



# Are decision aids leading to shared prostate cancer screening decisions among African-American men?: iDecide

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## Abstract

**Purpose** African-Americans have prostate cancer mortality rates that are double their White counterparts. To reduce prostate cancer disparities, it is suggested that men engage in shared decision making about prostate cancer screening with their healthcare provider after learning about the benefits and harms of these screenings. While researchers have developed decision aids to support African-American's screening decisions, there is some uncertainty whether these aids lead to shared decision making. The goal of the current study was to investigate the efficacy of iDecide, a computerized decision aid, for promoting African-American men's engagement in shared decision making.

**Methods** Six months after their use of iDecide, a prostate cancer screening decision aid, 76 participants were surveyed to determine whether they spoke with a provider about screening, what this conversation entailed, and if shared decision making occurred.

**Results** While iDecide is an effective tool for enhancing African-American's intention to engage in shared decision making, there is no evidence this aid increased their likelihood of discussing prostate cancer with a provider or participation in shared decision making.

**Conclusion** Future research should employ stronger research designs and assess the various contexts that can affect the relationship between decision-aid use and shared decision making among African-Americans.

**Keywords** Prostatic neoplasms · Early detection of cancer · Decision making · Decision support techniques · African Americans

## Introduction

African-Americans (AAs) have prostate cancer (PrCA) mortality rates that are double their White counterparts [1]. The American Urological Association [2], American Cancer Society [3], and the United States Preventive Services Tasks Force [4] recommend that men engage in shared decision

making (SDM) with their healthcare provider after learning about the benefits and harms of PrCA screening. Elwyn and colleagues define SDM as

“an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” [5].

SDM is critically important when deciding on whether or not to receive a prostate specific antigen test for PrCA screening because this exam can yield a false positive which can prematurely lead to biopsy and treatment, each of which carries their own risks [6]. Digital rectal exams, though less controversial, also warrant SDM because of the lack of evidence supporting the test's diagnostic efficacy [7]. To prepare AAs for engaging in SDM for PrCA screening, researchers have developed few culturally tailored decision aids (DAs) [8]. Existing DAs for AAs have led to outcomes such as increases in PrCA knowledge, self-efficacy, and

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SDM intention, and a reduction in decisional conflict [9–13], but researchers rarely measure whether DAs lead to SDM about screenings for PrCA or other cancers [14, 15]. Even studies that incorporate follow-up data collection into their study designs often focus on assessing the effect of DAs on PrCA screening uptake and satisfaction with decision making [16].

To enhance the capacity for AAs to engage in SDM about PrCA screening, a three-phase (needs assessment, DA development, usability testing) community-based participatory research process was implemented to develop iDecide, a culturally tailored, computer-based DA for AAs [17]. Similar to prior DAs implemented with AAs, an evaluation of the two-part intervention (i.e., education and role-play exercise; see description below) among 354 AAs showed that iDecide produced higher PrCA knowledge, decision self-efficacy, technology use self-efficacy, and intention to engage in SDM [9]. The goal of the current study was to investigate the efficacy of iDecide for promoting AA men's engagement in SDM about PrCA screening following their use of the intervention.

## Materials and methods

### Intervention description

iDecide is a computer-based decision aid that contains evidence-based information about PrCA anatomy, risk, symptoms, and screening recommendations; the controversy about the effectiveness of PrCA screening; and the importance of SDM. The decision aid was divided into two 5-min sections. The first section featured an AA embodied conversational agent (i.e., animated, human-like character) who portrayed a health educator and provided information to enhance AA men's knowledge about PrCA. Section One also included interactive question and answer exercises which appear throughout the section to reinforce information presented by the embodied conversational agent. For example, one question on prostate anatomy asks participants about the location of the prostate (a. In the scrotum; b. In the rectum, or c. Below the rectum and in front of the bladder)? An incorrect answer elicits audio and text that informs the participant that their answer is not the best available and encourages them to try again. Similarly, a participant who answered a question correctly would receive an audio and visual message stating that their answer was correct.

Section Two of iDecide featured an AA embodied conversational agent dressed as a healthcare provider. In this section, AA men were engaged in a role-play exercise designed to increase their SDM self-efficacy. Within this section, participants are presented with a limited set of options that represent common questions men might have during

a conversation about PrCA (e.g., What are my chances for having PrCA?). When men selected options that were too general (e.g., I am here for a basic checkup), they were provided with audio feedback informing them why they should choose an option that is PrCA specific. For example, men who selected the basic checkup option were informed that because current screening recommendations do not suggest annual receipt of PrCA screenings, conversations about a basic checkup may likely not include information about PrCA screening. Therefore, they were encouraged to choose an option that was PrCA specific such as "I would like to discuss PrCA screening." The conversation ends with the embodied conversational agent asking the participant whether he is ready to make a decision about PrCA screening. If the participant selects no, he is encouraged to repeat the module and then forwarded to additional sources that provide more information about PrCA (e.g., website and phone number for the American Cancer Society. If the participant selects that he is ready to make a decision about screening, he is directed to a page that asks if he is ready to receive screening today; there are three options on this page from which the participant can select: yes, no, or I am interested, but I would like to speak with my family first. Each of these options will lead participant to a screen where the embodied conversational agent will acknowledge their choice (including the fact that by choosing an option through the role play exercise that the participant has engaged in SDM), reminds them generally about what they have learned through "iDecide," and encourages them to use their knowledge gained through iDecide to engage in SDM with their provider. The final page of "iDecide" contained contact information for the principal investigator and phone numbers/websites where participants can find more information about PrCA or where they can receive screening should they not have access to a regular healthcare provider. The research team did not track whether or not participants utilized resources beyond our decision aid, and the principal investigator did not receive any calls from participants. In the original study, iDecide was accessed on a 10-inch tablet computer with headphones [8].

## Methods

### Data collection

A series of follow-up calls were made to all 354 participants from our prior evaluation of iDecide. Each of the participants received three calls before follow-up efforts were halted. Participants received these calls 6 months following their use of iDecide and were informed/consented to follow-up calls during the initial evaluation. During these calls, two AA research coordinators administered a telephone

survey to 76 participants (21% response rate). The survey, which included both open and closed-ended questions created by the research team, sought to determine whether (1) participants spoke with a provider about screening (yes/no) (2) what this conversation entailed (open response), (3) reasons for visiting the doctor (open response), (4) if a decision was made about whether or not to receive PrCA screening (yes/no), (5) what screening decision was made (PSA and/or DRE, decided to wait, decided not to be screened), (6) if they perceived that SDM occurred (yes/no), as opposed to paternalistic or individual decision making, and (7) why men felt their decision to screen or not screen was right for them (open response). These data were self-reported and not triangulated with other forms of data such as provider or medical record data. All demographic (Table 1) and SDM intention data (i.e., I intend to make a share decision in the next 6 months about PrCA screening; yes/no) was collected in a prior study [9]. Responses for each participant were recorded on individual surveys in Microsoft Word™ and later transferred to SAS version 9.2 (closed-ended questions) and Microsoft Excel™ (open ended questions) for analysis. Each call lasted approximately 30 minutes, and each man received a \$10 gift card for their participation.

## Data analyses

In addition to demographic statistics, Spearman correlations were conducted in SAS version 9.2 to examine associations between our dependent variables (i.e., spoke to provider, engaged in SDM) and independent variables (i.e., age, income, education, and intention to engage in SDM). The spearman correlation was employed because most of our variables were ordinal and the distribution of these variables were not normal. This procedure is conservative compared to a Pearson correlation which gives us a basic understanding about the relationship between variables of interest. Associations between these variables in our correlation were considered significant at  $p \leq 0.05$ .

Themes from open-ended responses were identified using a multi-step process to organize and analyze data. The first step involved concatenating participant open-ended responses from each individual survey into Microsoft Excel™. The second step involved employing a word/phrase frequency formula in Microsoft Excel™ to determine if there was language that was used across participants on a given question that might help better organize the data. Following this process, a second Microsoft Excel™ sheet was created where quotes with common phrases were paired together and organized underneath general headings for each question. The fourth step involved a traditional open coding process where the research coordinator and the lead author read through each of the responses to assign contextual relevancy to the quotes and develop preliminary themes [18].

**Table 1** Descriptive statistics

Variable (respondents)	Frequency	Mean (SD) or %
Age ( $n = 76$ )		58.38 (+9.74)
Education ( $n = 76$ )		
Less than high school	6	7.89
High school	11	14.47
Some college or vocational school	29	38.16
Completed college or vocational school	19	25.00
Post graduate school	11	14.47
Marital status ( $n = 75$ )		
Single/never married	13	17.33
Married	47	62.67
Separated	12	16.00
Divorced	2	2.67
Other	1	1.33
Income ( $n = 75$ )		
< \$19,999	15	20.00
\$20,000–\$39,999	9	12.00
\$40,000–\$59,999	15	20.00
\$60,000–\$79,999	20	26.67
\$80,000–\$99,999	6	8.00
$\geq$ \$100,000	10	13.33
Employment ( $n = 73$ )		
Full time	42	56.00
Part time	1	1.33
Retired	21	28.00
Unemployed	9	12.00
Health Insurance (type) ( $n = 75$ )*		
Employer	28	37.33
Private	70	93.33
Medicare	56	74.66
Medicaid	67	89.33
Military healthcare	58	77.33
Prescription drug coverage	66	13.33
No coverage	8	10.77

\* Question accommodated multiple responses so frequencies will not add to 100%

A discussion of these themes led to a draft codebook. This codebook was used to code approximately a quarter of the participants responses, and interitem reliability was determined using a percent-agreement method where the number of agreed codes are divided by the total number of items coded [19]. We reached an 80% agreement which is considered acceptable, but discussed coding differences until 100% agreement was reached [19]. The lead author then employed axial coding, to recode all responses, comparing and contrasting emergent themes between participants [18]. In a final step, the lead author used Microsoft Excel™ to quantitate themes.

## Results

### Demographics

The 76 AA male participants had a mean age of 58.38 ( $\pm 9.74$ ) years (Table 1). Most were married (63%,  $n=47$ ), insured (89%,  $n=67$ ), employed (57%,  $n=43$ ). Participants also reported variable household incomes with almost half earning between \$40,000–79,999 (46%,  $n=35$ ). Furthermore, the majority of participants had either completed some, or finished, college of a vocational program (63%,  $n=48$ ).

### PrCA screening and SDM

While 48 of 76 (63%) participants had an intention to engage in SDM, about half ( $n=25$ ) participated in PrCA screening conversations with their provider. Seventeen participants who had no intention of engaging in SDM also spoke with a provider. When asked what prompted the visit to their healthcare provider most participants reported their visit to a healthcare provider was an annually scheduled physical exam or appointment for maintenance of an existing health condition (e.g., heart condition), but few report visiting the doctor specifically to talk about PrCA screening for those who had conversations about screening, participants often asked providers about their personal risk for PrCA and often reported being informed by providers about the importance of receiving routine PrCA screening. No participants report receiving information from providers about the risks associated with PrCA screening. Of participants who spoke with their providers about screening ( $n=42$ ), about a quarter ( $n=11$ ) engaged in SDM. Most participants ( $n=25$ ), however, reported making screening decisions independently of the provider. In addition, our Spearman correlation (Table 2) revealed no significant associations between participants'

intention to engage in SDM and participation in screening conversations ( $p=0.52$ ) or SDM ( $p=0.37$ ). Similar results were found for correlations between our dependent and demographic variables: with exception to age which had a significant positive correlation with participation in screening conversations ( $p\leq 0.001$ ).

At the conclusion of their conversations with healthcare providers about PrCA, 43%, or 18 of 42 participants decided to receive both the PSA and DRE screenings for PrCA, 29%,  $n=12$  solely received a PSA screening, 14%,  $n=6$  solely received the DRE, 12%,  $n=5$  decided not to be screened, and only one participant decided to wait to make a decision about screening at a later date. When asked why they perceived their decision to screen or not screen was right for them, the majority of participants spoke about the importance of being proactive about their health which included the receipt of PrCA screening. This proactivity was particularly important to some men given their ages (40+) and the prior education they had received from their healthcare providers and other educational resources. Equally salient to their PrCA screening decision was their higher perceived risk for PrCA based on their race.

## Discussion

While iDecide is an effective tool for enhancing AAs intention to engage in SDM, there is no evidence this DA increased their likelihood of discussing PrCA with a provider or participation in SDM. Our findings about the lack of translation between SDM intention and participation in conversations with providers or engagement in SDM are consistent with prior research [20, 21]. For example, Woods-Burnham et al. [20] found that less than half of AAs engage in conversations about PrCA with a healthcare provider. Furthermore, Lepore et al. [21], the only recent study that measured SDM in relation to cancer screening among

**Table 2** Spearman correlation coefficients  $\text{Prob} > |r|$  under  $H_0: \text{Rho} = 0$

	SDM intention	SDM	Screening discussion	Age	Education	Income
SDM intention	1.00000	0.07538	-0.10520	-0.12892	0.08350	0.03833
		0.5204	0.3690	0.2770	0.4733	0.7441
SDM	0.07538	1.00000	0.36748	0.16550	-0.16516	-0.00094
	0.5204		0.0012	0.1647	0.1568	0.9936
Screening discussion	-0.10520	0.36748	1.00000	0.37998	-0.06985	0.02924
	0.3690	0.0012		0.0010	0.5515	0.8047
Age	-0.12892	0.16550	0.37998	1.00000	-0.08313	0.02034
	0.2770	0.1647	0.0010		0.4844	0.8654
Education	0.08350	-0.16516	-0.06985	-0.08313	1.00000	0.60243
	0.4733	0.1568	0.5515	0.4844		<.0001
Income	0.03833	-0.00094	0.02924	0.02034	0.60243	1.00000
	0.7441	0.9936	0.8047	0.8654	<.0001	

AAs, concluded that intention to engage in PrCA screening SDM following use of a DA does not lead to actual participation in SDM in African-American and Caribbean-born men. Lepore's et. al's [21] findings mirror those of larger systematic reviews of the effects of DAs on SDM for cancer and other health-related screening and treatments among the general population [15, 22]. These findings demonstrate that DAs either have no effect on SDM [15] or, as in our study, may influence patients to report taking more individual roles in decision making as opposed to SDM [22].

Our findings regarding AAs general lack of participation in SDM also corroborate national data which show that most men who receive PrCA screening do not engage in SDM regardless of race [23–25], though Pucheril et al. [25] report that AAs have the strongest odds of reporting SDM of the few men who do elect to engage in SDM. In addition, some of these national data demonstrate that when men receive information about PrCA screening, they are far less likely to receive information about the disadvantages and likely to only hear about screening benefits [24]. However, men who receive information about the advantages of the PSA and/or receive a physician recommendation are far more likely to receive PSA screening despite not having participated in SDM [24]. Not having a thorough knowledge about the disadvantages of PrCA screening (i.e., the high potential for false negatives and false positives), can lead to men electing to undergo invasive treatments for indolent cancers [6]. These treatments carry the potential for side effects, such as impotency, which can severely affect men's quality of life [26].

In general, there are multiple individual (e.g., medical mistrust) [27], interpersonal (e.g., provider communication style) [27, 28], and institutional (e.g., short provider–patient visit) [29] barriers to AA participation in SDM about a range of diseases and across the continuum of care (screening, treatment, survivorship). In a recent systematic review of 18 studies with 50% or more of racial and ethnic minorities, Jolles et al. [29] found that minority patients (including African-Americans) most often prefer a paternalistic model of health decision making, which is counter to our findings. The authors attribute this lack of active participation in SDM primarily to patient's insufficient information about a given health condition and higher trust in the provider's ability to make an informed decision, but challenges also include limited time with the provider and provider impersonality [29]. Similarly, while there is evidence that AAs prefer to engage in SDM over other decision-making models [30, 31], Peek et al. [27] found that AAs are far more likely to adopt a paternalistic model of decision making, particularly with White providers, because of perceived racial/cultural barriers (e.g., White physicians perceived to be domineering over AAs and less likely to listen to their needs). Based on their SDM studies with minority breast and colorectal

cancer patients, Hawley et al. [32] note that “SDM may be a difficult concept to those patients who either lack trust in the health system or believe that physicians are supposed to make decisions.” While these studies are not all specific to PrCA screening, the pattern is consistent that AAs are not engaging in SDM.

## Conclusions and research implications

Even though iDecide did not lead to SDM among AA men, our study points to a salient gap in PrCA and SDM research: to what extent are DAs influencing participation in SDM about PrCA screening, particularly among AA men who often elect either paternalistic or individualized decision roles? To date, researchers have determined that DAs can effectively change constructs historically associated with SDM (e.g., knowledge, self-efficacy, SDM intention) among AA men, but these studies relied heavily on pre- and postintervention research designs with no follow-up. These research designs limit the ability to determine whether and to what extent these DAs affect SDM. In the absence of more rigorous research designs, researchers will be unable to establish culturally appropriate, evidence-based DAs that can be used confidently in standard practice with AAs. In addition, future research should also evaluate the many contextual variables that might affect a DA's impact on SDM such as the perceived quality of doctor–patient communication, length of appointment, the DA's location, proximity of DA use to time of the PrCA screening decision, and whether or not the DA is used jointly by the provider and patient during consultation. Furthermore, there is a need to consider tailoring future DAs in ways that can assist patients with learning about, and discussing concerns about social determinants that may influence their healthcare preferences and their desired role in healthcare decision making.

## Limitations

There were some notable limitations in this study. The 76 participants who responded to this phone survey were only a subset of a larger population of 354. The small population of African-American participants resided in one region in South Carolina; so, findings may not be applicable to other African-American men. Furthermore, most men in our study had received PrCA screening at least once in the past, so the implications of our intervention on men who do not have a history of screening are limited. Despite these limitations, our study has provided valuable information regarding the efficacy of a computer-based prostate cancer education program to promote informed decision making about PrCA screening among AA men. Future studies will focus on

conducting follow-up studies to determine if and to what extent their PrCA interventions led to behavior change.

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### Compliance with ethical standards

**Conflicts of interest** We certify that all authors, Otis L. Owens, Simon P. Kim, and Abbas Tavakoli, have no conflicts of interest to disclose.

**Research involving human participants and/or animals** This research involved the inclusion of human subjects. We certify that this study was reviewed and received approval from the Institutional Review Board at the University of South Carolina.

**Informed consent** Informed consent was obtained from all individual participants included in the study.

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