



PROACT: Iterative Design of a Patient-Centered Visualization for Effective Prostate Cancer Health Risk Communication.

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Context: prostate cancer

- 80% of cases clinically localized
- Two treatment categories
 - Active treatment (surgery, radiation)
 - Conservative treatment (watch & wait)
- Only 10% of patients choose conservative treatment
 - Fear of cancer (“death sentence”)
 - Lack of information

Patient lack of information

- Existing tools physician-oriented
- Patient numeracy can be problematic
- Cognitive biases exist

Your CAPRA Score is 6 X

This indicates high risk prostate cancer

Among 3,000 men with CAPRA 6-10 who underwent radical prostatectomy at UCSF since 2000, the likelihood of:

- metastasis or dying from prostate cancer within 5 years was 3%
- detectable PSA or needing a second cancer treatment within 5 years was 32%

System goals

- Improve prostate cancer patient understanding of their individual health risk information
- Provide a framework for physicians to guide them in communicating risk information

Design process

- Iterative design based off patient & doctor evaluation of prototype
- First iteration
 - Narrative established from consulting experts
 - Visualizations inspired from review of health risk communication literature
 - Data sourced from validated clinical prediction models

Clinical prediction models

- Individualized prognosis estimates based on real evidence
- Not widely used
 - Incompatible with clinical practice
 - Not patient-oriented
- Two CPMs inform data in PROACT

Iteration #1



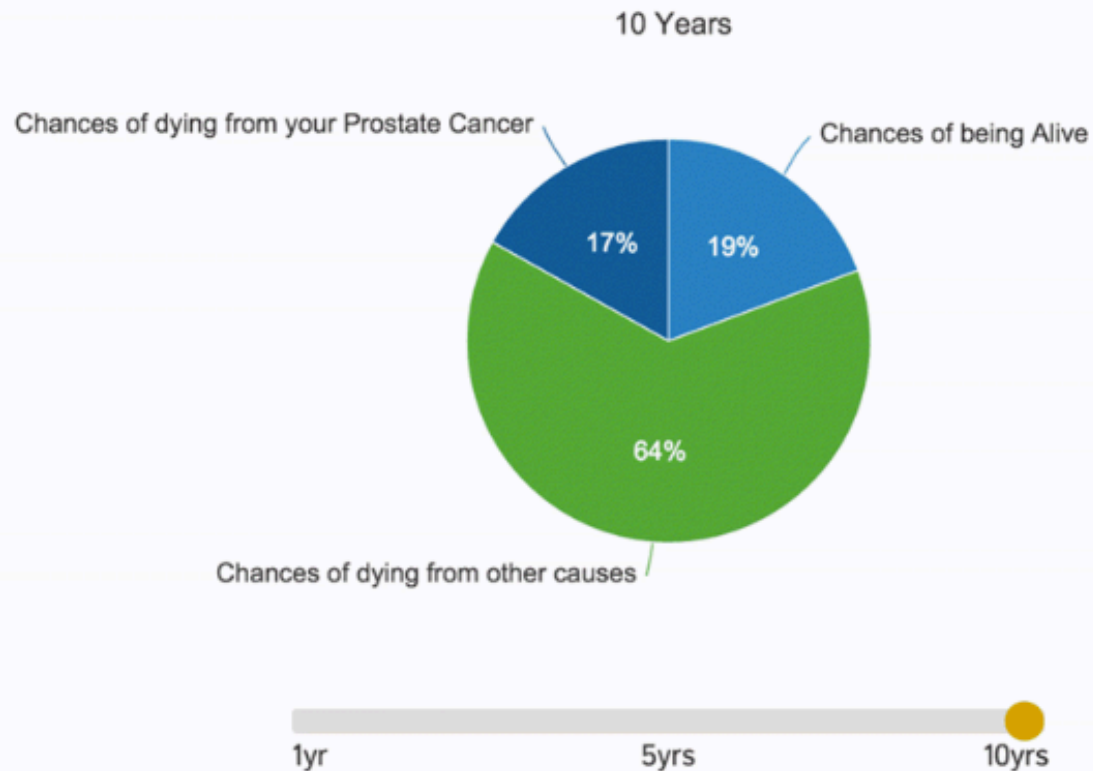
Risk of death

How big of a threat is my prostate cancer?

Before thinking about the benefits of specific treatments, it's helpful to first think about how big of a threat your prostate cancer is to your future survival. The pie chart below shows the following:

- Your chances of being alive (in BLUE)
- Your chances of dying from your prostate cancer (in DARK BLUE)
- Your chances of dying from other causes (in GREEN)

You can slide the bar to see learn about your chances at different time periods (1-year, 5-year, 10-year).



Probability of survival

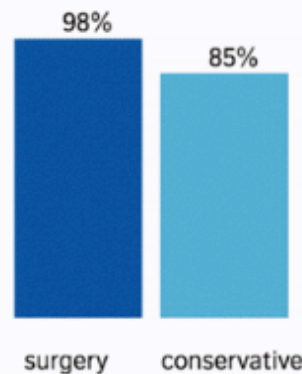
How effective are different treatments for my prostate cancer?

The expected benefits from active (surgery, or radical prostatectomy) treatment and non-surgical (conservative) treatment are listed below.

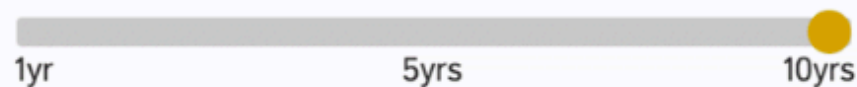
These results show your estimated chances of either surviving or dying from your prostate cancer at 1, 5, and 10 years, depending on whether you choose either surgery (DARK BLUE BAR) or conservative treatment (LIGHT BLUE BAR).

You can view these risks in terms of either survival or mortality.

Survival at 10 years



You can slide the bar to see learn about your chances at different time periods (1-year, 5-year, 10-year).



Combined probabilities

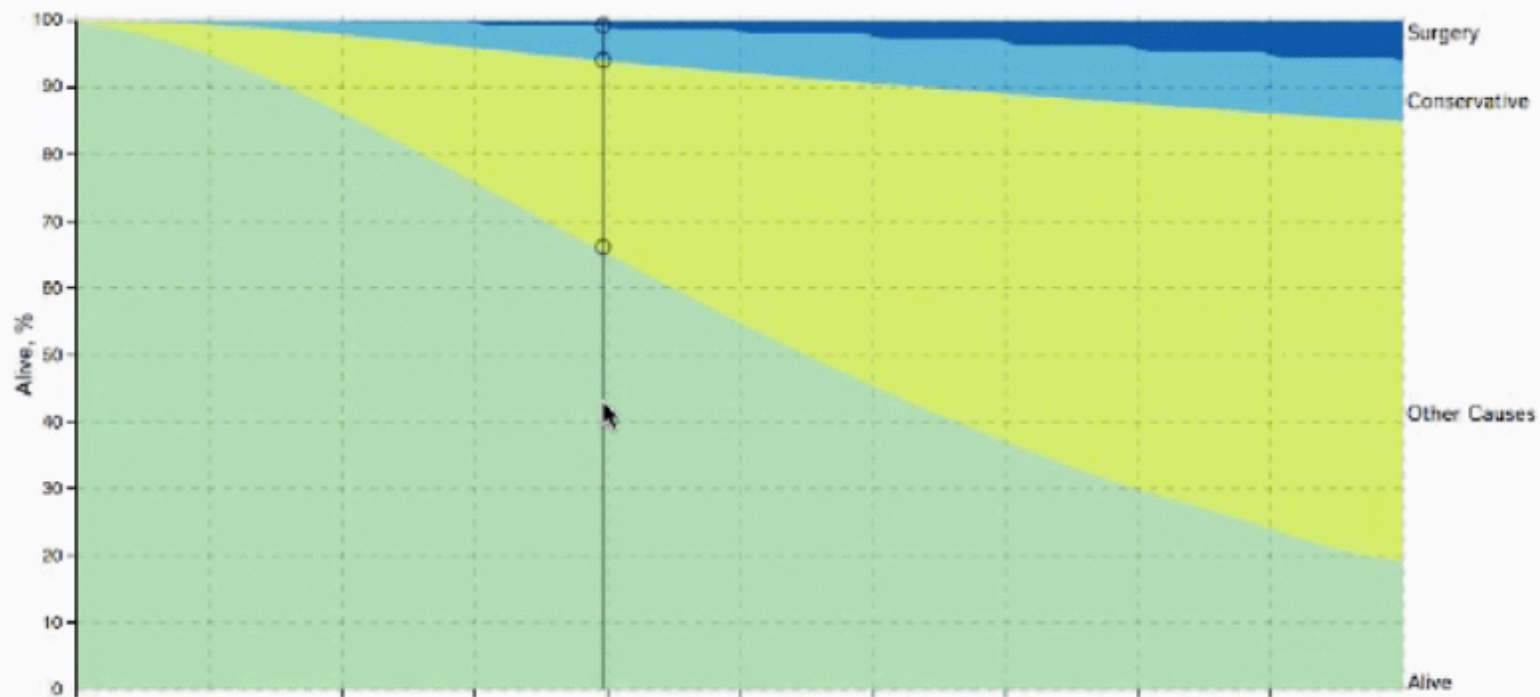
These interactive graphs give you a different way of seeing and thinking about the benefits of different treatments. Feel free to explore these graphs using your mouse.

After 3.97 years:

- 66% of people will be alive,
- 27% will die of something other than prostate cancer,
- 6% who followed conservative treatment will die of prostate cancer, and
- 1% who had surgery will die of prostate cancer.

In other words:

- 66 out of 100 people will be alive,
- 27 out of 100 will die of something other than prostate cancer,
- 6 out of 100 who followed conservative treatment will die of prostate cancer, and
- 1 out of 100 who had surgery will die of prostate cancer.



Hakone et al., IEEE Transactions on Visualization and Computer Graphics, 2017

Evaluation (iteration #1)

- 2 urologists and 6 prostate cancer survivors
- Hypothetical scenarios completed (patients: 4, urologists: 1)
- Decision confidence assessed at 4 points (patients only)

Findings (iteration #1)

- Sequence of narrative important – *“How much time do I have left?”*
 - Difficult to reason without this
- Context is critical – heightened emotional state causes difficulty in processing information
 - Suggests that first step of tool should calm the patient down

Findings (iteration #1)

- Sliders controlling temporal element were completely ignored
- Temporal area chart not understood by 6 out of 8 participants
- Perhaps participant demographics not properly considered
 - *“I like numbers, but I’m old so I often need time to study graphs”*

Findings (iteration #1)

- Participants confused as colors across visualizations were inconsistent, despite data being conditionally linked

Iteration #2



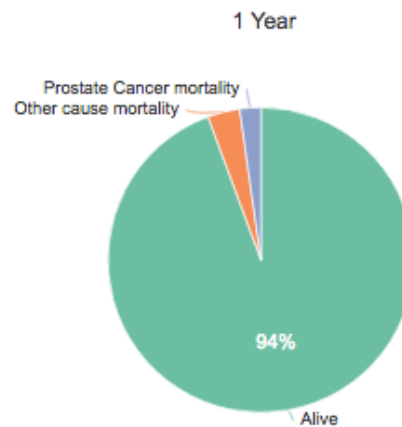
PROACT demo

How big of a threat is my prostate cancer?

In most cases, prostate cancer **progresses slowly**, and is **not lethal**.

In all cases, **you have time to think carefully** about what to do about your prostate cancer, before you decide.

For example, based on the data you provided **your risk of dying from prostate cancer after 1 year is 2%**, illustrated in the following chart:



- Your chances of being **alive (in GREEN)**
- Your chances of dying from your **prostate cancer (in PURPLE)**
- Your chances of dying from **other causes (in ORANGE)**

Before thinking about the benefits of specific treatments, it is helpful to first think about **how big of a threat** your prostate cancer is to your future survival.

Discussion

- All patients recalled lack of information provided by physician, and resorted to searching the internet for information
- Study contributions:
 - Allows patient access and understanding of clinical prediction models
 - Communication guide for consultations

Discussion: design guidelines

- Account for user's emotional state
 - Narrative flow of visualization is critical
- Distill complex models into simple visualizations
 - Minimize interaction
 - Sacrifices exploration
 - But for general public, this may improve understanding of data
- Grounded iterative design
 - Effective when used in target user groups

Critique

- Pros
 - Sample representative of target user
 - Converts physician-oriented clinical prediction models to patient-oriented risk visualizations
 - Simple visualizations so that wide range of target users can understand information

Critique

- Cons
 - Iterative process feels a little contrived – cannot imagine any 80 year old being able to understand the temporal area chart.
 - Sample size small
 - No effort made to represent and convey uncertainty
 - Only accounts for two treatments – other treatments available but not discussed
 - Only takes survival into account – other attributes (side effects, cost, etc.) not considered

References

- Hakone, Anzu, Lane Harrison, Alvitta Ottley, Nathan Winters, Caitlin Gutheil, Paul K. J. Han, and Remco Chang. "PROACT: Iterative Design of a Patient-Centered Visualization for Effective Prostate Cancer Health Risk Communication." *IEEE Transactions on Visualization and Computer Graphics* 23.1 (2017): 601-10.
- Stephenson, Andrew J., Michael W. Kattan, James A. Eastham, Eric A. Klein, Fernando J. Bianco, Andrew J. Vickers, Ofer Yossepowitch, and Peter T. Scardino. "Prostate Cancer-Specific Mortality After Radical Prostatectomy For Patients Treated In The Prostate-Specific Antigen Era." *The Journal of Urology* 179.4 (2008): 649.
- Lu-Yao, Grace L. "Outcomes of Localized Prostate Cancer Following Conservative Management." *Jama* 302.11 (2009): 1202.

Thank you!

Questions?