Dr. Robert Bree Collaborative | Prostate Cancer Screening

Public Comments Summary

We appreciate the many valuable and constructive comments by the 58 respondents.

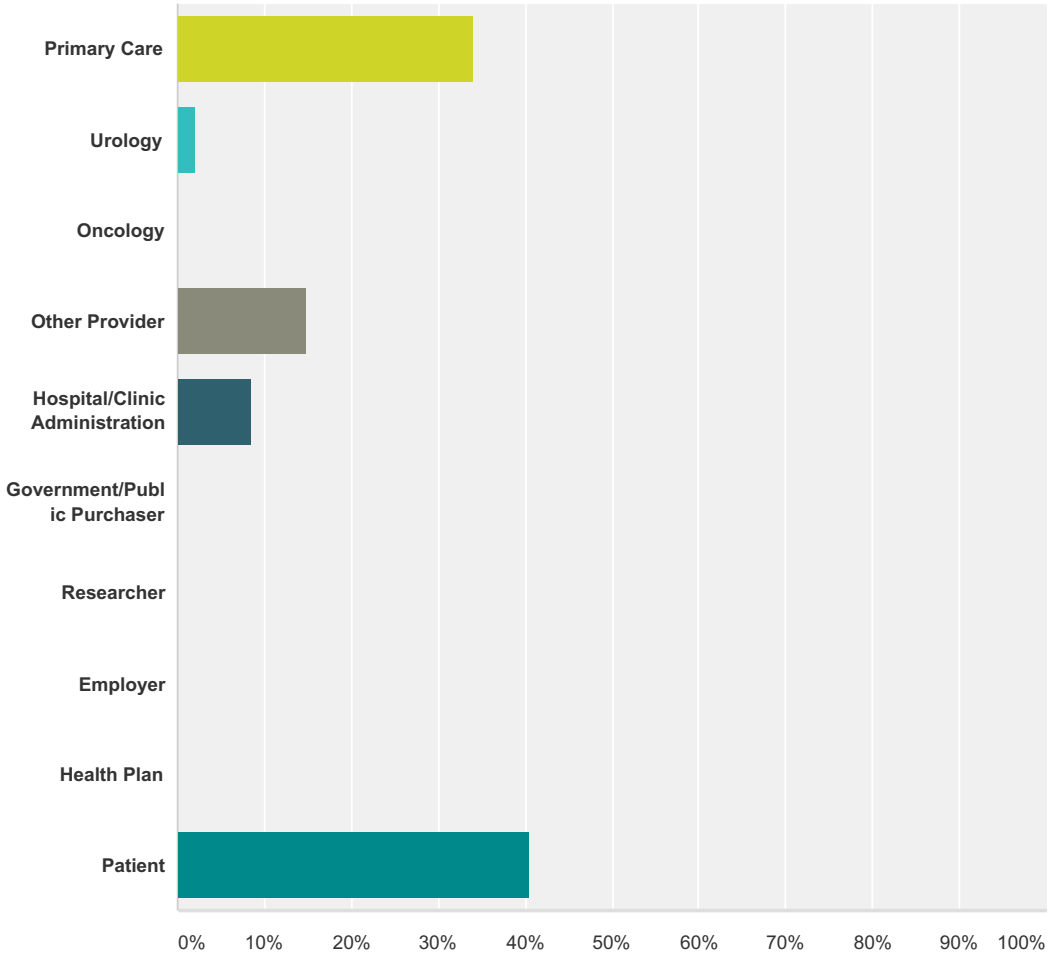
Changes made to the Report and Recommendations include:

- Page 1: Add overdiagnosis to executive summary and clearer language that shared decision making is a process not a document.
- Page 3: Add "*Although the cost of the PSA test itself is low, the potential for downstream complications due to follow-up tests and potentially unnecessary treatment is high*."
- Page 4: "*associated with*" changed to "*can cause*"
- Page 5: Add "*Not included in the 'Not Screened' figure are the men who would be diagnosed with prostate cancer without the PSA test*."
- Page 10: Add "*The workgroup also discussed the psychological benefit of a negative PSA test to reassure patients of health status. However, the inaccuracy of the PSA test and the psychological harms from a false positive PSA test must also be taken into consideration*."
- Page 11: Add "*The Bree Collaborative acknowledges the importance of the physician-patient relationship and the importance of physicians meeting individual patient needs*."
- Page 11: Edited language to read "*If patient decision aids are used to assist in the discussion, aids should strive to be those certified by Washington State when available. Patient decision aids should not be used alone without a comprehensive, patient-centered discussion*."
- Page 12: To Employers add "*Do not include PSA testing for prostate cancer screening in employee health fairs or incentivize PSA testing in a wellness program (e.g., granting points towards a reduction in deductible for those self-reporting a PSA test*)."

Thank you for helping us to improve health care quality, outcomes, and affordability in Washington State.

Q1 What sector do you represent? (Choose the option that is the best fit.)

Answered: 47 Skipped: 0



Answer Choices	Responses	
Primary Care	**34.04%**	16
Urology	**2.13%**	1
Oncology	**0.00%**	0
Other Provider	**14.89%**	7
Hospital/Clinic Administration	**8.51%**	4
Government/Public Purchaser	**0.00%**	0
Researcher	**0.00%**	0
Employer	**0.00%**	0
Health Plan	**0.00%**	0
Patient	**40.43%**	19

Total	47

#	Other (please specify)	Date
1	Washington State Medical Assn.	10/16/2015 4:53 PM
2	Wasington State Urology Society Comments	10/15/2015 6:21 PM
3	Licensed Oncology Massage Practitioner	10/14/2015 8:01 PM
4	Patient who had extensive screenings for 15 years, including biopsies but no other treatments	10/10/2015 4:45 PM
5	Boarded FP, not just GP...	10/7/2015 5:42 PM
6	Massage Therapy	9/30/2015 3:18 PM
7	pharmacist	9/28/2015 5:15 PM
8	Long term care nursing administration	9/28/2015 8:55 AM

Q2 Do you have any comments on the problem statement including on screening test accuracy and harms (pg 3-5)?

Answered: 47 Skipped: 0

#	Responses	Date
1	Yes: the breadth of clinical opinion internationally, accurately captured in the Work Group's thorough research, should be a component of the shared decision making model, so that patients are fully informed.	10/16/2015 4:53 PM
2	No concerns or comments.	10/16/2015 3:05 PM
3	I agree.	10/16/2015 1:44 PM
4	Yes, we think this has promise for improving quality and controlling costs.	10/16/2015 11:47 AM
5	1. The active surveillance trend has shown an increase in the number of very low risk and low risk prostate cancer patients in several studies (see below). Anecdotally his has been a particular trend locally. J Urol. 2015 Jan;193(1):95-102. doi: 10.1016/j.juro.2014.07.111. Epub 2014 Aug 5. (During the study period noncurative initial management increased in patients at low risk from 21% to 32% in SEER and from 13% to 20% in NCDB (each p < 0.001).) 2. Figure 1 suggests 50/110 patients have a complication. This is not seen a normal urology practice and the majority are Grade 1 complications (not significant complication).	10/15/2015 6:21 PM
6	No concerns or comments.	10/15/2015 2:25 PM
7	Since being diagnosed with Stage 4 prostate cancer I have reviewed available literature and reports concerning the the PSA test accuracy and harms. When my diagnosis was finally made, I had a PSA of over 700. I had been reporting urine stream problems adn back pain for the previous three years. I found and find the algorithm presented here to be similar to the existing one practiced by healthcare services. It really places a great deal of the burden of proof and practice upon the patient which results, as in my case, the patient fighting for thier lives. It seems a step back in problem solving rather than a step forward. As Daniel Libeskind noted: "Life it is not just a series of calculations and a sum total of statistics, it's about experience, it's about participation, it is something more complex and more interesting than what is obvious." Daniel Libeskind	10/15/2015 12:26 PM
8	No	10/14/2015 8:01 PM
9	no	10/14/2015 7:26 AM
10	Agree	10/12/2015 6:00 AM
11	This problem statement appears accurate and properly developed based on my personal patient experiences with numerous doctors and specialists and several hospitals in WA State.	10/10/2015 4:45 PM
12	No	10/9/2015 12:29 PM
13	No	10/9/2015 11:25 AM
14	There's an awful lot of material for one person to try to respond to in just one survey, but the main point is that men do die from prostate cancer and yet the graph or chart suggests the death rate is 5/ 1,000 regardless of screening. I grant I may be subject to selection bias, but in my practice over 25 years, I haven't had anyone die of prostate CA who was screened, but had several who died who weren't screened where the disease went undiagnosed until clinical sx of weight loss and pain heralded distant metastases. This is especially true of a few younger men with aggressive tumor types who would be dead now I think had they not been screened (and in early 50s, not just p/ age 55). Maybe our urologists here in Vancouver are just unusually conservative, but many, maybe half high PSAs don't get biopsied, and most of those who do even when biopsy shows CA don't get treated because they have low grade Gleeson scores. So in my limited sample I have seen the occasional life saved, and very little of the overtreatment and morbidity the study is concerned about.	10/7/2015 5:42 PM
15	none	10/7/2015 12:37 PM
16	Good as is	10/7/2015 11:50 AM
17	No	10/5/2015 11:59 AM
18	no	10/2/2015 8:05 PM

19	The P.S.A. exam is over rated as an indicator for cancer of the prostate. Prostate biopsy could do more harm than benefit. Most people die from something else before getting prostate cancer.	9/30/2015 3:18 PM
20	That should always be considered prior to any procedure.	9/30/2015 3:24 AM
21	Stated clearly.	9/30/2015 2:47 AM
22	It appears from reading this, that the main problem is that there is no real cure after diagnosis is determined, therefor, why bother testing.	9/29/2015 9:09 PM
23	looks good	9/29/2015 6:11 PM
24	No	9/29/2015 6:09 PM
25	Figure 1 is very powerful	9/29/2015 6:04 PM
26	no	9/29/2015 5:06 PM
27	The standard screening has been shown to be ineffective by at least three different studies. In Europe 47 men had to go through prostate biopsies for every one that survived.	9/29/2015 4:20 PM
28	Early detection is fundamental for best treatment outcomes. Continue more PSA testing.	9/29/2015 8:37 AM
29	NA	9/29/2015 7:53 AM
30	no	9/28/2015 5:15 PM
31	Only that the test is not 100% accurate and can show positive even when no cancer is present.	9/28/2015 12:03 PM
32	no	9/28/2015 11:11 AM
33	no	9/28/2015 9:28 AM
34	No	9/28/2015 8:55 AM
35	I certainly do have a problem. My PSA level rose by more than 100% each from the time I was 35 until I turned 40. At 39 the core samples tested showed no prostate cancer. At 40 the core samples showed cancer in three of the six sample sectors. I wouldn't have made it 55. I had that rare instance of rapidly advancing Prostate cancer in young men. What's the problem with a blood test?! We can learn a lot about a patient by taking blood. It's inexpensive, it was done as a part of my normal blood work annually. It costs next to nothing to do this and it saves lives. SHAME ON YOU. Btw, I'm adopted. No one knows what's in my family tree. So I'm grateful that I had a doctor who recognizes that annually I get full blood work on a variety of fronts.	9/28/2015 8:47 AM
36	no	9/26/2015 12:30 PM
37	see question 12	9/25/2015 1:11 PM
38	Yes,I was routinely psa screened once I reached 50. PSA elevation was detected at 60 with a Gleason 7. I am now 72 survivor .Thank foresighted medical staff to check psa	9/25/2015 10:04 AM
39	no	9/25/2015 9:11 AM
40	See Question 7	9/24/2015 4:10 PM
41	no	9/24/2015 12:24 PM
42	Yes. It seems that identifying the presence of cancer is the "problem." As an alternative, what is really suggested? The idea of waiting until some yet unidentified symptoms occur is tantamount to a death sentence.	9/23/2015 8:25 PM
43	I have friends who died because their physicians did not screen, and the prostate cancer was finally diagnosed well after it had developed to an advanced stage. Further, the side effects that were cited cannot be generalized to all forms of treatment, such as proton treatment, which has a long history of virtually no side effects.	9/23/2015 4:07 PM
44	My one and only screening test resulted in a PSA of 51, three years ago at age 62. DRE performed by my urologist indicated no abnormalities. No prior symptoms or family history. Without PSA and biopsy where would I be today??	9/23/2015 2:21 PM
45	PSA does NOT tell you if you have cancer. It is a biomarker that says you need to follow up with a DRE. Only then would a biopsy be considered.	9/23/2015 1:19 PM
46	no	9/22/2015 10:37 AM
47	There is no conflict regarding the effect of PSA screening on mortality. With hundreds of thousands of men included in two major randomized trials, it is clear that mortality (that is all cause mortality) is not reduced by PSA screening. This is critical. Men who are screened are no less likely to die than men who are not screened. In the European study for every 1000 men screened every 3 to 4 years, one death attributed to prostate cancer was avoided but there was no reduction in overall death.	9/22/2015 12:53 AM

Q3 Do you have any comments on PSA testing guidelines including additional guidelines that we should consider (pg 6-7)?

Answered: 47 Skipped: 0

#	Responses	Date
1	No further comments, other than to acknowledge the thorough research of the Work Group.	10/16/2015 4:53 PM
2	Recommend considering screening high risk groups between the ages 40-55.	10/16/2015 3:05 PM
3	The public health definition of screening is not the same as the way clinicians think of screening. Make the difference more clearly and repeatedly that none of this applies to case-finding or customizing care according to personal risk factors.	10/16/2015 1:44 PM
4	We support the adherence of guidelines in clinical practice and believe that they have the potential to improve health outcomes and reduce health care costs.	10/16/2015 11:47 AM
5	It is important that in men with urinary symptoms be evaluated fully including PSA to rule out cancer as a cause. This is not "screening". By over-exaggerating the potential detriment of PSA screening many primary physicians are not using the test when needed in symptomatic men.	10/15/2015 6:21 PM
6	Group recommends considering screening high risk groups between the ages of 40-55.	10/15/2015 2:25 PM
7	Earlier detection clearly shows a more positive result potential, but limiting the PSA within these guideline is like only putting a Phillips screwdriver in your tool box because of the statistical likely hood of there being no standard screws. These guidleines seem like only keeping a hammer, WD-40 and Duct Tape.	10/15/2015 12:26 PM
8	I agree with these guidelines unless patient requests these screenings.	10/14/2015 8:01 PM
9	no, two large studies, with limitations, are reviewed	10/14/2015 7:26 AM
10	Agree	10/12/2015 6:00 AM
11	I believe the guidelines are appropriate and well backed by the research later in the report. Excellent.	10/10/2015 4:45 PM
12	No	10/9/2015 12:29 PM
13	NO	10/9/2015 11:25 AM
14	I'm concerned patients will be denied testing (and/or doctors sanctioned for doing it). Not a few of the patients I see are high risk and don't know it. I find many of my colleagues still don't recognize breast cancer in female relative esp mom as a risk factor (as well as prostate CA in male), falsely reassuring patients they are low risk when in fact they may not be. My guys are generally displeased with what feels to them like guys being disenfranchised & thrown under the bus, that failing to test seems to guarantee that some guys who could have lived will die. And most of my more intelligent patients want to have say in the matter-- if the test is positive and if a biopsy shows cancer, they aren't sheep who automatically have to have treatment, but want to hear the pros and cons, understanding that maybe 95% of the time the best course will be to do NOTHING (actually, watchful waiting)	10/7/2015 5:42 PM
15	none	10/7/2015 12:37 PM
16	Good as is	10/7/2015 11:50 AM
17	No	10/5/2015 11:59 AM
18	no	10/2/2015 8:05 PM
19	No	9/30/2015 3:18 PM
20	notify the patient of the pro's and con's so that they can make an informed decision.	9/30/2015 3:24 AM
21	I agree completely. This is extremely well presented.	9/30/2015 2:47 AM
22	Yes, the main problem is the test need to be at min. asked by the provider, risks and this data be presented even at a younger age 50+.. Its a patients right to be informed.	9/29/2015 9:09 PM
23	no	9/29/2015 6:11 PM

24	No	9/29/2015 6:09 PM
25	Although the guideline comparison is nice, I don't see highlighted that it is quite obvious (see Figure 1) that screening harms outweigh benefits	9/29/2015 6:04 PM
26	no	9/29/2015 5:06 PM
27	It appears they are worthless.	9/29/2015 4:20 PM
28	It is a cheap test in comparison with early identification and improved prognosis. Do the PSA	9/29/2015 8:37 AM
29	NA	9/29/2015 7:53 AM
30	would not make this test until oncologists decides, it's a cancer	9/28/2015 5:15 PM
31	Yes, the provider should initiate discussion with patients starting at age 50.	9/28/2015 12:03 PM
32	no	9/28/2015 11:11 AM
33	no	9/28/2015 9:28 AM
34	It's fairly considered and realistic	9/28/2015 8:55 AM
35	Men should get their PSA tested as early as their mid/early 30s to get a sense of their true baseline. Guidelines don't mean $hit without a proper GP or other medical staff to lead the patient. I'd put my focus on the front line.	9/28/2015 8:47 AM
36	I think that Bree should very much defer to the USPSTF guidelines.	9/26/2015 12:30 PM
37	see question 12	9/25/2015 1:11 PM
38	What is cost of PSA screen compared to saving or as a minimum extending ones life.	9/25/2015 10:04 AM
39	no	9/25/2015 9:11 AM
40	See question 7	9/24/2015 4:10 PM
41	no	9/24/2015 12:24 PM
42	So here's the deal. I had never even heard of a PSA test when my GP suggested it. I am now 66, college educated, well read and an active participant in my health care.....and had NEVER heard of PSA until my GP brought it up. so waiting for someone to ask for the test begs the point. EDUCATION has to begin somewhere. I am alive today because that one doctor took the time to do his job. Had he waited for me....I'd be dead.	9/23/2015 8:25 PM
43	Physicians should be encouraged to screen using the PSA test. Digital rectal identifies cancer too late in the process.	9/23/2015 4:07 PM
44	the issue is not the blood test. That's all we have at this point in time.	9/23/2015 2:21 PM
45	The PSA test is VERY inexpensive. Men should have a PSA test every year on their birthday and look for increases. Doubling time and rate of increase are good indicators of a Problem. A need for a biopsyl	9/23/2015 1:19 PM
46	no	9/22/2015 10:37 AM
47	One of the things that all of the guidelines do not highlight is the following: instead of looking at it from the perspective of one man (that is my risk of dying of prostate cancer over the next 13 years might be reduced by one in 1000 if I am screeed with PSA testing every 3 to 4 years) It should be highlighted that if you look at it from the population perspective PSA screening definitely produces more harm than benefit. In the population of 1000 men screen compared to 1000 men not screened there are 30 to 35 more cases of over diagnosed prostate cancer, there are more infections from prostate biopsies, there is more erectile dysfunction, there is more proctitis, and there is more urinary incontinence. So he population of men who receive PSA screening is overall less healthy than a population of men who are not screened.	9/22/2015 12:53 AM

Q4 Do you have any comments on shared decision-making including suggestions for specific patient decision aids (pg. 8-9)?

Answered: 47 Skipped: 0

#	Responses	Date
1	See # 2 above. Patient's anxiety over the potential for a missed diagnosis by not performing a PSA test and the related failure to pursue more aggressive intervention may trump clinical research, even when the patient is required to pay out of pocket for the test.	10/16/2015 4:53 PM
2	Group recognizes this is a complex issue and agrees with use, but has concerns about implementation of shared decision making tools.	10/16/2015 3:05 PM
3	Yes, it would be nice to keep documentation of shared-decision-making as simple as possible.	10/16/2015 1:44 PM
4	We support the adherence of guidelines in clinical practice and believe that they have the potential to improve health outcomes and reduce health care costs.	10/16/2015 11:47 AM
5	A uniform decision-making aid is not practical for all specialties and all physicians. We are strongly against a policy that mandates a uniform decision making tool.	10/15/2015 6:21 PM
6	Group recognizes this is a complex issue and agrees with use, but has concerns about implementation of shared decision making tools.	10/15/2015 2:25 PM
7	Patients should always be included in an informed decision making process, which includes positive and negative outcomes. However, it should be noted that the one thing you do not want to hear is your PCP saying "I feel like I failed you." Other mitigating health factors should not be used as leverage to avoid aggressive prostate treatment.	10/15/2015 12:26 PM
8	I agree with shared decision making. The patient should be able to do this, using their own decision aids on their for cost efficiency.	10/14/2015 8:01 PM
9	no, tools for same are helpful	10/14/2015 7:26 AM
10	Agree	10/12/2015 6:00 AM
11	Yes. This is a vital area that deserves emphasis, consistency and accurate information be provided to patients. I personally had to do my own research in order to protect myself from needless testing and further, more extensive and more dangerous biopsies. Essential to implement this shared decision making protocol.	10/10/2015 4:45 PM
12	No	10/9/2015 12:29 PM
13	NO	10/9/2015 11:25 AM
14	All for it and I practice that way. Of course in the real world, men rarely come in only for prostate discussion, so that conversation has to compete with counseling on colon cancer screening, tobacco, lab testing eg cholesterol, infectious disease and immunizations, reviewing lab results, refilling meds, and addressing the problems our customer-the-patient wants addressed. So in the real world, with rare exception, one has to overview the issue. My guys are generally displeased with what feels to them like guys being thrown under the bus, that failing to test seems to guarantee that some guys who could have lived will die. And most of my more intelligent patients want to have say in the matter-- if the test is positive and if a biopsy shows cancer, they aren't sheep who automatically have to have treatment, but want to hear the pros and cons, understanding that maybe 95% of the time the best course will be to do NOTHING (actually, watchful waiting)	10/7/2015 5:42 PM
15	This is very appropriate	10/7/2015 12:37 PM
16	"Shared decision-making" is most important piece to prostate cancer screening. It leaves room for speciality bias, so I agree with recommendation to use decision aids.	10/7/2015 11:50 AM
17	I support and use shared decision making in my practice. However, I don't have funding or any way to put video clips into my practice for patients in the office. In addition, not all patients will respond to one media approach. It would be best to have a variety of aids.	10/5/2015 11:59 AM
18	I think that is excellent and should spread to almost every aspect of doctor/patient care	10/2/2015 8:05 PM
19	No	9/30/2015 3:18 PM
20	keep them informed	9/30/2015 3:24 AM

21	I would like to see these, as I often have trouble explaining to patients about the issues with PSA screening if they have had a "positive" test done elsewhere.	9/30/2015 2:47 AM
22	The chart that indicated per 1000, who where false positive vs not etc. is very informative and can be presented to, but ultimately is need to be the patients choice.	9/29/2015 9:09 PM
23	no	9/29/2015 6:11 PM
24	No	9/29/2015 6:09 PM
25	What kind of education is being provided to patients outside of their provider discussions in order to aid in their shared decision-making? If a provider is acting on outdated practice, they will educate their patient on skewed advice, thus biasing the decision-making and causing potential harm. I do not see patient education campaigns or awareness being brought to this issue & it isn't a new change.	9/29/2015 6:04 PM
26	no	9/29/2015 5:06 PM
27	It should be left to the patient.	9/29/2015 4:20 PM
28	When in doubt, check it out. Do the PSA	9/29/2015 8:37 AM
29	NA	9/29/2015 7:53 AM
30	agree	9/28/2015 5:15 PM
31	Treatments should be discussed with the patient, with the patient being fully aware of the side effects of treatment.	9/28/2015 12:03 PM
32	no	9/28/2015 11:11 AM
33	I agree	9/28/2015 9:28 AM
34	I agree with the shared decision-making	9/28/2015 8:55 AM
35	Is it so freaking hard to imagine that patients and medical providers actually talk and listen and exchange information? As a patient, I want to be lead through conversations on these topics. Is a five minute annual medical exam less than helpful? You bet! And not taking advantage of routine blood work results is an abomination. (Seriously, do you have any sense of shame in making these recommendations?)	9/28/2015 8:47 AM
36	Shared decision making is time consuming, I know, I do it. the time is not compensated and most of my colleagues probably don't do it with more than a passing comment. Overtesting and overtreatment won't stop until it is unambiguously given a don't do this recommendation. How many prostates should surgeons harvest to save one live, how many impotent, incontinent men will they leave in their wake? 90-plus % of men given a dx will elect treatment rather than watchful waiting. Bree needs to be less than impotent itself and recommend against"screening"	9/26/2015 12:30 PM
37	see question 12	9/25/2015 1:11 PM
38	Yes encourage men to seek second opinion and don't always trust your PC physician. Seek urologist or oncologist treatment trends are great. Encourage and fund additional research	9/25/2015 10:04 AM
39	no	9/25/2015 9:11 AM
40	No	9/24/2015 4:10 PM
41	psa test is relatively inexpensive so why not screen if ptient wants it.	9/24/2015 12:24 PM
42	See answer to #3 above.	9/23/2015 8:25 PM
43	Discussions of all 8-9 forms of treatment, which can cure the cancer, and known side effects. If you had cancer, would you want it removed?	9/23/2015 4:07 PM
44	Shared decision making is utmost. Patient needs all of the information available to make an informed decision with family and physician.	9/23/2015 2:21 PM
45	Every man should be encouraged to have a PSA along with his colesterol, blood sugar, and other blood tests. There are no dangers of a PSA blood test that are any worse then these other blood tests.	9/23/2015 1:19 PM
46	need patient care instructions to help with this to put in to EHR	9/22/2015 10:37 AM
47	Again I think it is critical that patients be spared the fact that if they choose screening they are entering the population that 10 years later will be less healthy than if they choose no screening. Finally, the European trial only screened every 3 to 4 years And used a cut off for biopsy of A PSA level of three to trigger a biopsy. The USA trial could be interpreted as a trial of annual screening compare to less frequent screening, and it showed no improvement in prostate cancer mortality. So the date it definitely shows the annual screening is not any more effective than screening every 3 to 4 years.	9/22/2015 12:53 AM

Q5 Do you have any comments on prostate cancer treatment trends (pg. 9)?

Answered: 47 Skipped: 0

#	Responses	Date
1	No.	10/16/2015 4:53 PM
2	Support the use of active surveillance.	10/16/2015 3:05 PM
3	Less is more.	10/16/2015 1:44 PM
4	No	10/16/2015 11:47 AM
5	As noted above there is a very appropriate rise in the non-curative treatment options of active surveillance and watchful waiting for low risk prostate cancer. This really drives down the number need to treat to a more appropriate level and gives patients with American Joint Committee of Cancer intermediate and high risk disease a chance of cure. Prostate cancer is the 2nd leading cause of cancer death in men in the US (man dies of prostate cancer every 19min) and screening does save lives. Development of multiple serum (eg 4K score) and genetic/tissue markers to help clinicians differentiate aggressive and indolent cancers may change the landscape of screening and treatment in the near future. Patients and physicians should remain engaged in screening given these improvements.	10/15/2015 6:21 PM
6	Group supports the use of active surveillance.	10/15/2015 2:25 PM
7	Research in prostate treatment trends are changing rapidly. A man in my support group was diagnosed with almost the same stage 4 w metastasis as me and given 2 years to live. That was 12 years ago. Early detection is a proven successful approach. Treatments for advanced prostate cancers are evolving. Combined approaches and treatments with less emphasis on heavy chemo therapy is proving more successful. Not all shoes come in one size.	10/15/2015 12:26 PM
8	Curative local treatments and observations should be used before aggressive treatments.	10/14/2015 8:01 PM
9	no	10/14/2015 7:26 AM
10	Agree	10/12/2015 6:00 AM
11	Yes. Comprehensive, understandable and meaningful for both doctors and patients at all ages in the assessment process. Well done.	10/10/2015 4:45 PM
12	No	10/9/2015 12:29 PM
13	NO	10/9/2015 11:25 AM
14	I'm concerned patients will be denied testing (and/or doctors sanctioned for doing it). Not a few of the patients I see are high risk and don't know it. I find many of my colleagues still don't recognize breast cancer in female relative esp mom as a risk factor (as well as prostate CA in male), falsely reassuring patients they are low risk when in fact they may not be. As far as the "life expectancy less than 10 years", I don't know about you, but I don't have great confidence in my ability to estimate that accurately (unless it's obviously short) so I don't find that well-meaning criterion very easy to apply in clinical practice...	10/7/2015 5:42 PM
15	none	10/7/2015 12:37 PM
16	No	10/7/2015 11:50 AM
17	No comment	10/5/2015 11:59 AM
18	no	10/2/2015 8:05 PM
19	NO	9/30/2015 3:18 PM
20	No	9/30/2015 3:24 AM
21	No.	9/30/2015 2:47 AM
22	The focus should be finding other forms of curing and testing for this.	9/29/2015 9:09 PM
23	no	9/29/2015 6:11 PM
24	No	9/29/2015 6:09 PM
25	no	9/29/2015 6:04 PM

26	no	9/29/2015 5:06 PM
27	It should reflect the current data as to the efficacy of the current testing protocol.	9/29/2015 4:20 PM
28	Treatment is only as good as initial detection. Do the PSA	9/29/2015 8:37 AM
29	NA	9/29/2015 7:53 AM
30	no	9/28/2015 5:15 PM
31	I agree with moving towards active surveillance	9/28/2015 12:03 PM
32	no	9/28/2015 11:11 AM
33	no	9/28/2015 9:28 AM
34	We're seeing a number of our younger admissions in SNF with Prostate CA and this test will help.	9/28/2015 8:55 AM
35	I appreciate that we are emphasizing "mindful watching" after a preliminary diagnosis. But this one-size fits all approach doesn't actually fit all. Sometimes, you gotta move forward with something more aggressive than watching. IFF someone is going to get this before they are 55 and it's fast moving, what is the harm in testing the blood? There is no harm. The harm is this guideline. If my GP followed your guideline I'd be dead by 43 and unable to tell you what fools you are. I've got kids I'd love to see grow up. Are you telling me that the harm is my having a blood test so that I'm still here when they go to college? You are soulless.	9/28/2015 8:47 AM
36	no	9/26/2015 12:30 PM
37	see question 12	9/25/2015 1:11 PM
38	No	9/25/2015 10:04 AM
39	no	9/25/2015 9:11 AM
40	No	9/24/2015 4:10 PM
41	no	9/24/2015 12:24 PM
42	Everyone is different. But a biopsy won't kill you. If my cancer had allowed it, I would have undergone a biopsy yearly to avoid the surgery I elected. And now, 6 years down the road I am not thrilled with some of the side effects, but I will watch my grand-daughters graduate from high school, at the very least. Fair trade. And I'll probably out live my ex-wife,....just a bonus as it were.	9/23/2015 8:25 PM
43	Proton treatment appears to be the most efficacious and without side effects, killing the cancer without harm to the patient.	9/23/2015 4:07 PM
44	New treatments are outstanding. Research needs continued and increased funding.	9/23/2015 2:21 PM
45	There are many options for men diagnosed with PCa. Active survalliance for slow growing and other treatments if agressive. All known by the Gleason score on the biopsy.	9/23/2015 1:19 PM
46	no	9/22/2015 10:37 AM
47	Whenever there is an improvement in treatment of prostate cancer, the value of screening decreases. These randomized trials were started before current or effective methods of treating prostate cancer were available. Consequently they overstate the value (if any) of PSA prostate cancer screening.	9/22/2015 12:53 AM

Q6 Do you have any comments on our primary care recommendation against routine screening for average risk men under 55 or over 70 years old, with significant co-morbid conditions, or with a life expectancy less than 10 years. (pg. 11)?

Answered: 47 Skipped: 0

#	Responses	Date
1	No.	10/16/2015 4:53 PM
2	We agree with this recommendation	10/16/2015 3:05 PM
3	Yes, urologists are not qualified to make population health recommendations. The washington urologists should eb reminded they are about to become the laughing stock of the country unless they stick to the data and what they know best.	10/16/2015 1:44 PM
4	No	10/16/2015 11:47 AM
5	No, but should also include ethnicity and family history.	10/15/2015 6:21 PM
6	No concerns or comments.	10/15/2015 2:25 PM
7	I have been involved in dementia research, treatment and care for more than a decade, and senior care for more than three decades. The approaches suggested here with poor risk assessments tied to age remind me of early approaches to Alzheimer's. Men can get aggressive prostate cancer before 55. Writing off seniors for treatment because of age or co-morbidity conditions assumes that treatment for many other conditions seems a bit ageist and sexist. I fit several of the risk conditions that give me the potential for living less than 10 years. I have no intention of quitting, no do I endorse any physician who tends to wash their hands because of risk. I intend to fight for myself and my loved ones.	10/15/2015 12:26 PM
8	The patient should have the utmost right in decisions for their health care regardless of what decision the clinician has determined in shared decision making for their care.	10/14/2015 8:01 PM
9	no, I agree with the recommendations	10/14/2015 7:26 AM
10	Agree	10/12/2015 6:00 AM
11	I agree based on my own personal experiences and those of my father who died at age 82 of natural causes not associated with his diagnosis of prostate cancer at age 80. Recommendations are well-developed and should be implemented.	10/10/2015 4:45 PM
12	No`	10/9/2015 12:29 PM
13	NO	10/9/2015 11:25 AM
14	Not much, as long as patients can opt for it if they want. I find many of my colleagues still don't recognize breast cancer in female relative esp mom as a risk factor (as well as prostate CA in male), falsely reassuring patients they are low risk when in fact they may not be. As far as the "life expectancy less than 10 years", I don't know about you, but I don't have great confidence in my ability to estimate that accurately (unless it's obviously short) so don't find that well-meaning criteria very easy to apply in clinical practice...	10/7/2015 5:42 PM
15	it is right on target	10/7/2015 12:37 PM
16	Good as is	10/7/2015 11:50 AM
17	Agree, provided that PCPs can take individual circumstances and patient preferences into account.	10/5/2015 11:59 AM
18	I agree with it	10/2/2015 8:05 PM
19	NO	9/30/2015 3:18 PM
20	No	9/30/2015 3:24 AM
21	Agree.	9/30/2015 2:47 AM

22	This makes sense, however, If I personally had a life expectancy less than 10 years, I still would want to have a choice, and my choice respected. It my life, my family that has to live with these choices, its not up to anyone else to determine this, just for a cost issue, or use a phycaligial issue for a way to "get out of paying for this test"	9/29/2015 9:09 PM
23	no	9/29/2015 6:11 PM
24	No	9/29/2015 6:09 PM
25	no	9/29/2015 6:04 PM
26	no	9/29/2015 5:06 PM
27	Seems to be a total waste according to research data.	9/29/2015 4:20 PM
28	Advise detection in the circulation as the most significant element is total prevention of metastasis. Do the PSA	9/29/2015 8:37 AM
29	NA	9/29/2015 7:53 AM
30	agree	9/28/2015 5:15 PM
31	No	9/28/2015 12:03 PM
32	I have a problem with the entire concept that others should have control over whether I engage in available testing regarding my body functioning. I am capable, in consultation with a physician who can inform me of the latest applicable data, to make a decision regarding my body and resent your telling me what I can and cannot do.	9/28/2015 11:11 AM
33	Prevention saves lives and quality of life.	9/28/2015 9:28 AM
34	Routine screening is necessary just like the breast screening. But, a combined decision including second opinion from other physician will be necessary.	9/28/2015 8:55 AM
35	N/A	9/28/2015 8:47 AM
36	yes, it is not strong enough, it should be a blanket recommendation against 'screening" , USPSTF guidelines should be followed, Inconsistancy by Bree will not benefit patient care and outcomes	9/26/2015 12:30 PM
37	see question 12	9/25/2015 1:11 PM
38	What is a man s life worth with out screening and supportive treatment?	9/25/2015 10:04 AM
39	no	9/25/2015 9:11 AM
40	yes see Question 7	9/24/2015 4:10 PM
41	no	9/24/2015 12:24 PM
42	Really? so if a guy probably won't last another 10 years, just skip it? Wow, glad you're not my doctor. I had to find a new doctor last year - the one that saved my life with screening retired. I asked the new one (without his knowing I'd had prostate cancer) if he supported PSA screening. If he had answered "No", I'd have walked out, even though I no longer need it. Its a mind set - I want a dr. that wants me alive.	9/23/2015 8:25 PM
43	I have seen cancer in 35 year old men. I developed it when I was 54. Your criteria is not realistic.	9/23/2015 4:07 PM
44	We cannot legislate age into a disease. Age factor should have nothing to do with recommendations.	9/23/2015 2:21 PM
45	Sounds like those men who have prostate cancer before those ages don't count. Just let then die. Seriously, because some doctors don't understand the PSA and can describe it accurately, NO man uncer 55 should have the opportunity to know if he has cancer. What a waste of mankind.	9/23/2015 1:19 PM
46	no	9/22/2015 10:37 AM
47	Only got the recommendation against routine screening in these groups should be extended to all men.	9/22/2015 12:53 AM

Q7 Do you have any comments on our primary care recommendation that clinicians who believe there is overall benefit to screening with the PSA test "should order this test for average risk men between 55-69 years old only after a formal and documented shared decision-making process" OR if clinicians believe there is overall harm from screening "may initiate testing of average-risk men aged 55-69 at the request of the patient after a formal and documented shared decision-making process (pg. 11)."

Answered: 47 Skipped: 0

#	Responses	Date
1	No.	10/16/2015 4:53 PM
2	Recognize decreased risk of harms with improved diagnosis and treatment of prostate cancer	10/16/2015 3:05 PM
3	This makes PSA permissible. This is acceptable. No one should ever prohibit a physician from doing what they think is best, unless there is definitive evidence of harm, which is not the case with PSA outside of the screening recommendation.	10/16/2015 1:44 PM
4	No	10/16/2015 11:47 AM
5	This comment regarding "those that believe and those that don't believe" emphasizes the difficulties of making a uniform decision making tool.	10/15/2015 6:21 PM
6	Group recognized decreased risk of harm with improved diagnosis and treatment of prostate cancer	10/15/2015 2:25 PM
7	I support clinicians who believe there is overall benefit to screening with the PSA test "should order this test for average risk men between 55-69 years old after a formal and documented shared decision-making process"	10/15/2015 12:26 PM
8	No.	10/14/2015 8:01 PM
9	no, well worded	10/14/2015 7:26 AM
10	Agree	10/12/2015 6:00 AM
11	Yes. This matches my own personal experienced during the same age range of 55 to 69. Very important to implement as recommended based on my own experiences.	10/10/2015 4:45 PM
12	Yes. this is extremely unusual., the goal of evidenc based guidance is to avoid physician belief in clinical care, and rely on evidence. I think its better to say that if they believe the evidence suggests benefit for an individual in their office (knowing their tolerance for uncertain test results, chagrin for a delayed diagnosis etc) it would make more appropriate as a recommendation.	10/9/2015 12:29 PM
13	NO	10/9/2015 11:25 AM
14	I'm all for informed consent discussions, though see caveat on the reality in a busy practice with multi-issue visits above. My concern is it makes it too easy for busy clinicians and especially ones who are just "phoning it in" to cut corners and not really give patients the full story, just to get that issue crossed off the "To Do" list. My guys are generally displeased with what feels to them like guys being thrown under the bus, that failing to test seems to guarantee that some guys who could have lived will die. And most of my more intelligent patients want to have say in the matter-- if the test is positive and if a biopsy shows cancer, they aren't sheep who automatically have to have treatment, but want to hear the pros and cons, understanding that maybe 95% of the time the best course will be to do NOTHING (actually, watchful waiting). And of course, I have many who are happy to decline testing (though often I think because cancer and male sexuality are scary issues)	10/7/2015 5:42 PM

15	on target	10/7/2015 12:37 PM
16	Most important recommendation	10/7/2015 11:50 AM
17	I strongly object to a "formal and documented shared decision-making process" It is essential that time be provided in patient visits to meet the concerns of the patients. Adding a "formal" process implies an excessive burden on a single screening test. We currently discuss the pros, cons, risks, benefits with our patients and document this. I don't see the need for adding a formal process that further gets in the way of direct patient care. Further being tied only to a decision aid that is WA state certified unduly restricts us from using CDC or other more useful aids when they become available.	10/5/2015 11:59 AM
18	I agree with this	10/2/2015 8:05 PM
19	NO	9/30/2015 3:18 PM
20	Yes that is a sound idea.	9/30/2015 3:24 AM
21	Reasonable.	9/30/2015 2:47 AM
22	As long as the patient is completely involved and has been asked if they want to the test and the pro's and con's have been discussed. It would be appropriate	9/29/2015 9:09 PM
23	makes sense	9/29/2015 6:11 PM
24	No	9/29/2015 6:09 PM
25	no	9/29/2015 6:04 PM
26	no	9/29/2015 5:06 PM
27	No	9/29/2015 4:20 PM
28	The blood test is simple, easy and affordable. It should be done routinely. Do the PSA	9/29/2015 8:37 AM
29	Agreed	9/29/2015 7:53 AM
30	after oncologists opinion	9/28/2015 5:15 PM
31	No	9/28/2015 12:03 PM
32	The clinician should order the test if I say I want it. Period!	9/28/2015 11:11 AM
33	Nothing wrong with shared decision making. Patients need to understand their care.	9/28/2015 9:28 AM
34	Yes	9/28/2015 8:55 AM
35	BULLSHIT.	9/28/2015 8:47 AM
36	yes-it is not about beliefs, it is about what the evidence shows. "Screening" doesn't work and Bree should say so	9/26/2015 12:30 PM
37	see question 12	9/25/2015 1:11 PM
38	BS about formal documentation	9/25/2015 10:04 AM
39	For twenty-five years I have enjoyed the "documented shared decision-making process" while using only one treatment: Self-brewed Essiac Tea, taking 1 ounce daily at 9:00 p.m.	9/25/2015 9:11 AM
40	This should include men over the age of 69 that are healthy and lead an active life...I am 83 continue to snow ski, play golf and lead an active life..I have no reason to believe that I won't live for at least 10 more years...I monitored my PSA annually up to age 79 and the results were between 3 and 4...I did not have a PSA test for the following 5 years..When I insisted on being tested this year my PSA had skyrocketed to 16...I did my research and then underwent a Biopsy which resulted in 9 of 12 samples indicating cancer..No after affects from the biopsy..(I think that after affects have been overblown in this report) My Gleason score was 8.Further tests showed no indication that cancer had spread outside the prostate...I underwent IMRT and ADT...It has been 5 months since beginning treatment..I have finished the radiation and 5 months of ADT...My PSA went from 16 to almost non detectable (0.03)...One would have a hard time convincing me not to have had the PSA test...I am doing fine now and hopefully I will die of a cause other than Prostate Cancer...	9/24/2015 4:10 PM
41	no	9/24/2015 12:24 PM
42	Sure, make the whole process as difficult as possible. NO, NO, let me repeat that...NO, I don't support that idea. A doctor can explain the pros/cons, but a dr. is either screen and stay alive or don't screen an take your chances. Easy choice here.	9/23/2015 8:25 PM

43	I believe that over-burdening the process with documentation puts a disincentive between the patient and the care, and in the way of the doctor's relationship with the patient. It is indirect manipulation of the system to support these bad recommendations.	9/23/2015 4:07 PM
44	Again - age should not be a factor.	9/23/2015 2:21 PM
45	The issue has NEVER been over diagnosis, it has been over treatment. That is the doctors fault, not the patient. Man deserve to know the state of their health. If caught early, it can be cured.	9/23/2015 1:19 PM
46	no	9/22/2015 10:37 AM
47	I definitely agree that if a clinician is to recommend or offer PSA testing it is wrong to do so without providing the patient a robust shared decision-making approach. However I think the overall science as well documented in the US task force report, verifies that men who will undergo PSA screening are more likely to be harmed and to receive benefit.	9/22/2015 12:53 AM

Q8 Do you have any comments on our recommendations for men belonging to a higher risk group (pg. 11)?

Answered: 47 Skipped: 0

#	Responses	Date
1	See # 2 and 4 above.	10/16/2015 4:53 PM
2	No concerns about high risk group designation, but again recommend considering screening high risk groups between 40 and 55.	10/16/2015 3:05 PM
3	No	10/16/2015 1:44 PM
4	No	10/16/2015 11:47 AM
5	We appreciate that the PCS group/Bree Collaborative has recognized that men with high risk of having prostate cancer (African American, 1st degree family relative, agent orange, etc..) should be offered PSA screening via shared decision making.	10/15/2015 6:21 PM
6	No concerns about high risk group designation, but again recommend considering screening high risk groups between 40-55.	10/15/2015 2:25 PM
7	Always include the patient in an educated decision making process, but do not treat them as a cost-benefit item in a spread-sheet approach to medical care.	10/15/2015 12:26 PM
8	No.	10/14/2015 8:01 PM
9	no	10/14/2015 7:26 AM
10	Agree	10/12/2015 6:00 AM
11	Yes. Recommendations are well developed based on the research findings. As a high-risk patient, I had to make this decision numerous times over the years with my doctors. Risks related to biopsies, concerns over high PSA and other factors was a yearly ordeal I would not want anyone to experience without benefit of multiple consultations, facts, data and careful analyses. Side effects of biopsies (mine were eighteen samples) and risks are very problematic. After the first set (which showed no sign of cancers) I refused to consider any more biopsies. PSA readings were always high, up to 11 or higher but were related to genetic size of the prostate, which was always the case from a young age.	10/10/2015 4:45 PM
12	No	10/9/2015 12:29 PM
13	NO	10/9/2015 11:25 AM
14	Sounds ok, but again seems naïve in clinical practice (ie too vague to use) without more enumeration of how to apply testing to, say, a black man. Or 2 relatives with relevant cancer. What a about an algorithm with a scoring sheet to help quantify risk, like the Framingham is for CAD?	10/7/2015 5:42 PM
15	none	10/7/2015 12:37 PM
16	Good as is	10/7/2015 11:50 AM
17	Mostly agree	10/5/2015 11:59 AM
18	no	10/2/2015 8:05 PM
19	NO	9/30/2015 3:18 PM
20	No	9/30/2015 3:24 AM
21	Agree.	9/30/2015 2:47 AM
22	no	9/29/2015 9:09 PM
23	no	9/29/2015 6:11 PM
24	No	9/29/2015 6:09 PM
25	no	9/29/2015 6:04 PM
26	no	9/29/2015 5:06 PM

27	A better screening test needs to be developed.	9/29/2015 4:20 PM
28	Do the PSA	9/29/2015 8:37 AM
29	Agreed	9/29/2015 7:53 AM
30	no	9/28/2015 5:15 PM
31	No	9/28/2015 12:03 PM
32	no	9/28/2015 11:11 AM
33	They also need to work on the things that make them higher risk.	9/28/2015 9:28 AM
34	None	9/28/2015 8:55 AM
35	My PSA level rose by more than 100% each from the time I was 35 until I turned 40. At 39 the core samples tested showed no prostate cancer. At 40 the core samples showed cancer in three of the six sample sectors. I wouldn't have made it 55. I had that rare instance of rapidly advancing Prostate cancer in young men. What's the problem with a blood test?! We can learn a lot about a patient by taking blood. It's inexpensive, it was done as a part of my normal blood work annually. It costs next to nothing to do this and it saves lives. SHAME ON YOU. Btw, I'm adopted. No one knows what's in my family tree. So I'm grateful that I had a doctor	9/28/2015 8:47 AM
36	no	9/26/2015 12:30 PM
37	see question 12	9/25/2015 1:11 PM
38	PSA screeing is vital for early detection and survival	9/25/2015 10:04 AM
39	no	9/25/2015 9:11 AM
40	See answer to Question 7	9/24/2015 4:10 PM
41	x	9/24/2015 12:24 PM
42	This is not that clear on page 11. No comment.	9/23/2015 8:25 PM
43	Mandate PSA screening.	9/23/2015 4:07 PM
44	Want my physician to treat all of my health issues regardless of risk.	9/23/2015 2:21 PM
45	Men do not know if they are High Risk, unless they have a biopsy and know the state of their cancer.....or not. Most cancer is not genetic. It is a mutation that is NOT predictable. We are not Statistics, we are MEN.	9/23/2015 1:19 PM
46	no	9/22/2015 10:37 AM
47	It is a hypothesis that such men will benefit if they undergo PSA screening. That should not be assumed that they are more likely to benefit. So while I agree that high-risk men (just like average or low risk men) should only be screened after a robust shared decision-making approach has been undertaken, I think the recommendation there is the same do not routinely offer PSA screening. if a man in a high-risk group requests screening or discussion about screening then shared decision-making should be undertaken before PSA screening.	9/22/2015 12:53 AM

Q9 Do you have any comments on our recommendations to hospitals (pg. 11)?

Answered: 47 Skipped: 0

#	Responses	Date
1	No.	10/16/2015 4:53 PM
2	Do not support hospitals providing cancer screenings during acute hospital stays	10/16/2015 3:05 PM
3	No	10/16/2015 1:44 PM
4	No	10/16/2015 11:47 AM
5	Hospitals do not have anything to do with screening. They do not order tests. These decisions should be between the patient and physician.	10/15/2015 6:21 PM
6	No comments	10/15/2015 2:25 PM
7	Treat the patients with respect and include positive potentials to outcomes. "It may seem a strange principle to enunciate as the very first requirement in a hospital that it should do the sick no harm." -Florence Nightingale observation remains cogent and valid even in today's healthcare reform environment.	10/15/2015 12:26 PM
8	No.	10/14/2015 8:01 PM
9	no	10/14/2015 7:26 AM
10	No	10/12/2015 6:00 AM
11	Excellent. Use this standard.	10/10/2015 4:45 PM
12	no	10/9/2015 12:29 PM
13	NO	10/9/2015 11:25 AM
14	Don't practice in hospitals. Why do I have to answer it?!	10/7/2015 5:42 PM
15	none	10/7/2015 12:37 PM
16	No	10/7/2015 11:50 AM
17	Agree	10/5/2015 11:59 AM
18	no	10/2/2015 8:05 PM
19	NO	9/30/2015 3:18 PM
20	Shorten the wait time. A year is a little excessive.	9/30/2015 3:24 AM
21	Agree.	9/30/2015 2:47 AM
22	no	9/29/2015 9:09 PM
23	no	9/29/2015 6:11 PM
24	No	9/29/2015 6:09 PM
25	no	9/29/2015 6:04 PM
26	no	9/29/2015 5:06 PM
27	no	9/29/2015 4:20 PM
28	Offer PSA routinely.	9/29/2015 8:37 AM
29	NA	9/29/2015 7:53 AM
30	no	9/28/2015 5:15 PM
31	no	9/28/2015 12:03 PM
32	no	9/28/2015 11:11 AM
33	no	9/28/2015 9:28 AM

34	None	9/28/2015 8:55 AM
35	My PSA level rose by more than 100% each from the time I was 35 until I turned 40. At 39 the core samples tested showed no prostate cancer. At 40 the core samples showed cancer in three of the six sample sectors. I wouldn't have made it 55. I had that rare instance of rapidly advancing Prostate cancer in young men. What's the problem with a blood test?! We can learn a lot about a patient by taking blood. It's inexpensive, it was done as a part of my normal blood work annually. It costs next to nothing to do this and it saves lives. SHAME ON YOU. Btw, I'm adopted. No one knows what's in my family tree. So I'm grateful that I had a doctor	9/28/2015 8:47 AM
36	no	9/26/2015 12:30 PM
37	see question 12	9/25/2015 1:11 PM
38	Provide support groups to patients	9/25/2015 10:04 AM
39	no	9/25/2015 9:11 AM
40	See Question 7	9/24/2015 4:10 PM
41	x	9/24/2015 12:24 PM
42	Except as an emergency procedure or running an out-patient clinic, hospitals shouldn't be in this business. Clearly insurance companies must love this idea. Saves them a bunch, too.	9/23/2015 8:25 PM
43	Yes. PSA should be used to confirm potential diagnosis. Bioposy is not dangerous, if performed by a competent professional and should be mandated.	9/23/2015 4:07 PM
44	Delete this - "Only men who express a definite preference for screening should have PSA testing."	9/23/2015 2:21 PM
45	Include PSA tests along with other general blood tests. You may save their lives by catching a raising PSA.	9/23/2015 1:19 PM
46	no	9/22/2015 10:37 AM
47	Your recommendation to hospitals is inadequate. Because PSA screening increases utilization, hospitals benefit financially from reaching out to me in and doing PSA screening in the community. As I have noted, this reduces the overall health of the population of men who are screen. The collaborative should make a recommendation that hospitals should stop offering PSA screening.	9/22/2015 12:53 AM

Q10 Do you have any comments on our recommendation to health plans (pg. 12)?

Answered: 47 Skipped: 0

#	Responses	Date
1	No.	10/16/2015 4:53 PM
2	We support additional reimbursement for use of shared decision process as this process takes a lot of time with either providers, care management RN's or other clinical staff.	10/16/2015 3:05 PM
3	No	10/16/2015 1:44 PM
4	No	10/16/2015 11:47 AM
5	PSA counseling should be reimbursed regardless of any insurance protocol. A "Washington State-approved patient decision aid" is no appropriate or reasonable. The specific specialty physician and patient population will have different needs.	10/15/2015 6:21 PM
6	No comments	10/15/2015 2:25 PM
7	They state part of the obvious and seem to emphasize the negative aspects of these recommendations.	10/15/2015 12:26 PM
8	There shouldn't be an added charge for the decision making but included in the initial appointment.	10/14/2015 8:01 PM
9	no, it would be nice to be reimbursed for shared decision making time	10/14/2015 7:26 AM
10	Agree	10/12/2015 6:00 AM
11	None. Well done.	10/10/2015 4:45 PM
12	No	10/9/2015 12:29 PM
13	NO	10/9/2015 11:25 AM
14	I'm all for evidence-based care and cutting waste where the evidence is clear and non-controversial, but I'm concerned this will be used as an excuse to deny care. I'm concerned patients will be denied testing (and/or doctors sanctioned for doing it). Not a few of the patients I see are high risk and don't know it. I find many of my colleagues still don't recognize breast cancer in female relative esp mom as a risk factor (as well as prostate CA in male), falsely reassuring patients they are low risk when in fact they may not be. My patients want to have the option of being tested if and when indicated, not told "too bad!" because it is no longer politically correct.	10/7/2015 5:42 PM
15	none	10/7/2015 12:37 PM
16	No	10/7/2015 11:50 AM
17	If you require we spend time in "formal" education then you have to reimburse for it. Our reimbursement is being cut and we're expected to do more and more for free. This is not a sustainable model of care.	10/5/2015 11:59 AM
18	no	10/2/2015 8:05 PM
19	NO	9/30/2015 3:18 PM
20	No	9/30/2015 3:24 AM
21	Good ideas.	9/30/2015 2:47 AM
22	Just to make sure, If the patient wishes to have the test that is be paid for as a preventive measure. Even if one live is saved, it is worth it.	9/29/2015 9:09 PM
23	no	9/29/2015 6:11 PM
24	No	9/29/2015 6:09 PM
25	Flag providers who have inordinate amounts of claims coming through for PSA testing and send them reports (just as you would for high-risk meds)	9/29/2015 6:04 PM
26	no	9/29/2015 5:06 PM
27	no	9/29/2015 4:20 PM
28	Offer PSA routinely	9/29/2015 8:37 AM

29	NA	9/29/2015 7:53 AM
30	no	9/28/2015 5:15 PM
31	no	9/28/2015 12:03 PM
32	If I want the test, I want my insurance plan to pay for it.	9/28/2015 11:11 AM
33	Cover prevention and early detection	9/28/2015 9:28 AM
34	None. It must be covered as preventive	9/28/2015 8:55 AM
35	My PSA level rose by more than 100% each from the time I was 35 until I turned 40. At 39 the core samples tested showed no prostate cancer. At 40 the core samples showed cancer in three of the six sample sectors. I wouldn't have made it 55. I had that rare instance of rapidly advancing Prostate cancer in young men. What's the problem with a blood test?! We can learn a lot about a patient by taking blood. It's inexpensive, it was done as a part of my normal blood work annually. It costs next to nothing to do this and it saves lives. SHAME ON YOU. Btw, I'm adopted. No one knows what's in my family tree. So I'm grateful that I had a doctor	9/28/2015 8:47 AM
36	no	9/26/2015 12:30 PM
37	see question 12	9/25/2015 1:11 PM
38	Health plans should include PSA screening	9/25/2015 10:04 AM
39	no	9/25/2015 9:11 AM
40	See Question 7	9/24/2015 4:10 PM
41	x	9/24/2015 12:24 PM
42	Insurer will love the extra steps drs. must go thru before testing. That should minimize drs. recommending the test as it will mean more work for them. How stupid is that!!	9/23/2015 8:25 PM
43	They should support screening and treatment of prostate cancer, specifically with regard to effective forms of treatment, such as proton tx.	9/23/2015 4:07 PM
44	Delete this.	9/23/2015 2:21 PM
45	PSA screening should be included IF the patient feels they want a PSA test. After all, it only costs $25-35.	9/23/2015 1:19 PM
46	no	9/22/2015 10:37 AM
47	I understand that this is not widely believed, but every day people make decisions on the value of purchases. How an individual chooses to spend their money reflects the value to them of that product. When it is perceived that someone else is paying, we make different choices. I believe that Health plans should remove a PSA test done for the purpose of screening from their covered benefits.	9/22/2015 12:53 AM

Q11 Do you have any comments on our recommendation to employers and other health care purchasers (pg. 12)?

Answered: 47 Skipped: 0

#	Responses	Date
1	No.	10/16/2015 4:53 PM
2	While we are very supportive of shared decision making with this test, we are concerned about possible restrictions to patient access if employers/purchasers only contract with groups who do an "approved, certified or prescribed" shared decision making tools/process.	10/16/2015 3:05 PM
3	Be more directive with employers NOT to do unnecessary testing when offering work-place screening. (I have seen business models for workplace health workers that do harmful testing)	10/16/2015 1:44 PM
4	No	10/16/2015 11:47 AM
5	See answer to question 10.	10/15/2015 6:21 PM
6	No comments	10/15/2015 2:25 PM
7	There is more to healthcare than these recommendations. If cost-benefit is the only concern (as implied) it should also focus on prevention as well as part of the decision making process.	10/15/2015 12:26 PM
8	No. See above.	10/14/2015 8:01 PM
9	no	10/14/2015 7:26 AM
10	Agree	10/12/2015 6:00 AM
11	None. Well done.	10/10/2015 4:45 PM
12	No	10/9/2015 12:29 PM
13	NO	10/9/2015 11:25 AM
14	I'm all for evidence-based care and cutting waste where the evidence is clear and non-controversial, but I'm concerned this will be used as an excuse to deny care. I'm concerned patients will be denied testing (and/or doctors sanctioned for doing it). Not a few of the patients I see are high risk and don't know it. I find many of my colleagues still don't recognize breast cancer in female relative esp mom as a risk factor (as well as prostate CA in male), falsely reassuring patients they are low risk when in fact they may not be. My patients want to have the option of being tested if and when indicated, not told "too bad!" because it is no longer politically correct.	10/7/2015 5:42 PM
15	none	10/7/2015 12:37 PM
16	No	10/7/2015 11:50 AM
17	Agree	10/5/2015 11:59 AM
18	no	10/2/2015 8:05 PM
19	NO	9/30/2015 3:18 PM
20	No	9/30/2015 3:24 AM
21	Agree.	9/30/2015 2:47 AM
22	same as quesiton 10	9/29/2015 9:09 PM
23	no	9/29/2015 6:11 PM
24	Make testing mandatory	9/29/2015 6:09 PM
25	no	9/29/2015 6:04 PM
26	no	9/29/2015 5:06 PM
27	no	9/29/2015 4:20 PM
28	Offer PSA routinely	9/29/2015 8:37 AM

29	NA	9/29/2015 7:53 AM
30	no	9/28/2015 5:15 PM
31	no	9/28/2015 12:03 PM
32	no	9/28/2015 11:11 AM
33	Cover prevention and early detection	9/28/2015 9:28 AM
34	None	9/28/2015 8:55 AM
35	My PSA level rose by more than 100% each from the time I was 35 until I turned 40. At 39 the core samples tested showed no prostate cancer. At 40 the core samples showed cancer in three of the six sample sectors. I wouldn't have made it 55. I had that rare instance of rapidly advancing Prostate cancer in young men. What's the problem with a blood test?! We can learn a lot about a patient by taking blood. It's inexpensive, it was done as a part of my normal blood work annually. It costs next to nothing to do this and it saves lives. SHAME ON YOU. Btw, I'm adopted. No one knows what's in my family tree. So I'm grateful that I had a doctor	9/28/2015 8:47 AM
36	no	9/26/2015 12:30 PM
37	see question 12	9/25/2015 1:11 PM
38	No	9/25/2015 10:04 AM
39	no	9/25/2015 9:11 AM
40	none as long as the option for PSA testing remains an option for use based on discussions between the patient and his Dr...	9/24/2015 4:10 PM
41	x	9/24/2015 12:24 PM
42	See 10 above.	9/23/2015 8:25 PM
43	Support PSA screening.	9/23/2015 4:07 PM
44	Delete this.	9/23/2015 2:21 PM
45	If you want to save your employees life, identify the cancer early and get treated so they can be Cured. Waiting to save money on PSA testing may rack up huge cost to treat advanced PCa.	9/23/2015 1:19 PM
46	no	9/22/2015 10:37 AM
47	No comment.	9/22/2015 12:53 AM

Q12 Do you have any comments on our recommendation to the Washington State Health Care Authority (pg. 12)?

Answered: 44 Skipped: 3

#	Responses	Date
1	No.	10/16/2015 4:53 PM
2	We are concerned about the mandated use of shared decision making tool and how it will be implemented and what specific criteria will be used to designate what is considered a shared decision making tool.	10/16/2015 3:05 PM
3	No	10/16/2015 11:47 AM
4	We agree with the use of shared decision making processes being included in contractual requirements (ex ACO). Again, without the "State-approved patient decision aid".	10/15/2015 6:21 PM
5	The group was concerned about the mandated use of shared decision making tool and how it will be implemented and what specific criteria will be used to designate what is considered a shared decision making tool	10/15/2015 2:25 PM
6	A step back, rather than a step forward.	10/15/2015 12:26 PM
7	No.	10/14/2015 8:01 PM
8	no	10/14/2015 7:26 AM
9	Agree	10/12/2015 6:00 AM
10	Excellent. My experience with Group Health since my age of 70 is commendable and greatly appreciated. Discussions were open and considered my prior experiences with numerous other hospitals, doctors and insurance plans.	10/10/2015 4:45 PM
11	No	10/9/2015 12:29 PM
12	NO	10/9/2015 11:25 AM
13	I'm all for evidence-based care and cutting waste where the evidence is clear and non-controversial, but I'm concerned this will be used as an excuse to deny care. I'm concerned patients will be denied testing (and/or doctors sanctioned for doing it). Not a few of the patients I see are high risk and don't know it. I find many of my colleagues still don't recognize breast cancer in female relative esp mom as a risk factor (as well as prostate CA in male), falsely reassuring patients they are low risk when in fact they may not be. My patients want to have the option of being tested if and when indicated, not told "too bad!" because it is no longer politically correct.	10/7/2015 5:42 PM
14	none	10/7/2015 12:37 PM
15	No	10/7/2015 11:50 AM
16	no	10/2/2015 8:05 PM
17	NO	9/30/2015 3:18 PM
18	monitor this and see if it needs to be changed later.	9/30/2015 3:24 AM
19	This should be done soon.	9/30/2015 2:47 AM
20	Same as #10	9/29/2015 9:09 PM
21	no	9/29/2015 6:11 PM
22	No	9/29/2015 6:09 PM
23	Don't make one more "screening tool" that must be implemented for a check box; this is an important issue, but in the big scheme of things, clinics cannot keep up with the drips and drabs of everything that keeps getting added as a requirement and still provide adequate patient care	9/29/2015 6:04 PM
24	no	9/29/2015 4:20 PM
25	Offer PSA routinely	9/29/2015 8:37 AM
26	Agreed	9/29/2015 7:53 AM
27	no	9/28/2015 5:15 PM

28	no	9/28/2015 12:03 PM
29	no	9/28/2015 11:11 AM
30	no	9/28/2015 9:28 AM
31	None	9/28/2015 8:55 AM
32	My PSA level rose by more than 100% each from the time I was 35 until I turned 40. At 39 the core samples tested showed no prostate cancer. At 40 the core samples showed cancer in three of the six sample sectors. I wouldn't have made it 55. I had that rare instance of rapidly advancing Prostate cancer in young men. What's the problem with a blood test?! We can learn a lot about a patient by taking blood. It's inexpensive, it was done as a part of my normal blood work annually. It costs next to nothing to do this and it saves lives. SHAME ON YOU. Btw, I'm adopted. No one knows what's in my family tree. So I'm grateful that I had a doctor	9/28/2015 8:47 AM
33	no	9/26/2015 12:30 PM
34	Here Here JIM Absolutely i was getting regular PSA checks till 2009 (PSA 2.76) then they stopped all together , because they weren't required by the national health society to do the test any more . Today , i just made appointment to have my prostate removed by surgery, because i had a funny feeling in my penis (about 2 months ago) and had a PSA test done , guess what , I had a PSA of 9.56 and a Gleason score of 7 (8 out 12 positive for cancer from biopsy) . I think we could of done something earlier , but how do we know if no if one checks (by the way there is know prostate cancer in my family) Tom	9/25/2015 1:11 PM
35	Yes continue PSA screening without hitches	9/25/2015 10:04 AM
36	no	9/25/2015 9:11 AM
37	see question 7	9/24/2015 4:10 PM
38	x	9/24/2015 12:24 PM
39	Again, the more effort that goes into getting the testing done will certainly minimize the screening getting done. A really poor idea, and lives are at risk.	9/23/2015 8:25 PM
40	Support the use of PSA screening. Men are dead due to failure to diagnose. My life was saved through PSA screening. Saving one life is worth the cost. There is no better way to screen for prostate cancer than PSA, and subsequent bioposy, if required. Digital rectal identifies the cancer after it has grown beyond the molecular level and is harder to kill.	9/23/2015 4:07 PM
41	Another layer of contractual standards for medicine? I don't get it.	9/23/2015 2:21 PM
42	Recommend ALL men age 45 have an annual PSA test. If they have a family history or are African American start at age 40.	9/23/2015 1:19 PM
43	no	9/22/2015 10:37 AM
44	I would recommend extending the recommendation to remove screening PSA testing has a covered benefit to your recommendation to the Washington state healthcare authority. That is health plans Overseen by the authority should not include PSA testing done for the purpose of screening as a covered benefit.	9/22/2015 12:53 AM

Q13 Do you have any comments or suggestions on implementation and measurement (pg. 13)?

Answered: 47 Skipped: 0

#	Responses	Date
1	No.	10/16/2015 4:53 PM
2	We recommend that the HCA not be too prescriptive in its implementation, (ex. Requiring that the guidelines be embedded in an EHR) so to make it more widely adopted in various clinical settings and workflows.	10/16/2015 3:05 PM
3	No	10/16/2015 1:44 PM
4	No	10/16/2015 11:47 AM
5	1. We are vehemently opposed to more regulation. No PSA prior-authorization. 2. The "Cascade" in Appendix C should not be utilized. It is not accurate. 3. We agree that shared decision making regarding screening should be reimbursed, but the urologist, who is a primary provider for many men, should be included in this statement. 4. Oversight of PSA screening is not feasible and would likely be inaccurate. The administrative burden of tracking PSA screening is a negative for men's health and prevent screening in appropriate patients (eg. high risk patients).	10/15/2015 6:21 PM
6	We recommend that the HCA not be too prescriptive in its implementation guidelines so its possible for more groups to adopt the guidelines in a variety of clinical settings and workflow.	10/15/2015 2:25 PM
7	Need to go back to the drawing board. Research into prostate cancers is changing rapidly, The previous treatment algorithm has proven outdated and linked to the old saws and approaches of " It is the slowest growing of all cancers." "Something else will kill you before prostate cancer." True, unless you have one of the "aggressive forms of prostate cancers. This reads like a legislative, cost-saving approach to treatment, rather than overall effective patient treatment. The horse is out of the barn, boys and girls. As a prostate cancer victim facing and fighting the Grim Reaper on my part and for my family and loved ones, I would want a legacy of using all tools in treatment. If all tools had been appreciated and used two years ago or so instead of an outdated algorithm, my wife and I would be looking forward to starting our third careers instead of my third set of treatments..	10/15/2015 12:26 PM
8	No.	10/14/2015 8:01 PM
9	no	10/14/2015 7:26 AM
10	Thank you for your work on this issue - difficult to overcome the pressure from media and sports celebrities about this issue	10/12/2015 6:00 AM
11	Yes. As a so-called "high risk" category patient over 70 years of age with 15+ years of high PSA readings, I believe the Bree's recommendations are excellent. Records connecting Medicare into Group Health's patient records (electronic) could be a useful tool to track anonymous findings beyond age 70. Thank you for your professionalism, excellent review of data and solid, well-documented decision making for recommending implementation.	10/10/2015 4:45 PM
12	I would try to develop publicly available shared decision making tools to facilitation patient knowledge and preference setting without requiring medical care to do this.	10/9/2015 12:29 PM
13	NO	10/9/2015 11:25 AM
14	I hope it won't go as far as patients being denied testing and/or doctors sanctioned for doing it. I wouldn't be surprised if there are outliers, docs basically running mills or operating on autopilot who just automatically order PSA on everyone (male!), --that's not appropriate and if it is going on should be addressed, but I don't know of any. But there should be latitude for regular docs exercising prudent professional judgment to help their patients, and giving male patients a fraction of the choice women are given.	10/7/2015 5:42 PM
15	none	10/7/2015 12:37 PM
16	No	10/7/2015 11:50 AM
17	You really thought of prior authorization for PSA screening and your only objection is that it was too burdensome for heath care plans. Did you even think of the PCP who wastes hours of time on PA for this that and the other thing that is not in the best interest of our patients. Where is the representation of PCPs in this group. There does not seem to be representation from that group.	10/5/2015 11:59 AM
18	no	10/2/2015 8:05 PM

19	NO	9/30/2015 3:18 PM
20	No	9/30/2015 3:24 AM
21	No.	9/30/2015 2:47 AM
22	No, have said what is valid	9/29/2015 9:09 PM
23	no	9/29/2015 6:11 PM
24	No	9/29/2015 6:09 PM
25	no	9/29/2015 6:04 PM
26	no	9/29/2015 5:06 PM
27	no	9/29/2015 4:20 PM
28	Offer PSA routinely	9/29/2015 8:37 AM
29	NA	9/29/2015 7:53 AM
30	no	9/28/2015 5:15 PM
31	No	9/28/2015 12:03 PM
32	no	9/28/2015 11:11 AM
33	no	9/28/2015 9:28 AM
34	None	9/28/2015 8:55 AM
35	My PSA level rose by more than 100% each from the time I was 35 until I turned 40. At 39 the core samples tested showed no prostate cancer. At 40 the core samples showed cancer in three of the six sample sectors. I wouldn't have made it 55. I had that rare instance of rapidly advancing Prostate cancer in young men. What's the problem with a blood test?! We can learn a lot about a patient by taking blood. It's inexpensive, it was done as a part of my normal blood work annually. It costs next to nothing to do this and it saves lives. SHAME ON YOU. Btw, I'm adopted. No one knows what's in my family tree. So I'm grateful that I had a doctor	9/28/2015 8:47 AM
36	as above	9/26/2015 12:30 PM
37	see question 12	9/25/2015 1:11 PM
38	Screen for prostate cancer is vital to Early detection, treatment and xsurvival	9/25/2015 10:04 AM
39	no	9/25/2015 9:11 AM
40	See Question 7	9/24/2015 4:10 PM
41	x	9/24/2015 12:24 PM
42	3the issue of co-morbidity was on the table. But the studies don't seem to care or cover life style or other health factors in addressing life expectancy. At 70 how many will live to 90? do you even care? without cancer in them, some guys might actually live that long. I plan to - but, oh yeah, I'm now cancer free.....	9/23/2015 8:25 PM
43	Study this more. Clearly identify side effects, at an objective level, since there is little consensus on that, and focus on treatments that are effective and have few side effects. Measure from those levels. Count the lives saved. How many is enough to justify health screening of this kind? Only one. Mine was one of those.	9/23/2015 4:07 PM
44	Let's not put an age restriction or limit common sense medicine. 230,000 annual new diagnoses and 30,000 annual deaths should say enough. Similar to breast cancer!	9/23/2015 2:21 PM
45	Please include men and their families who are actually experience the results of these suggestions. See your local support group.	9/23/2015 1:19 PM
46	no	9/22/2015 10:37 AM
47	No comment.	9/22/2015 12:53 AM

Ginny,

There are many like me. In 2011 I was seen as a very fit, athletic 61 year old man who looked like he was in his early 50's. Good gene pool:)
But then I got my annual PSA test that went up from 1.1 to 9.9 in a little over a year. Off I went to see the Urologist and to my complete surprise I was diagnosed with stage IV advance prostate cancer. When I asked my Urologist when would I have found out (with out a PSA test) that I had cancer, his reply was that I would have probably found out when I broke my leg skiing and found out that I had cancer that has spread thought out my body.

I know you can't make policy decisions based on one man's voice but I hear this consistent story of this type of scenario across the country from many men.

Thank you for listening.

Comment to Lisa –

While you're "Always Working for a Safer and Healthier Washington"

would you also advocate that women skip PAP and mammogram screening since they also has certain controversies?

Just to put a face on the recommendation for you:

I have a father who was diagnosed and treated for Prostrate Cancer in his early 70's – he lived on to 87.

I have a step-father who DIED of Prostrate cancer in his late 60's – he was NOT screened until too late.

I did read the BREE study on the suggested web-site of 1000 men tested and 50 treated who experienced adverse effect there doesn't seem to be much any notice placed on the fact that they did not DIE of their cancer (at least as far as can be seen in the study results included).

Statistics do not lie but the manner in which they are presented can certainly lean toward the opinion and objectives of the publisher.

Sincerely –

-

Dear Rick,

Mike Glenn and Bob Mecklenberg were kind enough to share the draft Prostate Cancer Screening Report and Recommendations from the Bree Collaborative with Kas Badiozamani and me this past week.

This is obviously an important and timely topic, and I appreciate the opportunity to comment.

While much of the Bree draft recommendations echo that of the USPSTF, what I found particularly insightful were the extensive discussions of decision aids and shared decision making as it relates to prostate cancer screening.

Coincidentally, at Virginia Mason, we just competed a clinical trial in which 600 patients in primary care practices were randomized into one of 3 arms as it relates to PSA based prostate cancer screening:

1. Standard of care (with scripting)
2. Decision Aid alone (patients were provided with a DA similar to that included in the Bree document
3. Shared Decision Making (patients reviewed the DA point for point with their primary care provider in addition to a scripted conversation

Patients were subsequently provided with multiple questionnaires. The endpoints included:

1. Prostate cancer screening knowledge
2. Anxiety level vis a vie prostate cancer
3. Perception of quality of provided care
4. Ultimate decision as it relates to prostate cancer screening

We have completed patient accrual and data analysis and are in the process of writing a paper (I hope to have it ready for submission by the end of the month). Even though I suspect you may not be able to factor in the findings of our study without having an opportunity to review the final paper with your committee (and recognizing the tight time frame), I'd be happy to meet to show you the results. Most notably patients provided with a DA were far less likely to be satisfied with their care (even in the context of SDM). Further, these same patients had a lower prostate knowledge score and a higher level of anxiety. In short, regardless of the means by which it is provided, a DA as it relates to prostate cancer screening is viewed by patients in primary care settings negatively. Further, interestingly, the most satisfied patients were those in the SOC arm (rather than SDM).

This is not to say that SDM isn't important, but rather to wonder whether tying primary care provider productivity to SDM (as it relates to prostate cancer) is ideal.

The field of PSA based prostate cancer screening is muddled. Between PLCO and the European studies the data is clearly divergent. We believe that the best means of limiting harm is to tackle the issue of overtreatment of the disease rather than potentially impact the ability of patients to have access to screening. Further, we feel that there is under recognized value as it relates to the reassurance that a negative screening study (low PSA or negative prostate needle biopsy) provides.

I'd be happy to meet to review our above data if you're available.

Best,

J

John M. Corman, M.D.
Medical Director
Virginia Mason Cancer Institute

1100 9th Avenue, C7-URO, PO Box 900
Seattle, WA 98101
206-223-6772
FAX 206-223-7650
VirginiaMason.org

Here Here

Absolutely i was getting regular PSA checks till 2009 (PSA 2.76) then they stopped all together , because they weren't required by the national health society to do the test any more . Today , i just made appointment to have my prostate removed by surgery, because i had a funny feeling in my penis (about 2 months ago) and had a PSA test done , guess what , I had a PSA of 9.56 and a Gleason score of 7 (8 out 12 positive for cancer from biopsy) . I think we could of done something earlier , but how do we know if no if one checks

Ginny,

How many prostate cancer survivors do you have on your policy making committee?

Your recommendation on PSA screening will put us back 20 years when men were diagnosed with prostate cancer because of back pain. When the cancer had already spread to their bones. Sure saved a lot of money because men died shortly thereafter.

I would encourage you to attend one of our prostate cancer support groups here in Olympia to hear "real life" stories of men having advanced prostate cancer because they were not getting annual PSA tests. As you may know, there are no warning signs of prostate cancer. That's why it is often regarded as a "silent killer".

The WA health dept. had a Prostate Cancer Task Force for many years, but discontinued it two years ago. It looks like no one really cares if men die of prostate cancer.

The American Cancer Society has stated, "get it early and get it our" if you want a cure. Once cancer has spread to other parts of the body, there is NO CURE.

Respectfully,

Member of Olympia PCa Warriors group

DAVID NORRIS CONSULTING, LLC

DECISION ANALYSIS · CAUSAL INFERENCE · PREDICTIVE MODELING

October 14, 2015

Ginny Weir
Program Director
The Bree Collaborative
705 Second Ave, Suite 410
Seattle, WA 98104

Dear Ms. Weir:

Thank you for inviting comment on these draft Recommendations. I applaud the draft's consistent emphasis on *formally* and *accountably* engaging patients in decision-making. My suggestions for improving these Recommendations are directed to 3 aims:

- Future-proof your recommendations by grounding them explicitly in a decision-theoretic problem analysis recognizing the conditions that have necessitated your recommendations, and anticipating future developments likely to supersede them.
- Abandon the draft's academic voice in favor of plainer language accessible to policy-makers, journalists and the public.
- Scrupulously avoid language that blurs distinctions between the interests of health consumers and the interests of payers.

Executive Summary

Your Executive Summary will be much more effective if it highlights several characteristics of prostate cancer screening that surely will have shaped the Workgroup's deliberations and recommendations:

1 Stress in plain language the near-inevitability of prostate cancer, as suggested in the numbers provided on p. 4. Embedding a graphic along the lines of Figure 1 from Rebbeck & Haas[1] may be necessary to communicate this fact with full impact.

2 Draw the contrast between the obvious (but wrong) question, "Do I have prostate cancer?" and the subtler (and more useful) *precision medicine* question, "Given the prostate cancer I already have (or hope to live long enough to develop), which dynamic plan of screening, testing and treatment/surveillance has the best balance of benefits and harms for me?"

3 Highlight the core fact that makes these Recommendations necessary, and determines their form and content: No widely accepted predictive model is available for converting the *data* from PSA testing into *information* useful as input to rational, personalized choice of the next action to take in this intrinsically *dynamic* decision problem. (Cf. 'future-proofing'.)

4 Acknowledge the paradox this gives rise to, such that the acquisition of *more data* may lead to a *worse decision*. This is a true paradox, and should be addressed *as such* in an Executive Summary aimed at a general audience. (That this paradox is rife in clinical medicine, that many clinicians are inured to it and fail to see it for the truly remarkable thing it is, does not diminish *but only increases* the need to address this paradox explicitly.)

5 Introduce *overdiagnosis* by name in your Executive Summary. This is by far the most important single word describing the problem your recommendations aim to address, and it cannot be omitted from an Executive Summary.

Points of usage

On various points, usage in the draft could be changed to communicate more precisely and effectively the aims of the Workgroup:

"reduce variation in PSA testing rates" (p. 13)

- The Workgroup may wish to clarify that it aims to reduce *unwarranted* or *idiosyncratic* variation in PSA screening practices. This would be the intent of ESHB 1311 in citing "variation in practice patterns" specifically as an "*indicator* of poor quality" (emphasis mine). Although the legislation's mandate does include in general "identifying goals for appropriate utilization rates," it would of course be unthinkable to undertake such 'central planning' of so personal a decision as PSA screening.

"men deserve to be aware of the cascade of decisions that may be *put into motion* by having a PSA test" (p. 13; emphasis mine)

- I have already indicated an analysis of key underlying *concepts* in remarks (3, 4) above regarding the Executive Summary. Here, I stress rather that this language is entirely in the wrong *spirit*. Men deserve in fact to be aware that there is **no such thing** as a self-propelling cascade of actions *entailed* by any medical test result or other finding. (The obvious exception—the acute emergency in the unresponsive patient—only proves the rule.)

"associated with"

- This phrase should be expunged from the Recommendations. In the biomedical literature this tiresome argot is employed to affect a kind of false modesty, to avoid the appearance of impropriety in drawing causal claims from non-experimental data. The academic luxury of holding causality at arm's length is however unavailable to a workgroup aiming to advise clinicians how to act. (By definition, *causal* effects are the effects of *interventions/actions*.[2]) Thus, I advise edits such as:
    - However, evidence conflicts as to whether the PSA test when used for prostate cancer screening ~~has been associated with reductions in~~ **reduces** prostate cancer mortality~~., and if present,~~ **Any** absolute risk reduction is small, **likely not exceeding ___ deaths per 100,000 men.** (pp 2, 3)
    - Use of the PSA test ~~has been associated with an~~ increase**s** ~~in~~ the number of men diagnosed and ~~is~~ also ~~associated with a~~ shift**s** ~~from~~ diagnosis ~~of~~ **from** later-stage disease to earlier-stage disease. (p 3)

"PSA testing may expose men to increased risk of harm, lower quality of life, and undue cost" (pp. 1, 2, 4, 15)

- My expectation is that under current arrangements the *financial* costs of PSA testing (as opposed to *quality-of-life* costs mentioned separately) are likely to be borne mainly by (government and private) insurers. If this expectation is wrong, and if there are indeed significant financial costs actually borne directly by patients, then this would be a genuinely interesting fact deserving special discussion. If this is the case, please quantify these costs separately from those borne by insurers; however, if my expectation is correct then please clarify as follows:
    - PSA testing may expose men to increased risk of harm and lower quality of life**, and may unduly burden public and private insurers with needless costs.**
- Alternatively, the word 'cost' could simply be expunged, since (see p. 10) the Workgroup seems to have specifically avoided endorsing any cost-effectiveness studies in what is described as a "mixed" literature.

On quoting the literature

- It is appreciated that the Workgroup has undertaken a substantial effort to assemble and review relevant literature.
- But many quoted numerical facts are tossed in desultorily, rather than assembled methodically to corroborate a coherent view of the problem already expressed in clear prose. The 2nd sentence of your Problem Statement (p. 3) is but one particularly egregious example of the many 'number grenades' with which the whole draft is littered.
- These, along with the abovementioned proliferation of "associated with," contribute to a quasi-academic tone that creates unnecessary distance between your Recommendations and the broad audience they should reach.
- A formal approach to rectifying this would be to adopt an editorial policy relegating all numerical support to figures, tables and footnotes. Thus denuded, the prose will more clearly exhibit deficiencies of analysis and of synthesis that need to be addressed, and will be more amenable to the necessary revisions.

On 'scientific uncertainty'

- This term appears 11 times on 5 pages in the draft, and is given pride of place beside 'benefits' and 'harms' among those core elements of the PSA screening decision-problem to be communicated to men during shared decision making.
- Yet nowhere in the draft is this uncertainty treated analytically or coherently. This omission is conspicuous.
- Undertaking an explicit, decision-theoretic exploration of the prostate cancer screening problem *from an individual-patient perspective* should provide you with a conceptual framework for elaborating those aspects of 'scientific uncertainty' to be communicated in shared decision making around PSA testing.
- In such an exploration, you may find that the 'scientific uncertainty' in this matter can be largely identified with *the lack of an accepted predictive model*, as discussed in comment 3 above. Identifying 'scientific uncertainty' thus with what is often called 'model uncertainty' would enable you to discriminate it from other forms of uncertainty implicated in this problem, such as 'parameter uncertainty' and 'stochastic uncertainty'. (See e.g. the taxonomy of uncertainty provided in Table 1 of Briggs et al.[3]) To be useful, notions of 'uncertainty' must serve as *analytical devices* having discriminatory power. But as used in this draft, 'scientific uncertainty' serves merely as a *convenience*—much like a 'wastebasket diagnosis' in medicine.
- Please consider that, chief among the opportunities created by assembling a Workgroup such as yours are:
    - to coherently frame a complex decision problem that has been widely misinterpreted or misunderstood
    - to characterize the forms of uncertainty involved, along with their anticipated future resolution
    - to establish thereby both *present* and *forward-looking* guidance to the development of patient decision aids.
- Its failure explicitly to analyze 'scientific uncertainty' makes inevitable this draft's deference to "the [individual] physician's interpretation of the evidence … [regarding] *overall benefit*" (p. 1; emphasis mine). In recommendations from a body convened to reduce unwarranted variation in clinical practice, this seems a perverse capitulation to idiosyncratic variation at the provider level. Equally concerning is that (through the reference to *overall* benefit) the draft's language here subverts the precision medicine principle that *it is at the **individual-patient** level where variation arises appropriately*—a principle entirely aligned with the draft's otherwise consistent emphasis on informed patient engagement in decision-making.

I thank the Workgroup for its efforts to bring multiple stakeholders into convergence against unwarranted variation in PSA screening practices in the State of Washington. The problem is well selected—important not only in its own right, but also as a mirror of grand themes pervading clinical practice and our health system. Again, **I heartily applaud this draft's consistent emphasis on formally and accountably engaging patients as informed participants in health decision-making.** My comments are offered entirely in the spirit of supporting you in achieving that end.

Sincerely,

David C. Norris, MD
David Norris Consulting, LLC
523 Broadway E, Suite 348
Seattle, WA 98102-5348
david@dnc-llc.com

1. Rebbeck, T. R. & Haas, G. P. Temporal trends and racial disparities in global prostate cancer prevalence. *Can. J. Urol.* **21,** 7496–7506 (2014). http://www.canjurol.com/html/free-articles/V21I5_15_FREE_DrRebeck.pdf

2. Pearl, J. *Causality: Models, Reasoning and Inference*. (Cambridge University Press, 2009).

3. Briggs, A. H. *et al.* Model Parameter Estimation and Uncertainty Analysis: A Report of the ISPOR-SMDM Modeling Good Research Practices Task Force Working Group–6. *Med. Decis. Making* **32,** 722–732 (2012).

C R Y S T A L R E S E A R C H

9112 Tucker Road SE, Olympia, WA 98513-8904 • TEL: (360) 459-2455 • query@crystal-research.com

Comments on Bree Draft Prostate Cancer Screening Recommendations (Sept 2, 2015)

As a prostate cancer patient, I am disturbed by your injudicious tradeoffs, by your proposal to impose restrictions before, rather than after, PSA screening, and by your failure to include prostate cancer specialists or patients in your panel. Moreover, as a research scientist and editor of a scientific journal, I object to the confusion between side effects of diagnosis vs. treatment and to the lack of essential data in the reference and figure you cite. My specific objections are as follows:

1. Recommendations based on comparison between outcomes of different treatments are usually valid. In contrast, recommendations based on tradeoffs between improved outcome and cost, although increasingly common, are controversial. However, neither of these situations applies to the present case, since PSA tests are low-cost and have as yet no comparable alternative.

2. Recommendations based on tradeoffs between outcomes and side effects are only acceptable if they correspond to the priorities of patients who have undergone or are likely to undergo such treatment. However, your report shows no indication of having consulted such patients. Having had contact with hundreds of such patients in USTOO meetings, I can assure you that the overwhelming consensus is that side effects, such as biopsy-caused infections, impotence, or incontinence, although highly undesirable, are less threatening than the possibility of suffering or death due to advanced prostate cancer. If you choose to hold a public hearing on the matter, I think you will be swamped with prostate cancer patients who would corroborate this prioritization.

3. Your report seems to be based on the principle that “ignorance is bliss”. Considerations of ultimate outcomes are valid with regard to treatments but should not be applied to the evaluation of diagnostic procedures. On the contrary, except in cases where the diagnostic procedure itself is extremely expensive, dangerous, or misleading, diagnosis is always valuable. By way of example, PSA tests are analogous to the role of mammograms in detecting breast cancer; neither test is as specific or sensitive as we might wish but the diagnostic value is greater than the cost or discomfort.

4. The proper place to consider regulation is after an adverse PSA test and before radical treatment. A PSA test is primarily an indication that further diagnosis is needed. However, a minority of patients develop a get-this-thing-out-of-me panic and a minority of physicians, motivated by ignorance or greed, urge treatment without further diagnosis. Therefore, it is at this point that restrictions, such as the ones you propose, might be applicable. I strongly recommend that you alter your report accordingly.

5. A major problem with your recommendations (and with the reference you cite) is the limits on age and lifespan. The risk of prostate cancer increases with age and the onset-to-death span is highly variable. Men in their eighties have been diagnosed with aggressive prostate cancers that have killed them within a few years.

6. Finally, I feel obliged to take issue with Figure 1, which is the most dramatic confirmation of your premise. The referenced website that posted this infographic cited a reference to a paper which led to a reference that I could not access. However, judging from the infographic itself, the study appears to be flawed, if not downright biased. By way of preliminary comment:

- The method of group selection, time period of the study, and the mode of PSA screening are not described in any detail. However, it should be noted that one year of PSA screening is inadequate. The most significant aspect of PSA screening is a rise after a period of stability, which apparently was not considered here.
- The degree of specificity, although far from ideal, is adequate. Essentially 80% of the group are cleared and the remaining 20% have a 50% likelihood of having prostate cancer.
- The study lumps together side effects of diagnosis with side effects of treatment for cancer. This is either stupid or highly biased, since the alternative of the latter would be advanced cancer or death.
- The second half of the infographic (i.e. the unscreened group) merely shows five PCa deaths. It does not show the number ultimately diagnosed with prostate cancer—which should be the same as the number in the first group. If it is less, then the difference would represent the number of men who have prostate cancer and don't know it!
- No numbers are given for the aggressiveness and staging of the cancers. I suspect that the screened group would have earlier stages, because of earlier diagnosis and treatment.

Finally, I hope that you will carefully consider the apparent gender bias of your report. Prostate cancer and breast cancer are closely parallel in number of cases, number of deaths, and inadequacy of screening techniques. And yet, I doubt that you would have the temerity to recommend against mammogram screening.

Sincerely,

Paul J. Shlichta

October 7, 2015

Ms. Weir: While deleting old messages I found this from Jim. Adding to his point, my son age 51, had suggested to his Dr. A PSA exam because I had told all of my boys about my P cancer at age 75. She told him no need, as I found mine at such old age. Then when frequency & urgency necessity sought a urologist, they found PSA 11, T2, & G. 3+4 , the same as mine. He gets De Vince surgery in 8 days.

Please reconsider testing.

Found the Bree information in a different folder. I having some delay on my email/internet server. Will read it and submit my point of view, as one who was not actively screened and followed up even after a diagnosis of BPH, which puts me in that category of men who are now fighting actively for my life. I continue to be amazed by those in the research community who cannot make the link to those who will die. As one who used to be in the scientific research community, I can definitively note the difference between being a statistic and being one who may die.

Just read the draft of the Bree survey and took the survey to offer my feedback.

While I am a rather more casual attendee of Jim Kiefert's Olympia support group than others, I still am amazed at the determination of people trying to provide "quality health" care that would actually continue to support this concept.

I really do not understand what the benefits are - really. I am white, 66, college educated, well read, and reasonably healthy. I plan to see my grand-daughters graduate from high school, if not from college. I certainly plan to outlive my ex-wife.

I've had a biopsy of my prostate - didn't kill me. I've had surgery to remove that cancer, after consulting probably 5 or six doctors. I've had additional surgery (my choice) to address some side effects - yep, still alive.

Why? Because a general practitioner cared enough to encourage me to be screened then sent me to a urologist when the screen came back a bit high. I'm living evidence of the benefits of screening.

I could relate horror stories I've heard regarding what happens when symptoms are the alert that cancer is present. Not on my list of things to experience.

I suppose you will do what you want with the survey. But I for one will tell my sons and sons-in-law what they need to do - and as I have some experience behind me, I believe they will listen.My previous doctor (now retired) saved my life by believing in screening. My current doctor was selected because he supports screening - even though I no longer have the cancer I still do the blood work every 6 months....I sleep better.

Failure to screen only helps the insurance companies as far as I can see. Please don't condemn men who don't know to fight for this, to waiting for symptoms before discovering they have cancer.

regards,

6 year and counting survivor thanks to screening

Washington State Hospital Association

October 16, 2015

Hugh Straley, MD, Chair (hlstraley@comcast.net)
Dr. Robert Bree Collaborative

Rick Ludwig, MD, Chair (rickl@pacmed.org)
Prostate Cancer Screening Workgroup Chair

Foundation for Health Care Quality
705 Second Avenue, Suite 410
Seattle, Washington 98104

Re: Dr. Robert Bree Collaborative – Prostate Cancer Screening

Dear Doctors Straley and Ludwig,

The Washington State Hospital Association (WSHA) acknowledges the considerable efforts by the Prostate Cancer Workgroup in developing the recommendations, which seek to address the variation or overuse of prostate cancer screenings. We respectfully submit the following comments on behalf of our 99 member hospitals.

As an active participant in the Bree Collaborative, WSHA fully supports efforts to improve patient safety and reduce costs associated with prostate cancer screening. While prostate cancer is the most common type of cancer diagnosed among men, screening guidelines vary, leading to the potential of overtreatment or unanticipated outcomes. Given the conflicting evidence, we support the Bree Collaborative's recommendation which acknowledges the variations between guidelines while placing emphasis on a shared decision-making process.

We hope the use of evidence-based guidelines and a shared decision-making process will lead to fewer and more appropriate prostate cancer screenings across the state.

Should you have any questions, please feel free to contact me.

Sincerely,

Ian Corbridge
Policy Director, Clinical Issues
Washington State Hospital Association

ec: Ginny Weir, Program Director gweir@qualityhealth.org
Bob Perna, Senior Director rjp@wsma.org
Carol Wagner, Senior Vice President, Patient Safety carolw@wsha.org
Claudia Sanders, Senior Vice President, Policy Development claudias@wsha.org

Enclosure

Enclosure: PSA Screening

WSHA's comments on the Bree Collaborative prostate cancer screening recommendations appear in order and format as they do on the Bree Collaborative public comment survey tool.

1. **What sector do you represent?**
    - Hospitals/health care

2. **Do you have any comments on the problem statement including on screening test accuracy and harms?**
    - Yes, we think this has promise for improving quality and controlling costs.

3. **Do you have any comments on PSA testing guidelines including additional guidelines that we should consider?**
    - We support the adherence of guidelines in clinical practice and believe that they have the potential to improve health outcomes and reduce health care costs.

4. **Do you have any comments on shared decision-making including suggestions for specific patient decision aids?**
    - We strongly support the concept of shared decision-making.

5. **Do you have any comments on prostate cancer treatment trends?**
    - No.

6. **Do you have any comments on our primary care recommendation against routine screening for average risk men under 55 or over 70 years old, with significant co-morbid conditions, or with a life expectancy less than 10 years?**
    - No.

7. **Do you have any comments on our primary care recommendation that clinicians who believe there is overall benefit to screening with the PSA test "should order this test for average risk men between 55-69 years old only after a formal and documented shared decision-making process" OR if clinicians believe there is overall harm from screening "may initiate testing of average-risk men aged 55-69 at the request of the patient after a formal and documented shared decision-making process."**
    - No.

8. **Do you have any comments on our recommendations for men belonging to a higher risk group?**
    - No.

9. **Do you have any comments on our recommendations to hospitals?**
    - No.

10. **Do you have any comments on our recommendation to health plans?**
    - No.

11. **Do you have any comments on our recommendation to the Washington State Health Care Authority?**
    - No.

12. **Do you have any comments or suggestions on implementation and measurement?**
    - No.