User-Centered Design of Quality of Life Reports for Clinical Prostate Cancer Care

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A thesis

submitted in partial fulfillment of the

requirements for the degree of

Master of Public Health

University of Washington

2013

Committee:

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Program Authorized to Offer Degree:

School of Public Health

University of Washington

Abstract

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Background: Primary treatment of localized prostate cancer can result in bothersome urinary, sexual, and bowel symptoms. Yet clinical application of health-related quality of life (HRQOL) questionnaires is rare. We employed user-centered design to develop graphical dashboards of prostate cancer patients' questionnaire responses that would facilitate clinical integration of HRQOL measurement.

Methods: We interviewed 50 prostate cancer patients and 50 providers, assessed literacy with validated instruments (Rapid Estimate of Adult Literacy in Medicine short form, Subjective Numeracy Scale, Graphical Literacy Scale), and presented participants with prototype dashboards that display prostate cancer-specific HRQOL with elements derived from patient focus groups. We assessed dashboard comprehension and preferences in table, bar, line, and pictograph formats with patient scores contextualized with HRQOL scores of similar patients.

Results: Health literacy (mean score 6.8/7) and numeracy (mean score 4.5/6) of patient participants was high. Patients favored bar charts (mean rank 1.8, $p=0.12$ vs line graphs, $p<0.01$ vs tables and pictographs); providers demonstrated similar preference for table, bar, and line formats (ranked 1st by 30%, 34%, and 34% of providers, respectively). Providers expressed unsolicited concerns over presentation of comparison group scores (n=19, 38%) and impact on clinic efficiency (n=16, 32%).

Conclusions: Based on prostate cancer patient and provider preferences, we developed the design concept of a dynamic HRQOL dashboard that permits a base patient-centered report in bar chart format that can be toggled to other formats and include error bars that frame comparison group scores. Inclusion of lower literacy patients may yield different preferences.

Introduction

Primary treatment of prostate cancer (PCa) usually involves surgical removal of the prostate or radiation therapy to eradicate the cancer, and can result in substantial changes in health-related quality of life (HRQOL) for urinary, sexual, and bowel function.(1-4) Yet patients are often unaware of the magnitude of their dysfunctions relative to expected outcomes,(5) despite consideration of HRQOL assessment with validated instruments as a quality performance measure.(6, 7) Unfortunately, clinical implementation of survey assessment is onerous. This results in limited availability of HRQOL data for PCa patient counseling, either before treatment to aid decision-making, or after treatment to track HRQOL convalescence. Integration of HRQOL measurement into clinical care has potential to empower patients with improved understanding of their HRQOL detriments, leading to more informative discussions with their providers and greater self-efficacy for their PCa care.(8)

We sought to address deficiencies in PCa care limiting discussion of the HRQOL impacts of treatment. We address these deficiencies through the user-centered design of an HRQOL measurement and presentation system informed by input from patients and providers. Herein, we report on the initial user-centered design in which we identified patient-centered HRQOL dashboard elements and assessed comprehension and preferences of prototype dashboards for inclusion in the system. Although HRQOL assessment tools that target clinician users have established effectiveness in clinical care for other conditions,(9-11) research is limited on the design of meaningful presentations of HRQOL data that engage patients and providers as collaborative system users.

User-centered design is an informatics framework that directly incorporates target users in software development.(12) Soliciting input from target users during iterative prototyping cycles results in technology that is more readily adopted by end users.(13) Through user-centered design of graphical reports of PCa HRQOL, or dashboards, we generate important design concepts that can enhance the clinical care of PCa survivors.

Methods

We conducted our user-centered design in two phases. First, in our preliminary work, we identified HRQOL dashboard elements that are meaningful to patients through focus groups with PCa survivors.(14) When asked what questions an HRQOL dashboard could help answer, participants rated the following questions highest: "how am I doing compared with patients like me?"; "how am I doing compared with before treatment?"; and "what can I expect in the future?" These questions map to the longitudinal presentation of patients' HRQOL with the context of comparison group scores derived from HRQOL outcomes of matched patients. This representation facilitates comparison with similar patients, enabling comparison of current HRQOL with HRQOL before treatment, and permits patients to project expected outcomes based on the HRQOL trends of comparison group patients.

In the second phase of user-centered design, we designed four prototype HRQOL dashboard formats (Figure 1) that illustrate the patient-centered elements: (1) bar charts and (2) line graphs as common representations of information displayed over time; (3) tables that display HRQOL data in raw form; and (4) facial expression pictographs modeled after the Wong-Baker FACES pains scale,(15) as pictographs have exhibited strong information transfer for lower literacy patients.(16) We then conducted individual interviews with patient and providers to ascertain comprehension and compare preferences among prototype HRQOL dashboard formats.

Study Participants

This study was approved by the University of Washington Institutional Review Board. Written consent was obtained from all participants. We tested prototype dashboards with 50 PCa patients and 50 PCa providers. We recruited patients from local PCa support groups and from UW Medicine urology clinics. Eligible patients were at least 21 years old, had a diagnosis of PCa irrespective of stage or time since treatment, and could read and understand English. Eligible providers were recruited from area

urology and radiation oncology clinics and were included if they participated in PCa care. Feedback from focus group patients established that patients commonly engage non-physician providers (i.e., nurses or nursing aides) in HRQOL discussions. Thus, we enrolled 25 physician providers and 25 non-physician providers. We collected demographic and clinical information from all participants.

Participant Literacy Assessment

We assessed participants' health literacy, numeracy, and graphical literacy with validated literacy instruments. To measure health literacy, we used the short form Rapid Estimate of Adult Literacy in Medicine (REALM-SF),(17) a prevalent health literacy instrument that uses medical word recognition and pronunciation to stratify individuals into health literacy levels. The REALM-SF is highly correlated with education level and other measures of health literacy(18-20) and is scored from 0 to 7. We did not evaluate providers with the REALM-SF as providers are familiar with medical language.

We assessed numerical literacy using the Subjective Numeracy Scale (SNS).(21) The SNS measures self-perceptions of mathematical faculty rather than objective performance of mathematical operations. The Preference subdomain measures predilections for information in numerical versus prose formats; the Ability subdomain measures individuals' subjective capacity to perform calculations. SNS is highly correlated with objective numeracy scales,(22) but may cause less frustration among study participants.

We evaluated graphical literacy with the Graphical Literacy Scale (GLS) (23). The GLS assesses whether individuals understand common graphical representations of numerical health information and is divided into three subdomains: Reading, Reading Between, and Reading Beyond. *Reading* measures the ability of an individual to extract information from a graph. *Reading Between* measures one's ability to compare groups based on graphical displays. *Reading Beyond* measures one's ability to generate predictions based on graphical displays.

Dashboard Evaluation

Following literacy assessment, participants viewed each prototype dashboard and responded to questions that measured comprehension and perceived usefulness. Participants then rank-ordered the HRQOL dashboards according to their preferences and provided qualitative input on design elements.

Each dashboard illustrated sample HRQOL data for a fictitious patient scenario based on assessment of example patients with the Expanded Prostate Cancer Index (EPIC).(24) EPIC is the most commonly used PCa-specific HRQOL instrument,(25) measuring symptom severity on a 0-100 scale for urinary, sexual, and bowel domains, with a higher score indicating better HRQOL. Dashboards were counterbalanced for positive and negative framing (i.e., the example patient was doing better or worse than comparison group patients) with randomized order of chart format presentation.

We tested participant comprehension for each prototype dashboard according to the three subdomains of graphical literacy. Thus, to assess Reading, we asked participants to determine HRQOL scores of example patients at interval time points before or after treatment. To assess Reading Between, we asked participants to indicate the relationship between the HRQOL trend of example patients' HRQOL and comparison group scores. To assess Reading Beyond, we asked participants about expected HRQOL at future time points within the time scale of the prototype dashboard.

We evaluated perceived usefulness of dashboards by asking the participant to rate the helpfulness and their level of confidence using each prototype on a 4-point scale. Predilections for the formats were established by rank order preferences. We combined the quantitative assessments with semi-structured interview questions to elicit qualitative feedback about prototype HRQOL dashboards. With each format, we inquired about challenges with comprehension and reasons for rank order preferences. We transcribed responses and sorted them into common themes using affinity diagraming.(26)

Statistical Analysis

We summarized participant characteristics with descriptive statistics and assessed literacy differences using Mann Whitney U tests. We scored dashboard comprehension as percentage of questions correct for each dashboard. Differences between patient and provider participants in HRQOL dashboard comprehension were assessed with Mann Whitney U tests to compare Reading, Reading Between, Reading Beyond, and total comprehension scores. We assessed differences between perceived helpfulness and confidence ratings using Kruskal Wallis tests. We present qualitative feedback as the number and percentage of participants expressing common themes.

Results

Patient and provider participant characteristics are displayed in Tables 1 and 2, respectively. Most patient participants were white, married/partnered, and had localized PCa. Patients had high educational attainment, with 78% having at least a college degree. Providers were experienced, with most (74%) having been in clinical practice more than 10 years. Most physician provider participants were urologists with the remainder practicing radiation oncology. Most non-physician providers were registered nurses or nursing aides.

Table 3 displays the literacy of participants. The health literacy of patient participants was high, with mean REALM-SF score approaching the maximum REALM-SF score of 7, consistent with at least a high school reading level. The numeracy of patients and providers was similar overall and within SNS subdomains of Preference and Ability. Despite high health literacy and high numeracy among patients, their graphical literacy was lower than that of providers. Within subdomains, patients had comparable Reading and Reading Between scores, but significantly lower Reading Beyond scores.

Comprehension of prototype HRQOL dashboards varied by participant group (Table 4). Providers had high graphic literacy for prototype dashboards, including high Reading Between and Reading Beyond scores irrespective of chart type. Patient participants had lower Reading Between and Reading Beyond scores for all formats. Differences in comprehension between patients and providers were largest for pictographs. Patients had high Reading scores for the table format.

Among prototype dashboard formats, pictographs had the lowest helpfulness ratings ($p<0.01$ for patient and provider participants compared with table, bar, and line graph formats) and the lowest ratings of confidence in interpretation ($p<0.05$ for patient participants and $p<0.01$ for provider participants compared with table, bar, and line graph formats). Concordant with helpfulness and confidence ratings, preference rankings for pictographs were low: 72% of patients and 68% of providers ranked pictographs last as the least preferred dashboard format. Preference rankings among patients favored the bar charts, with 44% of patients ranking bar chart dashboards first as most preferred (mean ranking 1.8±0.9, $p=0.12$ vs line graphs, $p<0.01$ vs tables and pictographs). In contrast, there was no universally preferred dashboard format among provider participants, of whom 30% ranked tables first (mean 2.3±1.1), 34% ranked bar charts first (mean 1.8±0.7), and 34% ranked line graphs first (mean 2.3±1.1).

Several themes emerged from patients' qualitative feedback. Pictographs, which demonstrated low comprehension and low preference rankings, were found to be too complicated, with "too many steps to interpret" in 20% of patients and difficulty disentangling the facial expressions, felt to be "too similar" by 18% of patients. The tables, which demonstrated high Reading comprehension scores, were felt to be easy to understand by 16% of patients, but 18% of patients felt this format made HRQOL trends difficult to interpret.

Themes elicited from providers focused on concern about utilization of a comparison group and concern about the effect of an HRQOL dashboard on clinic efficiency. Concern over presentation of

patient HRQOL contextualized with comparison group scores was expressed by 38% of provider participants including 47% of urologists. Provider participants suggested eliminating the comparison group entirely, informing the comparison group scores with confidence intervals or error bars to better counsel patients about the meaning of their scores, and consideration of conditional presentation of comparison group scores depending on a patient's HRQOL results. Several provider participants (32%) expressed concern that utilization of HRQOL dashboards in their clinic could adversely impact the efficiency of their clinics and inhibit patient throughput.

Discussion

Our study contributes several important findings. First, implementation of HRQOL measurement in clinical PCa practice using graphical reports will likely require a dynamic interface. Patient preferences strongly favored the bar chart format. This finding corroborates previous publications assessing graphical preferences in other patient populations, where vertical bars with scales were found to be the fastest and most accurately interpreted graphical format for communication of risk.(27) Graphical trends in the popular press further support our finding among patient participants. Graphs presented in *USA Today* Snapshots Online were found to employ bar chart formats in 74% of graphs analyzed, including 71% of graphs depicting percentages.(28)

Providers, however, did not exhibit a consensus dashboard format preference. Equal proportions of provider participants favored tables, bar charts, and line graphs. We can exclude table formats from further consideration due to the expressed challenge among patients of inferring HRQOL trends from tables. Yet system users may prefer visualizing longitudinal data in line graph formats. Among cancer survivors, line graphs have been shown to convey HRQOL information better than other chart types.(29) A dynamic dashboard in which the graphical format may be toggled depending on individual preferences may aid information transfer during a clinic visit. A dynamic HRQOL dashboard

would also allow inclusion of additional elements that may be provider-centered, but may also enhance the ability of HRQOL dashboards to be used for patient counseling. For example, providers suggested that the addition of error bars or confidence intervals would help them better explain differences between patients and their comparison groups.

Second, comprehension, perceived usefulness, and preference for pictographs were low. This finding is at odds with prior studies. McCaffery, et al., compared pictographs with bar charts to test optimal graphical formats for conveying risk to adults with lower educational attainment and lower literacy levels.(30) They found that pictographs resulted in fewer errors and faster interpretation when the risk percentages were low. In a study of over 2,000 individuals recruited through the internet, pictographs were rated highly by both high and low numeracy participants.(31)

Our findings may not indicate that pictographs provide poor representations of HRQOL; rather, it may be that our prototype pictographs were poorly designed. In order to compare comprehension among prototype dashboard formats corresponding to subdomains of graphical literacy, our study design required participants to abstract scores from the pictographs, which necessitated a scale. This extra step in interpretation was noted to be a barrier to comprehension of pictographs by several patients. Additionally, temporal trends are difficult to represent with existing pictograph formats. Further study will explore whether relational pictographs without a scale offer greater ease of interpretation than the prototype pictographs we studied.

Lastly, providers underscored potential barriers to clinical implementation of HRQOL dashboards. Almost half of the urologists expressed concern about inclusion of comparison group scores on the prototype dashboards. The study design underlying development of our HRQOL dashboard focused on creating a patient-centered tool. Patients participating in focus groups that informed prototype design indicated that the most important function of the HRQOL dashboards would be to allow patients to compare their HRQOL trends with those of similar patients.(14). Thus, despite provider

concerns, inclusion of a comparison group should remain a central design element of PCa HRQOL dashboards. Providers also articulated reservations about the impact of HRQOL dashboards on clinic efficiency. Certainly, efforts to implement HRQOL dashboards broadly in clinical PCa practice would require detailed workflow and patient flow assessments to minimize detriments to the efficiency of the patient-provider encounter and ensure sustainability of HRQOL dashboards. For some patients—especially those with good HRQOL—use of the dashboard might actually increase the time efficiency of the in-person patient-provider encounter. Furthermore, a dashboard could streamline collection of HRQOL data within providers' practices, which may facilitate emerging quality improvement initiatives that leverage HRQOL measurement.(6)

Our study has several limitations. First, given the small sample size and high literacy of our patient participants, our results may not be generalizable to the larger PCa population. We were limited to a convenience sample of patients derived from our clinics and from local PCa support groups, More than 3/4th of our patient participants had at least a college degree. Most notably, we cannot conclude that our findings represent the preferences and concerns of low literacy patients. Based on our findings from this study, we are exploring design modifications to pictographs—known to appeal to lower literacy individuals(16)—to enhance comprehension, including elimination of scale legends. Similarly, the results from our interviews with provider participants may not generalize to all practitioners caring for PCa patients. Concerns about the threatening nature of comparison scores and about detriments to clinic workflow may be specific to providers in this study. We hypothesize, however, that these concerns are indicative of common provider beliefs regarding new clinic interventions.

Despite these limitations, we believe that user-centered design with patients and providers has produced the important design concept of a dynamic HRQOL dashboard that will present patient-centered content in formats preferred by patients and providers, and augmented by elements that may enhance patient counseling. Our base concept presents a longitudinal bar chart with patient HRQOL

scores presented alongside comparison group scores matched to the patients' demographic and clinical characteristics, and baseline HRQOL. This format can be toggled to other graph formats with inclusion of error bars that augment a provider's ability to counsel patients about their HRQOL through dynamic interaction with the dashboard (Figure 2). Future research efforts will explore the impact of HRQOL dashboards on patient-provider communication and patient self-efficacy, and will identify patient characteristics that are associated with greater benefit from dashboard-integrated clinical PCa care.

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Funding

This work was supported by the National Cancer Institute at the National Institutes of Health, grant number R03 CA158054.

Figure Legends

Figure 1. Prototype HRQOL dashboards and accompanying scenarios for (A) table, (B) line graph, (C) bar chart, (D) and pictograph formats. The displayed dashboards demonstrate the positive frame versions.

Scenario
John had his prostate removed for prostate cancer 2 years ago. He is in clinic today for a check-up. The chart below shows John's urinary scores. Higher scores are better. Lower scores are worse.

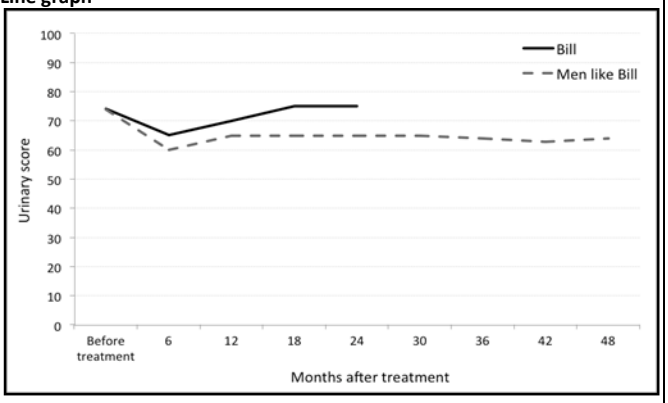
Table

Time of survey	John	Men like John
Before treatment	91	91
Months after treatment 6	65	60
12	80	75
18	85	78
24	85	80
30		80
36		80
42		80
48		80

A

Scenario
Bill had radiation therapy for his prostate cancer 2 years ago. He is in clinic today for a check-up. The chart below shows Bill's urinary scores. Higher scores are better. Lower scores are worse.

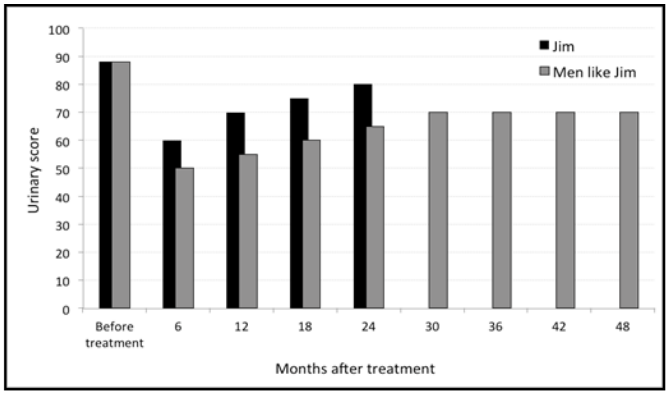
Line graph



B

Scenario
Jim had seeds placed 2 years ago for his low risk prostate cancer. He is in clinic today for a check-up. The chart below shows Jim's urinary scores. Higher scores are better. Lower scores are worse.

Bar chart



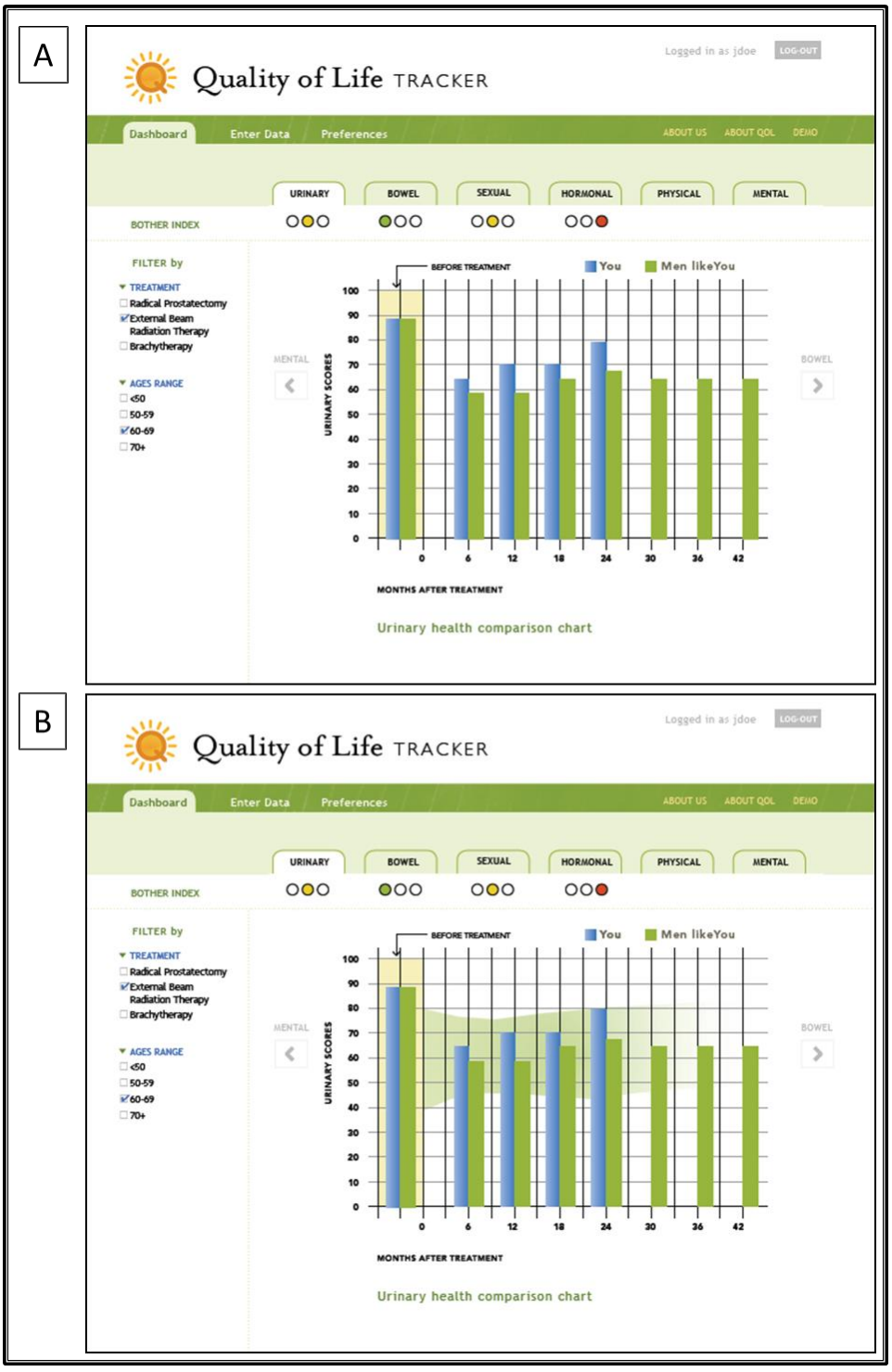
C

Scenario
Roy is on active surveillance for his prostate cancer. He was diagnosed 2 years ago and sees his urologist every 3 months. Roy is in clinic today for a check-up. The chart below shows Roy's urinary scores. Higher scores are better. Lower scores are worse.

Pictograph

D

Figure 2. Proposed dynamic dashboard which incorporates individual patient characteristics and preferences to generate the final visual display. The figure displays normative curves which can be seen both with (A) and without (B) error bars.



Tables

Table 1. Characteristics of patient participants.

Patient characteristic	No. (%)
Age (yrs), mean (SD)	71.2 (9.7)
< 60 years	8 (16)
60-69 years	12 (24)
70-79 years	20 (40)
≥ 80 years	10 (20)
Race/ethnicity	
White	44 (88)
Black	4 (8)
Other	2 (4)
Marital status	
Married/partnered	37 (74)
Divorced/separated	8 (16)
Single/widower	5 (10)
Education level	
Post-graduate	19 (38)
College graduate	20 (40)
< college graduate	11 (22)
Treatment	
Radical prostatectomy	23 (46)
External beam radiation therapy	16 (32)
Brachytherapy	8 (16)
Multiple therapies	17 (34)
Time since treatment (yrs), mean (SD)	5.5 (4.5)

Table 2. Characteristics of provider participants.

Provider characteristic	No. (%)
Age (yrs), mean (SD)	46.5 (10.4)
< 40 years	13 (26)
40-49 years	15 (30)
50-59 years	18 (36)
≥ 60 years	4 (8)
Race/ethnicity	
White	36 (72)
Black	2 (4)
Other	11 (22)
Medical training	
Physician providers	
Urology	19 (38)
Radiation Oncology	6 (12)
Non-physician providers	
Physician extender*	8 (16)
Registered nurse	12 (24)
Medical Assistant	5 (10)
Time in practice (yrs), mean (SD)	16.6 (11.1)

* Includes nurse practitioners and physician assistants

Table 3. Health literacy, numeracy and graphic literacy of patient and provider study participants.

	Patient Scores Mean (SD)	Provider Scores Mean (SD)	*P* value
Health literacy			
REALM score	6.8 (1.0)	N/A	N/A
Numeracy			
SNS total score	4.5 (0.9)	4.7 (0.9)	0.11
SNS Ability score	4.4 (1.0)	4.7 (0.9)	0.06
SNS Preference score	4.5 (0.9)	4.6 (0.9)	0.45
Graphic literacy			
GLS total score	79.2 (17.7)	86.8 (14.8)	< 0.01
GLS Reading score	94.5 (16.2)	96.5 (8.8)	0.94
GLS Reading Between score	81.0 (25.0)	88.0 (21.0)	0.09
GLS Reading Beyond score	65.6 (22.5)	78.0 (22.6)	< 0.01

REALM: Rapid Estimate of Adult Literacy in Medicine, scored 0-7; SNS: Subjective Numeracy Scale, scored 0-6; GLS: Graphic Literacy Scale, scored as percent correct

Table 4. Comprehension of patient and provider participants for prototype health-related quality of life dashboard formats according to dimensions of graphical literacy.

Pct. correct, mean (SD)	Patient Scores	Provider Scores	*P* value
Table			
Overall	89 (21)	99 (4)	< 0.01
Reading	96 (17)	99 (7)	0.31
Reading Between	82 (37)	99 (7)	< 0.01
Reading Beyond	88 (33)	99 (7)	0.05
Bar			
Overall	88 (23)	98 (6)	< 0.01
Reading	92 (25)	99 (7)	0.09
Reading Between	85 (35)	100 (0)	< 0.01
Reading Beyond	88 (31)	96 (17)	0.17
Line			
Overall	88 (18)	98 (7)	< 0.01
Reading	87 (28)	99 (7)	< 0.01
Reading Between	86 (34)	98 (14)	0.02
Reading Beyond	92 (23)	98 (14)	0.06
Pictograph			
Overall	79 (31)	97 (8)	< 0.01
Reading	77 (39)	98 (10)	< 0.01
Reading Between	87 (32)	96 (20)	0.05
Reading Beyond	73 (42)	98 (14)	< 0.01