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# Racial and ethnic differences in prostate cancer survivors' perceived engagement in treatment decision-making

Nynikka R. Palmer<sup>a</sup>, Steven E. Gregorich<sup>b</sup>, Jennifer Livaudais-Toman<sup>b</sup>, Jane Jih<sup>b</sup>, and Celia P. Kaplan<sup>b</sup>

<sup>a</sup>Department of Medicine, Division of General Internal Medicine at Zuckerberg San Francisco General Hospital, University of California San Francisco, San Francisco, CA, USA

<sup>b</sup>Department of Medicine, Division of General Internal Medicine, University of California San Francisco, San Francisco, CA, USA

# Abstract

**Objective:** We examined prostate cancer patients' perceived engagement in treatment decisionmaking and associated factors by race/ethnicity in a multiethnic sample.

**Methods:** We identified patients through the California Cancer Registry. Patients completed a cross-sectional telephone interview in English, Spanish, Cantonese or Mandarin. Multivariable logistic regression models, stratified by race/ethnicity, estimated the associations of patient demographic and health status characteristics on (1) doctor asked patient to help decide treatment plan and (2) patient and doctor worked out a treatment plan together.

**Results:** We included 855 prostate cancer patients: African American (19%), Asian American (15%), Latino (24%), and White (42%). Asian American patients were less likely than White patients to report that their doctors asked them to help decide a treatment plan (OR=0.31; 95% CI=0.18–0.53), and that they worked out a treatment plan with their doctors (OR=0.54; 95% CI=0.33–0.90). Language of interview was a significant contributing factor in stratified analysis for both outcomes.

**Conclusion:** Asian American prostate cancer patients reported less engagement in treatment decision-making, with Chinese language being a significant contributing factor. Future research should identify patient-centered strategies that effectively engage underserved patients and support healthcare providers in shared decision-making with multiethnic and multilingual patients.

# Keywords

prostate cancer; treatment decision-making; disparities; men; engagement

**Corresponding Author:** Nynikka R. Palmer, DrPH, MPH, Division of General Internal Medicine at Zuckerberg San Francisco General Hospital, Department of Medicine, University of California, San Francisco, 1001 Potrero Avenue, Building 10, 3<sup>rd</sup> Floor, UCSF Box 1364, San Francisco, CA 94143, USA, nynikka.palmer@ucsf.edu, Telephone: 415-206-4334, Fax: 415-206-5586.

Conflict of Interest: Nynikka Palmer, Steven Gregorich, Jennifer Livaudais-Toman, Jane Jih, and Celia Kaplan declare that they have no conflict of interest.

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

### Introduction

Prostate cancer presents demanding and complex treatment decision challenges for men. Prostate cancer treatment has been the focus of much debate because none of the primary definitive treatment options – surgery or radiation therapy – have proven superior for survival [1–3]. Every treatment option carries short- and long-term side effects that patients must be willing to accept and manage for the rest of their lives. Surgery and radiation can cause urinary, erectile, and bowel dysfunction [4,5]; yet a recent study by Daum and colleagues reported that over a third of men who had surgery or radiation were unaware of the long-term side effects [6]. And for men with low-risk disease who may not require immediate treatment, active surveillance is a monitoring option that requires regular followup testing, including repeat biopsies. Previous studies report some men misunderstand that active surveillance is a recognized management option and not merely "doing nothing" [7,8]; and some men on active surveillance report anxiety as a result of being uncomfortable living with an untreated cancer [9]. In this context and overall oncology care, it is vital that treatment decisions are shared and discussed between the patient and physician.

Shared decision-making, including the accommodation of patient preferences, is key in providing high-quality patient-centered cancer care [10]. This includes patients and physicians having a shared understanding of the problem, patients being fully informed of treatment options and the risks and benefits, and patients and physicians making treatment decisions based on clinical evidence and patients' values and preferences [10,11]. Patients who engage in shared decision-making with their physicians report better understanding of treatment options [11–16], higher confidence in decisions made [15,16], higher treatment compliance [16], greater satisfaction with care/decision [16], and better quality of life [17]. Alternatively, the lack of patient involvement in treatment decision-making has been linked with anxiety, dissatisfaction with care, and decision regret [18–20].

Unfortunately, there is limited knowledge about prostate cancer patients' perceived engagement in shared decision-making for prostate cancer treatment, particularly among a diverse population of racial and ethnic minorities, as most studies only compare African American and White prostate cancer patients [6,8,21–24]. Little is known about how other groups, such as Latinos and Asian Americans experience prostate cancer shared decision making. These groups experience greater challenges, as cultural as well as linguistic factors may affect their interactions with the medical environment [21]. There is increasing evidence that many patients want to be involved in treatment decisions [15,25]; however, non-cancer studies indicate that racial/ethnic minorities report less involvement in treatment decision-making [26]. In this study, we expand our understanding of shared decision-making in a multiethnic and multilingual population of prostate cancer survivors by exploring racial and ethnic differences in (1) their perception of their doctors requesting their engagement in decision-making, and (2) their self-reported involvement in treatment decision-making. To our knowledge, this is the first study to examine disparities in prostate cancer patients' perceived engagement in treatment decision-making among a culturally and linguistically diverse population. Study findings will have practice implications for patient-provider and patient-centered communication in shared decision-making among racial and ethnic minorities.

### Methods

#### Design, Recruitment and Sampling

Data were from a cross-sectional telephone interview of men diagnosed with prostate cancer in 2008 in the Greater San Francisco Bay Area and Los Angeles County [27]. Patients were identified through the California Cancer Registry. Inclusion criteria included men (a) diagnosed with stage I or II prostate cancer; (b) 18–75 years old; (c) self-identified their race or ethnicity as African American/Black, Asian American, Latino/Hispanic, or White/ Caucasian; (d) able to complete a telephone interview; and (e) spoke English, Spanish, Cantonese or Mandarin. Men who self-identified as Asian American were asked to selfreport their Asian subgroup (e.g. Chinese, Japanese, Filipino, etc.). Men were excluded if a physician recommended that they not participate in the study or if they had significant physical, cognitive, or mental disability.

Recruitment took place between November 2011 and November 2012. All eligible minorities (African American, Asian American, Latino) diagnosed with prostate cancer were recruited. We used simple random sampling to recruit non-Latino White men who self-identified as non-Latino White in the cancer registry. Physicians of each eligible patient listed in the registry were mailed a letter that explained the study and asked them to identify any patients who should not be contacted by the study. Eligible patients were mailed a recruitment letter in English, Spanish, Cantonese and Mandarin with opt-out options. After obtaining verbal informed consent, trained bilingual interviewers conducted 30-minute interviews in patients' language of preference.

All study activities were approved by the University of California, San Francisco Institutional Review Board. More detailed methods are published elsewhere [27].

#### **Outcome Variables**

Perceived shared decision-making was measured by two indicators (1) doctors asked patients to help decide treatment plan and (2) patients and doctors worked out a treatment plan together. Patients were asked "*Now please think about how the decisions were made for your prostate cancer treatment; how often did your doctors ask if you would like to help decide your prostate cancer treatment*" and "*how often did you and your doctor work out a treatment plan together*," with a 5-point Likert scale for each question (always, often, sometimes, rarely, never). Responses were dichotomized into "always" versus "less than always" for multivariable logistic regression models because of the positive skewed distribution of responses.

#### **Independent Variables**

**Demographic Characteristics**—Race and ethnicity was self-reported by patients, including the following categories: African American/Black, Asian American, Latino/ Hispanic, and non-Latino White (hereafter: White). We combined Asian subgroups (e.g., Chinese, Japanese, Filipino, Vietnamese, Hawaiian, other Pacific Islander, and other) due to small sample sizes. Patients' age was categorized as 40–54 years, 55–64 years, or 65 years and above. Marital status was dichotomized into single/divorced/separated/widowed versus

married/living with a partner. Education level was categorized into high school or less, some college, and college graduate or beyond. Geographic region was based on source of California Cancer Registry data (Northern versus Southern California). Language of interview was reported based on the language patients preferred to speak to complete the interview, and included English, Spanish, Cantonese or Mandarin.

Clinical and Health-related Characteristics—Health insurance coverage was categorized into private, public or government only, and no insurance. Health literacy was assessed using three validated questions: (i) how often do you have someone like a family member, friend, hospital worker or caregiver, help read hospital materials; (ii) how often are you comfortable with filling out medical forms by yourself, and (iii) how often do you have problems learning about your medical condition because of difficulty understanding written information [28]. Responses to each question ranged from 1 (always) to 5 (never). We created a health literacy score by averaging the responses of the three questions, with higher scores indicating higher health literacy. We then created a dichotomous variable where low health literacy < 3.5 and medium-to-high health literacy 3.5. Health status was assessed using one question, how would you rate your health, which we dichotomized into excellent/ very good versus good/fair/poor. Patients were asked to report if a doctor ever told you that you had any of the following health conditions – heart disease, high blood pressure, lung disease, diabetes, ulcer or stomach disease, kidney disease, liver disease, other cancer, depression, arthritis, other health conditions [29]. Responses were categorized into 0, 1, and 2 or more comorbidities. Gleason score, a grading system for prostate cancer tumors indicating likelihood of tumor spread and helps determine the best treatment options [30], was reported from the California Cancer Registry. We dichotomized Gleason score into 6 versus 7-10. A Gleason score of 6 indicates a low-grade indolent cancer that typically does not require definitive treatment, where active surveillance can be ideal to prevent overtreatment [31]. A Gleason score of 7-10 indicates an intermediate or high-grade cancer that likely requires active treatment (e.g., surgery, radiation, and/or hormone therapy). Prostate cancer treatment was self-reported with patients having the option to choose multiple treatments (e.g., watchful waiting/active surveillance, surgery, brachytherapy, external radiation, hormone therapy, chemotherapy, and any other treatment). We dichotomized treatment as with or without chemotherapy or hormone therapy, as first line of treatment typically consists of surgery or radiation therapy, and chemotherapy and hormone therapy are used for more advanced disease.

**Statistical Analysis**—All data analyses were completed using STATA/SE Version 14.0, and all tests of statistical significance were two-sided with alpha <0.05. We summarized participant characteristics, demographic and health-related, stratified by race/ethnicity, and tested differences between racial/ethnic groups using the chi-square statistic (Table 1). We conducted corresponding chi-square analyses of participant characteristics by our two outcomes – *doctor asked patient to help decide treatment plan* and *patient and doctor worked out treatment plan together* (Table 2). We fit multivariable logistic regression models, reporting odds ratios and 95% confidence intervals, in which each model adjusted for age, marital status, education, region, language of interview, insurance, health literacy, health status, comorbidities, Gleason score, and treatment. Overall adjusted models pooled data

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across all four racial/ethnic groups and contrasted each minority group to non-Latino White men. We also fit models stratified by race/ethnicity to examine specific factors associated with outcomes within each racial/ethnic group.

# Results

#### **Participant Characteristics**

Overall, 855 men with a history of prostate cancer completed the survey, with a response rate of 45% (855/1890; see Figure 1). Participant characteristics, stratified by race/ethnicity, are listed in Table 1. The study consisted of 19.2% African American, 14.7% Asian American, 24.1% Latino, and 42% non-Latino White (White) men. Over half of the sample was 65 years or older (52.4%), married or living with a partner (75.8%), college graduate or beyond (51.2%), from the Northern California region (58.7%), and completed the interview in English (83%). The majority of respondents had private insurance (79.9%) and medium to high health literacy (80.8%). Respondents almost equally reported excellent or very good health status (50.5%) versus good, fair or poor health status (49.5%), and had 2 or more comorbidities (63.0%). A little over half of respondents had intermediate or high-risk prostate cancer (56.5%; Gleason score 7–10). Few respondents reported having prostate cancer treatment with hormone therapy or chemotherapy (15.4%).

Racial and ethnic differences were noted across all demographic characteristics. More African American men were 64 years old or younger and were single, divorced, or widowed. African American and Latino men had lower education levels compared to Asian American and White men. Asian Americans and Latinos were the only groups who reported completing the interview in a non-English language. Racial/ethnic differences were also noted for health insurance, health literacy and health status. More minorities reported having public or no health insurance and poorer health status compared to White men. More Asian Americans and Latinos reported more low health literacy. No racial/ethnic differences were noted in Gleason score or treatment.

#### **Participant Characteristics by Outcomes**

In bivariate analyses, significant differences were identified among patients' characteristics by both treatment engagement outcomes of *doctor asked patient to help decide treatment plan* and *patient and doctor worked out treatment plan together* (Table 2). For race/ethnicity, fewer Asian American and Latino men reported that the doctor always asked them to help decide their treatment plan compared with African American and White men (34.7%, 52.8%, 67.1% and 71.7%, respectively; p<0.001), and that they worked out their treatment plan with their doctor (30.8%, 47.7%, 62.7% and 56.5% respectively; p<0.001). Patients with an education of high school or less had the lowest rates of doctor always asked them to help decide a treatment plan (50.7%) and that they worked out a treatment plan together (42.4%). Similarly, those who completed the interview in Cantonese/Mandarin had the lowest percentage of treatment engagement (6.1% and 3.0%), while Spanish (45.3% and 41.3%) and English (65.9% and 55.8%) were higher. Patients with public health insurance reported lower rates of the doctor always asked them to help decide their treatment plan (48.9%), while those with private or no insurance reported higher rates (63.4% and 66.7%,

respectively; p=0.006). However, patients with no insurance or public insurance reported lower rates of always worked out the treatment plan together (40.0% and 41.4%), while patients with private insurance reported higher rates (54.3%). Those of low health literacy reported lower rates of the doctor always asking them to help decided the treatment plan, compared to those with higher health literacy (48.3% versus 63.8%, p<0.001). However, those with low health literacy reported higher rates of working out the treatment plan with the doctor compared to those with higher health literacy (53.7% versus 43.7%; p=0.026). Patients who reported excellent or very good health status reported higher rates of treatment engagement for both outcomes compared to those who reported poor/fair/good health status (65.1% versus 56.2%, p=0.01; 57.6% versus 45.6%, p=0.001). No differences in outcomes were noted by age, marital status, region, comorbidities, Gleason score, or treatment.

#### **Multivariable Analysis**

In the overall model for the outcome *doctor always asked patient to help decide the treatment plan* (data not shown), Asian American men were significantly less likely than White men to report treatment engagement (OR: 0.31; 95% CI: 0.18–0.53). Cantonese/ Mandarin language of interview was the only significant covariate (OR: 0.10; 95% CI: 0.02–0.46). No significant differences were found for African American or Latino men compared to White men.

In models stratified by race/ethnicity (Table 3), among African American men, older age and higher Gleason score were significant factors associated with how often the doctor asked if the patient would like to help in treatment decisions (OR: 4.34, 95% CI: 1.09–17.22 and OR: 0.24, 95% CI: 0.10–0.58, respectively). Among Asian American men, completing the interview in Cantonese/Mandarin was significantly and negatively associated with this outcome (OR: 0.08, 95% CI: 0.01–0.63). Among Latino men, lower education was significantly and negatively associated with this outcome (OR: 0.28, 95% CI: 0.10–0.79). None of the patient factors were associated with this outcome among White men.

In the overall model for the outcome *always worked out treatment plan with doctor* (data not shown), Asian American men were significantly less likely than White men to report treatment engagement (OR: 0.54; 95% CI: 0.33–0.90). Cantonese/Mandarin language of interview (OR: 0.05; 95% CI: 0.01–0.42) and excellent/very good health status (OR: 1.57; 95% CI: 1.13–2.20) were significantly associated. Compared to White men, no significant differences were found for African American or Latino men compared to White men.

In models stratified by race/ethnicity (Table 4), for African American men, low health literacy and excellent/very good health status were significant contributors to discussions of treatment plans (OR: 5.64, 95% CI: 1.52–20.92 and OR: 2.87, 95% CI: 1.28–6.43, respectively). Again, among Asian American men, those completing the interview in Cantonese/Mandarin were less likely to report working out a treatment plan with their doctor (OR: 0.04, 95% CI: 0.01–0.25). None of the patient factors were associated with this outcome among Latino or White men.

#### **Discussion and Conclusion**

#### Discussion

Our study expanded the understanding of perceived engagement in treatment decisionmaking among multiethnic and multilingual prostate cancer patients. Overall, Asian American prostate cancer patients were less likely to report that their doctors asked them to help decide their treatment plan and that they worked out a treatment plan with their doctor. Language was a significant contributing factor to disparities identified in both outcomes. Relative to White patients, no disparities were identified for African American or Latino patients, despite previous cancer studies that identified disparities in treatment decisionmaking [22, 32]. However, several sociodemographic factors were significantly associated with these outcomes in stratified models. For African American men, older age, lower Gleason score, low health literacy, and excellent/very good health status were associated with treatment decision engagement. For Latino men, lower education was associated with patients less likely to report their doctors asked them to help decide their treatment plan.

Our finding that Asian American prostate cancer patients report less engagement in treatment decision-making compared to White patients is similar to other studies that included Asian American cancer patients. Turabi and colleagues [33] found Chinese and South Asian cancer patients from England were more likely to report a negative experience of involvement in treatment decisions compared to White patients. A systematic review of shared decision-making in cancer care found Punjabi women with breast cancer reported low involvement in the decision-making process [32]. Additionally, language of interview was significantly associated with less engagement in treatment decision-making, explaining some, but not all, of the association. Language and cultural differences in the expectations of the physician's and patient's role in cancer treatment decision-making, as well as sufficient patient-physician trust within the context of shared decision-making may contribute to this finding [34,35].

In race/ethnicity-stratified models, we found that Cantonese/Mandarin interview language use was significantly associated with lower reported engagement in shared treatment decision-making, which is similar to prior work focused on Asian American cancer survivors. Lee and colleagues [36] reported that among Chinese American women, limited English proficiency negatively affected communication during consultations about treatment options. In two qualitative studies of Chinese breast cancer patients, English as a second language impeded patients' ability to make informed treatment decisions [37,38]. As prostate cancer is the most common malignancy for nearly all Asian American men which is one of the fastest growing racial/ethnic groups in the U.S., addressing language and communication barriers is necessary to provide equitable, patient-centered care [39–41]. Further research is needed to understand the specific cultural and language drivers that influence treatment shared decision-making among Asian American men with prostate cancer. For example, in some Asian cultures, the role of the family is a key determinant to the decision-making process [42,43]; and patients' expectations of their provider's roles can significantly influence the decision-making process, as some Asian patients may perceive offers of different treatment options as doctors' incompetence [44].

Although no significant differences in treatment engagement were noted comparing African American and Latino prostate cancer patients to White prostate cancer patients, several factors were significantly associated with patients' perceived involvement in treatment decision-making in stratified analyses. For African American men, older age and lower Gleason score were significantly associated with reporting that their doctor always asked if they would like to help decide their prostate cancer treatment. Our finding of older age being associated with treatment decision engagement conflicts with studies examining age as a factor in decision-making; for example older men play more passive roles [45]. Physicians may be making more of an effort to engage older African American men with prostate cancer to balance cancer control with treatment consequences among a population with higher rates of comorbidities, functional impairments, and geriatric syndromes [46,47]. Furthermore, physicians may be more engaged because African American men have a much higher mortality risk from prostate cancer than another other group [48]. Similarly, physicians may be engaging men with low Gleason scores (low risk disease) in treatment decision-making more often because active surveillance (regular monitoring with PSA tests and periodic biopsies) is an option for low risk disease, and can preserve patients' quality of life and reduce overtreatment of low risk prostate cancer that would never threaten life [31]. Additionally, African American prostate cancer patients with low health literacy and excellent or very good health status were more likely to report that they always decided a treatment plan with their doctor. While our finding of low health literacy contradicts previous studies of decision-making [49,50], physicians may have spent more time with patients of low health literacy, noting the need to engage patients in treatment decisionmaking. We also know that previous studies have reported shared decision-making improves health status [51], although causation cannot be determined in our study due to the crosssectional nature.

Among Latino prostate cancer patients, patients with less education (High School or less) were less likely to report that their doctor always asked them if they would like to help decide their treatment. This finding is consistent with similar studies reporting patients with higher education levels had stronger supportive attitudes for autonomy in treatment decision-making [32]. Latino patients may not have a clear understanding of the diagnosis and treatment options and therefore do not feel empowered to engage in decision-making [52]. They may also feel unable to advocate for themselves and may therefore defer to physicians [32,53]. Studies of medical decision-making have shown Latino patients are more likely to permit their physician to take the dominant role in decision-making [54]. In addition, minority patients have reported feeling that their education was an important determinant in how physicians treated them [55]. While over half of study interviews among Latinos were conducted in Spanish, no differences in perceived engagement in treatment decisions were reported by language. This may reflect greater numbers of language concordant providers compared to non-English speaking Asian American patients.

There are several limitations of this study that are worth noting. First, we relied on patients' self-report of treatment decision engagement, which did not include an assessment of physicians' perspectives or observations of actual clinical encounters of treatment discussions. Previous decision-making studies in cancer have noted discrepancies between physicians' and patients' opinions regarding treatment decision-making [56], and

discrepancies between patients' perception and observations [57]. While we did not assess patients' preference for engaging in treatment decision-making, a recent study of cancer patients found preferred role does not modify the effect of the actual role played, underscoring the importance of involving all patients in decision-making [57]. Also, patients' responses were skewed toward high engagement in treatment decision making, with little variability. Second, the language of the study interview was used as a proxy for preferred language for each participant as we did not assess preferred language for healthcare interactions, limited English proficiency or use of interpreters during physician visits. Third, racial/ethnic differences in perceived engagement may reflect differences in survey response tendencies. For example, Murray-Garcia and colleagues suggest that Asian respondents tend to choose response options toward the middle of Likert scales [58]. Additionally, we were not able to measure if the disparities we found reflect cultural differences in how patients consider these questions or perhaps it reflects racial and ethnic differences in patients' perceptions of their clinical encounters or their beliefs in who should play a role in decision-making (e.g., family members). In addition, our results may not be representative of all men across the United States, as we focused on localized prostate cancer patients from Northern and Southern California, which may not represent those from other regions or with more advanced disease. Lastly, the racial/ethnic distribution of this study is from men diagnosed with prostate cancer in 2008 and interviewed in 2011–2012, which may not reflect the current United States population.

Despite these limitations, this study has several strengths that contribute to the existing literature. First, this multiethnic and multilingual, population-based study provides important new information on prostate cancer treatment decision engagement among minority populations who are traditionally underrepresented in research, yet overrepresented in cancer burden. To our knowledge, this is the first study to examine racial and ethnic disparities in patients' perceived engagement in prostate cancer treatment decision-making, and to compare across these racial/ethnic groups the specific demographic and health characteristics associated with treatment decision engagement. Most relevant studies only compare non-Latino White prostate cancer patients to African American or "nonwhite" patients [21-24]. This study adds to the sparse data on Latino and Asian American prostate cancer patients' engagement in prostate cancer treatment decision-making, and highlights the need for future research on cultural factors not measured in this study (e.g., patients' language preference in clinical encounters, family involvement, trust, etc.). Furthermore, our findings call attention to the necessity for quality improvement efforts in patient-centered prostate cancer care, in light of the preference-sensitive nature of prostate cancer treatment decision-making and the push for providers to engage in shared decision-making.

#### Conclusion

Engaging prostate cancer patients in shared decision-making is paramount as treatment decisions are complex and pros and cons of treatments and its side effects must be weighed in accordance with patients' preferences and values. Numerous guidelines advocate for the use of shared decision-making in cancer care [59]. Despite the importance, racial and ethnic variations in patients' perceived engagement in treatment decision-making persists. Asian American prostate cancer patients, particularly those with limited or no English proficiency,

are a vulnerable population. This study underscores the need for more research that includes underserved minority patients and interventions to engage patients in shared decisionmaking.

In clinical practice, engaging in culturally sensitive, patient-centered shared decision-making about cancer treatment with ethnically and racially diverse patients can be a significant challenge. A key element to helping overcome communication barriers between patients and physicians is the provision and regular use of qualified professional interpreters during visits with limited English proficient patients, especially during visits focused on treatment decision-making. Use of ad hoc interpreters such as family members or office staff may lead to interpretation errors [60] and place family members in an undesired position to discuss potentially culturally-sensitive or taboo topics such as prognosis or function of male reproductive organs. Giving sufficient time to elicit and recognize patient treatment preferences, values and goals, particularly within their socio-cultural context, are important steps in the treatment decision-making process. This process may take course over multiple clinic visits and involve the active participation of the patient's family as a whole, which may be the case for some Asian American patients. During this shared decision-making process, there is a need for culturally and linguistically relevant decision aids to help patients and providers discuss complex treatment decisions that have tradeoffs and impact quality of life while considering patient preferences and values and their contextual factors.

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Determination of study sample

#### Table 1.

# Participant Characteristics (n=855)

|                               | Total      | African American | Asian American | Latino      | White       | -       |
|-------------------------------|------------|------------------|----------------|-------------|-------------|---------|
|                               | N=855      | 19.2% N=164      | 14.7% N=126    | 24.1% N=206 | 42.0% N=359 | p-value |
| Demographic                   | n (%)      | n (%)            | n (%)          | n (%)       | n (%)       |         |
| Age                           |            |                  |                |             |             | 0.030   |
| 40-54 years                   | 53 (7.4)   | 17 (10.4)        | 7 (5.7)        | 20 (9.8)    | 19 (5.3)    |         |
| 55-64 years                   | 340 (40.1) | 77 (47.2)        | 43 (35.0)      | 79 (38.7)   | 141 (39.50  |         |
| 65 years                      | 444 (52.4) | 69 (42.3)        | 73 (59.3)      | 105 (51.5)  | 197 (55.2)  |         |
| Marital status                |            |                  |                |             |             | < 0.001 |
| Single/divorced/widow         | 204 (24.2) | 65 (40.4)        | 17 (13.7)      | 49 (24.3)   | 73 (20.6)   |         |
| Married/living with a partner | 638 (75.8) | 96 (59.6)        | 107 (86.3)     | 153 (75.7)  | 282 (79.4)  |         |
| Education                     |            |                  |                |             |             | < 0.001 |
| High school or less           | 214 (25.7) | 35 (21.7)        | 18 (14.7)      | 117 (59.4)  | 44 (12.4)   |         |
| Some college                  | 193 (23.1) | 70 (43.5)        | 14 (11.5)      | 41 (20.8)   | 68 (19.2)   |         |
| College graduate or beyond    | 427 (51.2) | 56 (34.8)        | 90 (73.8)      | 39 (19.8)   | 242 (68.40  |         |
| Region                        |            |                  |                |             |             | 0.025   |
| Northern California           | 502 (58.7) | 89 (54.3)        | 82 (65.1)      | 107 (51.9)  | 224 (62.4)  |         |
| Southern California           | 353 (41.3) | 75 (45.7)        | 44 (34.9)      | 99 (48.1)   | 135 (37.6)  |         |
| Language of interview         |            |                  |                |             |             | < 0.001 |
| English                       | 710 (83.0) | 164 (100)        | 90 (71.4)      | 97 (47.1)   | 100         |         |
| Spanish                       | 109 (12.8) | 0 (0)            | 0 (0)          | 109 (52.9)  | 0 (0)       |         |
| Cantonese/Mandarin            | 36 (4.2)   | 0 (0)            | 36 (28.6)      | 0 (0)       | 0 (0)       |         |
| Health-related                |            |                  |                |             |             |         |
| Health Insurance              |            |                  |                |             |             | < 0.001 |
| Private                       | 663 (79.9) | 129 (82.2)       | 90 (73.8)      | 135 (67.1)  | 309 (88.3)  |         |
| Public/government only        | 152 (18.3) | 27 (17.2)        | 31 (25.4)      | 57 (28.4)   | 37 (10.6)   |         |
| No insurance                  | 15 (1.8)   | 1 (0.6)          | 1 (0.8)        | 9 (4.5)     | 4 (1.1)     |         |
| Health literacy               |            |                  |                |             |             | < 0.001 |
| Low (<3.5)                    | 161 (19.2) | 23 (14.5)        | 28 (23.0)      | 82 (40.4)   | 28 (7.9)    |         |
| Medium to high ( 3.5)         | 676 (80.8) | 136 (85.5)       | 94 (77.0)      | 121 (59.6)  | 325 (92.1)  |         |
| Health status                 |            |                  |                |             |             | < 0.001 |
| Excellent/very good           | 431 (50.5) | 72 (43.9)        | 59 (47.2)      | 75 (36.4)   | 225 (62.7)  |         |
| Good/fair/poor                | 423 (49.5) | 92 (56.1)        | 66 (52.8)      | 131 (63.6)  | 134 (37.3)  |         |
| Number of Comorbidities       |            |                  |                |             |             | 0.028   |
| 0                             | 119 (14.0) | 18 (11.0)        | 22 (17.6)      | 35 (17.1)   | 44 (12.3)   |         |
| 1                             | 196 (23.0) | 30 (18.3)        | 21 (16.8)      | 58 (27.80   | 88 (24.6)   |         |
| 2 or more                     | 537 (63.00 | 116 (70.7)       | 82 (65.6)      | 113 (55.1)  | 226 (63.1)  |         |
| Gleason score                 |            |                  |                |             |             | 0.293   |
| 1–6                           | 369 (43.5) | 60 (37.0)        | 54 (43.2)      | 94 (46.3)   | 161 (45.0)  |         |
| 7–10                          | 479 (56.5) | 102 (63.0)       | 71 (56.8)      | 109 (53.7)  | 197 (55.0)  |         |

|  | Total      | African American | Asian American | Latino      | White       |         |
|--|------------|------------------|----------------|-------------|-------------|---------|
|  | N=855      | 19.2% N=164      | 14.7% N=126    | 24.1% N=206 | 42.0% N=359 | p-value |
| Demographic  | n (%)      | n (%)            | n (%)          | n (%)       | n (%)       |         |
| PCa Treatment with hormone therapy or chemotherapy |            |                  |                |             |             | 0.156   |
| Yes  | 130 (15.4) | 34 (21.0)        | 16 (13.0)      | 31 (15.5)   | 49 (13.7)   |         |
| No   | 713 (84.6) | 128 (79.0)       | 107 (87.0)     | 169 (84.5)  | 309 (86.3)  |         |

#### Table 2:

#### Participant Characteristics by Outcomes

|                               | Doctor As | ked Patient to H<br>Treatment Plan | elp Decide | Patient & D | octor Worked O<br>Plan Together | ut Treatment |
|-------------------------------|-----------|------------------------------------|------------|-------------|---------------------------------|--------------|
|                               | respond   | ed Always                          | p-value    | respond     | led Always                      | p-value      |
| Demographics                  | n         | (%)                                |            | n           | (%)                             |              |
| Race/ethnicity                |           |                                    | < 0.001    |             |                                 | < 0.001      |
| African American              | 104       | (67.1)                             |            | 99          | (62.7)                          |              |
| Asian American                | 41        | (34.7)                             |            | 37          | (30.8)                          |              |
| Latino                        | 105       | (52.8)                             |            | 94          | (47.7)                          |              |
| White                         | 236       | (71.7)                             |            | 186         | (56.5)                          |              |
| Age                           |           |                                    | 0.969      |             |                                 | 0.443        |
| 40-54 years                   | 37        | (59.7)                             |            | 29          | (46.8)                          |              |
| 55-64 years                   | 195       | (61.3)                             |            | 177         | (54.3)                          |              |
| 65 years                      | 253       | (60.8)                             |            | 209         | (50.7)                          |              |
| Marital status                |           |                                    | 0.680      |             |                                 | 0.839        |
| Single/divorced/widow         | 114       | (62.0)                             |            | 93          | (51.1)                          |              |
| Married/living with a partner | 367       | (60.3)                             |            | 319         | (51.9)                          |              |
| Education                     |           |                                    | 0.002      |             |                                 | 0.005        |
| High school or less           | 104       | (50.7)                             |            | 87          | (42.4)                          |              |
| Some college                  | 115       | (62.2)                             |            | 106         | (57.6)                          |              |
| College graduate or beyond    | 260       | (65.7)                             |            | 216         | (54.0)                          |              |
| Region                        |           |                                    | 0.510      |             |                                 | 0.731        |
| Northern California           | 283       | (61.7)                             |            | 243         | (52.3)                          |              |
| Southern California           | 203       | (59.4)                             |            | 173         | (51.0)                          |              |
| Language of interview         |           |                                    | < 0.001    |             |                                 | < 0.001      |
| English                       | 436       | (65.9)                             |            | 372         | (55.8)                          |              |
| Spanish                       | 48        | (45.3)                             |            | 43          | (41.3)                          |              |
| Cantonese/Mandarin            | 2         | (6.1)                              |            | 1           | (3.0)                           |              |
| Health                        |           |                                    |            |             |                                 |              |
| Insurance                     |           |                                    | 0.006      |             |                                 | 0.014        |
| Private                       | 398       | (63.4)                             |            | 345         | (54.3)                          |              |
| Public/government only        | 70        | (48.9)                             |            | 58          | (41.4)                          |              |
| No insurance                  | 10        | (66.7)                             |            | 6           | (40.0)                          |              |
| Health literacy               |           |                                    | < 0.001    |             |                                 | 0.026        |
| Low (<3.5)                    | 73        | (48.3)                             |            | 344         | (53.7)                          |              |
| Medium to high ( 3.5)         | 406       | (63.8)                             |            | 66          | (43.7)                          |              |
| Comorbidities                 |           |                                    | 0.348      |             |                                 | 0.141        |
| 0                             | 61        | (54.5)                             |            | 49          | (43.4)                          |              |
| 1                             | 114       | (62.0)                             |            | 101         | (54.6)                          |              |
| 2 or more                     | 311       | (61.6)                             |            | 266         | (52.6)                          |              |

|  | Doctor As | ked Patient to H<br>Treatment Plan | lelp Decide | Patient & Do | octor Worked O<br>Plan Together | ut Treatment |
|--|-----------|------------------------------------|-------------|--------------|---------------------------------|--------------|
|  | respond   | ed Always                          | p-value     | respond      | ed Always                       | p-value      |
| Demographics                                   | n         | (%)                                |             | n            | (%)                             |              |
| Health status                                  |           |                                    | 0.010       |              |                                 | 0.001        |
| Poor / fair / good                             | 221       | (56.2)                             |             | 180          | (45.6)                          |              |
| Very good / excellent                          | 265       | (65.1)                             |             | 235          | (57.6)                          |              |
| Gleason score                                  |           |                                    | 0.175       |              |                                 | 0.197        |
| 1–6  | 224       | (63.5)                             |             | 193          | (54.4)                          |              |
| 7–10   | 259       | (58.7)                             |             | 220          | (49.8)                          |              |
| Treatment with hormone therapy or chemotherapy |           |                                    | 0.591       |              |                                 | 0.662        |
| Yes  | 69        | (58.5)                             |             | 61           | (50.0)                          |              |
| No   | 413       | (61.1)                             |             | 352          | (52.1)                          |              |

# Table 3.

Multivariable logistic regression models estimating the effects of patient factors on patient-reported responses to doctor always asked patient to help decide prostate cancer treatment plan, stratified by race/ethnicity.

|   | Afric      | an American    | Asia | n American     |      | Latino         |      | White          |
|---|------------|----------------|------|----------------|------|----------------|------|----------------|
|   | OR         | 95% CI         | OR   | 95% CI         | OR   | 95% CI         | OR   | 95% CI         |
| Age ( <i>ref: 40–55yrs</i> )                            |            |                |      |                |      |                |      |                |
| 55–64 years   | 3.25       | (0.84 - 12.55) | 0.27 | (0.04 - 2.01)  | 1.01 | (0.34 - 3.05)  | 1.12 | (0.35 - 3.55)  |
| 65 years  | $4.34^{*}$ | (1.09 – 17.22) | 0.16 | (0.02 - 1.35)  | 2.09 | (0.69 - 6.33)  | 1.25 | (0.40 - 3.92)  |
| Marital status (ref: single/divorced/widow)             |            |                |      |                |      |                |      |                |
| Married/living together                                 | 0.52       | (0.20 - 1.35)  | 0.27 | (0.07 - 1.14)  | 1.71 | (0.75 - 3.89)  | 1.37 | (0.72 - 2.60)  |
| Education (ref: college graduate or beyond)             |            |                |      |                |      |                |      |                |
| Some college  | 0.66       | (0.25 - 1.73)  | 1.08 | (0.25 - 4.63)  | 0.46 | (0.17 - 1.24)  | 0.74 | (0.39 - 1.40)  |
| High school or less                                     | 0.49       | (0.14 - 1.69)  | 0.69 | (0.15 - 3.28)  | 0.28 | (0.10 - 0.79)  | 1.00 | (0.45 - 2.22)  |
| Language of interview (ref: English)                    |            |                |      |                |      |                |      |                |
| Cantonese/Mandarin                                      | 1          | ı              | 0.08 | (0.01 - 0.63)  | ı    | ı              | 1    | ı              |
| Spanish   | '          | ı              | '    |                | 06.0 | (0.39 - 2.04)  | ľ    |                |
| Region (ref: Northern CA)                               |            |                |      |                |      |                |      |                |
| Southern California                                     | 1.07       | (0.47 - 2.43)  | 1.37 | (0.42 - 4.46)  | 0.85 | (0.44 - 1.63)  | 0.82 | (0.48 - 1.39)  |
| Insurance ( <i>ref: private</i> )                       |            |                |      |                |      |                |      |                |
| Public/govt   | 0.53       | (0.15 - 1.79)  | 06.0 | (0.25 - 3.29)  | 0.82 | (0.36 - 1.86)  | 0.96 | (0.42 - 2.21)  |
| No insurance  | '          | ·              | '    |                | 5.32 | (0.84 – 33.64) | 1.57 | (0.15 - 16.00) |
| Health literacy (ref: medium to high)                   |            |                |      |                |      |                |      |                |
| Low   | 2.55       | (0.74 - 8.84)  | 1.80 | (0.36 - 9.02)  | 0.60 | (0.29 - 1.24)  | 1.19 | (0.44 - 3.23)  |
| Health status (ref: Good/fair/poor)                     |            |                |      |                |      |                |      |                |
| Excellent/very good                                     | 1.92       | (0.78 - 4.73)  | 1.10 | (0.40 - 3.01)  | 1.07 | (0.52 - 2.24)  | 1.12 | (0.63 - 2.00)  |
| Comorbidities ( <i>ref:</i> $\partial$ )                |            |                |      |                |      |                |      |                |
| 1   | 0.80       | (0.18 - 3.62)  | 6.77 | (1.40 - 32.69) | 1.52 | (0.54 - 4.27)  | 1.08 | (0.44 - 2.66)  |
| 2 or more   | 1.85       | (0.48 - 7.20)  | 1.97 | (0.57 - 6.82)  | 1.59 | (0.63 - 4.03)  | 0.93 | (0.41 - 2.12)  |
| Gleason score (ref:1–6)                                 |            |                |      |                |      |                |      |                |
| 7–10  | 0.24       | (0.10 - 0.58)  | 2.06 | (0.74 - 5.75)  | 1.10 | (0.54 - 2.22)  | 0.62 | (0.36 - 1.05)  |
| Treatment with chemotherapy / hormone therapy (ref: no) |            |                |      |                |      |                |      |                |

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|     | NIN I |               | w n  |                | NIO. |               | w n  |               |
|-----|-------|---------------|------|----------------|------|---------------|------|---------------|
| Yes | 0.43  | (0.15 - 1.24) | 3.41 | (0.55 - 21.03) | 1.13 | (0.48 - 2.70) | 1.43 | (0.64 - 3.21) |
| *   |       |               |      |                |      |               |      |               |

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# Table 4.

Multivariable logistic regression models estimating the effects of patient factors on patient-reported responses to patient always worked out treatment plan with doctor, stratified by race/ethnicity.

|   | Afric      | an American    | Asia | n American     |      | Latino        |      | White         |
|---|------------|----------------|------|----------------|------|---------------|------|---------------|
|   | OR         | 95% CI         | OR   | 95% CI         | OR   | 95% CI        | OR   | 95% CI        |
| Age ( <i>ref: 40–55yrs</i> )                            |            |                |      |                |      |               |      |               |
| 55–64 years   | 1.57       | (0.44 - 5.52)  | 2.05 | (0.25 - 17.11) | 1.28 | (0.40 - 4.10) | 2.31 | (0.86 - 6.19) |
| 65 years  | 1.42       | (0.41 - 4.99)  | 0.77 | (0.09 - 6.90)  | 1.32 | (0.40 - 4.30) | 2.59 | (0.97 - 6.91) |
| Marital status (ref: single/divorced/widow)             |            |                |      |                |      |               |      |               |
| Married/living together                                 | 0.64       | (0.27 - 1.54)  | 1.30 | (0.35 - 4.88)  | 1.03 | (0.49 - 2.19) | 1.61 | (0.88 - 2.95) |
| Education (ref: college graduate or beyond)             |            |                |      |                |      |               |      |               |
| Some college  | 0.57       | (0.23 - 1.41)  | 1.46 | (0.36 - 6.00)  | 1.74 | (0.67 - 4.51) | 0.95 | (0.51 - 1.75) |
| High school or less                                     | 0.71       | (0.22 – 2.26)  | 0.78 | (0.10 - 5.89)  | 0.79 | (0.30 - 2.04) | 0.89 | (0.43 - 1.83) |
| Language of interview (ref: English)                    |            |                |      |                |      |               |      |               |
| Cantonese/Mandarin                                      | I          |                | 0.04 | (0.01 - 0.25)  | 1    |               | 1    | ı             |
| Spanish   | I          |                | I    |                | 0.88 | (0.40 - 1.96) | ī    | ı             |
| Region (ref: Northern CA)                               |            |                |      |                |      |               |      |               |
| Southern California                                     | 0.96       | (0.45 - 2.05)  | 2.19 | (0.68 - 7.07)  | 1.08 | (0.58 - 2.02) | 0.76 | (0.47 - 1.23) |
| Insurance ( <i>ref: private</i> )                       |            |                |      |                |      |               |      |               |
| Public/govt   | 0.61       | (0.19 - 1.95)  | 0.59 | (0.15 - 2.37)  | 0.94 | (0.42 - 2.06) | 0.93 | (0.45 - 1.93) |
| No insurance  | ·          |                | '    |                | 1.24 | (0.27 - 5.70) | 0.97 | (0.10 - 9.63) |
| Health literacy (ref: medium to high)                   |            |                |      |                |      |               |      |               |
| Low   | $5.64^{*}$ | (1.52 - 20.92) | 1.99 | (0.40 - 9.88)  | 0.67 | (0.33 - 1.37) | 1.34 | (0.56 - 3.20) |
| Health status ( <i>ref: Good/fair/poor</i> )            |            |                |      |                |      |               |      |               |
| Excellent/very good                                     | 2.87*      | (1.28 - 6.43)  | 2.07 | (0.70 - 6.14)  | 1.40 | (0.67 - 2.92) | 1.45 | (0.87 - 2.42) |
| Comorbidities ( <i>ref:</i> 0)                          |            |                |      |                |      |               |      |               |
| Ι   | 3.49       | (0.78 - 15.51) | 2.10 | (0.42 - 10.47) | 2.15 | (0.80 - 5.75) | 1.30 | (0.58 - 2.90) |
| 2 or more   | 1.46       | (0.46 - 4.64)  | 1.14 | (0.28 - 4.66)  | 1.92 | (0.77 - 4.79) | 1.56 | (0.75 - 3.26) |
| Gleason score (ref:1-6)                                 |            |                |      |                |      |               |      |               |
| 7–10  | 0.64       | (0.28 - 1.48)  | 0.94 | (0.33 - 2.63)  | 0.82 | (0.41 - 1.66) | 0.64 | (0.40 - 1.02) |
| Treatment with chemotherapy / hormone therapy (ref: no) |            |                |      |                |      |               |      |               |

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| Yes 0.69 (0.26 - 1.84) 1.34 (0.21 - 8.51) 1.14 (0.48 - 2.72) 1.04 (0 | Yes 0.69 (0.26 - 1.84) 1.34 (0.21 - 8.51) 1.14 (0.48 - 2.72) 1.04 (0.51 - |     | OR   | 95% CI        |
|--|---|-----|------|---------------|------|---------------|------|---------------|------|---------------|
|  |   | Yes | 0.69 | (0.26 - 1.84) | 1.34 | (0.21 - 8.51) | 1.14 | (0.48 - 2.72) | 1.04 | (0.51 - 2.11) |

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\* p<0.05. All models adjusted for all covariates included in the table (except White and African American stratified models were not adjusted for language of interview).