

### NASPCC Annual Meeting

Developing Approaches to Help Prostate Cancer Patients Better Manager Their Emotional Journey

6 October 2012

Terry Kungel President & Chief Executive Officer Maine Coalition to Fight Prostate Cancer www.MCFPC.org

Helping people better manage their emotional journey is a really important topic. I am going to lay out some efforts we have done in Maine but I would like all of us to have a group discussion about this topic.

We definitely want to recognize and thank the Maine Cancer Foundation for supporting a portion of our work in this area with a \$10K grant.

This isn't a speech, it's a conversation, and I hope to leave enough time for everyone to participate.

Some of the most important ideas and insights are going to come from all of you.

I am going to start with the microphone but I hope we can go open mike and get everyone involved.



#### **Emotional Journey**

- Agenda
  - Conduct Grid Exercise
  - Explain Grid Template
  - Tell Stories
  - Provide Grid Perspectives And Insights
  - Present Major Findings
  - Discuss Issues
  - Encourage Group Discussion

Let me ask that all of you do a brief exercise with me. I will explain everything shortly but please work with me on this. Would you all please stand up. Please close your eyes.

NOW, imagine you are in the room where you normally do your support group meetings. Take a quick look around the room and see all the regulars who normally attend.

NOW notice that the room looks quite different. All the tables have been stacked on top of each other along the walls. All the chairs are near the tables in completely random order. In the center of the room on the floor are 4 ropes. They have been laid out like two railload tracks that intersect each other at 90 degrees. One set of two parallel ropes run North to South and another set of two parallel ropes run East to West. When we were all kids we played Tic Tac Toe. We are just looking at a Tic Tac Toe pattern on the floor that has 3 columns and 3 rows.

NOW I would like everyone to mentally imagine moving to the left side of your meeting room. I want to organize you into three groups.

High: If the clinical stage of your cancer was T2C, T3 or T4, If your Gleason score was 8, 9, or 10; If your PSA level was above 20ng; If your PSA velocity was above 1.0 in 12 months, then you are in the High group. Anyone who is in this category, please visualize yourself moving towards the front of the room on the left side of the ropes.

Medium: If the clinical stage of your cancer was T2A, T2B, If your Gleason score was 2+4, 4+2, 3+4, or 4+3; If your PSA level was between 11ng and 19ng; If your PSA velocity was between .5 and 1.0 in 12 months, then you are in the Middle group. Anyone who is in this category, please visualize yourself moving towards the middle of the room on the left side of the ropes.

Low: If the clinical stage of your cancer was T1A, T1B or T1C, If your Gleason score was 3+3; If your PSA level was below 10ng; If your PSA velocity was below .5 in 12 months, then you are in the Low group. Anyone who is in this category, please visualize yourself moving towards the back of the room on the left side of the ropes.

What we have just done is organize all of you by Disease Severity. The top row is high disease severity, the middle row is medium disease severity, and the bottom row is low disease severity. NOW I would like to organize you by Emotional Severity.

High: If you have met with a psychotherapist or taken depression medications, If you have virtually no energy, If you have been growing more and more isolated, If nothing seems to matter anymore, then let me suggest you have high emotional severity. Please visualize yourself moving inside the top left box if your disease severity was high, please move into the middle top box if your disease severity was medium, and please move into the right top box if your disease severity was low.

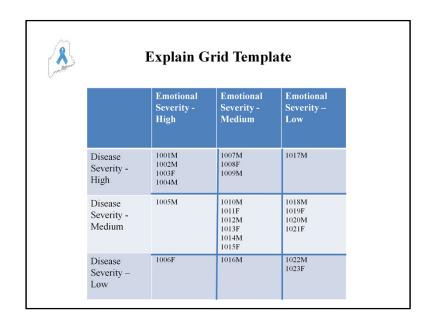
Medium: If you had moderate depression, If you had moderate anxiety, If it was rough but you got through it okay, then let me suggest you have medium emotional severity. Please visualize yourself moving inside the middle left box if your disease severity was high, please move into the middle center box if your disease severity was low.

Low: If your prostate cancer was more of a bump in the road rather than a fork in the road, If your cancer was more of a transition than a transformation, then let me suggest you have low emotional severity. Please visualize yourself moving inside the bottom left box if your disease severity was high, please move into the bottom center box if your disease severity was high, please move into the bottom right box if your disease severity was low.

You get to say whatever you think your emotional severity level is for whatever reason you want.

All of you should now be standing in one of the 9 boxes. Let me challenge each of you. Do you know your group well enough to know who is in the box with you?

Okay, please open your eyes, sit down, and write down your disease severity grade and your emotional severity grade.



Okay, here is what we just did. You can see the Tic Tac Toe grid here.

What you are looking at is the actual results of the Brunswick ME Prostate Cancer Support Group where we had 23 participate. The good news is we had a good spread and someone in every box. The numbers refer to specific individuals and whether they are male or female.

NOW the process I developed takes 90 minutes and we don't have that much time. So I am just going to talk you through what we would have done if I was a visiting speaker at your support group. There are four series of questions that are asked in a very specific sequence.



### **Explain Grid Template**

- Disease Severity
  - High: T2C, T3, T4: Gleason 8, 9, 10; PSA 20ng+; PSA Velocity 1+ In 12 Months.
  - Medium: T2A, T2b; Gleason
     2+4, 4+2, 3+4, 4+3; PSA 11 19ng; PSA Velocity .5 1.0 In
     12 Months.
  - Low: T1A, T1B, T1C;
     Gleason 3+3; PSA 10ng<;</li>
     PSA Velocity .5
     In 12
     Months.
  - No self reporting.

- Emotional Severity
  - High: Severe, debilitating depression; met with a psychotherapist/doctor; took depression meds; extensive anxiety.
  - Medium: moderate depression; moderate anxiety; it was rough but you got through it.
  - Low: It was a bump in the road, not a fork in the road; a transition, not a transformation.
  - All self reporting.

Here are the details. Please note I don't give you any discretion for reporting disease severity. I give you complete freedom on self reporting your emotional state. You will see why in a minute.



### **Explain Grid Template**

- Stage 1 Questions
  - Why do you think you are in this box and how do you feel about it?
  - What would you tell newly diagnosed patients about being in this box?
- Stage 2 Questions
  - How would you describe your resilience level during the first 24 months? High, Medium, Low
  - How did you think about achieving the best case rather than a worst case outcome?
  - How proactive were you in managing your situation?
     How much ownership of your situation did you take? High, Medium, Low

The first round of questions simply ask what you think about where you find yourself and how those insights might benefit what we do with newbies.

The second set of questions ask you to rate yourself against three measures, resiliency, hope and proactive engagement. We are only talking about you here.



### **Explain Grid Template**

- Stage 3 Questions
  - What can we do with newly diagnosed patients to improve resilience?
  - What can we do with newly diagnosed patients to help them achieve their best outcome rather than their worst outcome?
  - What can we do with newly diagnosed patients to help improve their proactive engagement and ownership of their situation?

- Stage 4 Questions
  - Explain your emotional journey
  - What did you learn about yourself?
  - How are you a different person?
  - Where are you now that you wouldn't be if you hadn't been diagnosed?

The third stage attempts to get you to use your own insights for formulating how we might help newbies improve their resilience, their hope and their self actualization.

The fourth stage is very personal and no one really has time to complete these questions, even if they are given 120 minutes.

These questions were presented to each group of people in each box. I gave them some time to write down their own answers and then I asked their group to discuss all of their answers. I asked different individuals in each group to share their group's findings with the entire audience for each stage of questions.

A	Tell Stories					
		Emotional Severity - High	Emotional Severity - Medium	Emotional Severity – Low		
	Disease Severity - High	1001M 1002M 1003F 1004M	1007M 1008F 1009M	1017M		
	Disease Severity - Medium	1005M	1010M 1011F 1012M 1013F 1014M 1015F	1018M 1019F 1020M 1021F		
	Disease Severity – Low	1006F	1016M	1022M 1023F		

So let's go to some of the stories we heard. We will be discussing people with Disease Severity Medium and Emotional Severity Medium. We will also talk about people who are facing a recurrence and where the prognosis is not good at all, Disease Severity High and Emotional Severity High.



#### **Tell Stories**

- Disease High, Emotion High
  - Recurrent prostate cancer that may have gone hormone independent.
  - Good news: Zytiga, Provenge, Jevtana, Xtandi, et. al.
  - Bad news: more choices and more uncertainty.
  - Not willing to admit it may be time for palliative care, not curative care.
  - "You can be healed without being cured."

- Disease Medium, Emotion Medium
  - "We changed our priorities. If it isn't about family, friends or fun, it's off the list."
  - "Stay in the present."
  - "You learn what's really important."
  - "Don't let cancer define who you are."
  - "Do what's most important on your bucket list and drop things that don't matter."
  - "Write the script you want to see played out."

The people in the top left box are in a really difficult situation. Some are having to come to terms with end of life. All of the people in this box at the Brunswick meeting were distressed for obvious reasons. The ALS community is instructive. This is a disease that claims 100% of the people diagnosed with it. They all have high disease severity but they have learned to say they are living with ALS, not dying from ALS.

The people in the middle box were a great group and they have all had been transformed by the disease. They have great insights and are clearly making new choices. Discuss specific bullet points.

A.	Tell Stories					
	Emotional Severity - High	Emotional Severity - Medium	Emotional Severity – Low			
Diseas Severi High	1000316	1007M 1008F 1009M	1017M			
Diseas Sever Mediu	ity -	1010M 1011F 1012M 1013F 1014M 1015F	1018M 1019F 1020M 1021F			
Diseas Severi Low		1016M	1022M 1023F			

Let me tell the stories of two additional members.

I expected that there would be some matchup between disease severity and emotional severity. A medium disease severity might generate a medium emotional severity. The data actually suggests a lot of scatter and a loose link between emotional state and disease state.

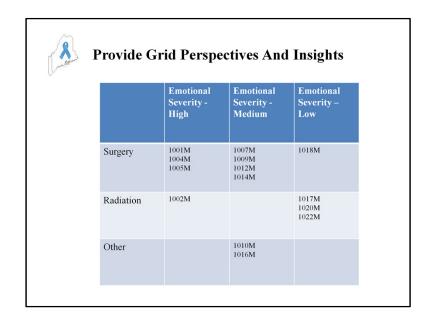


#### **Tell Stories**

- Disease Low, Emotion High
  - Woman who's husband is on active surveillance.
  - She is dealing with her own skin cancer.
  - "When I spend time reading, researching, my level of hope rises quite a bit! When I haven't checked the facts lately, I start to react emotionally and "forget" the facts." (Emotional reasoning.)
- Disease High, Emotion Low
  - Retired doctor who previously faced a near term terminal illness with lung cancer 10+ years ago.
  - Gentleman over 85 who is at peace with his remaining time
  - Interested in Quality of Life, not the length of the runway.

The reason why I don't give you the option to self report disease severity is a woman in the lower left box. Discuss data from the slide.

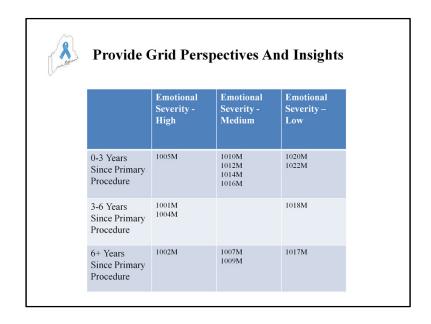
Just because the disease severity is very high doesn't necessarily mean the emotional severity has to be high. Discuss data from the slide.



There are some other useful insights from this 3X3 matrix.

Those choosing radiation appear to experience lower emotional severity. Those choosing radiation must rely more heavily on their doctor's opinions about their prognosis and they appear to need less definitive data about their situation. Member 1002M is dealing with advanced prostate cancer.

With the exception of Member 1018M, who is an older gentleman, the surgery group appears to contend with heightened emotions.



One might expect that as the elapsed time from a primary procedure lengthens the level of emotional severity might decline. Conversely, those closest in time to their primary procedure would presumably experience higher emotional severity. The limited data suggests that emotional severity is more specific to individuals rather than to time.



I have to tell you that my work with the emotional journey has totally changed the way I deal with men in Maine.

Previously, I made a big effort to learn each man's medical journey when I was first hearing about their situation. I asked them about their Gleason score, their PSA level, their PSA velocity, if they had surgery whether there was lymph node involvement, seminal vesicle involvement, and positive or negative margins. My intentions and motivation were all good. I mean, how can I help if I don't have their specific details?

But all of this was Totally wrong in terms of timing and approach. I was talking to their medical chart more than to the man. I was treating them more as a patient rather than as an adult. Sir William Osler said, "The good physician treats the disease; the great physician treats the patient who has the disease." I have taken that to heart in what I do.

My approach now when first meeting or talking with someone is to ask the simple question, "so it sounds you have been through a lot, where's your head on all of this?"

We need to know which of the 9 boxes a guy is in before we can really start to connect in a way that is important and useful to them. We also still need their medical data, but this should come later.



### **Present Major Findings**

- 40% to 60% Of Men Appear To Be Experiencing Severe Depression
  - Diminished sexual identity, loss of sexual prowess, sexual dysfunction, and incontinence lead to humiliation, shame and embarrassment. Treatment side effects appear to be grossly under reported.
  - The inability to come to terms or to accept a new normal that represents a significant loss.
- 50%+ Of Treatment Choices Are Unnecessary And May Be Fear Based
  - Approximately 15%-20% of men diagnosed with prostate cancer die from this disease. Unfortunately, nearly 90% of men elect to do a treatment, so there is a huge problem with over treatment.
  - Too many fear based decisions are made, generally with too little knowledge about options and risks. Premature closure is happening too frequently. Informed decision making is not occurring often enough.

The dimensions of the problems we collectively face are huge: (1) 40% to 60% of the men appear to suffer severe depression at some point, this translates into more than 100K a year; and (2) a 50% over treatment rate also means 100k a year. You all know your state numbers, take your annual numbers times 50%. We all have a lot of work to do.



#### **Present Major Findings**

- Patterns Of Success
  - Exhibited resiliency in the face of uncertainty and adversity.
  - Focused on what they needed to do to achieve a "best/better" scenario.
  - Assumed ownership for their situation and were proactive about managing things.

- Patterns Of Failure
  - Exhibited little or no resiliency. Appeared overwhelmed.
  - Exhibited little or no hope and did little to attempt to change their outlook.
  - Responded in a passive, floundering manner with little realization about how their behavior impacts outcomes.

Much of the material I am presenting is preliminary but I am comfortable with these major findings. In trying to draw useful insights, I looked at many things, read quite extensively, and most studies and articles were useful but not necessarily compelling. When I started looking for patterns of success and patterns of failure I think we did find something useful. It turns out there are time tested ways to screw this up and also demonstrated ways to do it better. Discuss items on the slide. Would recommend Dr. Jerome Groopman's book, *The Anatomy of Hope: How People Prevail in the Face of Illness*.

What emotions we follow is important. An old Cherokee chief is teaching his grandson about life after watching him get into a fight. "A fight is going on inside me," he said to the boy. It is a terrible fight and it is between two wolves. One is evil – he is anger, envy, sorrow, regret, greed, arrogance, self-pity, guilt, resentment, inferiority, lies, false pride, superiority, and ego." He continued, "The other is good – he is joy, peace, love, hope, serenity, humility, kindness, benevolence, empathy, generosity, truth, compassion and faith. The same fight is going on inside you – and inside every other person, too." The grandson thought about it for a minute and then asked his grandfather, "which wolf will win?" The old Cherokee simply replied, "the one you feed." Patient's success or failure definitely depend on what emotions they feed.



#### **Discuss Issues**

- Qualitative not Quantitative. Anecdotal insights but no firm data driven conclusions.
- Need to address which box a patient is facing. No single answer.
- Elapsed time since primary procedure isn't well understood. Five time periods identified but no unique insights found.
- Women appeared to have difficulty addressing their own emotional journey.
- Men who experienced multiple adverse childhood experiences are at much greater risk. They need much more oversight attention.
- There appears to be substantial variability over longer time frames but also within short time frames. Kubler-Ross model doubtful.
- · Project had limited time and funds, so findings are preliminary.
- The people we most need to reach aren't coming to support group meetings.

All of what we have done has to be considered a work in process.

Prosecutors make a distinction between what they know and what they are likely to able to prove in court. Much of what I have presented are insights I think I know to be true, but I really don't think I could prove much of this in court today. Not yet, at least.

I think the issue of elapsed time is really important but I don't think I made much progress here. I will also confess their was a heavy bias towards helping newbies because they are our largest group and presumably the most homogenous in terms of need. But even with this narrower focus I can't say much beyond the obvious.

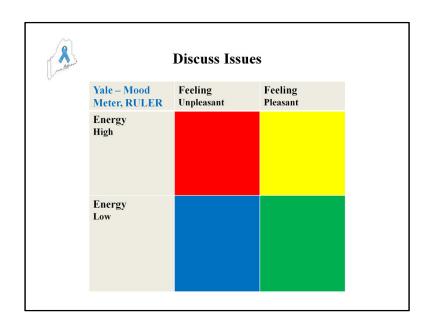
I was surprised at the Brunswick Group meeting by how much the women seemed to subjugate their own stories. Despite my encouragement for them to report on their own journey, virtually all of the women only reported their husband's perspective.

Read ACES conditions and provide brief explanation.

Explain Kubler Ross is denial, anger, negotiation, depression and acceptance. Didn't see any clear progression of this model by anyone.

We visited 9 support groups in ME, met 150+ patients, got 625+ patient hours of assistance, I spent 150-200 hours, collectively we all did well over 850 hours, and we drove 10K+ miles.

Use last bullet point to introduce the next slide.



There are some folks at Yale, Dr. Marc Brackett, doing interesting work in schools trying to teach emotional intelligence: improving self and group awareness, regulating and managing emotions, managing relationships, and increasing responsible decision making. It has been used to reduce bullying with great results. The children are all taught, along with their parents, to think about their moods and what is going on in their heads. They talk about whether they are feeling pleasant or unpleasant and whether they have low or high energy.

When I heard a presentation about this RULER Program a couple of weeks ago, it dawned on me that the problem we all have is that virtually everyone we are trying to serve is in the blue box. How do we connect with depressed people who are unhappy and lethargic? OH, and they have very defensible reasons for being depressed, unpleasant and lethargic.



### **Encourage Group Discussion**

- What has your group done that has worked? What are your success stories?
- How do we help the guys who don't attend support group meetings?
- How should we address higher cardiovascular death rates and suicides that occur after a cancer diagnosis?
- Resilience, patient engagement/ownership, and hopeful action plans are all teachable traits. How can we do this more effectively?
- Please join me in helping expand this work. Let's work across the silos and reduce "reinventing the wheel".

What I have presented is just one effort at addressing this very important challenge. I would like to now encourage your questions and to have everyone talk about what you have seen work, what your success stories are. How you are reaching the difficult to reach. How you are helping train people to better manage their emotions?

My sense is that while the NASPCC meets once a year there isn't a lot of work between the meetings among the different state groups. I would like to propose a task force that will work together over the next 12 months to move all this emotional journey work further along. I would invite any of you who are interested to contact me about how we might work together. I would definitely like to ask all of you to fill out the questionnaire I use at the support group meeting.



### **Maine Coalition to Fight Prostate Cancer**

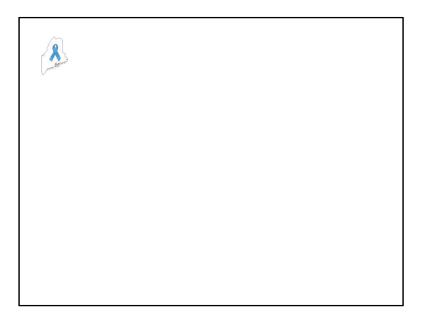
- Please visit our web site www.MCFPC.org
  - Time Warner videos; Radio broadcasts MPBN and WERU; Carefully selected information and resources.
- 10 Support Groups state wide
  - Augusta, Bangor, Bath/Brunswick, Damariscotta, Ellsworth, Island Falls. Lewiston, South Portland, Advanced Prostate Cancer Hormone Therapy Group, Gay Men's Group
- Men don't get prostate cancer, families/partners get prostate cancer. Caregivers are also supported every way we can help.
- Board Members: Terry Kungel, Mona Ervin, Ole Jaeger, Michael Mahan, Al Fitzmorris, Sandy Jaeger, and Stu Hunter
- TKungel@MCFPC.org (855) 552-7200 extension 800

Please visit our web site. Mona Ervin setup this up and does a terrific job managing it.

The Maine Coalition to Fight Prostate Cancer is fortunate to have a great Board of Directors and some terrific facilitators.

I have business cards up here for anyone who would like to reach me.

Let's turn the microphones over to all of you to hear what you have done.





# Goal: Develop a more realistic approach to decision making around screenings

- How the patient community is getting it wrong currently
  - Approximately 15%-20% of men diagnosed with prostate cancer die from this disease. Unfortunately, nearly 90% of men elect to do a treatment, so there is a huge problem with over treatment.
  - Too many fear based decisions are made, generally with too little knowledge about options and risks. Premature closure is happening too frequently. Informed decision making is not occurring often enough.
  - Shared decision making is not occurring. Dr. Han's work addressing
    patients' difficulty with risk assessments is sobering. Many patients
    feel left in the wilderness with poor or no treatment plans and with
    confusing or no handoffs between PCPs and specialists.
  - "It isn't a test, it's a cascade" Dr. Han. We all need to choose much more conservative treatment options, especially active surveillance.



# Goal: Develop a more realistic approach to decision making around screenings

- How the patient community could improve the situation
  - Become more informed and more proactive about health in general and prostate cancer specifically. Go heart healthy: exercise, lose excess weight, eat healthy, and stop smoking.
  - Share and promote road maps about what people should expect to see happen. Reduce the confusion and uncertainty that exists. Expand support groups, patient navigators, and One 2 One counseling.
  - Inform specialists of the need to give patients a short list of options to consider at the same meeting where they are told they have cancer.
     Recommend all of these discussions be face to face.
  - Ask PCPs and specialists to listen to needs and preferences, to provide a game plan, to communicate with everyone so there are no dropped balls or needless confusion.



# Goal: Develop a more realistic approach to decision making around screenings

- How the patient community could improve the situation
  - Encourage PCPs and specialists to engage in shared decision making with patients when discussing and deciding treatment options. Most patients deserve to be respected and treated as adults.
  - Assist Dr. Han's efforts to improve risk communication with patients.
  - Recognize there are two journeys to manage, the medical journey and the emotional journey.
  - Address the emotional issues before the medical issues.
  - Encourage and assist patients to be proactive and to take ownership of their situation, to be resilient, and to find realistic ways to be hopeful despite their situation. These are patterns of success.
  - Help patients overcome being passive, floundering, overwhelmed, and depressed. These are patterns of failure.



## Goal: Understand how and when to use screening most effectively

- MCFPC's old position: All testing (DRE & PSA), all the time (starting at age 35/40), for all men. Direct appeal to the men.
- MCFPC's position after March 2009 NEJM articles:
  - There is significant overtreatment that needlessly results in permanent quality of life issues. We need to encourage active surveillance and more conservative responses to test results.
  - We need to work through the doctors to ensure men are counseled not to make fear based decisions prematurely and that they understand the shortcomings of medical tests. Patients need to have informed discussion.
  - There are some men who shouldn't be tested: cognitively impaired who
    don't have guardians, severe comorbidities that can't handle surgery or
    radiation, life expectancies under five years, those over 80 years, and those
    who insist they won't do anything with the test results.
  - Why fly blind? The DRE and PSA provide useful information that can
    prevent enormously painful metastases. 95% of urologists and 78% of
    PCPs over 50 report having PSA tests. Discuss testing with your doctor,
    then learn your status through two simple tests.



## Goal: Understand how and when to use screening most effectively

- New advances that have to be considered in screening
  - USPSTF definition of the PSA was outdated:
    - PSA velocity, total PSA level, PSA test in combination with other tests.
  - Significant advances in imaging technology:
    - · Color Doppler Ultrasound
    - · MRI with contrast agents
    - · PET + MRI combined imaging
  - Substantial work underway on new tests:
    - · Beckman Coulter new FDA approved test
    - · 40+ biomarkers and 4-5 pathways.
    - · Circulating tumor cells
    - · Urine based tests.
    - · Multi-variable tests.



## MCFPC vs. ACS

	ACS Positions	MCFPC Positions
Routine Screening	"Does not support routine testing for prostate cancer"	Encourage most men to follow AUA guidelines and get routine tests
Starting Age for Screening	"Beginning at age 50 to men who are at average risk, at 45 for men at high risk, and 40 for men at even higher risk"	Baseline at 40 for average risk and 35 for high risk
Informed Consent	"(men) should discuss the potential benefits and limitations of early detection testing before any testing begins."	Informed consent should be established before testing and also treatment to warn of QOL issues, over treatment, and fear based decisions



## U. S. Preventive Services Task Force

• "Adequate evidence shows that nearly 90% of men with a PSA-detected prostate cancer undergo early treatment with surgery, radiation, or androgen deprivation therapy."