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Cancer Center



Us TOO NEW YORK
SUPPORT AND EDUCATION FOR PROSTATE CANCER FIGHTERS
THROUGHOUT THE NEW YORK METROPOLITAN REGION

Webinar Thursday April 16 at 6PM

Making Decisions about Prostate Cancer: Do **Decision Aids** Actually Help Us?



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Disclosures

Andrew Vickers is named on a patent for a statistical method to detect prostate cancer that has been commercialized as the 4Kscore test by OPKO Health. Andrew Vickers receives royalties from sales of the test and has stock options in OPKO Health.

Photos in the presentation are stock photos.



COVID-19 resources



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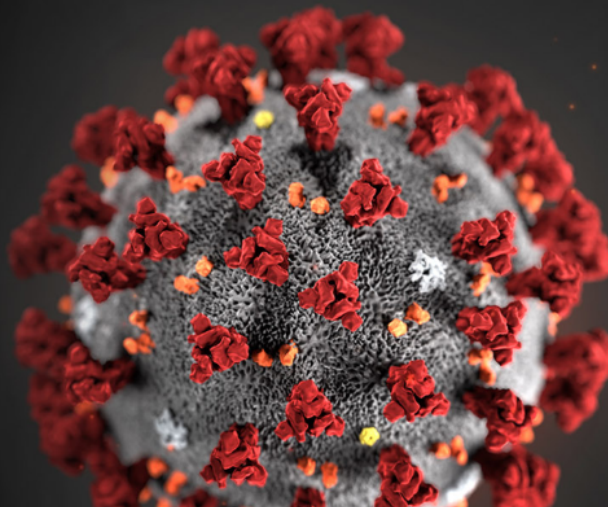
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Understanding the Coronavirus (COVID-19)

Learn about our preparedness for COVID-19 and our updated policies to protect our patients and staff.

[What you need to know](#)



<https://www.mskcc.org>



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ASCO page has a series of links on COVID-19

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BLOG

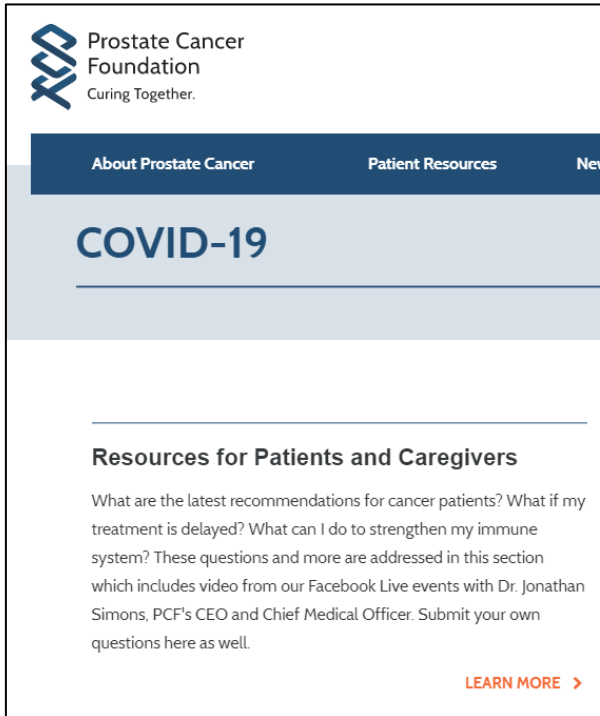
Coronavirus and COVID-19: What People With Cancer Need to Know

<https://www.cancer.net/blog/tags/coronavirus>



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PCF also has COVID-19 resources



The screenshot shows the Prostate Cancer Foundation website. At the top left is the PCF logo with the text "Prostate Cancer Foundation" and "Curing Together." Below this is a navigation bar with "About Prostate Cancer", "Patient Resources", and "New". The main heading is "COVID-19". Below the heading is a section titled "Resources for Patients and Caregivers" with a paragraph of text and a "LEARN MORE >" link.

Prostate Cancer Foundation
Curing Together.

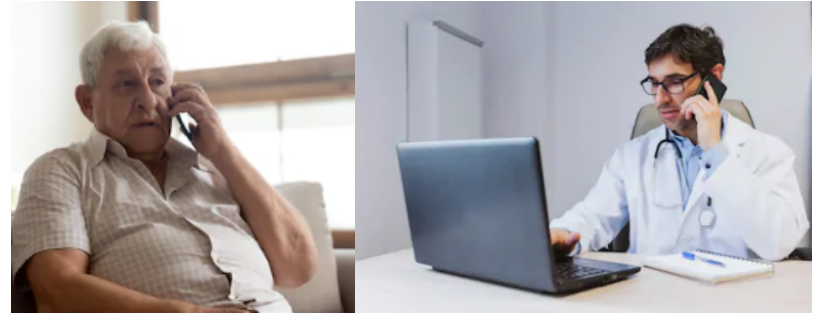
About Prostate Cancer Patient Resources New

COVID-19

Resources for Patients and Caregivers

What are the latest recommendations for cancer patients? What if my treatment is delayed? What can I do to strengthen my immune system? These questions and more are addressed in this section which includes video from our Facebook Live events with Dr. Jonathan Simons, PCF's CEO and Chief Medical Officer. Submit your own questions here as well.

[LEARN MORE >](#)



Every man's prostate cancer is different.

Talk to your doctor – by phone or video chat – about any changes in your care.

<https://www.pcf.org/covid-19/>



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A rustic wooden frame with a white sign inside. The sign has text in a typewriter font. The frame is placed on a black and white checkered cloth. In the background, there is a white ceramic vase with a floral pattern and a green plant with small round leaves.

THIS TOO SHALL PASS.

IT MAY PASS
LIKE A
KIDNEY STONE,
BUT IT WILL PASS.



Preference-sensitive decision

- More than one reasonable path forward (or option of doing nothing)
- Different paths have different combinations of benefits and risks

**Is the decision
preference-
sensitive?**



**Is the decision
preference-sensitive?**





At What Age Should You Get Screened for Prostate Cancer?

The following prostate cancer screening guidelines apply to men expected to live at least ten years.

Men ages 45 to 49

Men ages 45 to 49 should have a baseline PSA test.

- If the PSA level is 3 ng / mL or higher, men should talk with their doctor about having a biopsy of the prostate.
- If the PSA level is between 1 and 3 ng / mL, men should see their doctor for another PSA test every two to four years.
- If the PSA level is less than 1 ng / mL, men should see their doctor for another PSA test between the ages of 51 and 55.

Men ages 50 to 59

Men ages 60 to 70

Men ages 71 to 75

Men ages 76 and older





Is Prostate Cancer Screening Right for You?

Understanding the Potential Benefits vs. Risks for Men 55–69

Before deciding whether to be screened, men should have an opportunity to discuss the potential benefits and harms of screening and incorporate their values into the decision.

”shared decision making”

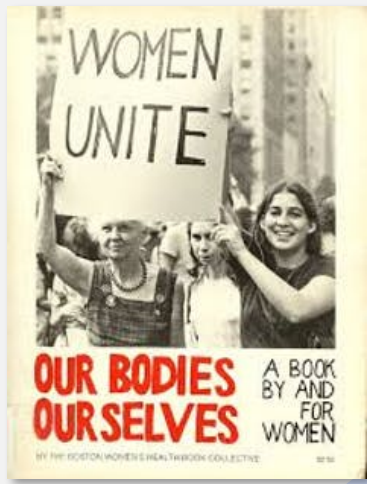


The clinician offers
options
and describes the
risks & benefits

The patient
expresses his
values and
preferences

How did we get here?





Women's Health Movement

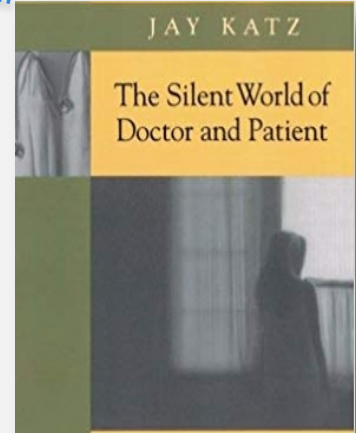
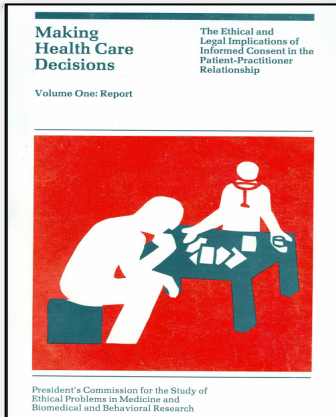
(1970s)
Medical ethicists
Patient autonomy

Critique of paternalism
"Just trust the doctor"

(1982)
Presidential commission explicates
"Shared Decision Making"
for the first time

(1984)
Jay Katz publishes book

Increased availability of online health information



The solution? DECISION AID



Prostate Specific Antigen (PSA) Test

Use this Grid to help you and your healthcare professional decide whether or not you will have a prostate specific antigen (PSA) test. This test measures the amount of activity in your prostate. Men usually consider this test when they are aged 50 or older.



Frequently asked questions	Having a PSA test	Not having a PSA test
If my PSA level is high, what are the chances that I have prostate cancer?	30 out of every 100 men with a high PSA level (30%) have prostate cancer. Other causes of a high PSA level are inflammation and infection.	If you choose not to get the PSA test then you will not know your PSA level.
If my PSA level is normal, can I be sure that I don't have prostate cancer?	No, you cannot be sure. About 15 out of every 100 men (15%) with a normal PSA level do have prostate cancer.	If you choose not to get the PSA test then you will not know your PSA level.
Will getting the PSA test reduce my risk of dying from prostate cancer?	At most, 1 death is prevented for every 1000 men who get the PSA test (0.1%). 4 out of every 1000 men who get the PSA test (0.4%) will still die from prostate cancer.	5 out of every 1000 men who do not get the PSA test (0.5%) will die from prostate cancer.
What are the advantages?		



Prostate Cancer Screening: Making the Best Choice

HELP EXIT

- Introduction
- How to Use this Program
- Making the Best Decision
- Prostate Cancer Facts
- Screening
 - What is "Screening"?
 - Is Screening Right for You?
 - Steps Involved in Screening
 - Screening Results
- Treatment Issues
 - Facts About Treatment
 - Decisions About Treatment
 - Side Effects of Treatment
 - Steps You Can Take
 - Know Your Risk Factors
 - Learn the Symptoms
 - Talk with Your Doctor
- Decision Aid
 - Your Decision Worksheet
 - More Information
 - Statistics & Research
 - National Organization Links
 - Glossary
 - References

WELCOME TO

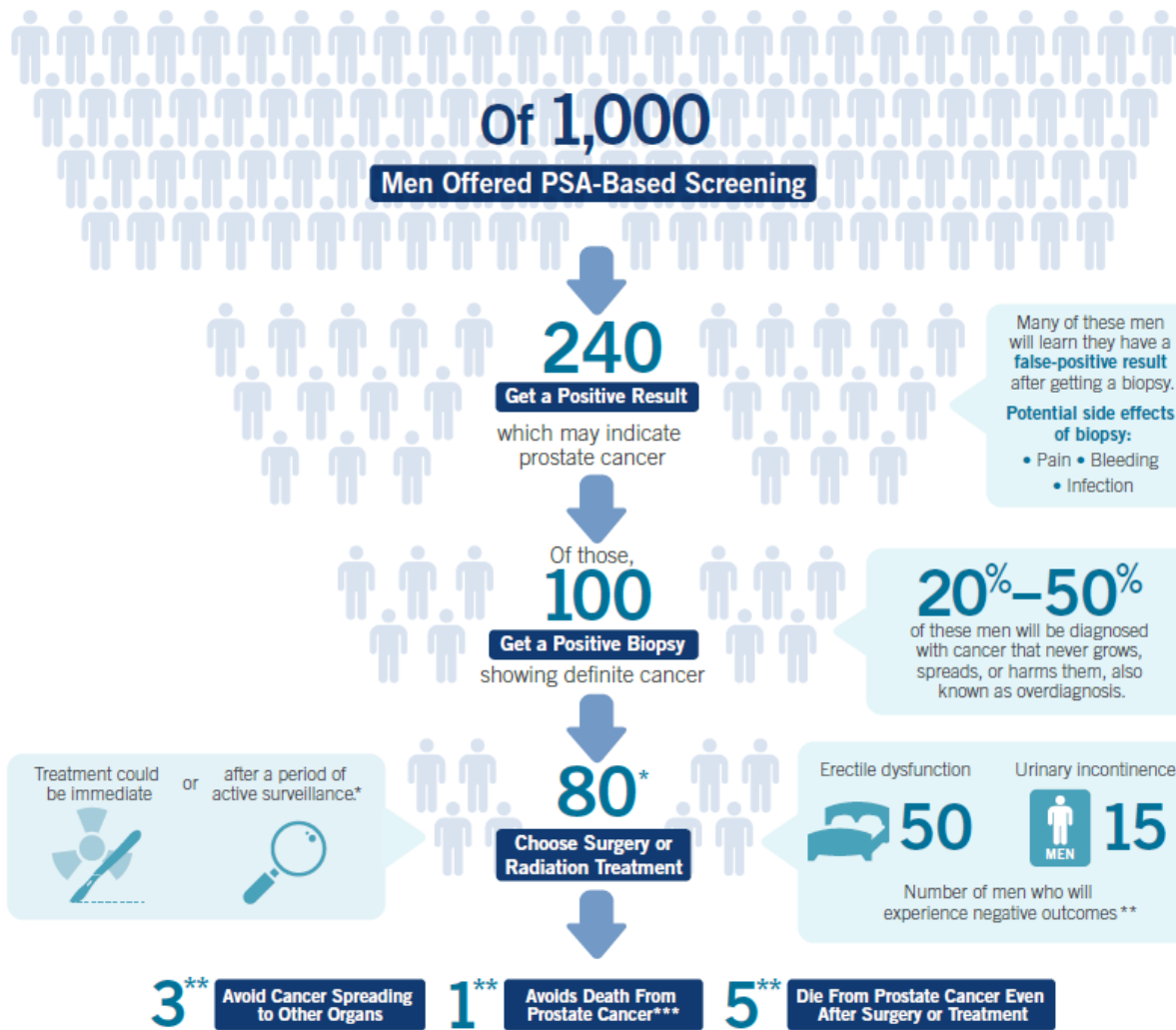
Prostate Cancer Screening: Making the Best Choice

[Click here to get started](#)



Content updated January 2014






Prostate Specific Antigen (PSA) Test *Yes or No?*

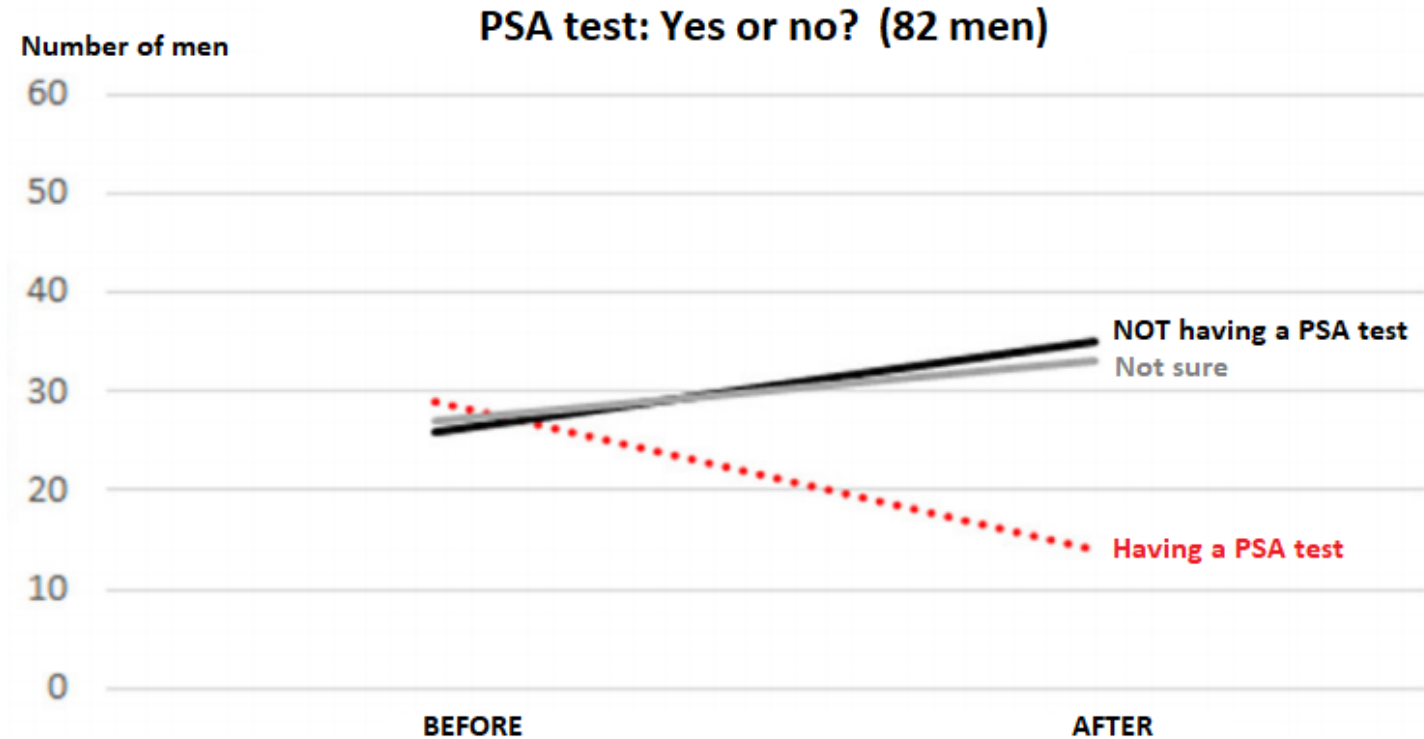
The prostate-specific antigen (PSA) test looks for signs of prostate cancer in your blood. Use this decision tool to help you and your healthcare team decide whether or not to have a PSA test. Men usually consider this test when they are between 55 and 69 years old. Men of black race may have different risks.

Patient Questions	Having a PSA test	Not having a PSA test
What does the test involve?	This blood test measures the level of prostate specific antigen (PSA) in your blood. Discuss costs.	No blood test is done.
Does a high PSA level mean I have cancer?	High PSA levels can be due to many reasons, including infection. To check for cancer, you will likely have a sample taken from your prostate gland (a prostate biopsy).	You will not know your PSA level.
Does a normal PSA test mean I do not have cancer?	No, about 15 of 100 men (15%) with a normal PSA level will have prostate cancer sometime in the next 15 years.	You will not know your PSA level.
How many men will die from prostate cancer?	Up to 6 of 1,000 men (0.6%) will die from prostate cancer sometime in the next 15 years.	Up to 7 of 1,000 men (0.7%) will die from prostate cancer sometime in the next 15 years.
What are the benefits?	Benefits are uncertain. You may be the 1 man in 1,000 (0.1%) who avoids death from prostate cancer.	You will avoid biopsies, having prostate cancer treatment, and the risks that come with having treatment.
What are the risks?	If your PSA level is high, you will likely have an outpatient prostate biopsy. About 3 of 100 men (3%) will have a cancer that causes worry, but is unlikely to cause problems. Biopsies and treatments have risks.	You could be the 1 man in 1,000 (0.1%) who might have avoided death from prostate cancer sometime in the next 15 years.
What are the risks of a prostate biopsy?	Most men have pain or bleeding for a few days after a biopsy. Of 100 men: <ul style="list-style-type: none"> • 9 (9%) have infection including 1 (1%) needing emergency care • 7 (7%) have serious bleeding • 3 (3%) have problems peeing • 3 (3%) stay in the hospital for a problem after a biopsy 	You will avoid the risks of having a prostate biopsy.
What are the risks (if testing leads to treatment of prostate cancer)?	Of 100 men treated for prostate cancer: <ul style="list-style-type: none"> • more than 60 (60%) will have problems with erections • about 20 (20%) will leak pee 	Of 100 men not treated for prostate cancer: <ul style="list-style-type: none"> • up to 47 (47%) will have problems with erections • about 10 (10%) will leak pee



Here's the menu.
What do you choose?

Users of the Option Grid decision aid shifted men's preference away from having the PSA test



Review of research studies of PSA screening decision aids



↓ Decisional conflict

↑ Knowledge

19 studies

Did not affect whether physicians and patients discussed screening

Did not affect men's decision to undergo screening

Conclusion: Should decision aids be used?
Not convinced...

Review of research studies of prostate cancer treatment decision aids



Decisional
conflict
(maybe)

Knowledge
(maybe)

Satisfaction with
decision
(maybe)

Did not affect
treatment choice

14 studies

Conclusion: Decision aids would benefit from **user-centered design** that promote shared decision making

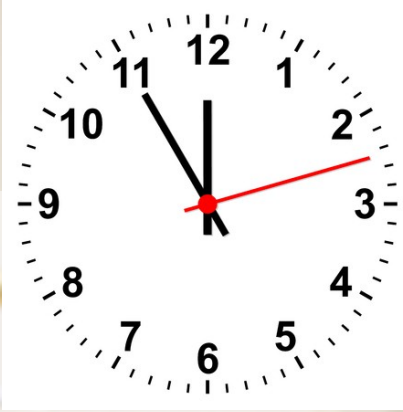


It is difficult to describe harms and benefits

People's preferences may vary over time



The real world...



Too much information Overwhelming



Information that might be difficult to understand

The United States Preventive Services Task Force has analyzed the data from the PLCO, ERSPC, and other trials and estimated that, for every 1,000 men ages 55 to 69 years who are screened every 1 to 4 years for a decade (5):

- 0 to 1 death from prostate cancer would be avoided.
- 100 to 120 men would have a false-positive test result that leads to a biopsy, and about one-third of the men who get a biopsy would experience at least moderately bothersome symptoms from the biopsy.
- 110 men would be diagnosed with prostate cancer. About 50 of these men would have a complication from treatment, including erectile dysfunction in 29 men, urinary incontinence in 18 men, serious cardiovascular events in 2 men, deep vein thrombosis or pulmonary embolism in 1 man, and death due to the treatment in less than 1 man.

Too little information to allow men to decide

“Some men will be helped because an aggressive cancer is cured but some men will be harmed by overtreatment”

“Treatment can lead to urinary, bowel, sexual and other health problems that may be significant or minimal, permanent or temporary”

Inaccurate information

“It is currently not possible to predict which men are likely to benefit from treatment”

Unknown potential of the opponent? Not true.



LITERACY

- Average person reads at a **7th – 8th** grade reading level
- Decision aids are written at a **9th** grade reading level or higher





Which of the following numbers represents the biggest risk of getting a disease?

1 in 100

1 in 1000

1 in 10

1 in 5 gave an incorrect answer!

Preliminary results from patient interview study



21 men with prostate cancer



Treatment decision aid

“think aloud”



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The tool was educational and helped clarify their values

“It helped me identify my values, that I desire less side-effects such as urinary, sexual, and bowel dysfunction.”

“It was good to think this through and put my mind in the place of the things that can happen.”



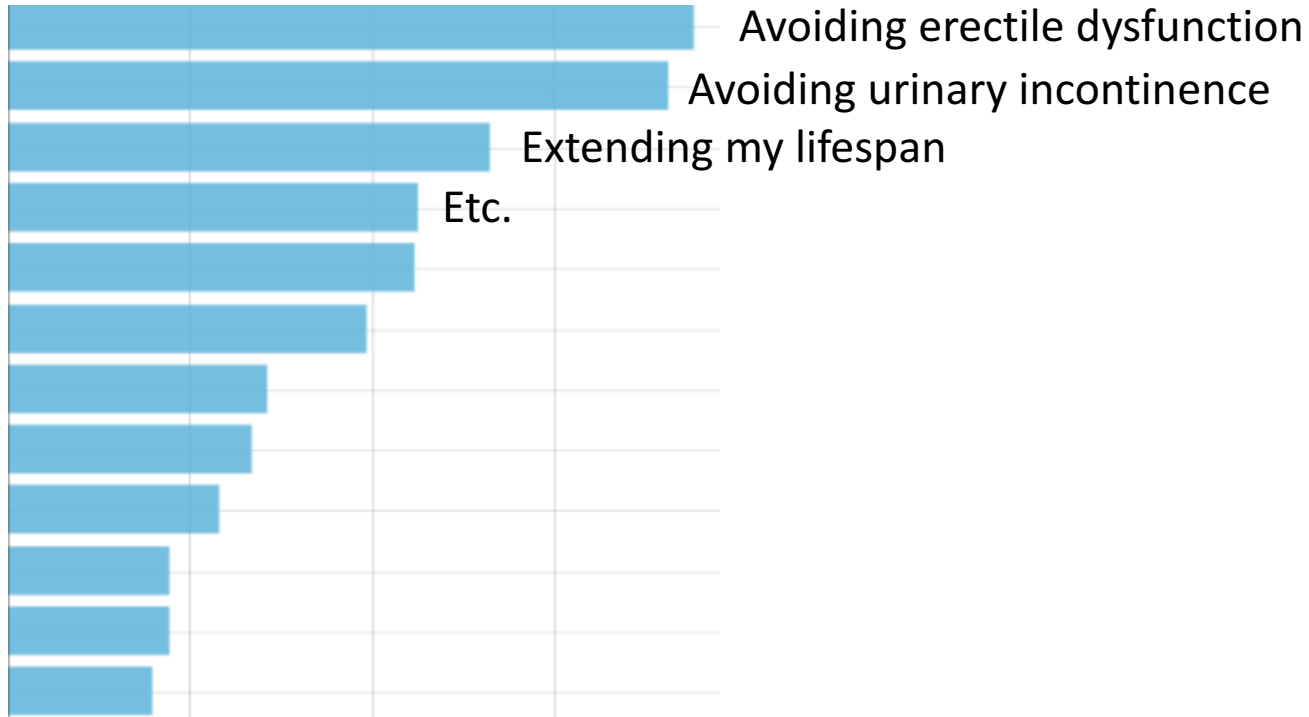
Patients interpreted the meaning of future health states

“It’s hard to place yourself in the shoes of these situations.”

“Do I want major abdominal surgery, or do I pee every time I smile? I’m a teacher. If I was incontinent and peed in class, I don’t think I could go to work.”

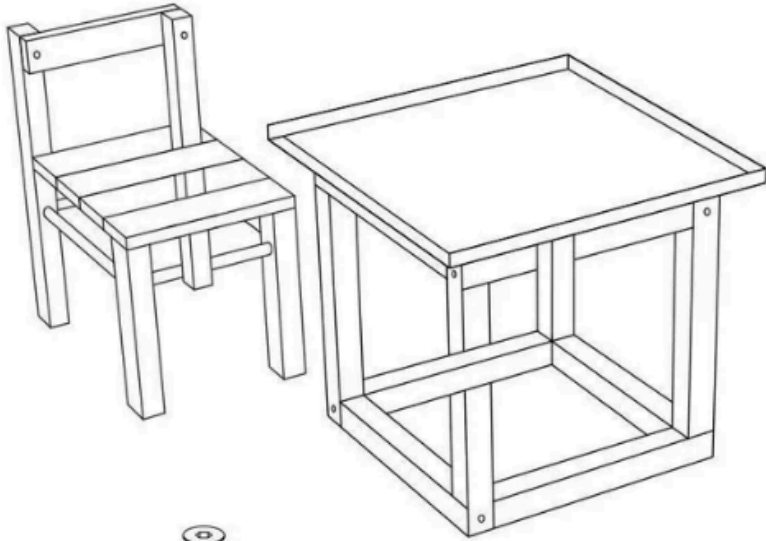


Values profile



PARADÖX

play table and chair



EFFECT

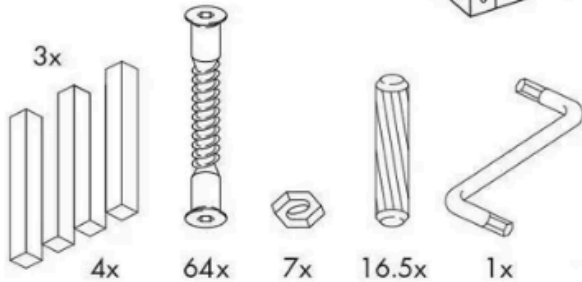


Table. Decision Tool for Prostate Cancer Screening

Key facts about prostate cancer and screening

Prostate cancer is common; most men will develop it if they live long enough.

Although only a small proportion of men with prostate cancer die of the disease, the best evidence shows that screening reduces the risk for prostate cancer death.

Screening detects many low-risk or “indolent” cancer cases.

In the United States, most low-risk cancer is treated and the treatment itself can lead to complications, such as incontinence, erectile dysfunction, and bowel problems.

Key take-home messages

The goal of screening is to find aggressive prostate cancer early and cure it before it spreads beyond the prostate.

Most cancer cases found by screening do not need to be treated and can be safely managed by a program of careful monitoring known as “active surveillance.”

If you choose to be screened, there is a good chance that you will be diagnosed with low-risk cancer and you may face pressure from your physicians or family to treat it.

Discrete decision

If you are concerned that you would be uncomfortable knowing that you have cancer and not treating it, screening may not be for you.

If you are confident that you would only accept treatment for aggressive cancer and would not be unduly worried about living with a diagnosis of low-risk disease, you are probably a good candidate for screening.

<http://annals.org/aim/fullarticle/1905132/simple-schema-informed-decision-making-about-prostate-cancer-screening>



Communication

Not *what* you say
but learning *how* to effectively say it



Patients seek to “get rid of” or “cure” the cancer

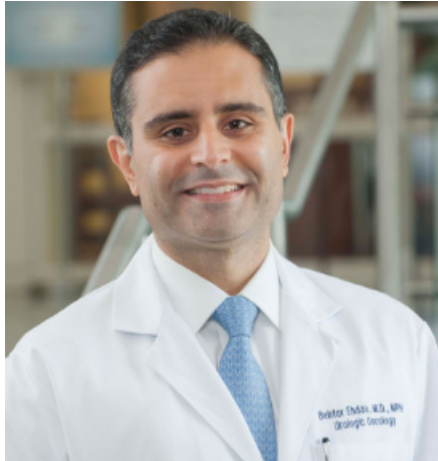
*“I don’t want to leave it alone
because it might spread.
I want to get it out of me if I can.”*



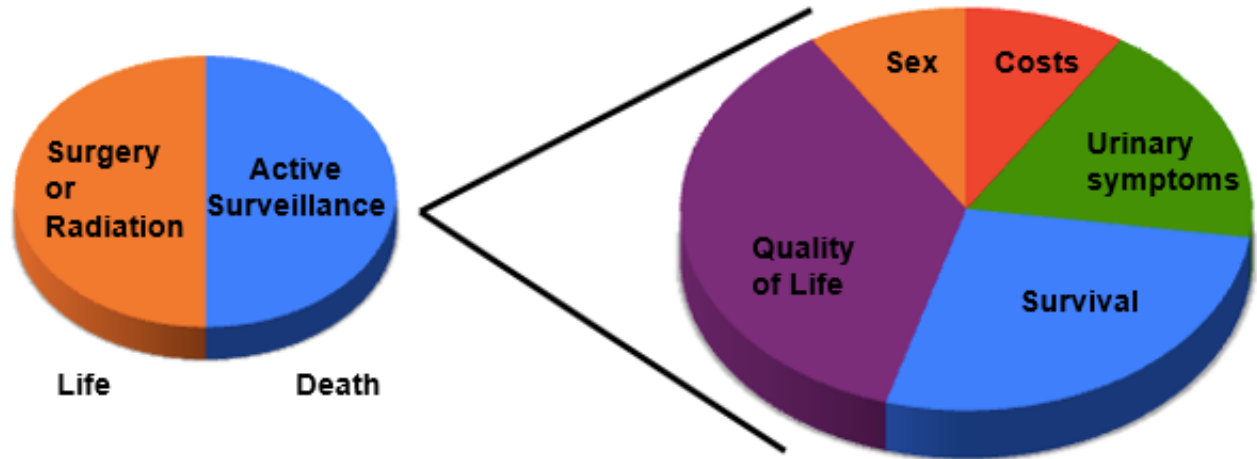
Some men feel unspoken pressure from their family to choose aggressive treatment

"My wife keeps asking me why I haven't chosen a treatment yet!"

Shifting the conversation from *positions*
(what the patient wants to do to treat their cancer)
to *interests*



Dr. Behfar Ehdai



Thank you for your attention!

Q&A



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