develop the materials to recruit patients.



The slide features a decorative header with a red and orange gradient. The title 'CISTO AAB ACTIVITIES' is centered at the top. Below the title is a bulleted list of activities. In the bottom right corner, there is the BCAN logo, which includes a stylized sun icon and the text 'BCAN Bladder Cancer Advocacy Network'.

CISTO AAB ACTIVITIES

- First meeting March 2019
 - Initially twice monthly online meetings, now monthly
 - Yearly in-person meetings at the Bladder Cancer Think Tank
 - Sometimes with External Advisory Board
- Helped develop materials to recruit patients
 - Recruitment video script
- Study slogan
- Review baseline patient survey
 - Time trade-off survey
- Review engagement goals
- Evaluation survey

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One of the main things is there is a recruitment video. At the sites that are trying to enroll patients, there is a video that the patients can watch, which lay out the basics. It's presented by patients and a doctor. They get a patient perspective on what it would might be like to enroll in this study. The other thing is, we've looked at a study slogan. We're looking at an information card that the patient can have to remind them of the details of the study, and helping making their decision about enrolling in the project.

Bob Lipman: One interesting thing was, we did a review of the baseline patient survey that the patients will be filling out when they're initially enrolled and over time. There was an interesting thing called the time trade off survey, which is not something that I'd ever seen before. It was disturbing questions, but it is used to evaluate patients' response of whether they thought they made a good decision. We're also reviewing the engagement call goals. All throughout this process, the people on the Advocate Advisory Board have been surveyed to get feedback on how we think things are going. Are there needs to be more interactions? Do we need to get more information from the other committees.

CISTO AAB ACTIVITIES

- Improve interpretation of study findings based on feedback
- Translate and communicate study findings to patients, their families, and caregivers
- Participate in Publications and Presentations Committee



To continue the activities we're going to be improving the interpretation of the study findings based on feedback. These are really things that are going to be happening in the future once we have those study findings, to translate and communicate that information to patients, their families and the caregivers. There's also a publications and presentations committee. Through this study, many publications will be developed and there is a representative from the advocate advisory board who is on that publications and

presentations committee. From a personal standpoint, I have found this to be very fulfilling, from a variety of standpoints. One, because this is answering a question that I had back in 2005, when I didn't really have any information for me to base my decision on.

I've been connected with Angie Smith, for several years on a variety of these PCORI-funded research activities, and I'm looking forward to more of that participation. It's also just to hear from the researchers' perspective and coming to a common ground between the advocates and the researchers, where the researchers might have some ideas of what is appropriate for a patient, and really find out that maybe that's not true when they hear what the advocates have to say and the patients have to say. Likewise, as a patient advocate, I'm learning a lot more about research. It's certainly not the kind of clinical trials where we're testing out new drugs and things like that, but it's really broadened my perspective on the whole area of research, advocacy and patient-centered outcomes.

This webinar was funded through the Patient-Centered Outcomes Research Institute grant for the PEER Integration and Scaling Methods (PRISM) Project.