



What is Value for Patients in the Management of Prostate Cancer.

At all stages of and levels of prostate cancer, whether you have low, intermediate, or high risk disease, whether you are newly diagnosed, have recurrent disease or your prostate cancer has advanced and metastasized, the same questions arise.

- What is the right treatment for me?
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- Will this control my cancer?
- How do I know if my doctor is right?
- Do I accept my doctor's advice – if he offers one or do I seek a second opinion?
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So, what does define 'value' for patients in the management of prostate cancer? CureTalk's prostate cancer panel of Mike Scott, Tony Crispino, Joel Nowak, Richard Davis, Paul Carpenter and Jan Manarite will be sharing their experiences and thoughts on this.

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Full Transcript:

Priya Menon – Good evening and welcome to CureTalks. I am Priya Menon, Scientific Media Editor of CureTalks, joining you from India. This is CureTalks' 106th episode; and today, we are talking about prostate cancer. Our prostate cancer talks are conducted in association with Prostate Cancer International and the Prostate Cancer Foundation. At all stages and levels of prostate cancer, whether you have low, intermediate, or high-risk disease, whether you are newly diagnosed, have recurrent disease, or your prostate cancer has advanced and metastasized, the same questions arise. What is the right treatment for me? Do I need this treatment? Do the benefits of treatment outweigh the risks? Will this control my cancer? How do I know if my doctor is right? And do I accept my doctor's advice? So, what does define "value" for patients in the management of prostate cancer?

Priya Menon – CureTalks' prostate cancer panel of Mike Scott, Tony Crispino, Joel Nowak, Richard Davis, Paul Carpenter, and Jan Manarite will be sharing their experiences and thoughts on this. My co-host for the show is Mike Scott. Mike is Co-founder and President of Prostate Cancer International, a prostate cancer-specific and not-for-profit educational and informational organization based in Virginia. He is a former chairman of the board of the..., of the National Organization for Rare Disorders and is a board member of the International Myeloma Foundation. On the panel, we have Tony Crispino who is a 10-year survivor of advanced prostate cancer and is currently in remission. He works for the nation's top researchers as a patient advocate. Tony is a published co-author in ongoing clinical trials through PubMed, Medscape, JAMA,



Journal of Clinical Oncology, and ASCO. Joel Nowak is a survivor of five primary cancers, including thyroid, recurrent metastatic prostate cancer, renal cancer, melanoma, and appendiceal cancer as well as autoimmune disease, ankylosing spondylitis. He is the Director of advanced prostate cancer programs and advocacy for Malecare. Jan Manarite is Vice-president of advocacy and education at PAACT. Jan's perspective of patient empowerment is to help people understand their medical records, develop better questions, find missing information, and dispel information. The focus is "patient first always." She is widow of Dominic Manarite who lost his prostate cancer battle in 2013. Richard Davis is a patient advocate at UCSF, has moderated support groups, and is active in national online PCa forums. Ric is a social entrepreneur, promoting exercise to people living with serious and chronic illnesses and developing a virtual video platform for support groups; and Paul Carpenter is a patient advocate who was diagnosed with prostate cancer in 2007, and he has undergone six different treatment modalities so far. He works for a software company and in his off hours is very active in local stage and film video productions.

Priya Menon – Welcome to CureTalks, everyone! We will be addressing questions from the audience towards the end of the discussion. If you have a question for our panel, please press 1 on your keypads and let us know and we will bring you on air. Alternately, you can email your questions to priya@trialx.com or post them on the CureTalks' website, curetalks.com. With that, I will hand over to Mike to begin with the discussion. Mike, over to you!

Mike Scott – Thank you, Priya. Good afternoon or good evening, everybody. I appreciate you taking your time to be on the call. We are doing something little bit different this week. Instead of having a lecture and then being able to talk to an expert, I think what we have got on the call today is a number of experts other than me who have had prostate cancer or in the case of Jan Manarite, whose husband had prostate cancer; and one of the things that I had..., its been on my mind for a variety of reasons is what is value for a patient with prostate cancer. A lot of people in a lot of the healthcare industry are trying to measure different aspects of value, and my bias is that they are doing this without a great deal of patient input. So, what I would like to start by doing is simply going around the panel and asking people to try and tell me briefly please what the greatest value they ever received from one of their doctors was during the progress of their disease or for those who are in remission, the..., the stopping with progress of their disease. So, Paul, perhaps we could start with you, Paul Carpenter!

Paul Carpenter – Umm.... I... That's an interesting question. I would think the greatest value was being told of other men like me in my circumstances who had continued to survive for years and decades and being put in touch with them and being given example from their lives of how cancer is not a death sentence, even aggressive prostate cancer. So, it was..., it was hope, not a medical thing at all.

Mike Scott – And..., and this was something that your doctor helped you to be connected with?

Paul Carpenter – Yes. Eventually, after I found..., after I went through two or three other doctors who were entirely medical.

Mike Scott – Oh, well, that's another part of the issue. (Laughter)

Paul Carpenter – Yes, indeed.

Mike Scott – Ric, would you like to chip in? Hello, Ric! Okay, maybe we will come back to Ric. Joe;!

Joel Nowak – Yes. Hi! How are you? Its interesting because my response is going to be very similar to Paul's, but it did not come from a doctor. We may end up actually being pretty negative about the medical community where we are going. The best value that I received were from sitting down and learning from other men how important it is to be responsible for my own healthcare and that means going and educating myself and learning about my options and making decisions based on myself and my ability to absorb the information and unfortunately, no doctors particularly were good in any of my cancers in doing this. More came from my peers.



Mike Scott – Tony!

Tony Crispino – Yeah. Its directly from my doctor in the same meeting with which he tells me that I have a little cancer down there. He pulled out a pen and paper, and he wrote down the phone numbers of three or four other options available. He told me what he would do to treat my disease and he gave me the phone number to actually surprising me myself and having been in the same business unit, but doctors in southern California and other locations that did different types of treatment, but he volunteered this information to me while I was still kind of getting over the word, “you have cancer.”

Mike Scott – Have you heard that commonly from other doctors? I know you spent a lot of time around them recently.

Tony Crispino – No. I..., I think that that was just a very unusual circumstance because when I finally went online and started learning about this, I mean I didn't sleep for three days after that..., that meeting by the way, but I..., I started to look on around there and I started to see that I had a very unique situation, that the doctor was really kind of, if you will, on the ball. He..., he knew that I was kind of a researching kind of guy and he knew I would probably dig into that, so he beat me to the punch.

Mike Scott – And, Jan, what happened with your husband?

Jan Manarite – Well, it was a 13-year journey. So, obviously, a lot of things happened, but when you use the word “value” and I know you are talking about the medical system who is trying to define “value” for value-based healthcare system. From our journey, I just keep thinking about the conversation with the doctor. That was of great, great, great value; and the problem in my view is that the conversation that a doctor has with his patient doesn't get reimbursed. It just doesn't get reimbursed.

Mike Scott – True.

Jan Manarite – So, the doctor loses the..., the time in the clinic to do that. So, what happens is the conversation between the doctor and the patient gets choked for lack of a better word and therefore, the relationship does. For a patient to make a medical decision, he really needs to discuss it with his doctor and this is shared decision making, one-o-one. They need to have an in-depth conversation about what the doctor knows. I hear some noise in the background, sorry.... And what patient..., the patient knows, so you can come together and make a risk versus benefit decision. That's in conversation in the clinic. To me, that, you know, I can't think of anything else. As far as the value about a treatment decision, the value for a patient with priorities, they change constantly and that has to be worked out again in the clinic with the doctor in conversation and there's no time for it.

Paul Carpenter – So, I am not sure any of us really answered your question as posed, Mike. I am afraid I may have turned the situation.

Mike Scott – Oh, no! You... Oh, no! You...

Paul Carpenter – No? All right. Fine.

Mike Scott – You are asking the..., answering the questions as posed.

Paul Carpenter – Okay.

Mike Scott – Did..., did..., did Ric Davis come online?

Richard Davis – I am here. Can you hear me now? I could hear you before, but you couldn't hear me.

Mike Scott – That's okay, Ric. So, so..., what..., what..., what... What was valuable for you?



Richard Davis – I think that I was very fortunate to have..., to be assigned a very good urologist who told me even though I had high Gleason score, that I had three or four months to make a decision as to what my treatment was, which gave me enough time to..., to think about the right way to go. He wasn't pushing anything one way or the other and then from there I was able to combine both UCSF and Kaiser Permanente in my treatment, but I think that if my doctor would have put pressure on me to make a decision quickly, I..., I..., I wouldn't have made the right decisions.

Mike Scott – So, one of the things that..., that worries me in all of this, and I..., this is why I wanted to have the discussion is that regardless of where one is among one's journey and regardless of how much knowledge one brings to the table at a point in time because obviously most of the people, I think all of the people on this call have now become extremely knowledgeable. There..., there is..., there are points in time at which one is faced with the fact that one knows either nothing or very little; and the ability to be able to work out what you don't know and extract from wherever you can get it what you do need to know seems to me to be fundamental to good care in prostate cancer and I am using care in the sense not of medical care but of caringness and the whole issue of..., of..., of who is responsible for caring for the patient. I..., I..., I am just curious how people react to this.

Jan Manarite – Are you yet referencing the doctor, Mike? Is that what you are referring to?

Mike Scott – No. I mean some person, it..., it..., its how and who in the system, I mean obviously we will come across doctors who have extraordinary level of caringness, charm, and we probably will come across some, yet none.

Jan Manarite – Yes, clearly. So, generally, you know, if the conversation and the time between the doctor and the patient isn't allowed for, its just going to be..., its going to take an exceptional doctor to find a creative way to make that happen and it is the system that's swallowing up the patients and even the doctors and I would love to see that change. I don't know..., I don't know... I just keep coming back to the conversation which creates the relationship. We lost that a decade ago probably, maybe more.

Mike Scott – Is that a..., is that a shared perspective that everybody has?

Paul Carpeneter – No, actually, Mike, my wife taught me a very important lesson. When I had my recurrence, I went around to meet a number of oncologists and the oncologist who I currently use and have been using for the last eight years is not particularly warm type of person and I know when I went and interviewed him, he walked out of his office and I turned to my wife and said, "No way and whatever, is this doctor going to be my doctor," and she stopped and looked at me and she said, "Well, why not? He is brilliant, he does research, he know what's going on," and I said, "I can't imagine this doctor standing by my bedside at a hospital when I am dying and really care" and she said, "You know, you are probably right, but the reality of it is who are you hiring? Are you hiring a doctor to help treat you and keep you alive longer with the best quality of life or are you hiring someone to hold your hand. If you are looking for a hand holder, that's my job. I'll be there to do it." You have to decide what you want your doctor to be and that was an important lesson. Now, it turns out over the eight years, this gentleman and I have developed a relationship and a rapport, but he's not going to be there holding my hand when I am dying, but my wife tells me she is and I believe she is. So, as much as it would be nice to think that our doctor is really going to care and be involved and holding our hand, that's really not... When you come down to other than the emotional side, its probably not as important as I would like to think that it should be and that's reality for me and that's where I am with it.

Jan Manarite – Yeah. I am not referencing hand holding or emotional support because you can get that, you know, at other places, but the ability to talk through a treatment decision is what I am talking about. With objective information, you have to listen to the patient and listen to the doctor, you know, back and forth. That's what I am referring to.

Mike Scott – So, one of the things that I have probably told most of you and I have certainly told lots of



advocates over the years is that one of the hardest things to do is to put yourself back into the shoes of the person you were when you first got diagnosed, when you really probably knew nothing at all because.....every newly diagnosed patient is scared to death, whether they admit it or not.

Jan Manarite – Yes.

Mike Scott – And the first meeting that you have with that doctor in my mind or even the nurse, you know, while you are waiting to see the doctor is going to be colored by the degree of empathy that you feel is coming across. I mean I don't need the man to hold my hand. I do need to feel that he is paying attention to what I am saying and that he can at least say something if I was diagnosed with Gleason 9 disease and a PSA of 140 out of the blue, that he might say, that really sucks.

Jan Manarite- I am curious... Go ahead.

Mike Scott – Your point is taken well. When I..., when I look back on the days and I..., I have got pretty good memory of those days. When I look back on those days, you know, going through even the pre-diagnosis stage, as you know, through the biopsy, through the..., what the heck is a PSA, I mean that's where I was, that's really where I started from. I started to try to do all this research on my own and, you know, I didn't feel like as though I was going to depend on the Dr. Lee there to go ahead and hold my hand per se. I was hoping that they would just be level and giving me the information, give it to me straight so that I had the ability to go ahead and make decisions based upon that. I wasn't looking for him to make the decision. I was looking to make the decision. So, when I first got involved in this, it was just very basic. What is a PSA? I look it up, then I go ask. Then, I think what is a biopsy. I look it up, then I go ask and for each of those steps, I was looking for the answers to be the best form of caring support that I could receive.

Jan Manarite – I wanted to know if with other cancers, there's so much... With other cancers, are you told, #1, you have cancer and then #2, you need to make your own treatment decision, is how unique is that to prostate cancer because that's a big, big deal.

Joel Nowak – Maybe I can add to that, Jan, having five...

Jan Manarite – Yeah.

Joel Nowak –primary cancers and the answer..., the answer is, you get no more information than when you get when you have, when told you have prostate cancer and it really becomes the responsibility of the patient to figure it out. My most recent cancer was appendiceal cancer which is a rare cancer and there's not much known about it and not many people have treated it. It involved getting six different consults across the country and each person, you know, giving me six recommendations as to what..., what to do. It ranged from what I would equate to active surveillance, not doing anything, and just seeing it moved to doing this massive surgery that was an 18-hour surgery in chemotherapy and then I had four other opinions that ranged between those and ultimately it became my responsibility to make a decision as to where I would go after having spoken to them and I actually did find two or three people who also had had the cancer and I was able to have a conversation with them and they did different things and that's, you know, what the process was with all my other cancers, I can tell you, I got absolutely no additional information than most of us get when we are told we have prostate cancer. Its the same as...

Jan Manarite – So, it was quite similar?

Joel Nowak – Very similar.

Jan Manarite – Okay. Thanks, that helps.

Mike Scott – Those..., those are exceptions to that..., that general rule, but I..., I think one of the problems today is that we know so much more than we used to know and so, it used to be relatively easy for a



physician to say to you, “You have x and we should do y.” Its a lot harder for them today, not to mention the fact that they have got somebody else waiting in the next room down the corridor who they have to go and see within the next 10 minutes.

Absolutely true. I think if we went back 10 years ago, you think 10 years ago what the options were back then and you look at what the options are today. You know, it was a lot easier I think to make a decision back then because it was only..., the standard of care at the time was the gold treatment which was surgery and I didn't really look too much elsewhere. I mean I discussed cryo, I discussed radiation, but today the patient is going to be mired in a lot of different decision making process and that is, do I treat the cancer. That was not even a question back then. Do I treat the cancer and what do I do if I don't treat it. How do I go about not treating it and there's just a whole lot of different ideas and thoughts to go on through. So, today if you are making a decision on prostate cancer, you are facing a myriad more decisions than perhaps we did when we were dealing with this 10 years ago.

Mike Scott – Would you agree with me that I mean the people on the school generally are probably a great deal more capable of taking on some of these decision making requirements than perhaps the average guy in the street who, you know, has got little to no signs of an education and maybe not even the financial resources that some of us have.

Paul Carpenter – Yeah. Of course. The frustration for me was support groups for men that just seemed to walk to put their faith in something, anyone, anything and that's frustrating to me. You've got to make your own decisions. So many people put their faith in whatever happened to be in the magazine they were reading. Its very frustrating to me. So, yes, I think we are an unusual bunch here.

Richard Davis – Mike, but I want to explain this...

Priya Menon – Mike, we have Allen Needle join us...

Richard Davis – Okay. Thank you.

Priya Menon- Allen is a prostate cancer survivor and member of two prostate cancer support groups as well as online groups and often acts as a patient advocate in the Los Angeles area. So, welcome, Allen. Please join the panel.

Mike Scott – So, Allen, I will ask you the same question as I have already asked everybody else, which is, what was the thing that was of greatest value for you in your prostate cancer journey and what was the thing that you felt I really..., this was really important for me and how did you come by that value? (Pause) Hello!

Priya Menon – Mike, I think we just lost Allen again.

Mike Scott – Okay. Then, we'll..., we'll..., we'll go back to where we were. Ric, you... Ric, you had a comment you were about to make.

Richard Davis – Yeah. I want to bring... I want to bring this back to the value proposition, Mike, and I also want to expand the problem, talking about people that are newly diagnosed to people who may be well on their way in the journey because the..., the questions we are talking about really affect those people too. I mean, when you have got recurrent cancer, all of a sudden you are having to meet new doctors that you never met before, whether they are radiation oncologists or..., or they are medical oncologists. Again, you find yourself in a new situation. So, this is not a unique discussion for people that are newly diagnosed and..., and I feel that as patient advocates, one of the things that we all do is we try to teach and to in view those that we help with the ability to..., to..., to manage their doctors. A lot of this is about walking into an appointment and not viewing the doctor as someone on a pedestal but being willing to ask the questions that have to be asked and insisting on the answers that you need and one of the things that we can do to help people get the right information is to teach them how to..., how to handle their sessions with their relevant doctors.



Mike Scott – So, Joel used a very interesting term when he was talking just a few minutes ago. He..., he used the term “interviewed the doctor.” This is something that I always do personally. You know, when I go to see a new doctor, I will grin at them and say I do not care what you charge my insurance company for today, I am here to make sure that you and I can actually deal with each other because I am probably the nearest thing you will see to a complete nightmare as a patient. I know way too much. (Laughter)

Joel Nowark – You are right, Mike. I absolutely agree with you about interviewing the doctor, not about you as a patient.

Jan Manarite – Yeah, unfortunately we are not talking about how to interview a doctor, how to go ahead and pose the right questions, that clearly is some great..., great experience from a rather unlucky guy, I am sorry, Joel, but the fact of the matter is that I caught that term too when he said it and...

Paul Carpenter – Yeah...it is absolutely, I think, what would be in a grand way to..., to continue to do as Ric and I do in the support groups, as go on out there and letting the patients know that this is their cancer, you are the one who is going to be your #1 advocate. You are going to have to ask the tough questions, and you are going to have to know what those questions are and if you don't know what they are, then you need to continue to work and educate yourself because at the end of the day an educated decision is always going to be better than an emotional decision. I think its vital to make your needs and demands known.

Joel Nowark – I have had a funny spot on my leg that I knew was bad and I went to different doctors and nobody would do a biopsy and I forced a biopsy by telling the doctor that I wasn't going to leave the examining room until either they did the biopsy or they called the New York City police and they took me out in handcuffs and I will be wearing my paper gown with my butt hanging out the back...and I thought that would be a problem, so they did biopsy. You listen..., you learn..., you learn to listen to your body obviously and that's important and, of course, they did the biopsy and I had melanoma. So, I think on another occasion I have actually put myself physically between the doctor and the door when they were trying to leave and I still had question that needed to be answered as the answer that they gave me wasn't adequate. You need to control and, you know, what the scent of you is and every time I see a doctor, its an interview. I am looking..., I am looking to gain as much information as I can.

Mike Scott – Yeah, and I..., I think there are different ways to do this and I mean, you know, I am in the lucky position that I can usually find a new piece of information to take with me to the doctor, that is not about me but its about his practice and how, you know, these are his specialty. So, I have become an..., I have become an information resource to them and that's why they quite like seeing me. That's until I start asking the harder questions. I have been known to send a study to..., to a doctor a week before I say we are going to talk about this when I come in. So...

Paul Carpenter – Can you have that regularly? That's what I always do so that he is prepared and isn't blindsided by the questions I am going to ask. There's another very important point, that different patients will make through these doctor's appointments, make a list of questions and give that list of questions to the doctor. Then the doctor is almost required in order to protect themselves to go through every one of those questions and to answer them. So, I recommend everybody to have their questions prepared, read them out and then hand those questions to their doctor.

Jan Manarite – Also, a great idea.

Mike Scott – So, let me ask the same question in a very different way. As we all know, our friends in the medical profession and all of the people who work with them are obsessed with measuring things. They..., they want to measure the size of your penis. They want to measure how fast you regain continence. They want to measure..., you know, you name it. If we were to want to measure the quality of care that patients receive from a value perspective, what should we be measuring?

Paul Carpenter – We being the doctors, the medical profession?



Mike Scott – Well, I mean let's..., let's..., let's imagine that we have a tame social..., social scientist with a massive interest in the..., in the quality of care delivered in America and we said to her, "Professor so and so, please come up with a..., with a..., with a way in which you can study the value of the care provided to prostate cancer patients.

Jan Manarite – How did you feel about..., how did you feel about your conversation with your doctor? How did your doctor appointment go because that leads to everything.

Mike Scott – I was going to go in the same direction as Jan there, but absolutely worth the exit interview. You know, understanding how that session went is how you are going to measure the care and you are going to have to look at it on an individual case from each doctor and I know some institutions will go on out there and send you a survey or questions, but are they asking the right questions, I don't know. I don't..., I..., I can say that when I received one, I didn't think they were the right questions. How is the quality of life and quality of care going, that's going to require an in-depth analysis of how that session went.

Paul Carpenter – Right. I..., I answered.... I am sorry. Go ahead.

Mike Scott – No, no. The..., the reason I am asking this is I have been asked to speak at the ASTRO meeting in September this year and this is, to my horror and this is the presidential symposium, so I am going to be on the stage in front of 8,000 plus radiation oncologists to talk about the patient perspective on prostate cancer care and I told the President when he asked me if I would do this that the subject of my talk was going to be along the lines of, I am not sure that anything you measure today is about value from a patient perspective.

Jan Manarite – Right.

Mike Scott – And he laughed and he said, "I think that would be a very interesting subject."

Paul Carpenter – Good.

Mike Scott – So, at least I think I will have one support (laughter).... in the room and obviously, I also don't want to come over as a complete, you know, prick and..., and so..., I am..., I am really interested in what you think we could and should be measured.

Jan Manarite – The conversation, the relationship with the doctor..., I..., I am being redundant I know it, but that's how I keep coming back to. I can't get away from it.

Mike Scott – And, Jan....How..., how well educated is the patient when you walk out of the room? Did you educate them? Are you sure they were educated? Did you follow up to see that they were educated? Is it much different than taking care of a good client? When you've got an individual with which you are going to be having him trust you for his care, you need to know that you are getting to him and you are actually getting the message across to him. I think that that's missing many times. I hear many times patients coming out of a..., out of a diagnosis and not knowing what a Gleason is or not knowing what a PSA is. Both of the times...

Jan Manarite – I'd like to comment... Yeah, go ahead.

Mike Scott – Go ahead.

Jan Manarite – I'd like to comment on the education because here is where I think the kerb gets before the horses, something gets behind something. Men can't make and caregivers can't make a decision about a prostate cancer treatment unless they know what kind of prostate cancer they have and every prostate cancer is different. The kind of prostate cancer you have is going to be told to you by your medical records. So, until you have a layman's basic understanding of your personal medical records and until you have



them, you are not ready to a research, google, whatever, be to make a decision. So, that's where the education really needs to start. That's the starting block, like you are a runner and that's your starting block.

Paul Carpenter – That's my point and here's the doctor telling them that you need to go find your care, here's what we have got for your information. I was lucky enough to have that kind of a doctor and I will never forget it because I look back at all the people that come into my support group or come on into the online support groups and it seems to be contrary to what their experience was and I think that that was kind of a key to this whole thing of moving on ahead is your patients. You got to make decisions, you know you do, but you will need to know where to start with so many things going through your mind. Its got to start somewhere and it's going to have to start in that doctor's office.

Jan Manarite – But give me one example of newly diagnosed, almost never, I think never, running helpline for over a decade, so I found a newly diagnosed patient who got a copy of, who knew what their prostate size was. The prostate size is prior to the treatment decision, its part of understanding your PSA, its part of your radiation decision and that's on the ultrasound record from the biopsy from the urologist. They never give it to the patient. I don't know why, but its missing. They need to know that before they proceed. That's one example and its not understanding the Gleason score, its understanding your Gleason score. Here's your report. Let me circle this for you. This is what this means. So, that for me is the education starting point. Yeah.

Joel Nowak – I think we're saying the same thing. You know, I think I am not disagreeing with anything that's being said. Its..., its really important, but I also, especially through your presentation at ASTRO, I..., I think that we should not lose sight of the outcomes and I think that that..., that does, you know, its nice to have the education, its vital, its important, so I don't want to undermine and..., and..., and say its not important, but also outcomes are important and I think that..., that has lot to do with value also. If you understand what's going on and you die in three weeks when you can live to 33 years, its not a value there. So, outcomes also have to be factored in at..., at the proper place.

Mike Scott – Right.

Jan Manarite – But clearly, the outcomes come from the treatment that you chose and you are not ready to choose that treatment until you understand what kind of prostate cancer you have.

Joel Nowak – You get my point. I understand its a process, but I don't want to lose sight that eventually outcomes are not important. So...

Jan Manarite – Yeah. Right.

Mike Scott – No, no, no. I mean I... Let's be..., let's be fair. I mean, you know, we..., we all understand the importance of well-conducted clinical trials, you know, that..., that actually do produce usable information. Nobody is..., nobody is squabbling over that, but..., but the discussions that people have been having about value are..., seemed to me to be a very different thing altogether and..., and that was the thing that I sort of, you know, when..., when I was asked to do this, my ears really perked up because I felt I..., it allowed me to bring something very different to the table potentially. So, the..., the..., the other thing that has crossed my mind multiple times over the years is that most patients when newly diagnosed or even probably when suddenly told that they have a recurrence are probably not ready to have the conversation about what to do about it and its almost as though good practice would be to say to the patient when you tell him he has been diagnosed, here are the three things that you really need to know today, Jan's point, this is your Gleason score, this is the size of your prostate, you have 9 out of 12 biopsy cores positive, whatever, and here are the names of four patients who are really well informed who you can go and talk to. I am going to ask you to come back in two weeks and then we will have the conversation about what to do about it. You see what I am saying?

Paul Carpenter – Absolutely.



Mike Scott Now, there..., there are obviously exceptional patients who you have got to do something about. I mean if the patient has got a PSA of 120 and you have already seen that he has got a blood red bone scan, you know, you can't wait two weeks, but for..., for a lot of patients that..., that giving of time to let everything sink in seems to me to be very important.

Paul Carpenter – Absolutely for most patients that's..., that's quite..., they need the time and the space to recover from the initial shock and also to know I have time. So often things are dramatized and there's not any time for consult, you have to make a decision now..., now. Almost no one with prostate cancer has to make a decision within a few days.

Jan Manarite – I think that's a great...

Paul Carpenter – They will need that reassurance. Go ahead.

Jan Manarite – Sorry. Speaks to Tony and Ric's point of being told and maybe Paul made this point too, being told that, you know, you do have prostate cancer, but you are not going to..., you are not likely to die of this right away, you have time. Even if you have a high Gleason, even if you have risk-free disease, you have time and to take away..., so that they can do the two weeks, you know, go home for two weeks and come back because cancer means they think they are going to lose their life soon, you know, so they just don't understand that.

Mike Scott – We..., we had a conversation a little while ago on one of these courses with Anne Katz who spent a lot of her life actually having this conversation with the patient after they have been told that they have cancer and what is being suggested they do about it. Anne is entirely focused on making sure that patients do understand, you know, this is a complicated issue. It comes with all sorts of up sides and down sides that need to be thought about, including the whole sex one.

I don't know anywhere in America where that happens. I mean I was in Canada.

Jan Manarite- I don't even...

Mike Scott – Does anybody know where in America that happens?

Jan Manarite- Nope. In fact, I was shaken, can't think of anywhere..., and again that's..., I am doing this with my husband for 13 years and running a helpline for almost 15 now. So, can't think of anything.

Mike Scott – When you talk about value, that..., that..., that seems to me as an enormously valuable conversation for the patient to have. Admittedly, some of them will just blow past it entirely.

Jan Manarite- And there again, you are talking about the conversation.

Mike Scott – Right.

Jan Manarite- Yeah.

Paul Carpenter – And that was my first response when you asked the question, was that this value doesn't mostly come from doctors.

Mike Scott – Right.

Paul Carpenter – It comes from what the patient learns on their own, talking with peers, researching on their own. The doctor can point them and urge them to do that, most don't, they should, but most of the value comes from this non-medical contact.



Mike Scott – Okay. So, we have now just identified something highly measurable. Did the doctor, does the doctor actually advise the patient of places where they can really go and get..., and sit down with somebody and get some neutral advice?

Jan Manarite- In my experience, most urologists know. I know I am stereotyping, but in my experience most urologists know.

Paul Carpenter – I agree with Jan. I..., I..., I have seen it changing, though, Mike. I think that, you know, what we saw when we were doing our diagnosis initially, I actually get guys that came on in and looked forward up to support groups and that's enlightening to me and I..., I think that its so in trend that we might be heading in the right direction there, that for the most part its along the lines of what both Paul and Dan are saying. Many times over they say that its easy to get bad information online. Its easy to get bad advice. I would..., I would recommend that you try to research this another way kind of thing and the reality of it is that from my personal experience, my peers and they are my #1 peers and I..., I think its been across the board on that that for all of us in here that we all found somebody willing to talk to us about it, #1, we got the feeling that we weren't alone and that was very, very important to move forward from there.

Mike Scott – What do people think about....

Jan Manarite- I would like to suggest a label.... Go ahead, but I want to come back to this.

Mike Scott – What do people think about... What do people think about decision aids?

Paul Carpenter – Can you clarify exactly what you are saying?

Jan Manarite- They are helpful, but you still need the conversation. You still need the conversation. You can do written material, written material. You still don't know what you have, you are all over the place. You've got to have that conversation to digest it and to process. You got to talk and listen, talk and listen.

Paul Carpenter – And, Mike, are you talking about like flow charts where a man goes ___?

Mike Scott – Oh, no! There are all sorts of decision aids available now, from.. from ones that are available on the internet to DVDs, things, systems in people's offices where..., where you can walk through your options, you know, based on your Gleason score and your risk levels and things like that. My own personal...

Paul Carpenter – For me, I think of that as a flow chart rather than...

Mike Scott – Okay.

Paul Carpenter – ...open give and take, its us to you. There is a path you are expected to take based on the information you come up with and supply. I...

Jan Manarite- Its helpful.

Paul Carpenter – I don't think that's personal enough, but yes, its helpful.

Jan Manarite – Yeah.

Yeah, I think as Jan says, its helpful, but it doesn't factor in something very important and it doesn't factor in an individual's risk tolerance which I think is really important, I mean.....you talk about the man who had active surveillance or not..., just because one man whose numbers are the same as another's, that one may well make the right decision for themselves to go ahead with the treatment as opposed to the other, may make the right decision to do active surveillance. It depends how tolerant you are of risk, who you are, your personality. I think that those are important to be factored in, and decision aids can't really respond to



those.

Mike Scott – No, I..., I think...

Paul Carpenter – ...and I think more importantly, anyone who is trying to go through that doesn't yet know what they don't know and I learned that 10 years ago. (Laughter) No, I am serious. Had I...

Mike Scott – No, no, no. I know you are and I agree.

Paul Carpenter – ...known about 10 years ago and one of my endpoints was... Okay, you have no such_____ for the rest of your life, I would say, okay, avoid that at all costs. Well, I learned a lot in the past 10 years and that's not such a bad end point after all, but I couldn't possibly have known that when I was diagnosed. I would have had to learn that from other men who had traveled along the path I was fated to travel along.

Jan Manarite – I think the best learning is both verbal and visual. If you think about it, that's how we went through 13 years of public school. That's why you go to class. You listen to the teacher and then she..., you know, you have a book in front of you and she puts something on the board. So, the verbal in this process is..., are those conversations. They are just that valuable and you can't make a..., a system can't create conversations, it can support them, but it can't create them. So, the visuals are important and so is the simple conversation.

Mike Scott – So, we..., we've..., we've I think covered a lot of ground here and we got about 17 or 18 minutes left and so I think we should throw this open for any questions from the outside audience to see whether we get any or..., any further interesting comments from some of the other people on the phone. So, Priya, you are..., you are..., you are back on.

Priya Menon – Thank you, Mike. Audience, if you have a question for our panel, you may please press 1 on your keypad and we can bring you on air to ask your questions. We have received a long list of questions, panelists, so I will quickly go through them and..., and before we take on callers or we can always take them on as they come up. So, I am just going through this list. I think we have..., you have been talking about some of the issues that the questions have brought up. Yeah. There's one... One of our listeners is asking, I have had prostatectomy. A year afterwards, radiation treatment, then approximately year thereafter detectable PSA. I have been given a hormone shot. Now, eight months after hormone shot, I would rather be proactive than reactive. Any immunotherapy or genetic drugs to maintain my remission or eradicate the spread or metastasis?

Jan Manarite – Loaded question. Can I take it?

Mike Scott – Sure.

Priya Menon – Yes, please.

Jan Manarite – I think where he ended was..., yeah..., was immunotherapy and I..., I think understand the thought behind that because everybody is interested in that right now. In prostate cancer right now, if you are on hormone therapy and you are looking for immunotherapy, the one that is FDA approved and is available is Provenge Sipuleucel-T. So, to be eligible for his insurance to pay for Provenge, he needs to be, #1 on hormone therapy, he is. #2, rising PSA. #3, metastatic. So, that might be the crossroads that he is at. So, again, this is..., get back to understanding your medical records and making sure he has read his bone scan reports and CT scan to see if there is any record there that it was metastatic because that can create options for him if he is.

Paul Carpenter – I suggest this particular...

Mike Scott – Or if there is any other test that he could take which would show that he was metastatic



because...

Jan Manarite – Yes.

Mike Scott – ...he might be able to get some other form of scan today when the bone scan showed that.

Jan Manarite – Right. That's right.

Paul Carpenter – This particular gentleman said it has metastasized to six spots on his bones, but he also indicates he is currently on ADT. Its working, but he wants to be proactive and that was why that question attracted my address because I am in exactly the same spot.

Jan Manarite – Okay.

Paul Carpenter – My disease is metastatic, but its currently controlled by ADT, but I want to get ahead of it and not be blindsided when the ADT stops working.

Jan Manarite – I might be saying that... I might say that the minute your PSA goes up, talk to your doctor about Provenge.

Paul Carpenter – Oh, no. I..., I have talked to him years long before it goes up and I have...

Jan Manarite – Who said you are eligible.

Paul Carpenter – Right.

Jan Manarite – Yes.

Paul Carpenter – ...but then see what do I do if that doesn't work? What do I do after that? And that's why I think its important to _____.

Joel Nowak – Let me come... Let me come back to this question because until somebody does a trial at the stage you are talking about, stage this gentleman, we really don't know there will be any benefit from doing Provenge at this time from, you know, and one thing that I have learned over the years, because something seems to make sense when you go off and you do a trial and you look for the evidence, sometimes its really surprising. From a rational standpoint, one would think that the stage you are at, the stage that this..., this questioner is at, that it would make sense to do now, but we don't know that. There is no evidence.

Jan Manarite – I am confused by your comment, Joe. I am sorry. I am confused.

Joel Nowak – The clinical trial, the only bit of evidence that we have that a person gets the benefit from Provenge is with they have to be...., they have to be, as you mentioned, metastatic, they have...

Jan Manarite – Right.

Joel Nowak –to be castrate resistant with the rise..., have a rising PSA, I think this gentleman is not in that situation. He is not... We don't know that he is —[00:47:25] — unless I missed..., missed the question...

Jan Manarite – Got it. Just giving him the information that when he would be eligible for immunotherapy.

Joel Nowak – Right. There is no evidence.

Jan Manarite – Yes.



Joel Nowak – And now his issue of..., that was clearly for insurance, which you are 100% correct, Jan, but we also don't have any evidence that will do any good.

I think to go back to what you were saying Joel...

Jan Manarite – I am trying to make _____[00:47:47]_____ where he is.

Mike Scott – Folks, I don't..., I don't want to... We can't afford to get into a long conversation about each particular question. We just can't. Because there are other people with questions, so I think...

Paul Carpenter – Okay.

Mike Scott –we need to move to the next question.

Priya Menon – Yeah. The next question is, irrespective the level of aggression indicated by Gleason score, is the disease likely to metastasize to some extent by the time the original tumor has been identified for imaging or biopsy?

Mike Scott – No. It is going to be highly dependent on the Gleason score. So, you can't say, you know, irrespective of Gleason score. We know today that the true Gleason 6 has a minimal chance of metastasis, whereas a clear Gleason 8 to 10 has a very high probability of metastasis. So, it is important, very important to be taking Gleason scores into account as well as PSA levels and other testing..., test data.

Joel Nowak – Mike, can I also...

Priya Menon- Thank you, Mike.

Joel Nowak –add to that that its important that..., that a man get a second opinion on their pathology, both..., both on the biopsy and also if they have had surgery on the surgical pathology. Most people don't realize that pathology reports are..., are very subjective. They are not objective. You can have two pathologists look at the same slide and come up with two different readings. So, its really important to have a second set of eyes and I..., I always recommend from a different institution to take a look to confirm Gleason score.

Mike Scott – Yeah, I..., I would agree with that because it does depend on who did the first one.

When you say its confirmed on the first one, the point is the second _____

I am not sure..., I am not sure I would agree with that. I am..., I am not sure I would agree with that because I think this raises a very important question, that you have to decide if you are going to go through a procedure or another test or scan or whatever it is that the results of that test will change your treatment decision. So, if you have a treatment decision in mind and the Gleason score is going to impact that treatment decision, for example, you are going to go on to hormone therapy with radiation and if you have a Gleason 3+4, the amount of time you might spend on the..., on hormone therapy is going to be a lot less than if it was a 4+3. Then, yes, by all means, go and get a second opinion. If you get a second opinion for the sake of getting a second opinion where it isn't going to change your treatment decision is not necessary. So, I always suggest to people, ask yourself before you do something, will this change the treatment that I am going to get or I am going to decide to get.

Jan Manarite- It might just be patient's choice. You know, it might just change their insomnia. You know, its up to the patient.

Paul Carpenter – And I thought that we were talking specifically about getting a second opinion on the slides, send it to a second pathologist.



Jan Manarite- Correct.

Paul Carpenter – Its cheap and if you...

That's exactly what I am talking about and..., and... my answer is, if you..., if you are told you have a Gleason 3+3 and a second opinion comes back and its Gleason 4+4, you know, its _____ whether you thought it was going to change your treatment, you know, decision, its got to change your treatment decision. So, its important to have the best information.

Mike Scott – Yeah. I..., I..., I mean I think..., I don't think any of us would..., would actually be insisting that if you got a pathology report that said you had Gleason 5+5 that you necessarily needed a second opinion. The chances are..

I would agree with..., I would agree with that, Mike. Yes. Yeah, that I agree with.

Mike Scott – So, what..., what's our next question, please?

Priya Menon- Yes. Jeff..., Jeff writes in saying he is an informed patient, has been on active surveillance for five years. His question is, how can a prostate cancer patient be sure that they are getting the best choice of treatment of care as a standard of care for prostate cancer is not equal across the US and who advocates the treatment changes and patient choice at the clinic or doctor's office and he says, "I am thankful for active surveillance, but if I want to preserve my quality of life and treatment is needed later and not locally available or supported by doctors and insurance carriers or equivocated by the FDA?"

Mike Scott – So, there..., there are no guaranteed ways to be able to be 100% sure that you are getting the very best standard of care because we don't know what the very best standard of care is a lot of the time. There is a big onus on the patient to do the sort of thing that Joel has been describing, which is to go and see several doctors and get different opinions, but in the end the patient has to make the decision about what he wants to do and that decision is going to vary depending, as you have also pointed out, on the risk tolerance of that patient.

Priya Menon- Thank you, Mike. We have received a couple of questions connecting eradication of disease to diet and exercise or maybe better management, so maybe you could comment on that.

Mike Scott – Ric, you want to talk about that? Its right up your sleeve.

Richard Davis – (Laughter) I mean, what..., what..., what's so pleasing to me is that in the years since I was diagnosed back in 2007, the whole attitude to diet to some extent but to exercise to a huge extent has changed immensely and there's no question of a doubt now that we..., we recognize with many cancers and certainly with prostate cancer that exercise does make an enormous amount of..., of difference from active surveillance, whether couple of big studies are being conducted right now, right way through to advanced disease, where Priya will recall we had..., and you will recall we had a conversation one time with..., with Donald Abrams, the medical oncologist, who told us about the..., the doc he knows who gives chemotherapy while his patients run a treadmill. So, yes, the exercise is huge. I would suggest to people if they..., if they want to read more about this, go to metafit.org and on the research page there are a lot of articles on the benefits of exercise. As far as nutrition is concerned, there are so many resources, but yes, nutrition is very important and we read, get hold of documentation and read what the right type of recommended diet is.

Jan Manarite- Can I make a quick comment for take home? Most experts tend to agree that a heart-healthy diet and lifestyle is the prostate cancer healthy diet and lifestyle.

Paul Carpenter – Yes.

Jan Manarite- That's a good ruler to use. Its so simple and it works. So, this particular caller, for example,



asked about cholesterol. So, getting his cholesterol under control would be probably good for both his prostate cancer and his cardiovascular health most likely.

Priya Menon- Thank you, Jan.

Mike Scott – So, Priya, do we have another question?

Priya Menon- Yes, there is another question. Ken writes in, rather quite a few questions touching upon various treatments, but I would just pertain..., all the ones pertaining to this discussion. He asks, any suggestions about asking your doctor questions, you may not write down or remember at visiting time. Talking with people online can cause me to think of questions I would like to pass on to my doctor. I also don't want to wait two weeks or two months to ask them and I don't want to be a pest but do want to stay informed and current. My face-to-face support group seems to be very set in its ways and not very likely to participate in a living exchange following any kind of presentation. I have no experience in putting groups together. Any feedback or suggestions? Also, along the side, do you find men involved in active support groups, we are better off than the sit and listen type?

Mike Scott – Tony, would you like to take that?

Jan Manarite- Everyone, we've passed, its okay. Sorry. (Laughter) Tony!

Tony Crispino- Yes.

Mike Scott – You have a nice, active support group. Will you like to take that one?

Tony Crispino- For..., for my particular side of it, I inherited support groups, more so than I started one up from start..., from scratch. I think that's what this individual is looking to do, is maybe start a support group. I will say that the support groups that I have had, the feedback that I get from everybody that comes on in through that door has always appreciated the fact that we have got the group going, that we are willing to take the time to volunteer to be a part of the survivor community and..., and I usually find them also willing to participate within the group as well, largely I think that I..., I have a standard core of people that are members of my groups, those are people that are strong to help support groups kick, you know, you have got your core survivors and then you have got people that are more of the fly-by-nights. They come on in and they want to get information. They get their information. You don't hear from them until something changes in their treatment choices later on down the road, but for me working with the community of physicians, working with the community of survivors, its..., its a natural thing for me to do and if you have got the heart to do it, god bless you do it, its..., its very heavily needed. I think that we need more groups out there, and we need more volunteers out there to make these groups stronger.

Mike Scott – So, on that subject, because I have got one more pet thing that I want to get off my chest here...

Paul Carpenter – Yes.

Mike Scott – ...there is in my mind a vast dearth of support for wives and partners and whatever else, who often are not that welcome in traditional support groups and I am wondering if anybody knows, if anybody is planning to do anything more about that.

Most of the time I don't differentiate. In fact, I get asked that question. Usually, I get caught by a wife or something like that and they want to know, they want to come on into the group if its okay for other women to attend and the door should always be open as far as my opinion is, but I do understand that some people don't feel comfortable about talking about, you know, an erection or sex or anything like that in front of a group of people. I mean, its just human nature and I fully understand that. The groups that I know that are out there, I don't know how strong they are because they don't allow me in there, to go in there and take a look at it. Maybe, Jan, you can throw something on that as far as the women's groups.



Jan Manarite- You know, other women are different, like for me, for example, I was the researcher and the treatment chooser, so, you know, as a different type of caregiver. I have had other women who didn't get involved with treatment decision but made sure that the home was comfortable and that the husband has his favorite meals and saw his friends, so everybody is different. So, I am really comfortable in a man's support group, but when it gets to the sexual issues and things like that, I understand the need to separate. So...

You know, I have..., I have run groups on both the model with..., with and without women and what I have done when I have had women is, the model is included, a prior lecture, and then we break up the groups into support givers and..., and patients and..., and that works well because it..., it answers both needs and we also allow the men to get together themselves, but the model that we use most often is just men, diagnosed men and we don't use a lecture. We simply have a conversation, I mean that's, you know, we talk men to men about the issues and problems that we are facing. So, there are..., there are various models and I think they have all had their place and its nice that we can somehow find a way to offer support to caregivers as well as patients, but I think we have to be sensitive that there are..., there is a need to be separate in certain circumstances.

Paul Carpenter – Mike, so...

Mike Scott – I think we have...

Paul Carpenter – Go ahead.

Mike Scott – Sorry, Paul.

Paul Carpenter – That's all right.

Mike Scott – I think we have run out of time and so, Priya, perhaps you would like to close this down. I appreciate everybody's input this evening. I think its been very useful and I hope its been useful for the rest of the audience as well.

Paul Carpenter – Thank you, Mike.

Priya Menon- Thank you, Mike. That was a great discussion panel. Jan, Tony, Paul, Joel, and Richard, thank you very much for your participation; and the transcript for today's talk will be available on CureTalks' website along with its replay. Please visit curetalks.com for details of our upcoming talks. Thank you, everyone.

Paul Carpenter – Thank you, Priya.

Mike Scott – Goodnight, everyone. Thank you very much indeed.

Paul Carpenter – Goodnight.

Jan Manarite- Thank you.