Visualization Co-Design with Prostate Cancer Survivors who have Limited Graph Literacy

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ABSTRACT

Visualizing patient-reported outcomes overtime has become a common strategy to help patients track their health. However, traditional line graphs and bar charts might be less accessible to people with limited numeracy and graph literacy. Although patient-reported outcomes (PRO) among prostate cancer survivors may be collected with extant validated instruments, such as the Expanded Prostate Cancer Index (EPIC-26), survivors with limited numeracy and graph literacy may not have access to or understand personal trends in their PRO data. The Graphical Representation of Symptoms of Prostate Cancer (GRASP) research team embarked on a 4-stage design process with prostate cancer survivors with limited graph literacy to investigate design considerations for timeline visualizations, including preferences, acceptability, and understandability. Through focus groups, surveys, and the recurring engagement of a community-based Patient Advisory Board, we identified 3 design approaches that reflect the needs of low graph literacy patients as well as show promise to increase acceptance and comprehension. We are developing these designs into interactive prototypes for evaluation through user testing. Findings from our design process provide insight into effective strategies for engaging vulnerable patients for visualization co-design using in-person and remote methods. Finally, the design considerations we identified for prostate cancer survivors with limited graph literacy that may provide insight for visualizations of PROs for other vulnerable groups.

Keywords: graph literacy, prostate cancer, patient reported outcomes

Index Terms: Human-centered computing; Visualization; Visualization application domains; Information visualization, Graph literacy, Patient-reported outcomes

1 INTRODUCTION

Among men in the United States, prostate cancer causes the highest rate of new cancer cases and second highest rate of cancer deaths[1]. Demographics play a role in prostate cancer occurrence and mortality with African American men experiencing almost double the incidence and death rate of any other race/ethnicity group[1]. It is not well-studied whether race or institutional racism is the social determinant of this disparity. Prostate cancer severely impacts a patient's quality of life, including urinary, sexual, bowel and hormonal symptoms, and entails making difficult decisions about primary treatment options[2]. Instruments used to collect patient reported outcomes (PRO) related to prostate cancer offer the potential to improve quality of life and health outcomes[3]. One such validated instrument is the Expanded Prostate Cancer Index Composite or EPIC-26[4], based on the UCLA Prostate Cancer Index[5], [6], that can be used to track changes in quality of life outcomes over time[7]. Despite the availability of these tools, prostate cancer survivors report a lack of empowerment to share information and communicate with their providers[8]. Visualization tools may assist in both empowerment and understanding of health information in this patient population.

Visualizing patient-reported outcomes overtime has become a common strategy to help patients track their health. Research suggests that monitoring PROs can improve survival rates for cancer patients[9], [10]. However, these traditional line graphs and bar charts might not be understood by people with limited numeracy and graph literacy. Although prior research investigates PRO visualizations for prostate cancer survivors with higher graph literacy[11]–[13] and a dearth of studies focus on tools for survivors with limited health literacy [14], [15], few focus design efforts on men with limited graph literacy, and none to our knowledge in our specific population - prostate cancer survivors. Visualization studies have found that a 'gradient line' design can help patients interpret lab results among mixed literacy and numeracy populations[16] and supplementing bar charts with an emoji icon helps patients with limited health literacy [17], but these designs have not been evaluated with limited graph literacy populations. Though a previous study provided evidence to understand pictorial representation needs of patients with mixed health literacy[18], there is still a need to understand acceptability and requirements for graphical representations showing timelines with limited graph literacy populations. Medical longitudinal data is challenging to show in any population[19], but patients with limited graph literacy may need non-graphic designs for better understanding [20].

Limited graph literacy and low numeracy may affect approximately one-third of the population in the United States, and numeracy and graph literacy are not directly correlated, thus indicating the need to understand the specific requirements for the limited graph literacy population[21], [22]. Graph literacy competencies assess whether a participant can interpret a graph in 3 ways: 1) reading the data or the ability to make a data point estimate, 2) reading between the data or the ability to compare two data points, and 3) reading beyond the data or the ability to project a future data point[21]. Considering the high prevalence of both limited graph literacy and prostate cancer in the population, there is a need to design timeline visualizations at the intersection of these two groups. Our project, the Graphical Representation of Symptoms of Prostate Cancer (GRASP), aims to address this gap in meeting the needs of prostate cancer survivors with limited graph literacy. In this study, we embarked on a multistage, patient-driven design process for timeline visualizations of patient reported outcomes (PROs). The objectives of our design study were to:
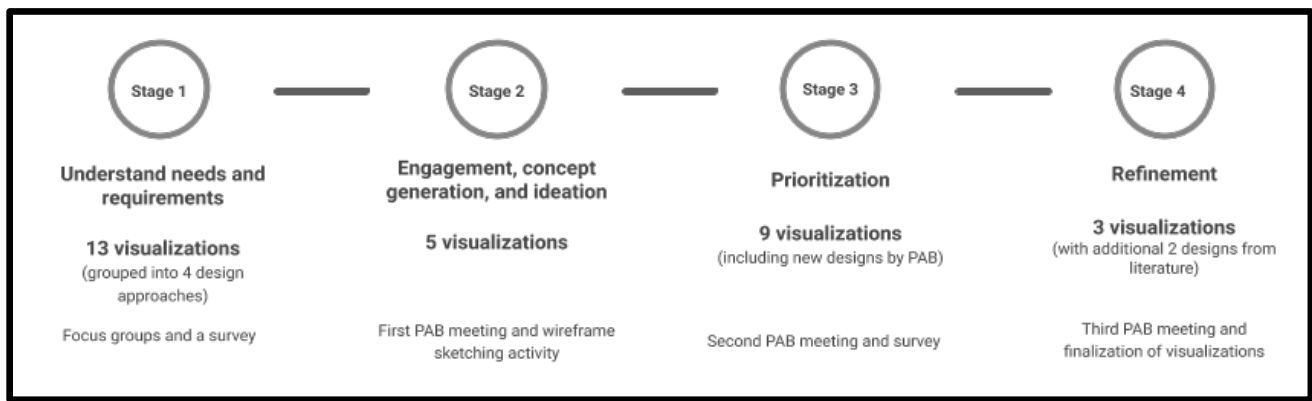
Figure 1: Stages of design process with objectives, visualizations, and activities

1. Characterize PRO timeline visualization needs of prostate cancer survivors with limited graph literacy.
2. Specify the requirements for PRO timeline visualizations for prostate cancer survivors with limited graph literacy.

2 MULTISTAGE DESIGN PROCESS

To characterize the needs of prostate cancer survivors with limited graph literacy (research objective 1), we took a multi-stage, patient driven approach following principles of user centered design. First, we held four focus groups with 16 prostate cancer survivors to understand their information needs for prostate cancer PROs and obtain feedback on 4 groups of timeline visualizations (stage 1). We then collaborated with 6 participants recruited from focus groups through the formation of a Patient Advisory Board (PAB). We held 3 workgroup meetings with the PAB to ideate (stage 2), prioritize (stage 3), and refine (stage 4) visualizations to identify the most promising approaches (research objective 2). Please see Figure 1.

2.1 Stage 1: Focus Groups

At the onset of this work, we held four focus groups with prostate cancer survivors to characterize their information needs and obtain initial feedback on visualizations.

Stage 1 Methods
We recruited 16 men from the IMPACT Program, using the Men's Health Study database, as well as from Martin Luther King Jr. Outpatient Center who had been diagnosed with prostate cancer within the last 6-10 years to take part in a 2-hour focus group. Participants consented to participate and were compensated for their time. Focus group facilitators were trained to guide the discussion using a semi-structured instrument guide. Using a flip board to document the discussion, facilitators first asked participants to describe what "Quality of Life" (QOL) means to them. We also asked which QOL topics participants considered most important and how prostate cancer has affected those topics. We also asked participants to prioritize the QOL topics on a flip board. Next we shared 13 visualizations exemplifying 4 timeline design approaches: 1) traditional charts and graphs, 2) metaphors, 3) isotypes, and 4) narrative storytelling visualization. For the traditional charts and graphs, we used visualizations similar to bar charts, line graphs and a sparkline visualization commonly used in patient-facing tools, such as personal health records. For metaphors, we used weather, stoplights, and leaves on a tree to illustrate trends. For the isotype group, we used a water pitcher, Legos (toy building blocks), and toilet paper[23]. Finally, for storytelling, we showed visualizations with animation, audio, and a comic depiction[24]. All visualizations illustrated the same fictitious data set of EPIC-26 symptom severity scores over 36 months (scores range from 1 to 100). We asked the participants to rate each visualization on a Likert scale from 1 ("not at all interested in using") to 5 ("very interested in using"). The focus groups were audio recorded and transcribed. Members of the research team thematically coded the transcripts for salient themes for QOL topics and summarized Likert ratings of visualizations with descriptive statistics.

Stage 1 Findings
The median age for participants was 62. Most identified as African American or Black (87.5%) and had a high school/GED or lower education level (68.75%). Please see Appendix 1 for demographic information. Thematic topics regarding QOL included sexual and urinary dysfunction and its effects on everyday life. Additionally, there was an emphasis on mental health and the toll the diagnosis played on this aspect of their overall health; these themes are further explored in another presentation[25]. The discussion and ratings of the visualizations emphasized the need for color encoding and easy to understand text. Participants favored interactivity and suggested that narration would be a useful feature to include with the visualization. They also preferred the legend of the tree metaphor because it showed individual leaves that could be counted and associated with their PRO scores. Traditional charts and graphs were the highest preferred formats (mean= 4.1, SD= 0.6), followed by: metaphors (mean =3.6, SD=1.6), narrative visualization (mean = 2.7, SD=1.4) and isotypes (mean = 2.2, SD =1.4). However, ratings of visualizations within each group was variable. When asked about the individual 13 visualizations within each group, the top rated visualizations were: 1) the bar chart (mean =3.7, SD=1.4 median= 4), 2) line graph (mean = 3.5, SD=1.6, median =4), 3) audio (mean = 3.3, SD=1.3, median = 4), 4) weather metaphor (mean = 3.2,SD=1.6, median = 3.5), and 5) water pitcher isotype (mean = 2.9,SD=1.5 median = 3). The top-rated groups and visualizations influenced our designs for subsequent stages. We chose not to pursue traditional charts and graphs because we do not expect those formats to facilitate comprehension among those with limited graph literacy, which was a primary objective of this work. The preference noted here may be caused by a number of reasons: 1) mixed participation and graph literacy 2) previous familiarity with these types of visuals and 3) incongruence between preference and comprehension. Due to constraints of the research study, we were unable to assess graph literacy, and this may have influenced preferences at this stage. Also, we believe the higher ranking might be associated with familiarity due to the prevalence of traditional

Urinary Function

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This tool tells you about your symptom scores following treatment

Scores range from 0 (poor function) to 100 (excellent function).

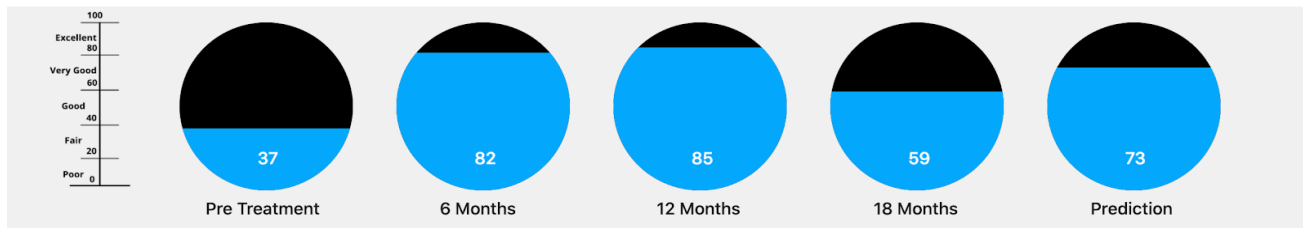Click on a disk to hear about your **Urinary** function.

Figure 2: Narrated "Disk" prototype used in Stages 2 and 3 The interactive prototype allowed the user to view urinary, hormonal, sexual, or bowel function scores and play audio that guides the user through the timepoints, and scores generated by his own PROs.

graphics. A previous study showed that low literacy patients were more likely to prefer bar charts, but this preference did not correlate with comprehension[26].

2.2 Stage 2: Patient Advisory Board formation and first meeting to ideate visualizations

After analysis of the focus group results, we formed a Patient Advisory Board (PAB) to further iterate our timeline visualizations. The PAB consisted of six men who participated in the focus groups and expressed interest in further participation. Participants consented and were compensated for their time for all PAB meetings. The purpose of our first meeting was engagement, concept generation, and ideation. We used focus group feedback to revise the most preferred, non-graphic visualizations from stage 1 to gain feedback and further iterate the audio, weather metaphor, water pitcher isotype, and tree metaphor designs. We also introduced new visualizations to explore additional formats.

Stage 2 Methods
The first meeting was held in-person on the UCLA campus. We introduced members of the PAB and research team and provided background on the project and expectations for participation. After sharing findings from the focus groups, members were asked to individually sketch out their own visualization ideas and work with a partner to discuss and share back their design ideas to the group. Finally, we shared a revised set of 5 visualizations based on stage 1: 1) seedling (revision of tree), 2) revised weather, 3) iceberg, 4) waves, and 5) demonstration of a revision of the water pitcher into an interactive web-based visualization of disks that included narration in the form of audio clips (Figure 2). We then held a workshop on quality of life topics and visualization design. During the workshop, we asked the PAB to list the 3 topics that were important to their quality of life.

Stage 2 Findings
During the meeting, the PAB members shared concerns about understanding the visualizations (engagement), explained the importance of topics related to quality of life (concept generation),

and offered ideas for visualization design (ideation). We heard the need to have a scale and frame of reference for the score to provide some contextual information. One participant articulated the ambiguity of individual scores, "*Does the score mean I am 81% sad or I've got 81% cancer?*". During the workshop, PAB members listed a range of different topics including incontinence, sexual health, and healthy diet and other lifestyle choices. Many members also mentioned topics related to mental health, specifically depression and self-esteem, concern about uncertainty about the future, romantic and familial relationships, lack of knowledge, and fear. The PAB generated several new ideas for design. Their sketches included a color-coded meter similar to a speedometer, and a qualitative or annotated timeline (Figure 3). One pair of participants discussed the need for personalized information; they shared a design that provided a reference point to their own 'normal' based on their personal data. They also shared visualization designs on depression and mental health resources.

2.3 Stage 3: Second PAB meeting to prioritize visualizations

We engaged with the PAB a second time to prioritize visualizations based on preferences and comprehension for future development. To achieve this objective, we administered an online pre-survey and held a virtual meeting with PAB. The survey included 9 visualizations based on the discussion from the first meeting, including 4 visualizations based on ideas that were sketched by PAB members (animated meter, qualitative timeline, arrows, and stairs), 1 visualization to exemplify audio narration, and 4 visualizations that were further iterations from previous stages (seedling, weather, iceberg, comic).

Stage 3 Methods
Between stages 2 and 3, Shelter In Place orders were instituted across California making it impossible to meet again with the PAB in-person. To facilitate a virtual meeting, one member of our team contacted each PAB participant to ensure they had access to our video conferencing platform downloaded and were able to join a

virtual meeting remotely. Prior to the meeting, we used an online survey to gather initial data on comprehension and preferences among the revised set of visualizations. To measure comprehension, we asked participants if the scores were getting "better" or getting "worse" for each visualization. To assess preferences, we asked how likely they would be to recommend each visualization to a friend. We also asked PAB members to choose their top 3 preferred visualizations.

In advance of the 2-hour virtual meeting, we mailed PAB members paper printouts of slides with visualizations to be discussed during the meeting so they would have a physical copy to reference. During the virtual meeting, we introduced and discussed a persona of a prostate cancer survivor as a user of the visualization to situate our discussion. We included 9 visualizations based on findings from prior stages: 1) comic, 2) animated meter, 3) qualitative timeline, 4) seedling, 5) iceberg metaphor, 6) weather metaphor, 7) stairs, 8) arrows, and 9) the interactive disk that included audio narration. To begin a discussion around technology platforms (desktop or smartphone), we changed the orientation of the interactive disk so that it could be viewed on a smartphone device. We also shared results from the survey to validate findings and gathered specific feedback to prioritize the best visualizations for future development. In the second part of the PAB meeting, we discussed if members would like to interact with the visualizations and how they might do so, including their technology platform preferences.

Stage 3 Findings
The survey results showed that the animated meter, qualitative timeline, and comics performed well for comprehension and were most preferred. During the meeting, these visualizations were favored by the PAB, and we collaboratively decided to continue refinement of the meter, words, and comic. We also gathered feedback on how to improve these designs, such as changes to coloring and detailing facial expressions on the comics. We heard that the ability to view the visualization on a smartphone was needed as well as accessible with low connectivity to data or the internet. PAB members noted that bandwidth was a concern if narration, animation, or video was necessary for the visualization. There was some pushback on animation as need for simplicity was emphasized.

2.4 Stage 4: Third PAB meeting to refine designs and explore competencies

In our third meeting with the PAB, we obtained more detailed feedback to inform prototype development and to understand how our 3 designs might help facilitate graph literacy competencies. We also introduced two comparison visualizations from the literature-- a bar chart with emojis and a gradient line--to the PAB to learn their impressions about these alternative designs.

Stage 4 Methods
In our final engagement with the PAB, our objectives were to refine the 3 selected visualizations (meter, words, and comic) from our Stage 3 and understand how those designs relate to graph literacy. Like stage 3, we mailed all materials prior to our virtual PAB meeting, including the visualizations and the presentation slides which included a series of questions. We asked participants for feedback on revised versions of the 3 visualizations to ensure we were responsive to their recommendations from the previous meeting. We also introduced 2 new visualizations based on related work to gather feedback for comparison [16], [17], including a bar

chart with emojis and color-coded gradient lines. In the final part of the meeting, we discussed if and how the different visualizations may improve graph literacy competencies, specifically 1) reading the data, 2) reading between the data, and 3) reading beyond the data [21]. Our question prompts PAB members to explain their interpretation of score, or their ability to 'read the data'. To measure their ability to 'read between the data', we included a comparator to 'men like me' showing the average of patients' scores. For the final graph literacy competency, 'reading beyond the data', we asked participants to estimate what the future might look like in comparison to the trajectory of the average scores for "men like me'.

Stage 4 Findings
During our final virtual meeting, the PAB reinforced our 3 visualizations as the best options for prototype development and evaluation. PAB members wanted the comic to show more emphasized facial expressions and wanted the qualitative timeline to include more color and be easier to read. PAB members did not prefer the comparison visualizations from the literature, including the emoji bars [17] and color-coded gradient lines[16], citing that they were too confusing and too similar to traditional graphs not designed for low graph literacy patients. PAB members responded correctly to the graph literacy competency of 'reading the data' and were able to explain the meaning of the numerical score in the context of the visualization. PAB participants provided some feedback on the design of the visualizations: they would like to see comparison data on side-by-side visualizations, but they were also hesitant to display too much information at once. They also questioned the definition of 'men like me' and the source of this data. There were mixed responses to the "reading between the data" competency, but some PAB members responded that it would be helpful information to have as a prostate cancer survivor.

3 DISCUSSION

Throughout our design process, engagement with and feedback from prostate cancer survivors was paramount. Their recurrent participation and increasingly specific design critiques guided and shaped the development of our visualizations. We learned that color encoding can be an important tool in design for this population, which is similar to color findings for other populations[27], [28]. We also learned that interactivity and flexibility was favored but needed to be balanced with the need for simplicity to avoid cognitive overload. Design concepts that were homegrown during our PAB meetings, such as the meter and qualitative timeline, were favored over other design alternatives. Other research studies suggest that visualizations similar to the meter and the comic, which were validated by our PAB, are also effective designs in other populations to convey health information[20], [29].

Our discussion regarding smartphones as a technology platform spurred some additional consideration of accessibility for patients with limited graph literacy. We learned from the PAB members that the need to simplify and streamline the visualization stemmed not only from limited graph literacy but also from the prostate cancer patient experience of information overload, overwhelm, and anxiety. Further, considering many prostate cancer patients experience multiple health conditions and are of advanced age, we developed the visualizations with a consideration for accessibility. We referenced the W3C web accessibility guidelines and health literacy guidelines for font size. For accessibility, we used color blind friendly color schemes as 8% of men suffer from vision
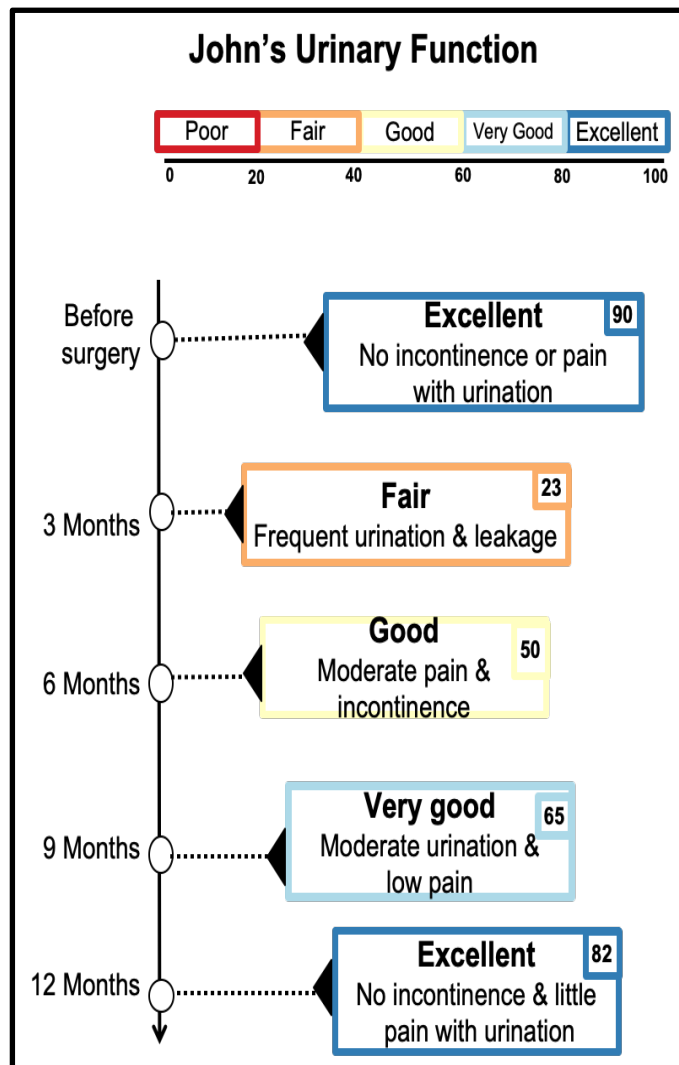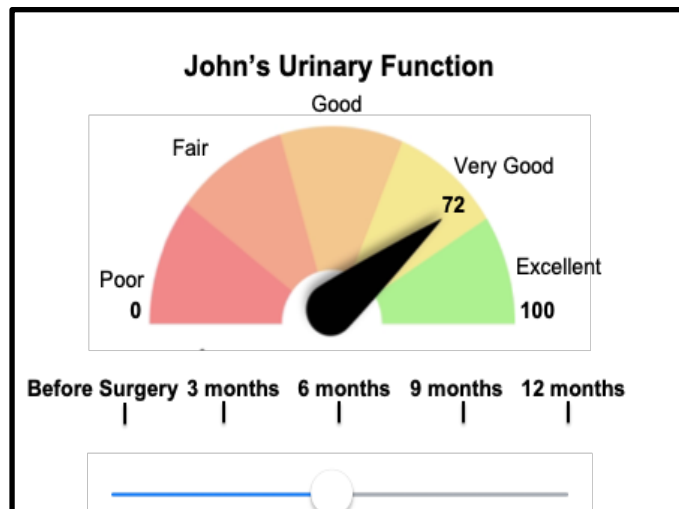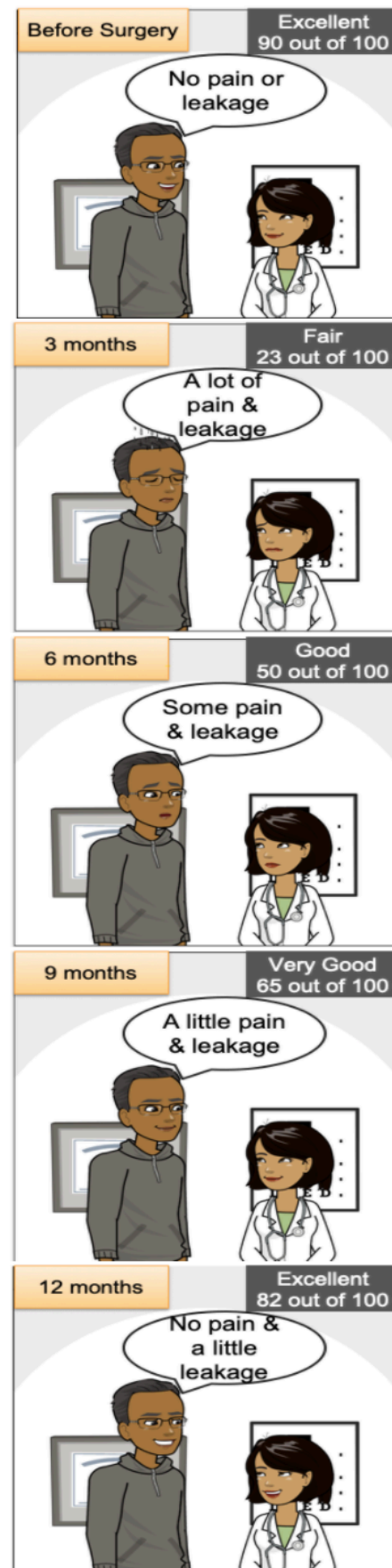
Figure 3: Meter, qualitative timeline, and comic visualizations co-designed with PAB meter during stage 4 of design process to show prostate cancer PRO scores over time.

impairment for color[30]. Finally, perhaps related to cultural or demographic factors, feedback from the PAB emphasized that some visual principles may need to be reexamined in this setting, as there has been little research on design for limited graph literacy populations. For instance, members of the PAB shared that they would intuitively read visualizations from the bottom up rather than from the top down as routinely considered the norm. We designed the visualizations on a longer frame as would be shown on a smartphone and PAB members expressed confusion about the top down reading order. We used a static prototype during this discussion, but an interactive version in future work may provide more insight into this user behavior.

The need to protect public health from COVID-19 infection necessitated the virtual and remote methods we used during stages 3 and 4 as well as upcoming work for our study. This change has entailed both technological and interpersonal effects. We consulted the grey and published literature for engagement strategies to help work with patients from afar and explored different technological avenues to consider how we might conduct the design virtually[31]–[33]. We found that mailing physical, paper copies of all presentation materials was helpful for participants with limited graph literacy and/or lower technological readiness. We also met virtually with participants individually prior to our meeting to help them install and provide a short demonstration of how to use the video conferencing application. We encouraged patients to use video during the PAB meetings but allowed participation through a desktop or phone with or without video. Finally, the shift to remote methods highlighted the need for low graph literacy patients to rely on engaging with technology through their smartphone and with limited data or connectivity. This finding may not have been as apparent using previously planned in person methods.

Feedback from the PAB continued to become more detailed and explicit in later meetings. The evolution of the PAB members from a critical eye to a co-designer of the visualization likely stemmed from their recurrent engagement and ensuing understanding of design processes, such as scenario development and interaction. There was a continual increase in the specificity and depth of the feedback from the PAB in our latter meetings. This progression is fundamental to the process of co-design and helps facilitate the end users to take an active role in the creation of a design[34]. Creating a safe space and level of trust with the members likely helped encourage their feedback in addition to having more time to understand and think about the design. Recurrent engagement or avoiding a one-time meeting with patients might be a helpful lesson for other health visualization designers looking to consult a PAB for their design.

4 UPCOMING WORK

Based on findings from our 4-stage design process, we are developing our 3 co-designed approaches (meter, qualitative timeline, comic) into high fidelity, interactive prototypes to evaluate for comprehension, usability, and acceptability. Similar to the shift from in-person to remote meetings in our design work, our evaluation will also take place by phone and video conferencing. We are conducting the evaluation through phone and internet to allow for participants at different stages of technological readiness and accessibility. Over the coming months, we will recruit prostate cancer survivors with limited graph literacy to participate in our user study.

5 CONCLUSION

Understanding trends in PROs can help prostate cancer survivors to track their quality of life and engage in their health and healthcare. Well-designed visualizations can offer the opportunity for patients with limited graph literacy to access and understand their own prostate cancer PRO data. We used a 4-stage design process that engaged patients through focus groups, surveys, and Patient Advisory Board workgroup meetings. We met with prostate cancer survivors to understand information needs about quality of life (stage 1). We held 3 workgroup meetings with the Patient Advisory Board to ideate (stage 2), prioritize (stage 3), and refine (stage 4) design approaches. This design process resulted in a better understanding of preferences, needs, and requirements of our target group and allowed us to co-design three visualization approaches that we are developing into interactive prototypes for future user testing. The design process also allowed us to learn that visualization design must be shaped not only by limited graph literacy concerns but also by the lived experiences of prostate cancer patients who pointed to information overload, overwhelm, and anxiety affecting their interaction with health information.

To meet our research objectives, we characterized the needs and requirements of prostate cancer survivors by identifying important themes around quality of life (objective 1) and design characteristics, such as simplicity, use of color, and interactivity (objective 2). We identified 3 visualizations (meter, qualitative timeline, comic) that was acceptable to our Patient Advisory Board and will be further evaluated for usability. Further, we demonstrated the use of remote methods to engage and gain feedback from patients and provide some lessons learned from our work, such as mailing physical copies of materials and training participants in the video conference application. Our research demonstrates an effective design process methodology with individuals with limited graph literacy and provides guidance for future design work in this space

6 ACKNOWLEDGEMENTS

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APPENDIX 1: Demographics of Focus Group Participants

	Group 1	Group 2	Group 3	Group 4	Total
	n = 5	n = 3	n = 3	n = 5	16
Median age, range	65, 8	61, 9	63, 5	62, 13	62.5, 19
Race					
Black/African American	5	1	3	5	14
Asian	0	1	0	0	1
White	0	1	0	0	1
Ethnicity					
Hispanic/Latino	0	0	0	0	0
Not Hispanic	1	1	2	1	5
Decline	1	0	0	2	3
Blank	3	2	1	2	8
Education					
Less than high school	1	0	0	0	1
High school/GED	4	0	2	4	10
Associate's degree	0	1	1	0	2
Bachelor's degree	0	2	0	1	3
Graduate degree	0	0	0	0	0