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

Presented by James Hicklin

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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"

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

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

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
- 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

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

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System goals
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Probability of survival
- How effective are different treatments for my 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")
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Combined probabilities
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Iteration #2
- Hypothesis completed
- Not widely used
- Incompatible with clinical practice
- Not patient-oriented
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- Sequence of narrative important – "How much time do I have left?"
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Risk of death
- Combined probabilities
- Individualized prognosis estimates based on real evidence
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**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

- 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**