

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

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Abstract—Prostate cancer is the most common cancer among men in the US, and yet most cases represent localized cancer for which the optimal treatment is unclear. Accumulating evidence suggests that the available treatment options, including surgery and conservative treatment, result in a similar prognosis for most men with localized prostate cancer. However, approximately 90% of patients choose surgery over conservative treatment, despite the risk of severe side effects like erectile dysfunction and incontinence. Recent medical research suggests that a key reason is the lack of patient-centered tools that can effectively communicate personalized risk information and enable them to make better health decisions. In this paper, we report the iterative design process and results of developing the PROgnosis Assessment for Conservative Treatment (PROACT) tool, a personalized health risk communication tool for localized prostate cancer patients. PROACT utilizes two published clinical prediction models to communicate the patients' personalized risk estimates and compare treatment options. In collaboration with the Maine Medical Center, we conducted two rounds of evaluations with prostate cancer survivors and urologists to identify the design elements and narrative structure that effectively facilitate patient comprehension under emotional distress. Our results indicate that visualization can be an effective means to communicate complex risk information to patients with low numeracy and visual literacy. However, the visualizations need to be carefully chosen to balance readability with ease of comprehension. In addition, due to patients' charged emotional state, an intuitive narrative structure that considers the patients' information need is critical to aid the patients' comprehension of their risk information.

Index Terms—Design studies; task and requirement analysis; presentation, production, and dissemination; medical visualization

1 INTRODUCTION

Prostate cancer is the most common male malignancy and the second leading cause of cancer deaths in U.S. men. Approximately 80% of newly diagnosed cases, however, involve clinically localized cancer for which the optimal treatment is unclear [29, 46]. Accumulating evidence suggests that the available treatment options, which include active treatment (e.g., radical prostatectomy¹ or radiation therapy) and conservative treatment², often have equivalent comparative effectiveness in terms of mortality. The recent landmark Prostate Cancer Intervention Versus Observation Trial (PIVOT) study [5], for example, showed no significant difference in all-cause and prostate-cancer mortality for men who were randomized to either radical prostatectomy or conservative treatment. Given the comparative effectiveness of conservative treatment with other forms of action, conservative treatment warrants consideration by men with localized prostate cancer, especially when factoring in the substantial potential harms of active treatments, such as incontinence and erectile dysfunction.

Despite the substantially elevated risks of side-effects and the near-equivalent effectiveness of treatment options, only 10% of localized prostate cancer patients in the U.S. choose conservative treatment [46]. There are several reasons for this pattern. One is the prevailing physician practice patterns. For example, a specialist in radiation therapy is

more likely to suggest radiation over surgery. Other factors, however, are patient-centered, which revolve around the fear of cancer and lack of information. For example, a cancer diagnosis is often equated with a death sentence, and there is often an overwhelming desire “to do something” rather than waiting and observing the cancer tumor [21, 46, 48]. As a result of these patterns, many patients choose treatments they do not need or later regret, and others initiate conservative treatment but eventually decide to pursue active treatment due to anxiety about the cancer. Central to the underutilization of conservative treatment, however, is a lack of diffusion of the evidence regarding the comparative effectiveness of active vs. conservative treatment.

The PIVOT findings regarding the comparative effectiveness of active vs. conservative treatment are relatively new. However, even long-established evidence on the comparable and favorable prognosis of localized prostate cancer patients following active vs. conservative treatment has yet to spread into clinical practice. A growing number of clinical prediction models (CPMs) have been developed to produce evidence-based, individualized estimates of prognosis following active vs. conservative treatment for localized prostate cancer [48]. If individualized information from CPMs could be used to clarify the comparable prognosis of localized prostate cancer following specific treatments, patients would be better able to make informed decisions among these treatment options.

Unfortunately, despite the value of these personalized CPMs, in a 2011 national survey, only 23% of U.S. prostate cancer specialists reported using prediction tools with newly diagnosed prostate cancer patients [33]. One possible reason is that these CPMs do not seamlessly fit into the current clinical practices [33]. Without integrating these CPMs in a cohesive tool, the doctors find using them to be time-consuming and cumbersome [33].

Furthermore, for the few risk communication tools that make use of CPMs, a recent environmental scan [45] shows that most of these tools are developed in a clinician- rather than patient-centered manner. They do not consider factors such as deficits in the patients' numeracy and visual literacy, or their psychological biases that make risk information difficult to understand [21, 22, 51]. For example, a study by Belkora et al. shows that breast cancer patients have poor understanding of estimates produced by *Adjuvant! Online*, a risk assessment tool aimed at doctors and patients [4]. Similarly, studies by Han et al. show that prostate cancer patients have equally poor understanding of individualized risk information, specifically in tools that use text-only

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¹Radical prostatectomy refers to the surgical removal of the prostate gland.

²Conservative treatment, or conservative management, refers to active surveillance or watchful waiting, where no active treatment is administered. The patient's condition is carefully monitored on a regular basis to detect if the disease worsens (e.g., an increase in the prostate-specific antigen result).

or horizontal bar graphs [21]. Taken together, these findings strongly suggest that simply making the data available is insufficient. Instead, health risk communication tools must become more patient-centered in their content, function, and use.

In this paper, we report the results of the iterative process of designing, developing, and evaluating a prostate cancer risk communication tool to address this need. The aim of the tool, named PROACT (PROgnosis Assessment for Conservative Treatment), is to effectively communicate active vs. conservative treatment options to patients with localized prostate cancer and to generate personalized risk predictions based on the patient's own health data using two published and validated CPMs. Designed for use by patients alongside their doctors in a clinical setting, PROACT serves two purposes: (1) empower the patient to better understand their own prostate cancer risk information, and (2) guide the doctor in communicating the prognosis and the treatment options, ensuring that all pertinent information is presented.

In collaboration with the Maine Medical Center, we conducted two rounds of evaluations with prostate cancer survivors and urologists to identify design elements and narrative structures that facilitate patients' comprehension of their health information. Overall, the results of the evaluations indicate that visualizations can be an effective means to communicate complex health risk information to patients with low numeracy and visual literacy. Both patients and doctors praised the benefits of PROACT, suggesting that the availability of these tools could increase the patients' awareness of treatment options and risks.

However, feedback from these evaluation sessions also revealed design considerations that can significantly affect the utility of the tool. For example, complex visualizations such as temporal area charts can be difficult for patients to understand. Instead, multiple simple visualizations such as pie charts that sample the temporal dimension are much more effective in communicating changes over time. Surprisingly, adding interactions to either simple or complex visualizations had an adverse effect – most patients either did not know how to use the interaction or not know how to effectively use it to explore the full range of the data.

In addition to the choice of visualizations, we also found the narrative structure of the tool to be critical. In particular, the patients in the study reported that they experienced heightened emotional state and increased anxiety upon receiving a positive prostate cancer diagnosis. Subsequently, they were unable to focus or process additional information from the doctor. As such, a key design component that we incorporated into the tool is to ensure that the most pertinent survival rate information is delivered as soon as possible to calm the patient down before presenting any additional information about treatment options.

In the rest of the paper, we present the two rounds of design, development, and evaluation of the PROACT tool. Specifically, our work makes the following contributions:

- Development of a prototype for a patient-centered online risk communication tool (PROACT), intended to help patients with localized prostate cancer understand and compare their expected prognosis following active vs. conservative treatment.
- Two iterative evaluation studies of the PROACT prototype with prostate cancer survivors and doctors. Usability and participant comprehension were assessed through task-based user studies and open-ended interviews following established methodologies in information visualization and human-computer interaction research.
- Design guidelines for choosing the appropriate visualizations for prostate cancer patients with low numeracy and visual literacy levels and for constructing effective narrative structures that account for both patient comprehension given charged emotional states and the doctor's current clinical practices.

2 RELATED WORK

2.1 Visualizing Healthcare Information

Medical and healthcare information visualization has been an important area of research for the visualization community. There have been numerous advancements, systems, and even competitions involv-

ing such visualizations [1]. Examples of these systems include LifeLines [44], EventFlow [38], DecisionFlow [20], Outflow [52] and the system by Zhang et al. based on the five W's [53]. However, with few exceptions, the focus of this line of research has predominately been on visualizing large amounts of patient health information, in particular electronic health records (EHR). EHR data is very complex: it is often voluminous, heterogeneous, and temporal. The goal of visualization and visual analytics of EHR data is therefore to enable doctors, researchers, administrators, and even patients to explore, analyze, and make better decisions regarding the patient's health [8].

Due to the temporal nature of health-related data, one common technique for detecting trends and patterns is the use of temporal visualizations (see the survey by Aigner et al. [2] for some examples). Beyond temporal visualizations, geospatial visualizations such as John Snow's map of cholera in 1854 London [49] and the U.S. Health Map [28] have also been useful to researchers and administrators for performing population-level analyses. More recently, dashboards (e.g. [11]) and visualizations on handheld and wearable devices (e.g. [10]) have become more widely adopted for physicians and patients to better monitor health information in real time. Throughout these studies, a recurring topic is whether the data be aggregated to fit into widely-familiar charts (e.g., bar and pie charts), or shown in a more complex visualization (e.g., time-varying area chart). Some studies have found that more complex visualizations are beneficial [12], while others show that patients misinterpret even the most basic charts [25]. Given the complexity of health data and the well-documented cognitive biases that follow it, more research is needed.

With the wide range of data, needs, and stakeholders in health, researchers have begun to categorize opportunities for data visualization in healthcare. A recent survey by Gotz et al. [19], for example, categorizes visual analytics of healthcare information into four groups: for health research, for clinical workflow, for clinicians, and for patients. Our proposed work does not immediately fit under the categories proposed by Gotz et al. Although PROACT can be loosely considered as enhancing "patient comprehension," it differs in that the goal is not about self-diagnosis (such as PatientsLikeMe³ and WebMD⁴), self-monitoring (such as the Wellness Diary [37]), or the *quantified self* [36]. Instead, the emphasis of our work lies in doctor-patient communication of the patient's health information and treatment options. In particular, our work falls under an area of medical research called "*health (risk) communication*," where the goal is to develop better tools and techniques to enhance patient comprehension of quantitative information about the probability of health outcomes.

A more appropriate categorization is that of Franklin, Plaisant, and Shneiderman, who put forward an information-centric framework for patient-centered risk communication [15]. While doctor-patient risk communication has been studied extensively in the medical community (e.g., Nelson et al. [39]), the framework from Franklin et al. explicitly considers the role of interactivity and the efficacy of different visual encodings. In later work, Franklin et al. enacted their information-centric framework through the TreatmentExplorer system [14]. Using a novel visual encoding (a hybrid of icon-arrays and area charts), TreatmentExplorer shows how different treatments lead to different outcomes over time. While TreatmentExplorer is a general tool for visualizing risk estimates and treatment options, PROACT focuses specifically on prostate cancer and the role treatment models and interactive visualizations can play in facilitating doctor-patient communication. Through design and development alongside patients and doctors, PROACT adds to the discussion around the integration of validated statistical risk models from the medical community with techniques from the interactive data visualization community.

2.2 Health Risk Communication

The idea that patients should be adequately informed about the potential risks and benefits of medical interventions has received growing emphasis in the medical community [47, 34]. *Shared decision-making*,

³<http://patientslikeme.com>

⁴<http://webmd.com>

a process in which an informed patient and the physician jointly discuss the treatment options and work together to reach a mutual decision about the preferred treatment, has become an increasingly accepted ideal for medical practice [3]. Shared decision-making is particularly important for certain life-threatening diseases such as cancer, for which multiple reasonable choice options exist, requiring patients to weigh and integrate their own values in the decision-making process. For example, women with early stage of breast cancer may be faced with a decision to have lumpectomy (partial breast removal) followed by chemotherapy and/or radiation or a mastectomy (full breast removal) [9]. Similarly, for men with early-stage prostate cancer, patients may need to choose between radical prostatectomy or a less aggressive option such as active surveillance, which is medically reasonable due to the slow-growing nature of prostate cancer.

Although shared decision-making is the recommended practice in many situations, the optimal method for informing the patients of their health risks, treatment options, and the advantages and disadvantages of these options remain an open area for medical researchers. A recent survey by Trevena et al. [51] outlines the key concepts in health risk communication and defines some best practices. These defined best practices include the use of quantitative, numeric risk estimates whenever possible to facilitate informed decision-making; minimizing cognitive burden by simplifying information (e.g., rounding, using consistent formats and denominators for comparing risk information); defining the reference class (the specific population for which a risk estimate applies); accounting for limitations in numeracy and literacy; conveying the uncertainty of risk estimates; and using visual representations to improve comprehension. Utilizing these practices to highlight quantitative data may mitigate some of the biases documented by Kahneman and Tversky's prospect theory [31], like the tendency of people to favor certain outcomes over probabilistic outcomes. For example, patients may consider surgery as a *definite* way to eliminate prostate cancer risk but consider active surveillance as only *probabilistic*, despite its advantage of avoiding harmful side effects.

This last task, the use of visual representations, is widely believed to aid comprehension of risk information, particularly for low-numerate individuals [18, 17, 15], but its effectiveness also depends on the individuals' visual literacy [16, 7, 6] and cognitive factors [40, 41, 54]. There is also emerging evidence that some visual formats (e.g., icon arrays or "pictograms," bar graphs), are more effective than others (e.g., pie charts) for representing risk [24]. While some initial work has investigated the design space of representing treatment options and side-effects [14], the optimal formats for specific tasks remain to be determined [13], particularly as they relate to patients who may not have experience in interpreting complex visualizations and data. Furthermore, new visualization techniques including interactivity and narrative formats represent a relatively untested area in health risk communication.

A recent environmental scan study found that existing web-based tools for calculating and communicating risks in prostate cancer treatment are clinician- rather than patient-centered [45]. In general, they simply present unembellished risk statistics in the form of point estimates (i.e., percentages), and make little effort to provide explanatory information to aid understanding. Few of the tools utilize visualizations such as bar graphs, however, no tool provides a narrative structure to guide clinical conversations between clinicians and patients.

3 OBJECTIVES OF PROACT

As evident from the PIVOT study [5], there is a prevalent need to educate localized prostate cancer patients about the different treatment options and associated side effects. In particular, an important message to convey to the patient is that there are effective treatments other than radical prostatectomy, and that these other treatments, such as conservative management, can have comparable if not favorable survival rates but without the impairing side effects. Additionally, as the patient ages and their health condition declines, it becomes more dangerous for the patient to undergo invasive procedures such as surgery, so much so that the risk of mortality from surgery surpasses that of the cancer. Combined with the fact that these older patients have a high risk of dying from their *comorbidities* (diseases and disorders other

than prostate cancer), the need for the patient to carefully consider all aspects of these treatment options in order to make an informed decision is apparent. As such, our two design goals of PROACT are as follows: (1) empower prostate cancer patients to better understand their own health risk information and make informed health decisions, and (2) guide the doctors in communicating the prognosis and the treatment options, ensuring that all pertinent information is presented.

3.1 Comprehending Health Information using Clinical Prediction Models

In order to provide the patients with personalized risk information, PROACT incorporates the use of clinical prediction models (CPMs), which are designed and evaluated around their ability to provide accurate estimates for individual cases. However, since not all information is represented in a single CPM, patients or doctors will need to interact with multiple CPMs to obtain accurate representations of the patients' overall health status. Because CPMs may represent different treatment options with different outcomes, understanding the outputs can be challenging, time-consuming, and potentially error-prone [33] without a tool that integrates them. The first design goal of PROACT is therefore to make these CPM prognoses accessible to patients by compiling and presenting the information in a comprehensible manner for older, localized prostate cancer patients (ages 65+).

3.2 Facilitating Doctor-Patient Communication

Our intended usage scenario for PROACT is in a clinical setting by the doctor with the patient, as a shared-decision making tool during the initial diagnosis consultation. Because PROACT will be used alongside the diagnosis consultation, it must aid, not interfere with, the doctor's conversation. However, since some physicians may leave out or overemphasize certain information due to legal considerations, personal biases, or prevailing practice patterns [26], our second design goal of PROACT is for the tool to serve as a guideline that standardizes the conversation between the doctor and the patient. In order to do so, the tool will need to constrain the navigation so that the users view all aspects of the information in a structured narrative sequence. The narrative should include crucial factors for decision-making, such as the existence of side effects and the fact that because prostate cancer is slow progressing, patients often do not need to make a treatment decision right away. The information must be sequenced to balance the usability needs of doctors and information needs of patients.

4 INITIAL PROTOTYPE

Our initial design of the first prototype of PROACT is based on the two design goals mentioned above: (1) making the prognoses of CPMs easy to comprehend by prostate cancer patients, and (2) developing a narrative structure that best facilitates doctor-patient communication. In order to select the appropriate visualization to accomplish the first goal, we surveyed visualizations commonly used in health risk communication literature, examined existing health risk communication tools, and applied our own experience in designing visualization tools.

The CPMs we utilized generated three types of data: (1) survival ratio between dying from prostate cancer and overall survival rate, (2) comparison of survival rates between active vs. conservative treatment, and (3) temporal trend of cancer prognosis. As a result, three visualizations were selected for the prototype based on visualization theory and best current medical practice: (1) a pie chart, shown to be effective at depicting part-to-whole relationships according to Hollands and Spence [27], (2) a bar graph to compare treatment options following the work by Han et al. [21], and (3) a temporal area chart to show patterns over time similar to the work by Lu-Yao et al. [35]. In addition, we utilized common visualization design guidelines, where these visualizations were made to be interactive to allow for user exploration.

For our second goal, we consulted urologists and researchers at the Maine Medical Center to determine the common narrative sequence used by doctors during prostate cancer diagnosis consultation. In addition, we considered the designs of existing online health risk communication tools to see how CPMs can be integrated into the narrative

flow. In the end, our narrative structure is a hybrid between the two. Similar to the online tools, we first ask the patients to enter their health information required by the CPMs. The outputs of the two CPMs are

then presented in a sequence based on a conversation that a prostate cancer doctor might have with a patient during a consultation.

In the sections below, we present the design of the first PROACT prototype and the CPMs used for personalized prediction, followed by the evaluation of the tool, analysis of the participants' feedback, and a summary of our revision plan based on the feedback.

4.1 Clinical Prediction Models Used in PROACT

In order to provide the patients with personalized risk information, PROACT incorporates the use of clinical prediction models (CPMs), which are designed and evaluated around their ability to provide accurate estimates for individual cases. We chose two complementary and well-validated models of prostate cancer mortality risk, obtained the underlying algorithms and equations of their models, and made necessary transformations to include them into an online web tool.

A multi-institutional model from Stephenson et al. (Stephenson-PSCM) estimates 15-year mortality risk following prostatectomy based on age, Gleason score, prostate-specific antigen level, clinical stage, and biopsy results [50]. The Stephenson-PSCM was validated in a national sample of 12,677 patients and accurately discriminates patients with low mortality risk, for whom conservative treatment may be appropriate. Patients with Stephenson-PSCM scores at the lowest quartile have less than 5% 15-year prostate-cancer mortality risk.

To obtain the Stephenson-PSCM model, we contacted the authors of the study, who sent us the underlying linear equations and coefficients, along with ground-truth data for validation. We then implemented the equations in Javascript and constructed tests using the ground-truth data to verify the accuracy of our implementation.

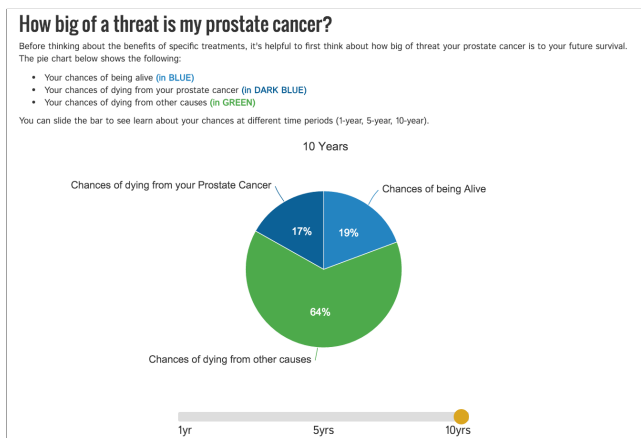
Similarly, a competing-risks model by Lu-Yao et al. estimates 10-year prostate-cancer and all-cause (overall) mortality following conservative treatment based on age, tumor grade, and clinical stage [35]. The model was derived from a cohort study of 14,516 patients aged 65 or over with stage T1 or T2 cancer treated conservatively, and demonstrates the favorable prognosis for many patients. For example, for men aged 65–69 with T1, moderately differentiated cancer, the 10-year prostate-cancer mortality is 2% versus less than 5% following active treatment from the Stephenson-PSCM study.

As with the Stephenson-PSCM, we contacted the authors of the study to obtain the Lu-Yao model. The Lu-Yao data differs, however, in that it uses a look-up table rather than linear equations. While not as compact as equations, look-up tables avoid the need for validation, since the data can be queried directly.

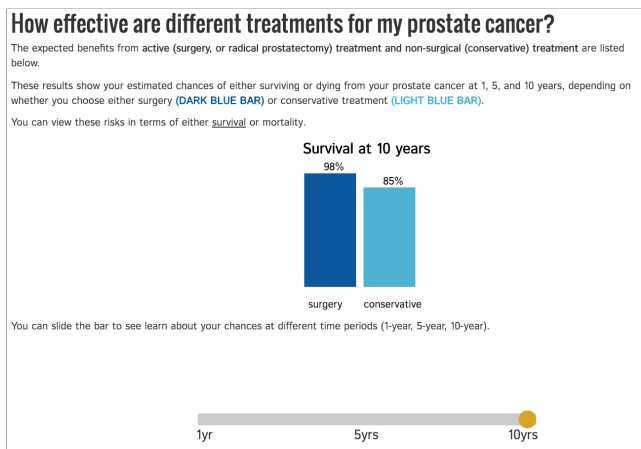
4.2 Design

PROACT is designed to be used via a web browser, and the visualizations and user interface are implemented using Javascript and the d3.js visualization library. Based on the two goals of the tool, we designed the first prototype using six pages:

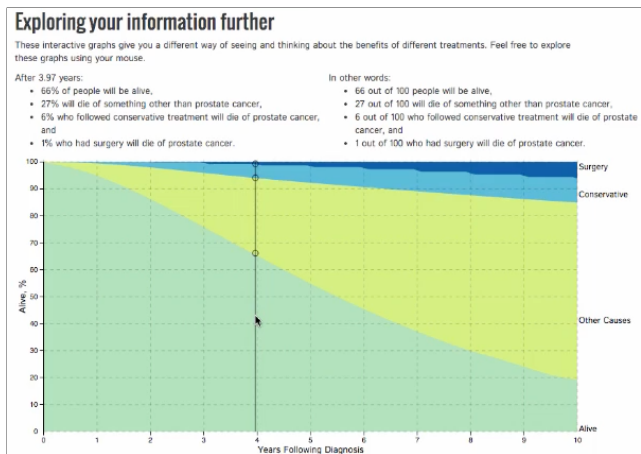
1. Disclaimer - for explaining what PROACT is and the legal implications of its use.
2. Input - for the user to input age, biopsy scores (PSA, Gleason score), cancer stage, and tumor tissue differentiation.
3. "How big of a threat is my prostate cancer?" (Figure 1(a)) - for showing the risk of dying from prostate cancer vs. dying from comorbidities vs. being alive. The percentages were displayed in a pie chart, defaulted at 10-year risk, with a slider to show 1- and 5-year risks.
4. "How effective are different treatments for my prostate cancer?" (Figure 1(b)) - for showing the survival and mortality risk after surgery (radical prostatectomy) vs. conservative treatment. The percentages were displayed in a bar graph, defaulted at 10-year risk, with a slider to show 1- and 5-year risks. Note that this information is conditional upon the probability that the patient dies from cancer. For example, if the probability of dying from cancer is 50% and the probability of dying after surgery is 20%, then the chance of the patient dying from cancer with surgery is 10%.



(a) Page 3. Uses a pie chart with an interactive slider to examine the 1, 5, and 10 year mortality rates from cancer, from all other diseases (i.e., comorbidities), and the survival rates.



(b) Page 4. Uses a bar chart to compare the survival rates of surgery vs. conservative treatment in 1, 5, and 10 years. Similar to the previous pie chart, this visualization also uses an interactive slider to explore time.



(c) Page 5. Uses a stacked temporal area chart to show the survival rates of the different treatment options. As the user mouses over the visualization, precise numeric estimate is shown in the text above the visualization.

Fig. 1. Example pages of the initial prototype of PROACT. In this prototype, all visualizations are made interactive to allow the users to explore the temporal dimension.

5. “Exploring your information further” (Figure 1(c)) - an interactive temporal area chart that gives a continuous 0 to 10-year risk of surgery, conservative treatment, comorbidities, and chance of being alive. The exact percentages were displayed above the area chart.
6. “More info” - included links to the CPMs used in PROACT as well as additional information not included in the tool such as side-effects and other treatment options.

Users could navigate between pages via the “< Prev” and “Next >” buttons or via the navigation bar at the top of the tool.

4.3 Evaluation

4.3.1 Participants

We recruited both patients and doctors for this study. Six patients were recruited through the Maine Coalition to Fight Prostate Cancer, a statewide non-profit patient advocacy organization that provides resources for prostate cancer survivors. All patients were male, above 65 years old, and post diagnosis and treatment; we did not include men with newly diagnosed cancer to avoid potential emotional distress at that vulnerable stage. We did not collect any additional demographic information to protect confidentiality. However, some patients volunteered to disclose their experience during the evaluation, and it was apparent that the participants came from diverse backgrounds and had various prostate cancer conditions and treatments.

In addition to the patients, we recruited two practicing urologists specializing in prostate cancer treatment for interviews. Interviews with the urologists were conducted at the Maine Medical Center hospital, and the evaluations with the patients were conducted at the Maine Medical Center Research Institute over the course of two days.

4.3.2 Materials

To help ensure participants engage with PROACT in a decision-making context, we constructed a set of four hypothetical scenarios representing newly diagnosed patients. Scenarios span a set of possible combinations of mortality risk and treatment option effectiveness:

1. High prostate cancer risk; high comorbidity mortality risk. Lower risk from surgery than from conservative treatment.
2. Low prostate cancer risk; high comorbidity mortality risk. Equivalent surgery and conservative treatment risk.
3. Low prostate cancer risk; low comorbidity mortality risk. Equivalent surgery and conservative treatment risk.
4. High prostate cancer risk; low comorbidity mortality risk. Lower risk from surgery than from conservative treatment.
5. Two additional scenarios were randomly constructed for training purposes.

In addition to assessing patients’ and doctors’ reasoning processes in different scenarios, we also administered a short questionnaire to the patients. The questionnaires were designed so that the patients had specific tasks that guided their interaction with the tool and to incite discussion between the participants and investigators.

The experiment setup consisted of a laptop (controlled by an investigator) that was connected to an external screen, keyboard, and mouse (controlled by the participant).

4.3.3 Procedure

Each session lasted one hour for all patients and half an hour for the doctors. After participants reviewed an IRB-approved informed consent packet, an investigator gave a verbal overview of the goals of PROACT. The investigator then demonstrated the use of PROACT using a training scenario, and participants were encouraged to ask questions about the tool’s interface, interaction, and visualizations. There was no time limit for the training scenario, and training was completed when participants confirmed they had no additional questions about the tool (mean=8.33 minutes). The procedure differed slightly for patients and doctors from this point.

Patients continued by iterating through four randomly ordered scenarios of hypothetical patients. To assess their reasoning about the current scenario, patients were asked to indicate whether they would seek treatment and how confident they were in their decision. These questions were repeated at four specific points in PROACT sequence: after seeing the hypothetical patient’s data (pre-visualization), after the comorbidity vs. prostate cancer risk page, after the surgery vs. conservative treatment risk page, and after the “more info” page (post-visualization).

Doctors continued by assuming the role of a clinician using the tool with a hypothetical patient, as if they were delivering the diagnosis to a patient for the first time. A designated investigator served as a stand-in for the hypothetical patient, using one of the scenarios chosen at random.

All participants had time after the scenarios (approximately 30 minutes for patients and 15 minutes for doctors) for a semi-structured interview. Participants were free to discuss PROACT or aspects of the decision-making process in general. To ensure that the discussion periodically returned to usability and practicality, investigators also asked specific questions about behavior they observed while the participant was using PROACT.

4.3.4 Data Collection

With the consent of the participants, we collected three types of data during the sessions. First, the participants’ screens were captured into a video. Second, the sessions were audio-recorded. This information is particularly important to our post-hoc analysis because the participants were encouraged to give comments, ask questions, and provide general feedback during the evaluation (similar to that of a think-aloud study protocol). Lastly, we collected the questionnaires after the participants completed the evaluation session.

4.3.5 Findings

The collected video, audio, and questionnaires were analyzed to identify the strengths and weaknesses of the PROACT design. Since the participants had diverse backgrounds and experiences, their questions and comments as well as the time they took for each phase of the session varied widely. We therefore opted to have one of the authors manually code and organize the video and audio, similar to the process used by Kandel et al. [32]. Below, we summarize the feedback and comments from our participants.

Utility Both patients and doctors were enthusiastic about the general utility of PROACT, i.e., creating personalized risk estimates based on respected CPMs and presenting them in an engaging and structured form. Three patients recalled the struggles of finding reputable sources other than their clinicians for educating themselves about their prostate cancer. One patient said, “*I wish I had a tool like this when I was going through the decision process.*” Two participants specifically noted they liked that PROACT used questions as headings because they “*didn’t know what questions to ask at first when diagnosed.*” Particularly encouraging was that all patients thanked us for our efforts and encouraged us to continue this research effort because these health risk communication tools are much needed and not enough support exists online or in hospitals for patients facing a prostate diagnosis. “*If a doctor gave me this tool, it would be good because there [is] a bunch of garbage on the Internet. With this, all of the necessary information would be right here.*”

Narrative Sequence Although the participants found PROACT to be generally useful, there are still many areas for improvement. An important piece of feedback was that PROACT did not take into account the value of the sequence of the narrative (i.e., flow of information). Two patients stated that one of the first questions after receiving their positive prostate cancer diagnosis was, “*How much time do I have left?*” The participants reflected that without that critical piece of information, they would not be able to process any subsequent information, however relevant or important it might be.

Emotional State Related to the previous point, participants noted

that a reason for not being able to process any additional information was due to their heightened emotional state. One participant recalled that “*No matter what you say, when you first hear you have cancer, you don’t hear it – it’s all blank;*” and it was not until after they had a chance to calm down that they were able to search for information about prostate cancer and the possible treatments. As such, two participants suggested that for PROACT to be useful in its intended setting, it is important to contain information that can help the patients “*get off the ledge.*”

Disease vs. Treatment Based on feedback from both the doctors and the patients, it became apparent that the “*How big of a threat is my prostate cancer?*” conversation is different and should be explicitly separated from the “*How effective are different treatments for my prostate cancer?*” discussion. Although the two topics are clearly related, typical patients cannot begin to consider possible treatment options until after they let the news of a positive diagnosis sink in. As such, information about these two topics should be presented separately to allow the patient the opportunity to focus on one topic before moving on to the other. In our current design the two topics appear in different pages. Nonetheless, patients and doctors would still like to see a clearer separation between the two.

Temporal Visualization Six out of eight participants reported that the ability to see the predicted disease progression is crucial when considering treatment options. We had anticipated this request and developed two types of interactive visualizations to enable the analysis of predictions over time. First, an interactive slider allows the user to see their mortality rate from prostate cancer and the effectiveness of treatment options between 1, 5, and 10 years (Figures 1(a) and 1(b) respectively). Second, an interactive temporal area chart allows the participants to see the trajectory of their disease progression and mortality rate over time (see Figure 1(c)). These two types of visualizations were selected following the best practice guidelines and study results [35, 24]. However, to our surprise, six participants, including both doctors, found the visualizations to be confusing. We observed that the participants were unable to comprehend the temporal area chart and were inconsistent in using the slider to see the 1-, 5-, and 10-year predictions. Despite their claims that seeing disease progression is critical, some participants did not use the slider to see all three time steps or did not use the slider at all.

Additional Information All participants reported that they would like to have more information regarding their treatment options and the associated risks. PROACT uses two CPMs for the risk of surgery and active surveillance, but many other treatment options exist (e.g. radiation therapy, cryotherapy). The participants noted that in order to make a fully-informed decision, it would be useful to have access to all of this information, including suggestions on seeking alternate opinions and counseling services such as support groups.

Nuances Matter During the course of the evaluation, we realized how nuances in the tool can affect the participants’ comprehension. On the use of visualizations, we found that most participants were more comfortable with pie charts, but surprisingly, not everyone was accustomed to using visualizations. As one participant reported, “*I like numbers, but I’m old so I often need time to study graphs,*” which is consistent with existing literature on how elderly use interactive media (for example, see [43]). Beyond visualizations, we found that consistency in wording and use of colors are important. For example, some participants were confused by the wording of “conservative treatment” because it does not refer to an active treatment. Similarly, some participants noticed that the colors used across the visualizations were different (see Figure 1(a), 1(b), and 1(c)) and had trouble realizing that the two pieces of information were connected in a conditional manner.

Doctor’s Suggestions Since the tool is meant to be used during the initial consultation with a doctor after the patient receives a positive diagnosis, it is important that the doctor can easily integrate the use of PROACT into their current routine. While both doctors in our study endorsed the spirit behind PROACT, they noted that the

narrative sequence does not fit their current flow of conversations with their patients. Similar to the feedback from the patients, they echoed the need to provide the most critical information first (i.e., “*how much time do I have?*”). In addition, they asked for the ability to *opt-out* of some of the material because in cases where the treatment options are clear (e.g. if the patient is too old to have surgery), “*the patients shouldn’t even think about treatment.*” Lastly, confirming our observation that some visualizations may be too complex, both doctors suggested that the temporal area chart may be too difficult to explain to patients.

Beyond the specific feedback about PROACT, many participants deviated from the study procedure and recounted their own personal experience facing cancer. One participant lamented the fact that he chose to have surgery too hastily without fully understanding the long-term side effects of the treatment and now suffers from incontinence and erectile dysfunction. All patients mentioned the difficulties they had conducting their own research online and feeling overwhelmed by the amount of dubious and conflicting information. These personal accounts were particularly somber, and they served as a reminder that more tools are needed to help these older patients comprehend their own health risk information and make decisions that are appropriate for them.

4.3.6 Revisions

Based on the findings from the patients and doctors, we generated a list of key revisions for the second iteration of PROACT. In general, our philosophy for the second round is to (1) reconsider the design and visualizations from a patient-centric standpoint where the patients are older men with possibly low numeracy and visual literacy, and (2) reorganize the flow of information to better support the patients’ needs while fitting in with the doctors’ current workflow.

(RV1) Modify the **narrative sequence** to address the question “*how much time do I have left?*” In particular, present the 1-year mortality rate first to ease the patient’s anxiety and **emotional state**. As a slow-progressing disease, patients will often have very high survival rates in the early years (in the range of 90% or above). In addition, provide a printable “summary page” in case the patient is too anxious during the consultation and needs to process the information on their own after they have had the chance to calm down.

(RV2) Provide an initial “road map” page of the prostate cancer treatment and the shared decision-making process to communicate to the users the scope and **utility** of the tool. This page will also acknowledge that PROACT is limited to the use of two specific CPMs. Other CPMs that provide **additional information** such as other treatment risks, probability of side effects, and quality of life are not considered for the prototype because they have not been vetted and evaluated by our physician collaborators. PROACT will instead provide external links to reputable and trusted websites to give the patients additional information about treatment options and their possible side effects beyond surgery and conservative treatment.

(RV3) Separate the discussion between **disease vs. treatment** to support the doctors’ current work flow. This can be done by providing a treatment introductory page. This page will mention some of the possible treatment options as well as communicate that the tool will now talk about the benefits (i.e., increase the chance of living) of treating prostate cancer. In addition, as per a **doctor’s suggestion**, we added an “opt-out” page with the heading, “*Should I consider treatment?*” before the treatment introductory page.

(RV4) Simplify all the visualizations and the interactions. As we observed, (1) the **temporal visualization** using an area chart (Figure 1(c)) is too complex for the patients to comprehend their disease progression, and (2) interactions of any form can be too complex for the users. For example, the participants did not know to use the slider to see temporal information. As a result, PROACT should use only the most basic forms of visualizations, pie charts and bar graphs, because of their ease-of-comprehension and pie charts’ abil-

ity to convey percentage (part-to-whole) information. In addition, these visualizations should be presented in a static manner to ensure that the patients are exposed to all the necessary information.

(RV5) Make all wording, color, and design elements consistent across all pages. Although these are relatively **nuanced**, we found that they do affect the patients' comprehension. Since many of our participants already find the information to be taxing, making the tool as easy to understand as possible will make a difference. For example, consistent color should be used to represent the same information between pages (see Figure 1(a) and 1(b)), and these colors need to be chosen to ensure that they are suitable for color blind individuals. Additionally, we chose to use precise terminology such as "active surgery" and "conservative treatment" to maintain consistency with current medical practice, but the impact of alternative terms that may be clearer to patients will need to be studied.

5 REVISED PROTOTYPE

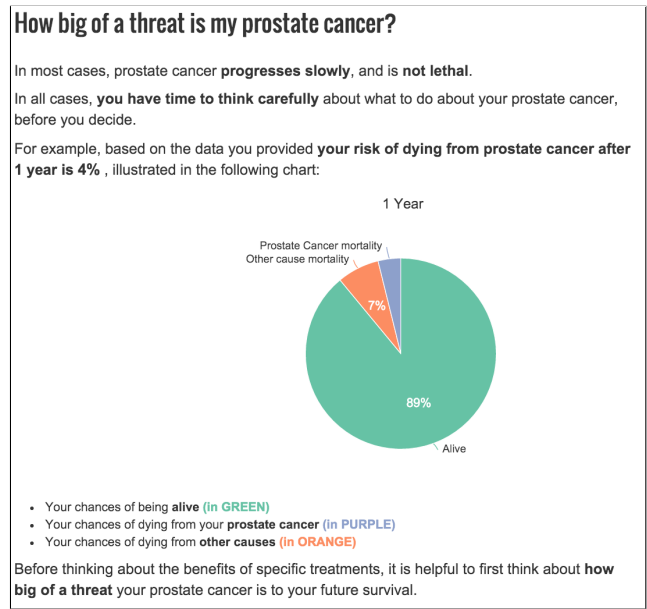
5.1 Design

Following an iterative design methodology, we redesigned the PROACT tool in a second prototype by integrating the revisions distilled from an in-person evaluation session with six patients and two doctors from the previous evaluation. After the design and implementation of the second prototype, we conducted another round of evaluation. Below we describe the design of the new tool, the evaluation session, and our findings.

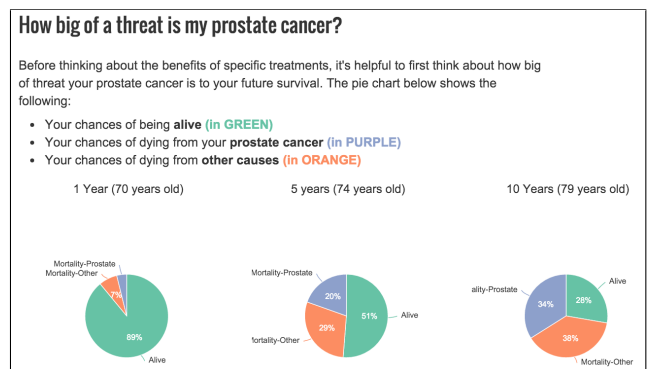
From a technical standpoint, the second prototype remains the same as the first one: the tool is written as a series of web pages using Javascript and d3.js, and the two CPMs (Stephenson-PSCM and Lu-Yao models) remain the same as well. With the new changes, this prototype grew to ten pages from the original six. In the outline below, new pages added from the original prototype are highlighted in bold.

1. Disclaimer (same as the initial prototype)
2. **"Road map"** - Addressing RV2, this page outlines the utility of PROACT, including estimates of risk for prostate cancer and comorbidity mortality rates that follow surgery or conservative treatment options. It also lists information on what PROACT does not contain, such as estimates of side effect risk and other treatment options (e.g., radiation therapy, cryotherapy).
3. Input (same as the initial prototype)
4. **"How big of a threat is my prostate cancer?" (year 1)** (Figure 2(a)) - Addressing RV1, using a pie chart, this page shows the patient's 1-year survival rate vs. mortality rate from prostate cancer vs. mortality rate from comorbidities. The goal of this page to reduce the patient's anxiety level and emotional state by showing that their survival rate from prostate cancer in the first year is likely to be high because prostate cancer is a slow-progressing disease.
5. **"How big of a threat is my prostate cancer?"** (Figure 2(b)) - Addressing RV4, we have removed the slider. This page now shows all 1-, 5-, and 10-year survival rate vs. mortality rate from prostate cancer vs. mortality rate from comorbidities.
6. **"Should I consider treatment?"** - Addressing RV3, this is an opt-out page for when the doctor decides to not discuss treatment. If chosen "Yes, I want to consider treatment," the tool continues onto the next page, else the tool jumps to the "More info" page.
7. **"What are my treatment options?"** - Addressing RV3, this page introduces the conversation of comparing the benefits between surgery and conservative treatment by listing common treatment options and providing external links to side effects.
8. **"How effective are different treatments for my prostate cancer?"** (Figure 2(c)) - Addressing RV4, we have removed the slider. This page now shows all 1-, 5-, and 10-year survival (and mortality risk via a toggle button) after surgery vs. conservative treatment in a bar graph.
9. **"What do I do next?"** (Figure 3) - Addressing RV1, this page is a

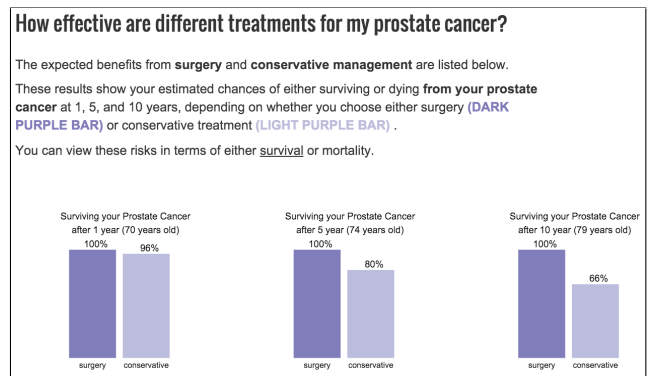
summary page containing the 1-, 5-, and 10-year pie and bar graphs and their corresponding percentages from pages five and eight.



(a) Page 4. Shows the 1-year survival rate. The purpose of showing this page early is to "calm down" the patient.



(b) Page 5. Revised visualization for showing the 1-, 5-, and 10-year mortality rate from cancer, from all other diseases (i.e., comorbidities), and the survival rate. Unlike the previous iteration, these visualizations are static.



(c) Page 8. Revised visualization to compare the survival rates of undergoing surgery or conservative treatment in 1, 5, and 10 years. Visualizations used in this page are also static.

Fig. 2. Example pages of the revised prototype of PROACT. In this prototype, the temporal dimension has been "flattened" and the visualizations are no longer interactive.

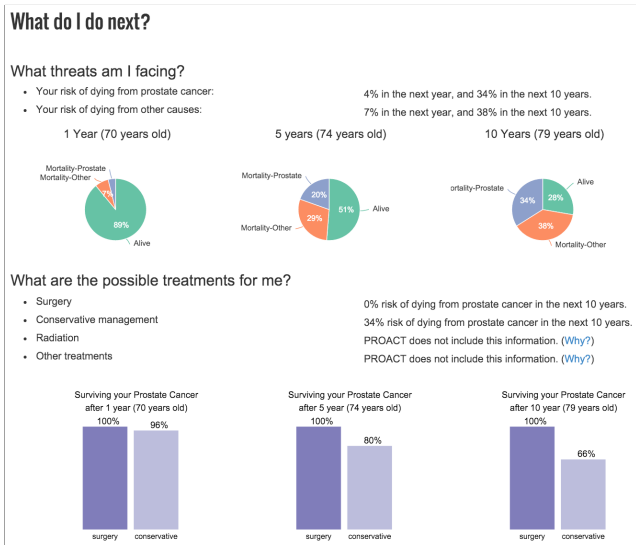


Fig. 3. Page 9. This is a summary page in the revised prototype showing all the information in the tool in a condensed form. The purpose is for the page to be printed and given to the patient to take home.

10. “More info” - same as in the initial prototype, but it emphasizes the limitation of the tool and includes more links to external resources.

Users could navigate between pages via the “<” and “>” buttons or via the navigation bar at the top of the tool.

5.2 Evaluation

5.2.1 Participants

The second study was carried out two months after the original study. We recruited six new patients and the same two doctors for this study in a similar manner as in the evaluation of the first prototype. Interviews with the doctors were conducted at the Maine Medical Center hospital, and evaluations with the patients were conducted at the Maine Medical Center Research Institute over the course of two days.

The six new patients were also recruited through the Maine Coalition to Fight Prostate Cancer and shared the same demographics as the first study (male, over 65 years old, and prostate cancer survivors). For the same privacy concerns, we did not request additional health or demographic information.

The two doctors who participated in the interview were the same two doctors from the previous evaluation session. The purpose of interviewing the same doctors was to preserve some consistency across the two studies.

5.2.2 Materials, Procedure, and Data Collection

The questionnaires, experimental setup, study procedure, and the data collection methods were all the same as in the first prototype (Section 4), maintaining consistency between the two sessions.

5.2.3 Findings

Similar to the data analysis of the evaluation of the first prototype, we analyzed the video, audio, and questionnaire data collected from the participant sessions. Overall, the comments from the second prototype were markedly more positive than that from the first. However, what is just as interesting as the positive feedback is the *lack of* negative feedback on many of our revisions. For example, unlike the first evaluation where the participants raised questions about the wording or the color schemes (RV5), we received no questions or comments regarding the usability of the tool. Below, we summarize these findings and describe how our revision met the expectations of the patients and the doctors.

Narrative Sequence One of the major considerations when making the revisions was the narrative sequence of the tool. The revised version of PROACT included a “road map” page (RV2), intended

to communicate the role of PROACT inside the broader context of decisions commonly considered after a prostate cancer diagnosis. Both patients and doctors thought the flow of information presented in the “road map” page was ideal and thought PROACT successfully followed that sequence. One of the doctors said, “*The flow is fine. I wouldn’t change the order of anything.*” We also emphasized the transitions within the sequence such as the difference between the prostate cancer risk discussion and the treatment option discussion, thus addressing the feedback on making the “*How big of a threat is my prostate cancer?*” conversation distinct and separate from the “*How effective are different treatments for my prostate cancer?*” discussion (see the **Disease vs. Treatment** finding in section 4.3.5). The doctors we interviewed in the second prototype were the same doctors who participated in the previous evaluation, and one doctor commented on the second prototype, “*I can’t even remember how the first one looked like, because this flows so much better.*”

Emotional State Since all participants from the previous evaluation noted that answering “*How much time do I have left?*” was of critical importance after learning of a positive diagnosis, we added the page “*How big of a threat is my prostate cancer in year 1?*” to the start of the PROACT tool to address this need while reducing the anxiety of the patients (RV1). We received positive feedback on this addition, with patients noting, “*I’m so glad we started with the first year because it was comforting,*” and “*Many people make emotional decision[s] even though it’s not the right choice.*”

Temporal Visualization Two big changes to the visualizations used in the second prototype were (a) the use of “simple” visualizations such as pie charts and bar graphs, and (b) the removal of all interactivity from the visualizations (RV4). Due to the low visual literacy levels of our participants, we were concerned that “flattening” a temporal visualization into multiple static pie charts (see Figure 2(b)) would cause information overload or confusion for some participants. However, none of the patients or the doctors raised any questions or expressed any concerns about the amount of information presented or the lack of interactivity in the visualizations. In fact, this arrangement led participants to talk about the temporal progression of prostate cancer more actively than in the previous sessions. The new design of using simple, non-interactive visualizations appears to have improved comprehension of disease progression.

While the above feedback supports our redesign, not all participants agreed with all elements of the redesign. In particular, the “opt-out option” received mixed feedback.

Opt-out Option Per a **doctor’s suggestion**, we added an “opt-out” option in the revision (RV3) in case the doctors feel like the treatment option is clear and obvious (e.g. if the patient is too old to have surgery). Surprisingly, this new option received mixed feedback. Four patients and a doctor raised some concerns over this option. A patient commented, “*How do I know if I want treatment without [being] given the treatment options?*” One doctor raised similar concerns and said, “*The treatment drop-off option is weird – the doctor should have the treatment talk anyway, but tailor it according to the patient.*” It was apparent that the patients wanted more, not less information, even in cases where the treatment option appeared to be obvious. The overwhelming number of negative reactions to the opt-out feature a doctor proposed suggests that the doctor’s needs may not coincide with the patient’s needs.

5.3 Future Works

Although we received a multitude of positive feedback on the second prototype of PROACT, we recognize that PROACT is still a prototype and there are specific issues that need to be addressed before deployment to clinical settings. For the first and second prototypes, we implemented two models – the models by Stephenson et al. [50] and Lu-Yao et al. [35]. Combined, they provide personalized estimates of prostate cancer morality following radical prostatectomy and conservative treatment. Understanding the survival and mortality rates asso-

ciated with prostate cancer is important, but from interviews with both doctors and patients, it is clear that other factors, such as side effects, recovery time, quality of life, localized vs. metastatic (cancer spread outside of the prostate), and other treatment options, are also crucial for deciding treatment options. CPMs that predict some of these factors currently exist or are in development, and it would be beneficial to incorporate these models in future versions of PROACT.

While the focus of these prototype evaluations were on constructing a narrative structure that increases patient comprehension, one patient raised an interesting point that he wished “*there were more information on uncertainty.*” Even though the CPMs generate personalized risk predictions, they do not currently produce confidence intervals to quantify uncertainty. In the current version of PROACT, we only display the prediction values returned by the models, but it will be valuable for future iterations of PROACT to explore how best to convey uncertainty using confidence intervals and other methods.

6 DISCUSSION

6.1 Need for Personalized Health Risk Communication Tools

The results of the two iterative design sessions indicate that PROACT attends to a prevalent unmet need for patient-centered health risk communication tools, especially ones that incorporate existing CPMs that are currently inaccessible and difficult to use and understand without the specialized knowledge of clinicians. All of the patients we interviewed recalled the lack of information disclosed by their primary physicians during their own consultations. Thus, patients had to spend time researching, trying to find reputable information in the form of books, online sources, support groups, and second opinions from other clinicians. There are many potential reasons that physicians do not communicate prognostic information or utilize evidence-based prognostic models. The current study attempted to address the problem of access to these models in a clinically usable, understandable form.

PROACT’s contribution to patient-doctor shared decision-making is twofold: (1) it serves as a communication guide for the consultation, and (2) it makes esoteric CPMs comprehensible to patients. Although PROACT does not include detailed information about side-effects, other treatment options, and other risk factors, it mentions them in the “road map” page and throughout the tool so that the doctor is reminded to talk about them. Furthermore, PROACT generates simple visualizations from complex CPMs and frames the information in a narrative that is accessible for patients. Personalized statistics from CPMs are not usually available from support groups or from clinicians, which makes PROACT unique and vital to health risk communication.

6.2 Design Guidelines for Health Risk Communications

Over the course of developing PROACT we came to realize that designing a patient-facing health risk communication tool can be significantly different from designing visualization or visual analytics systems for other domains. Based on our experience, we suggest the following design considerations that we believe made PROACT a success with the patients and doctors who evaluated the tool.

6.2.1 Accounting for User’s Emotional State

Due to the nature of the health risk communication, the users of tools like PROACT are likely going to be personally invested and emotionally charged when using such tools. While researchers in the visualization community are aware of the importance of considering a user’s cognitive states (e.g. cognitive load [42], emotion [23]) and cognitive traits (e.g. personality traits [54], individual difference [41]), less attention has been paid to considering the narrative flow of the visualization and its information content.

Our study shows that it is important for health risk communication tools to account for the users’ heightened emotional state by first trying to “calm the user down” before presenting them with additional information. As informed by our participants, when confronted with the grave news of having cancer, most patients lose their ability to process complex information and make an objective decision. Our design of first presenting the users with their 1-year mortality rate was useful,

but this approach might only be useful for slow-progressing diseases like prostate cancer. Further research of techniques that can reduce the users’ anxiety level and lower their emotional state would be very useful in designing future health risk communication tools.

6.2.2 Minimizing Complex Visualizations and Interactions

Our initial assumptions about what visualizations would be most useful did not fit well with our intended user group. Given that our users are older men with low numeracy and visual literacy levels, complex visualizations with high degrees of interactivity made it difficult for them to understand the information. As seen in the initial prototype, some users did not even utilize the slider interaction feature, and thus the tool did not guarantee that everyone will see all of the necessary data. This could be because individuals who are not familiar with visualizations do not know how to use sliders to “animate” the visualizations to determine temporal trends. Because personalized health risk communication tools will be used by a wide variety of patients, we need to account for individuals with low numeracy and visual literacy. As such, when developing tools for the general public, it is likely that simpler, static visualizations may be better than those with high interactivity, even if it means sacrificing exploratory features.

6.2.3 Valuing Grounded Iterative Design

Finally, when developing a patient-centered risk communication tool, an iterative design (i.e., produce, test, and revise prototypes) is vital to ensuring that the tool content conforms to the users’ needs. Following the grounded evaluation process of visualizations [30], we found that the iterative design process of health risk communication tools are most effective when used in conjunction with the target user groups. In PROACT, we recruited prostate cancer survivors and urologists for testing. Interviewing such specific population was beneficial because they were able to recall from their own experience and identify key factors that contribute to treatment decision-making. From a design standpoint, we would not have been able to predict that designing for the patient’s emotional state would be such an important factor nor that visualization interactions would be difficult with those with low visual literacy had we just one evaluation or the evaluations been conducted with any group of users other than prostate cancer survivors.

7 CONCLUSION

In this paper, we report the iterative design process and the findings of developing the Prognosis Assessment for Conservative Treatment (PROACT) tool, a personalized health risk communication tool for localized prostate cancer patients. PROACT utilizes two published clinical prediction models (CPMs) to communicate the patients’ personalized risk information of prostate cancer and compare treatment options. In collaboration with the Maine Medical Center, we conducted two rounds of evaluations with prostate cancer survivors and oncologists to identify the design elements and narrative structures that would increase the users’ comprehension of their health information.

Most importantly, our results indicate that tools like PROACT that help patients understand their personalized health risk information are greatly needed, and visualization is integral to effectively communicate complex risk information to patients. However, the design of these tools needs to be done with a great deal of care. As many of these patients have low numeracy, visual literacy, and heightened emotional states, careful narrative structure and visualization designs are necessary to help the patients reduce their anxiety and increase comprehension. Although the current version of PROACT does not yet incorporate all the treatment options for prostate cancer due to a lack of available CPMs, our initial evaluations of the PROACT tool have been very positive. Through continued collaboration with the Maine Medical Center, we seek to further refine PROACT and hope that the tool will be available publicly in the near future.

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