

Supplemental Table 2 – Areas of variation in perspectives between men with low grade prostate cancer and physicians

Topic	Differences in perspectives	Illustrative quotes	
		Physicians	Men diagnosed with prostate cancer
Quality of life	Men emphasized maintaining quality of life as a key factor in balancing their decision-making about active surveillance to a greater extent than did clinicians	<ul style="list-style-type: none"> • <i>The primary treatment of prostate cancer to improve quality of life for a certain period of time.</i> • <i>So, there are times when active surveillance would have been appropriate but the individual man wants treatment; we need to support their decision.</i> • <i>If you have a 90 percent chance of being disease free, well symptom free, at least from their prostate cancer, then the risk of intervention for any patient doesn't make sense.</i> 	<ul style="list-style-type: none"> • <i>I told him I was not interested in anything of that [treatment] ...it's about quality of life. I don't have symptoms now, so I am going to wait.</i> • <i>You kind of have to figure out what you need for surviving and what you need for quality of life. It just seemed to me that active surveillance gave me options. I did not have a lot of disease and, who knows, if I wait for treatment until I really need it, there could be other things available.</i> • <i>If I live for another 35 years, I would like it to be a good quality I don't want to deal with cancer ...me? I would just do it [treatment]. So I said, 'Don't wait, let's just do it.</i> • <i>My father had treatment for prostate cancer and his life was never the same again. I didn't want that for me. I am too young.</i> • <i>You have to weigh it all, what's involved, what the consequences are. Some treatments have pretty drastic after effects that you would have to live with.</i>
Patients and doctors varied in the clarity of descriptions regarding criteria	<p><i>The criteria for active surveillance</i></p> <p><i>The interpretation of test results</i></p> <p><i>What constitutes a standard approach to active surveillance</i></p> <p><i>The amount of collaboration among health care providers</i></p>	<ul style="list-style-type: none"> • <i>Surely everyone knows about active surveillance and what it is.</i> • <i>The problem is there's no standard protocol.</i> • <i>I agree, the acceptance or tolerance of the risk of patients is variable from one physician to another.</i> • <i>I tell them we adjust according to patient, according to pathology, according to age ...and we will see you in 3 months and we will do the PSA.</i> • <i>It is pretty well case by case; it's not standardized. Sometimes they come and ask for surveillance and our role in this case is to be sure this is right for the patient.</i> • <i>Even PSA, you know, multiple groups, Hopkins, UCSF, have shown it's a horrible marker for progression. So the only thing we have right now is, um, the biopsy.</i> • <i>Most of us probably are not using the same protocol, we adjust for age ...pathology ...I am more aggressive</i> 	<ul style="list-style-type: none"> • <i>Some men come [to the support group] and seem to have a pretty good handle on their circumstances ...they have done their own research, asked some questions ...and have a doctor that was forthcoming. There are some seem to be, well, clueless - a dismal ignorance of their circumstances.</i> • <i>My friend, who is a doctor, said to me, 'the gold standard is to take it out - so you should just deal with it and get it taken out.' So that's the prevailing wisdom around the thing.</i> • <i>There is a Gleason score that is almost 6, which I guess is viewed as relatively low. There is also a, is it a PIN? ...I should have remembered that. Or is it a PPP score? There's another one that means it's low.</i> • <i>I was surprised, reading more about it, realizing there was no particular treatment and there's not 100% agreement as to what is appropriate and what is not.</i> • <i>I was a little taken aback when I was told often times there isn't a consensus how to treat and that you couldn't just</i>

		<p><i>in doing the biopsy routine...it's unfortunate, but that's the way it is now.</i></p> <ul style="list-style-type: none"> • <i>It is a moving target, the concepts change as more is known, more publications, longer follow-up with multiple series.</i> • <i>I send most of my patients to my rad onc, my colleagues, for discussion as well.</i> • <i>We pretty much have the conversation at the same time as the urologist, because most of our urologists send them to us upfront.</i> 	<p><i>leave the decision to your care provider. You've got to make the decision yourself.</i></p> <ul style="list-style-type: none"> • <i>The PSA is not the most reliable accurate tool, which surprises me to no end.</i> • <i>I am 100% supportive of the test results.</i> • <i>And because there was no change, and I keep on having my PSA as my guiding light...which I now they don't have much faith with these days, but whatever, nobody has told me to panic yet and I am easy to panic.</i> • <i>I don't know if it's possible for the PSA not to go up but your prostate cancer to just spread. I'd like to know that.</i> • <i>There's a 3 plus 4, 4 plus 3, a primary sort of [number], whether it's 4 plus 3, I guess that's not as good as 3 plus 4.</i>
<p>Patients and health care providers varied in their description about information needed and provided</p>	<p><i>The clarity of information actually provided to patients</i></p> <p><i>How much information is needed by patients to make a decision about active surveillance</i></p> <p><i>The type of information</i></p> <p><i>The time it takes to make a decision about a course of action regarding active surveillance or treatment</i></p>	<ul style="list-style-type: none"> • <i>Often times, I find myself explaining things, in order for the patient to understand, in a very simple manner, which how the disease behaves and we monitor is not simple at all. So I think that's a big limitation.</i> • <i>The biggest challenge is translating the evidence. It comes down to being able to share the perspectives on risks and benefits.</i> • <i>Most of the patients want to understand many of the things, but some just don't. Some just don't have capacity and that's fine too. It's part of the understanding who you are talking to and you know, how much information do they actually want? Because information overload is very bad as well. So you have to give it in a, a presentable manner, with presentable quality that they will respond positive and to understand. So, it all depends.</i> • <i>You know, it is so variable. You have to individualize...active surveillance isn't their only option. They will have to figure it out.</i> • <i>I find that I discuss more what the different options of the intervention are and their side effects. And then I found it much easier to convince them of Active Surveillance.</i> • <i>It's about their sexual function and incontinence, these are the main problems the patients want to avoid when</i> 	<ul style="list-style-type: none"> • <i>They have to give you the options, but I am the one, I have to be the one, balancing the options and making a decision, listening to my body.</i> • <i>You have to help people prepare for what they are heading into.</i> • <i>Dissemination of information is very important on a direct basis...you should give as much information as you can</i> • <i>I read a lot and I talked to a lot of people and the information is not really clear.</i> • <i>You really need to go and find it out yourself...they don't really tell you a lot about what is going to happen...it is really like blind flying.</i> • <i>You need to explore all the options so when push comes to shove and you need to cross that bridge, at least you are better armed to make an informed decision.</i> • <i>I talked with the surgeon and really just had one option offered to me. I was not satisfied with that, I wanted to have all of my options explained. So I went to another doctor.</i> • <i>What the doctors say, there was slight variations, but not much. There's some consensus there. So I went to what I thought were reliable sources on the Internet...so I decided on that basis.</i> • <i>Going through all the different treatments an, you know, what the consequences are, both the benefits and what the consequences are, that helps a lot in making a decision.</i>

		<i>they weigh their treatment [options]. Those are the issues I discuss with them.</i>	<ul style="list-style-type: none">• <i>I needed time to make a decision...the best one for me. I needed to know the options for me and the possible impacts in my situation before I made it.</i>
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