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Article

The influence of the "cancer" label on perceptions and management decisions for low-grade prostate cancer

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Abstract

Background: Grade Group 1 (GG1) prostate cancer should be managed with active surveillance (AS). Global uptake of AS remains disappointingly slow and heterogeneous. Removal of cancer labels has been proposed to reduce GG1 overtreatment. We sought to determine the impact of GG1 disease terminology on individual's perceptions and decision making.

Methods: Discrete choice experiments were conducted on 3 cohorts: healthy men, canonical partners (partners), and patients with GG1 (patients). Participants reported preferences in a series of vignettes with 2 scenarios each, permuting key opinion leader–endorsed descriptors: biopsy (adenocarcinoma, acinar neoplasm, prostatic acinar neoplasm of low malignant potential [PAN-LMP], prostatic acinar neoplasm of uncertain malignant potential), disease (cancer, neoplasm, tumor, growth), management decision (treatment, AS), and recurrence risk (6%, 3%, 1%, <1%). Influence on scenario selection were estimated by conditional logit models and marginal rates of substitution. Two additional validation vignettes with scenarios portraying identical descriptors except the management options were embedded into the discrete choice experiments.

Results: Across cohorts (194 healthy men, 159 partners, and 159 patients), noncancer labels PAN-LMP or prostatic acinar neoplasm of uncertain malignant potential and neoplasm, tumor, or growth were favored over adenocarcinoma and cancer ($P < .01$), respectively. Switching adenocarcinoma and cancer labels to PAN-LMP and growth, respectively, increased AS choice by up to 17%: healthy men (15%, 95% confidence interval [CI] = 10% to 20%, from 76% to 91%, $P < .001$), partners (17%, 95% CI = 12% to 24%, from 65% to 82%, $P < .001$), and patients (7%, 95% CI = 4% to 12%, from 75% to 82%, $P = .063$). The main limitation is the theoretical nature of questions perhaps leading to less realistic choices.

Conclusions: "Cancer" labels negatively affect perceptions and decision making regarding GG1. Relabeling (ie, avoiding word "cancer") increases proclivity for AS and would likely improve public health.

Over 1 million men every year are told "you have prostate cancer." Of these, approximately one-third (1) are diagnosed with Grade Group 1 (GG1; or Gleason score 6) for which high-level and consistent evidence shows it is incapable of causing symptoms or metastasis, posing an insignificant (if any) risk to their overall health when adequately monitored (2,3). The preferred management of men with GG1 disease is active surveillance (AS), as recommended by all international guidelines (4-6). Nonetheless, in certain countries, adoption of AS has been disappointingly slow and heterogeneous: approximately 40% of men with low-risk GG1 disease are treated with surgery or radiation in the United States, whereas this percentage can be 100% for some providers and practices (7).

A disease can be innocuous, but its labeling is not (8,9). To most people, the word "cancer" conveys an aggressive and lethal

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malady, with subsequent emotional responses that may be amplified and mismatched to its oncologic risk (10). Impulse, bias, and heuristics are major influences that sway patients toward radical treatment, even when the potential benefit is negligible and risk of harm substantial (11,12). To curtail overdiagnosis and resulting overtreatment of indolent cancers (13), including GG1 disease (14), terminology changes and removal of cancer labels have been proposed. The latter has been resisted based on morphologic definitions, molecular traits, sampling error, and other practical considerations (15,16). For others, the potential relabeling of GG1 is evidence based, feasible, and perceived as beneficial to patients and public health (17,18). Concerningly, there is paucity of data quantifying the public's (eg, patients and their support spheres) perceptions and decision-making processes around current and potentially modified labeling of GG1 disease.

Several methods exist to elicit public preferences for health care, with discrete choice experiment (DCE) methodology being one of the most favored (19). DCE is a quantitative method primarily established in marketing research for measuring preferences and understanding consumer demand for goods and services. In DCE, existing and new paradigms (eg, nomenclature, product, intervention) are usually described by their categorical features (ie, attributes), with each of these allotted a range of defined dimensions (ie, levels). DCE allows for the quantification of preferences by analyzing decisions made by participants when asked to choose between competing scenarios, each consisting of different combinations of attribute levels. Responses (preferences) across scenarios determine the implicit valuation placed on each of their elements, thus revealing the strength of preferences for each level within attributes without explicitly asking for them (20). Further, the relative importance of each attribute can be determined based on how respondents are willing to trade preferences in one for those of another.

Herein, we conducted a series of DCEs across healthy men, partners, and patients with GG1 to determine how they might be influenced by the disease labels in the context of other attributes that go along with the diagnosis, such as management options and prognosis. We quantified the weight individuals bestow to each of these when making treatment choices about a GG1 diagnosis. These public-centric data are essential to inform the discussion around potential taxonomic changes for GG1 disease and quantify their impact on disease management decisions, particularly those favoring unnecessary treatment.

Methods

This study and its encompassing activities were approved by an institutional research ethics board (21-5267; University Health Network. Toronto, ON). We designed, conducted, and analyzed a DCE among healthy men, canonical partners ("partners"), and patients diagnosed with GG1 ("patients").

Expert panel to define appropriate descriptors

A panel of international experts in prostate cancer was assembled and surveyed. These key opinion leaders (KOLs) (Supplementary Method 1, available online) selected potential attribute levels that were collated by authors (AB, MR, GP, TvdK, SE) and deemed appropriate for use in clinical- and patient-centric discussions (Supplementary Method 2, available online). The most frequently selected descriptors were included in the DCE.

DCE survey design

DCE mainly stems from evaluation frameworks in marketing economics, whereas new products can be broken down into attributes (eg, price, brand, material type, etc), allowing economists to quantify how influential these attributes are for customers during decision-making processes (21). The DCE in this study was based on hypothetical case vignettes of GG1 prostate cancer scenarios (Supplementary Method 3, available online; Figure 1) that included most relevant elements for decision making in the setting of indolent GG1 consisting of 4 categorical attributes and 2 to 4 KOL-endorsed levels each: 1) biopsy label (adenocarcinoma, acinar neoplasm, prostatic acinar neoplasm of low malignant potential [PAN-LMP], or prostatic acinar neoplasm of uncertain malignant potential [PAN-UMP]); 2) disease label (cancer, neoplasm, tumor, or growth); 3) management options (AS or radical treatment); and 4) recurrence risk (<1%, 1%, 3%, or 6%). The combination of attributes' levels across all scenarios were defined according to a D-efficient design (DCEtool R package). The main DCE consisted of 10 clinical vignettes of paired scenarios (Figure 1), thus forcing the respondents to make trade-offs based on their preferences (22).

Pilot DCEs (25-50 voluntary participants and study members) were conducted, allowing adjustments based on qualitative feedback, without any changes made to the established DCE attributes or levels. The main DCE was distributed to study cohorts after no further feedback was received. As a sensibility check, we also conducted a separate validation DCE (eg, with different D-efficient–determined combination of attributes' levels across the 10 clinical vignettes) in an independent cohort of healthy men ("validation men").

Participants were first presented with information about prostate cancer screening, diagnosis, management options, and their corresponding risks; this information could be accessed any time during the experiment (Supplementary Method 3, available online). The participants were shown the DCE vignettes and asked to select their preferred scenario in each of them (Figure 1).

To assess participants' concentration, 2 attention check vignettes were included consisting of identical attribute levels (ie, biopsy, disease, treatment) with exaggerated difference in recurrence risk (1% vs 6%). Respondents with illogical responses were excluded. Additionally, to ascertain participant's treatment preference, 2 extra vignettes with direct validation questions were embedded into the DCE. These contained scenarios with identical attribute levels (ie, biopsy, disease, and recurrence risk) differing only on management option: current (adenocarcinoma, cancer, AS/radical treatment, 1%) vs alternative (PAN-LMP, growth, AS/radical treatment, 1%) labeled vignettes.

Study participants

Demographic information was used to target voluntary participants: 1) healthy men and validation men: male, aged 50-99 years, any marital status, sexual orientation, race, employment status, and education at minimum some high school; 2) partners: women, aged 50-99 years, married or domestic relationship, heterosexual or bisexual, any race, employment status, and education at minimum some high school; and 3) patients: initially diagnosed with GG1 at a tertiary cancer center. Participants in cohorts men, validation men, and partners were recruited using SurveyMonkey Audience, which retains and compensates panels of respondents and has been used for similar purposes in healthcare research (23,24). For patients, we queried an existing institutional database of men first diagnosed with GG1 on prostate

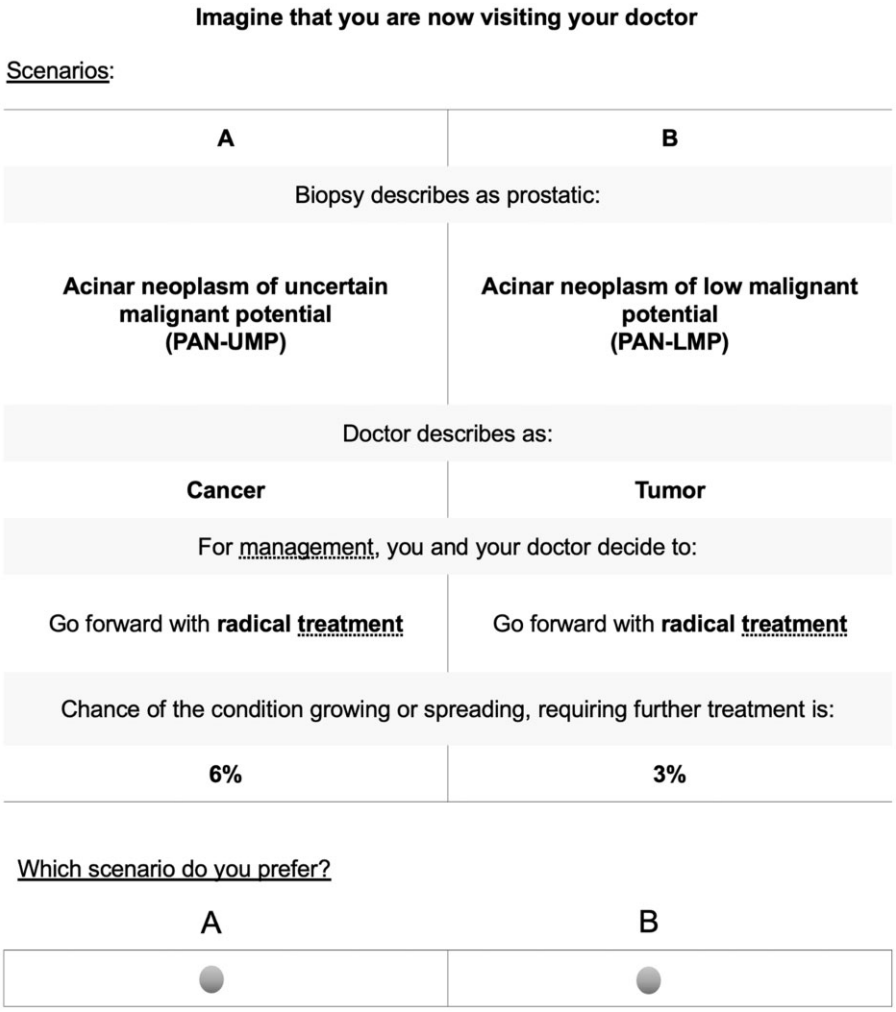

Figure 1. Example of vignette with choice scenarios. Participants indicated their preferences through 10 vignettes in both the main and validation discrete choice experiment (DCE). The introduction to the vignettes and details of management options (Supplementary Method 3, available online) could be reviewed at any time during the study.

biopsies between 2010 and 2020. The main DCE plus additional questions pertaining to their specific disease and journey (Supplementary Method 4, available online) was distributed to those with e-mail registered in the electronic medical records.

Statistical analysis

Sample size requirements for DCE can be approximated by the formula $N > 500c/(t \times a)$, where c = largest number of levels in any attribute, t = number of completed choice sets/vignettes per respondent, and a = alternative scenarios per choice set/vignette. The required sample size could be estimated from 100 to 167 participants based on the number of choice set vignettes (6-10), c (4), and a (2). Considering that sample size estimations for DCE are intended to serve as guides (25) and are not for attaining a specific power, we aimed for a conservative sample of approximately 167 completed responses for each study cohort.

A conditional logit model was used to model the scenario choices as a function of attributes. For analyses, the conventional or highest level (ie, biopsy = adenocarcinoma, disease = cancer, treatment = radical, and recurrence risk = 6%) was used as reference for preference weight estimates. The relative strength of preference of AS over radical treatment was expressed in terms of willingness to accept or avoid different levels across the remaining attributes and portrayed by corresponding marginal rates of substitution (MRS). The MRS is a ratio of preferences between defined levels in 2 attributes, thus providing a figure on the rate at which respondents are willing concede preferences between these attributes. This has the advantage of scaling the preference for a disease state-label in similar terms to other disease-related phenomena, such as prognosis and treatment intensity. For example, in our analyses, an MRS < 1.0 indicates that the preference for the compared alternate level (eg, growth vs cancer) has an influence of greater magnitude than the preference for AS over radical treatment. Responses to the direct validation questions were compared within each cohort using paired McNemar tests. Data processing and statistical analysis were performed on R environment (version 4.2.2).

Results

Participants

In total, 1254 participants (308 men, 256 partners, 332 patients, and 358 validation men) from North America enrolled. Of those who accessed the main DCE, 194 (63%) men, 159 (78%) partners, and 159 (48%) patients completed all choice sets and passed attention checks and were thus deemed valid and analyzable (Figure 2). Each valid response contributed equally to the DCE,

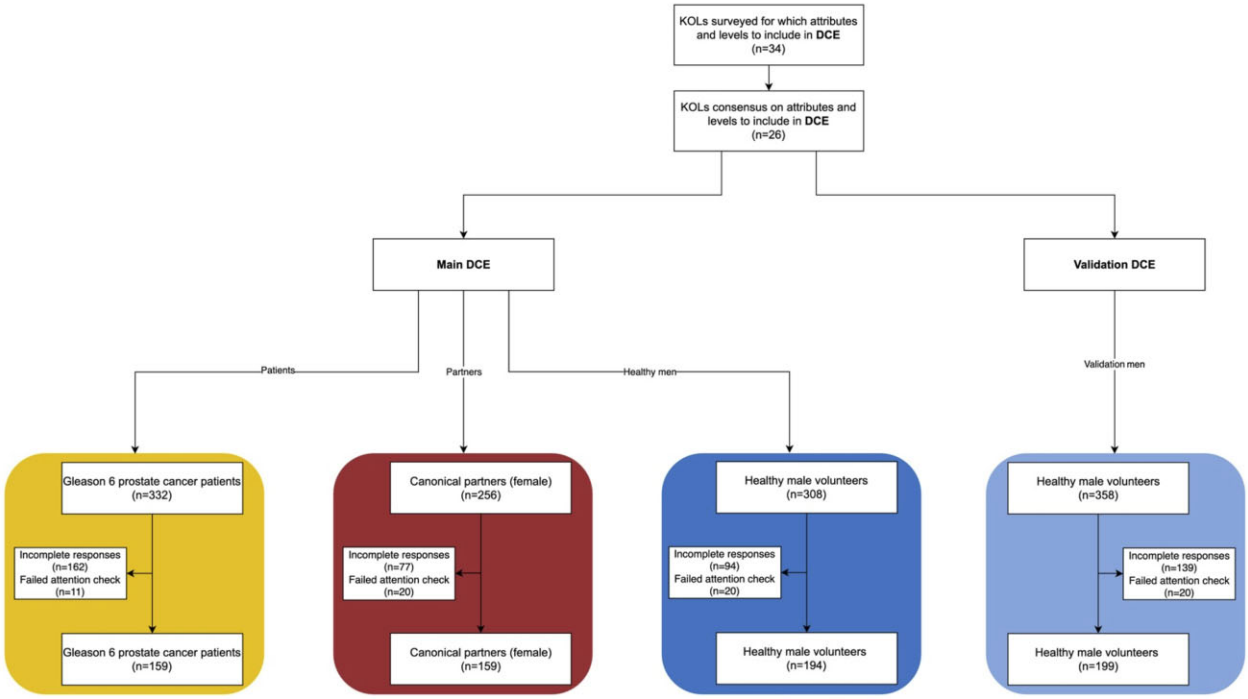

Figure 2. Study flow diagram. DCE = discrete choice experiment; partners = canonical partners; KOL = key opinion leaders; patients = patients diagnosed with Grade Group 1 (GG1).

corresponding to 3880 (men), 3180 (partners), and 3180 (patients) responses. The validation men cohort DCE encompassed 199 (56%) participants with valid and analyzable responses.

Overall, the patient cohort was older (92%, >60 years), reported being White or Caucasian (89%), was more highly educated (38% completed graduate school), and more likely to be retired (65%) (Table 1; Supplementary Table 1, available online). Participants were most often married, heterosexual, and in good to very good overall health, similar to patients and partners cohorts of newly diagnosed prostate cancer.

Preferred attribute levels

All cohorts favored AS for disease management and recurrence risk less than 1% (Supplementary Table 2, available online), as expected. For the alternative labels, we similarly found that all cohorts favored noncancer terminology in the chosen scenarios. PAN-LMP and tumor were the most frequently preferred biopsy and disease labels, respectively (Supplementary Table 2, available online). Compared with reference conventional or highest attribute levels, all cohorts showed preference for any of the alternative levels except for "acinar neoplasm" in men and partners (Figure 3; Supplementary Table 3, available online). The results from the validation men cohort (n = 199) were highly congruent with those of the main DCE men cohort, except for acceptance of "acinar neoplasm" and aversion to the "tumor" label in the former. Compared with the other cohorts, partners were less likely to prefer AS (54% of chosen scenarios, contrasting to 58% of men and patients; $P = .016$). Overall, a greater proportion of treated patients preferred radical treatment compared with those managed with AS (50% vs 35%, respectively, $P < .01$), whereas their acceptance of recurrence risk reflected in their scenario choices seemed comparable ($P = .94$) (Supplementary Tables 2 and 4, available online).

Differential magnitude of preferences

We sought to determine the differential magnitude of preferences for each attribute. MRS portray the rate at which respondents are willing to trade their choices in 1 attribute for preferred levels on another attribute. In our DCE, the MRS highlights the relative strength of preference of AS vs radical treatment over other attribute's levels; in other words, if the choice of AS over treatment was preferred to the same extent as the alternate levels (eg, growth vs cancer), the MRS describing this effect would be 1.0. Conversely, an MRS less than 1.0 indicates greater preference for the compared alternate levels, whereas an MRS of 2.0 depicts a preference for AS over radical treatment being twice stronger than the preference for the alternate levels. In the men and patients cohorts, the preference for AS over radical treatment was of greater magnitude than the preference for alternative biopsy and disease labels (ie, MRS >1) (Figure 4). In contrast, partners exhibited a preference for AS vs radical treatment of comparable magnitude with that of PAN-LMP vs adenocarcinoma (MRS = 1.09, 95% confidence interval [CI] = 0.56 to 1.62) and that of growth or neoplasm vs cancer (MRS = 1.05, 95% CI = 0.46 to 1.64; and 1.05, 95% CI = 0.42 to 1.68, respectively). Further, partners showed stronger preference for tumor vs cancer compared with the treatment decision (MRS = 0.77, 95% CI = 0.44 to 1.10). These results highlight that for partners, as opposed to healthy men and patients, the choice of AS contributes less to their overall preferences than the favoring of alternate biopsy or disease labels.

Prognosis (ie, recurrence risk) had a distinct impact on the preferences across cohorts. Participants reduced their preference for AS over radical treatment at increased recurrence risk. Men favored treatment if the recurrence risk was 6% vs 3% (MRS = 1.09, 95% CI = 0.82 to 1.36). Patients had a similar willingness but with higher risk aversion, favoring treatment when presented with 6% vs 3% recurrence risk (MRS = 1.28, 95% CI = 0.83 to 1.73)

Table 1. Participants characteristics[a]

Characteristics	Healthy men (n = 194)	Partners (n = 159)	Patients (n = 159)
Highest level of formal education, no. (%)			
Not graduated high school	3 (2)	1 (1)	2 (2)
Graduated from high school	25 (13)	25 (16)	16 (10)
Not graduated college	50 (26)	57 (36)	22 (14)
Graduated from college	38 (20)	43 (27)	51 (32)
Not completed graduate school	15 (8)	5 (2)	6 (4)
Completed graduate school	59 (31)	28 (18)	60 (38)
Ethnicity/race, no. (%)			
American Indian or Alaskan Native	0 (0)	1 (1)	0 (0)
Asian/Pacific Islander	11 (6)	8 (4)	10 (6)
Black or African American	5 (3)	4 (3)	0 (0)
Hispanic	4 (2)	6 (4)	2 (1)
White/Caucasian	172 (88)	139 (87)	141 (89)
Multiple ethnicity/Other	2 (1)	1 (1)	5 (3)
Relationship status, no. (%)			
Partnered	137 (71)	139 (82)	131 (82)
Previously partnered	39 (20)	17 (11)	18 (11)
Never partnered	17 (9)	3 (2)	10 (6)
Sexual orientation, no. (%)			
Straight	173 (89)	149 (94)	138 (87)
LGTBQ	21 (11)	10 (6)	19 (12)
Employment status, no. (%)			
Employed	91 (47)	83 (52)	48 (30)
Not employed	11 (6)	16 (10)	5 (3)
Retired	92 (47)	60 (38)	104 (65)
Self-reported overall health, no. (%)			
Very good	34 (18)	38 (24)	42 (26)
Good	93 (48)	83 (53)	84 (53)
Fair (or moderate)	61 (31)	31 (20)	26 (16)
Bad	4 (2)	5 (3)	5 (3)
Very bad	1 (1)	0 (0)	1 (1)
Age, no. (%), y			
45-60	67 (35)	84 (53)	12 (8)
>60	126 (65)	75 (47)	147 (92)
Management course, no. (%)			
Primary AS	n/a	n/a	51 (32)
Remained on AS			48 (30)
Progressed to treatment			3 (2)
Upfront treatment	n/a	n/a	108 (68)
Radiation therapy			50 (31)
Surgery			26 (16)
Other			32 (20)

[a] AS = active surveillance; LGTBQ = lesbian, gay, transgender, bisexual, and queer; men = healthy men. Missing: education 6, ethnicity 1, relationship status 1, sexual orientation 2, employment status 2, self-reported overall health 4, age 1.

but also equally accepting it when presented with 6% vs 1% (MRS = 0.96, 95% CI = 0.72 to 1.20). In contrast, among partners the strength of preference for prognosis, across all recurrence risk levels, remained more influential than the preference for AS (ie, MRS < 1).

Embedded direct validation

Influence of current biopsy and disease labels on management decisions were further assessed directly by the 2 additional validation vignettes. Each of these vignettes depicted scenarios with identical attribute levels other than management: current (biopsy = adenocarcinoma, disease = cancer, and recurrence risk = 1%) and alternative (biopsy = PAN-LMP, disease = growth, and recurrence risk = 1%). Compared with current labeling, the preference for AS increased with alternative labeling by up to 17%: healthy men (15%, 95% CI = 10% to 20%, from 76% to 91%, $P < .001$), partners (17%, 95% CI = 12% to 24%, from 65% to 82%, $P < .001$) and patients (7%, 95% CI = 4% to 12%, from 75% to 82%, $P = .063$) (Figure 5; Supplementary Figure 1, available online). Among patients, those managed with AS were not influenced by biopsy and disease labels on their choice of AS (89.6%, 95% CI = 77.4% to 95.9%; and 87.5%, 95% CI = 74.9% to 94.5% in current vs alternative labeling vignette; $P > .9$, respectively), contrasting with those who had undergone treatment (69.4%, 95% CI = 60.2% to 77.2%; and 80.2%, 95% CI = 71.7% to 86.6% choosing AS in the current vs the alternative labeling vignette, respectively; $P = .031$). (Supplementary Figures 2 and 3, available online).

Discussion

The diagnosis of cancer can be unsettling to patients and their support network due to heterogeneity of prognosis, outcomes, and experiences under a singular label. The "cancer" label (8,26) elicits strong instincts toward radical treatment even when it does not provide any oncologic benefit (9). In this work, we exposed and quantified such deleterious impacts in low-risk GG1 "cancer" nomenclature across healthy men, partners, and patients with prostate cancer. Through a discrete choice experiment, we show that current labels (eg, cancer, adenocarcinoma) have significant and important impacts on disease perceptions and decision-making. Avoiding these terms increases the probability of preferring AS by up to 17%. These results support

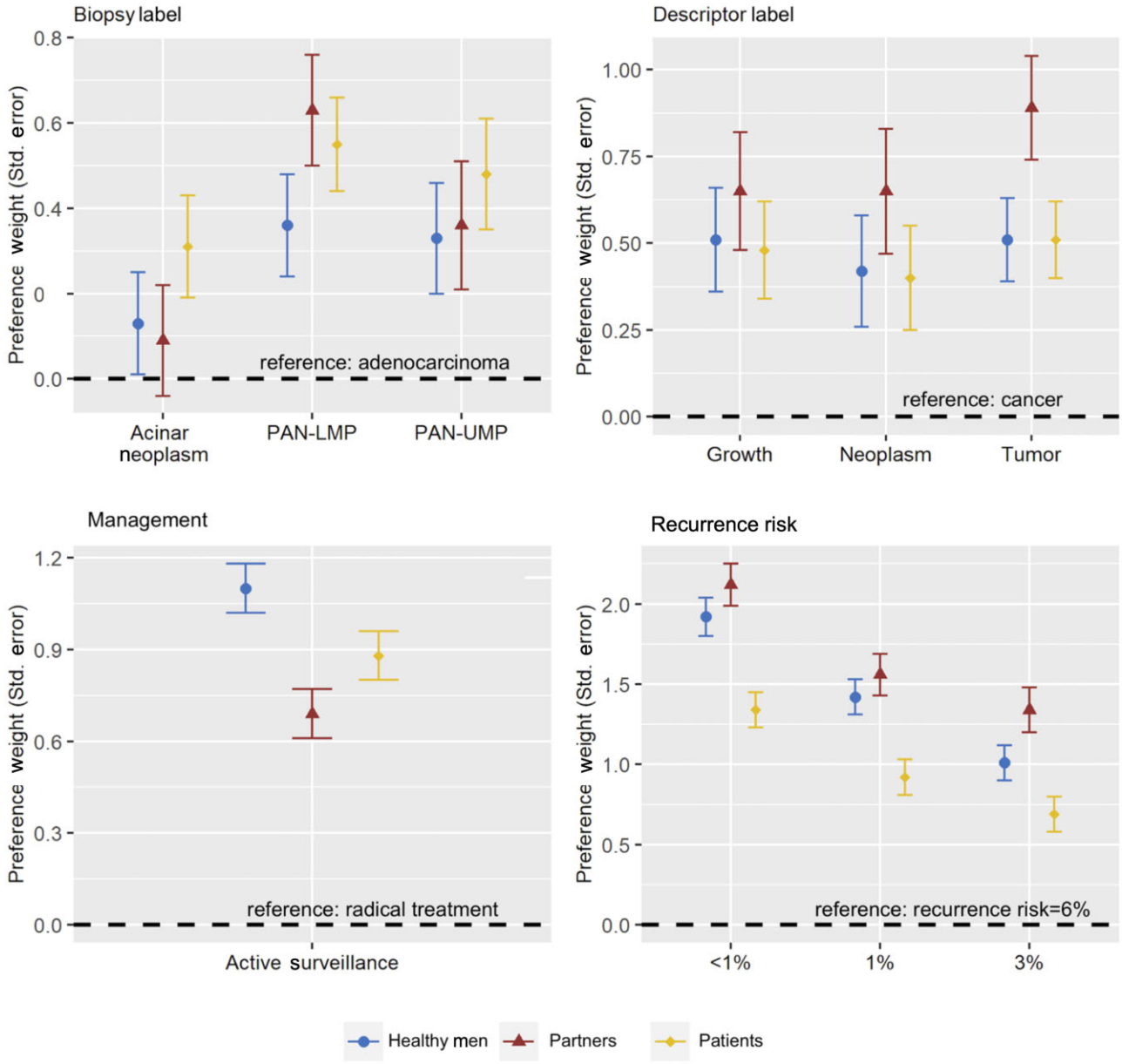

Figure 3. Preference weights for attribute levels across cohorts. Positive values indicate preference for the labeled level over the corresponding attribute's reference conventional or highest level constrained at zero. Means and standard errors for each preference weight are shown. PAN-LMP = acinar neoplasm of low malignant potential; PAN-UMP = acinar neoplasm of uncertain malignant potential; partners = canonical partners; patients = patients diagnosed with Grade Group 1 (GG1).

consideration of modifying GG1 descriptors towards public-preferred labels without "cancer" (such as PAN-LMP and tumor) and may lower overtreatment of this indolent disease. The final determination regarding terminology should be a matter of multi-stakeholder discussion (18) that incorporates the public voice elicited in our study.

Genitourinary pathology experts previously changed the prostate cancer grading system, from Gleason score 6 (out of a grading scale of 2-10) to GG1 (out of a grading scale of 1-5) as an aid to better convey the indolence of the disease and potentially reduce its overtreatment (27). The rates of AS for men with GG1 have remained largely stable, but the possible impact of such modification on patients' perceptions and decisions was subject to subsequent qualitative studies. Loeb et al. (28) surveyed 25 patients with prostate cancer and showed that 88% favored GG1 over Gleason score 6 and 80% felt it would be more comfortable doing AS with the former grade descriptor. Hundall et al. (29) surveyed 718 men without prostate cancer, presenting them with 1 hypothetical low-grade prostate cancer scenario, and showed how grading nomenclature affects initial perceptions and decision making (eg, GG1 associated with lower rates of anxiety and immediate treatment compared with Gleason score 6). Our data provide evidence of the 1) importance and influence of biopsy and disease labels in the presence of a GG1 descriptor of grade, which alone might be necessary but not sufficient to provide the public with the clearest insights of GG1 disease, its prognosis, and optimal management strategy; 2) impact of nomenclature on healthy men, partners, and patients' perceptions, leveraging broader insights for nonpaternalistic interactional dynamics during shared decision making (30); and 3) study methodology that

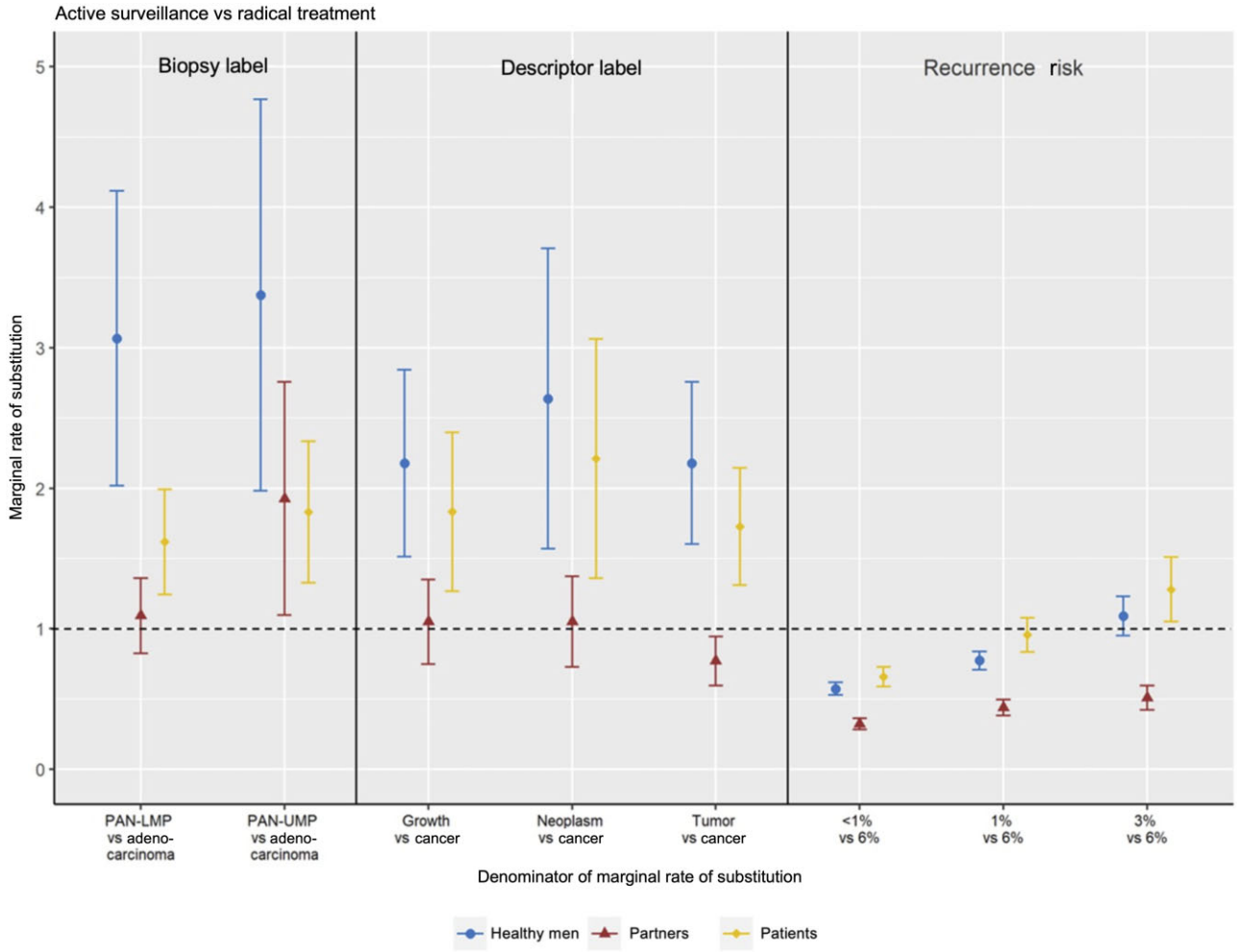

Figure 4. Marginal rate of substitution (MRS) across cohorts for the choice of active surveillance (AS) over radical treatment relative to the preferences for biopsy and disease descriptors, and recurrence risk. An MRS less than, equal to, or greater than 1.0 reflects greater, equivalent, or less influence, respectively, of the indicated comparison than the preference for AS over radical treatment. Means and standard errors for each MRS are shown. PAN-LMP = acinar neoplasm of low malignant potential; PAN-UMP = acinar neoplasm of uncertain malignant potential; partners = canonical partners; patients = patients diagnosed with Grade Group 1 (GG1).

allows for enhanced quantification of disease labeling effects, accounting also for management and prognosis preferences. Furthermore, permutation of attribute levels across independent choice sets or vignettes better conceals the study hypothesis, thus preserving the validity of responses throughout the experiment and the embedded direct validation questions.

The current study provides unique observations and informs the deliberations around GG1 disease relabeling. First, we show pervasive impact across relevant stakeholders (healthy men, partners, and patients), all perceiving alternate labels as more desirable than cancer and adenocarcinoma. Second, the presented prognosis is vastly influential, with seemingly trivial differences (eg, <1% vs 1% vs 3%) being relevant and persuasive. Third, among patients under similar experimental conditions, those who endured radical treatment exhibited lower tolerance to recurrence risk and acceptance of AS compared with those undergoing surveillance. These results can stem from individual differences present at time of diagnosis or from shifted preferences influenced by their previous choices and experiences. Regardless, it emphasizes the need for encompassing the true population at risk of a new GG1 diagnosis (ie, healthy men) and diverse groups of patients, to provide a more comprehensive understanding of perceptions, preferences, and decision-making. Lastly, the susceptibility towards GG1 labeling is different between men and their partners, with the latter showing greater aversion to cancer labels and recurrence risk with a lower predilection for AS. This observation is in keeping with previous work showing those in a relationship are more likely to undergo treatment (31). How information flows and decisions ensue among patients and their support spheres could influence behavior, as others' judgements sway the risk tolerance and decisions that one would express alone (32). Similarly, individuals' perceptions and preferences differ in first- vs second-person, requiring awareness and consideration during the shared decision-making processes (33). The concern that viewpoints pertaining to relabeling GG1 have been dominated by those who did not directly experience the disease (eg, second- or third-person) underscores the importance of the present work bringing partners' and patients' perspectives to the fore.

Our findings should be considered within the study limitations. First, online methodology could have introduced selection biases, reflected partially in the characteristics of participants (eg, White/Caucasian, higher education, income), because sociodemographic and economic factors influence AS-related decision

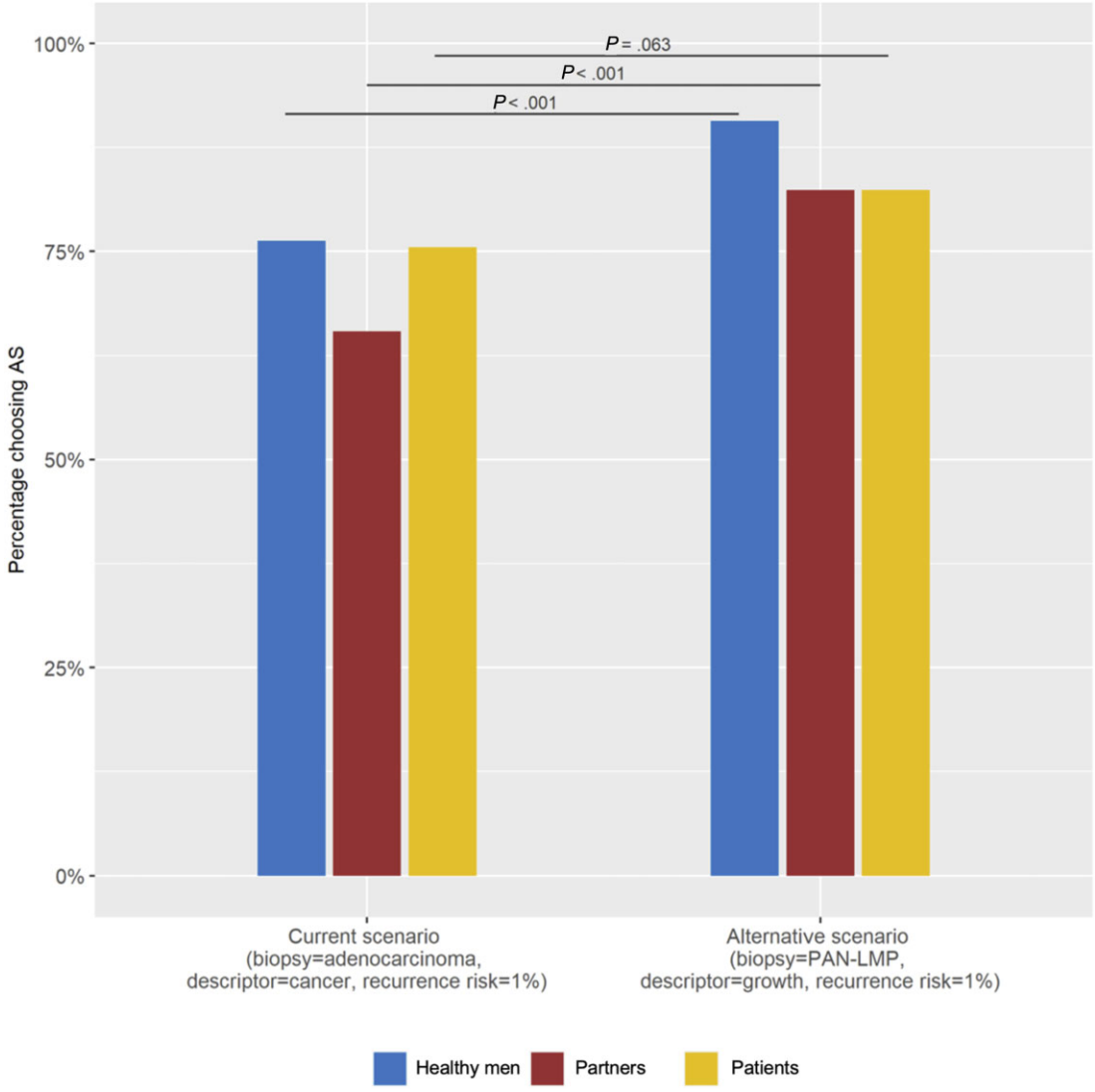

Figure 5. Direct validation question across cohorts. Assessment of participant's preference for active surveillance (AS) by 2 validation vignettes depicting scenarios with identical attribute levels except treatment options. *P* values correspond to McNemar tests. PAN-LMP = acinar neoplasm of low malignant potential; partners = canonical partners; patients = patients diagnosed with Grade Group 1 (GG1).

making (34). Conversely, the methodology could be relevant in the current era of high digital interfacing and literacy among prostate cancer patients (35), where transparent and accessible health information is fostered (36). Balancing precision, clarity, and emotional aspects of disease labels seems pertinent when "you have prostate cancer" is increasingly seen first-hand by patients and support spheres through digital communication. Second, the theoretical nature of the study scenario and vignettes may have led to less realistic and/or attentive choices, possibly different from what participants would exhibit in real life settings. However, the likelihood of such limitation is lessened by the comparable results between healthy men and patients, decreasing the possibility of personal experience dramatically changing our observations; attention checks to exclude inattentive responses from final analyses; and consistency and coherence (eg, preference weight inversely related to recurrence risk) of results across cohorts. Nonetheless, our study may not totally reflect decisions stemming from personalized and extensive discussions. Previous work has shown how GG1 nomenclature influences individuals, but also how such an effect fades with disease-specific education and counseling (29). The importance of dynamic ascertainment of comprehension and shared decision-making is indisputable, but so is the disproportionate impact of initial information and early impressions on final judgements (37). Third, the specificity of our study precludes direct application to other cancers where consideration for relabeling is also relevant (38-40). However, the observed impact and magnitude of cancer labels across various stakeholders suggests similar influence may be at play in other low-risk neoplasms, thus warranting analogous research efforts. Last, although our data supports consideration of changing GG1 disease labeling to help partners and patients in their perceptions and decisions toward AS, the sufficiency and robustness of such a change in the context of patient-provider interactions remains unknown. External influences might be inferred by the relative strong proclivity towards AS across participants contrasting with current rates of AS adoption. For example, downstream incentives may foster certain behaviors (41) that juxtapose favoring of AS, thus

rendering taxonomic changes as insufficient to modify the GG1 management status quo. Similarly, additional work would be required to minimize the likelihood a new terminology could misleadingly downplay the erstwhile GG1-associated risk of underlying nonindolent cancer and need to adhere AS protocols.

In conclusion, this work provides quantitative data supporting the redesignation of GG1 to avoid the use of the word "cancer." Current biopsy (eg, adenocarcinoma) and disease (eg, cancer) labels negatively affect perceptions and clinical decision making regarding low-risk GG1, decreasing the proclivity for AS in favor of unnecessary treatment. Multistakeholder discussions are required to define the optimal terminology that does not misleadingly downplay erstwhile GG1 and the need to follow AS protocols.

Data availability

The data that support the findings of this study are available on request from the corresponding author, AB. The data are not publicly available due to institutional restrictions and public sharing will breach research ethic board agreements in place. Therefore, upon request, Data Sharing Agreements will be composed to facilitate sharing of deidentified study data.

Author contributions

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Conflicts of interest

All authors declare no conflict of interest specifically related to this work. Matthew R. Cooperberg, a *JNCI* Associate Editor and coauthor on this article, was not involved in the editorial review or decision to accept and publish the manuscript.

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