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

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
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).

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

- Surgery: 98%
- Conservative: 85%

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

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

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
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.

http://tuftsvalt.github.io/proact/demo/pilot2/
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


Thank you!

Questions?