

# A Stepping Stone for Participatory Design of an Artificial Intelligent Digital Assistant to Improve Shared Decision Making for African American Men Diagnosed with Localized Prostate Cancer

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## Introduction

It is estimated that in 2019 approximately 29,570 African American (AA) men were newly diagnosed with prostate cancer (PCA). Disparities in PCA among AA men have been documented at all stages of the cancer continuum, i.e., diagnosis to treatment to survivorship. Shared decision making (SDM) a process in which patients and clinicians work together to make medical decisions based on clinical evidence is vital to the selection of treatment. However, for an individual to make an informed decision and fully participate in the SDM process they must understand the disease and its treatment options. The overall goal of our project is to improve SDM for AA men who have been diagnosed with localized low risk PCA.

## Methods

Five focus groups were conducted with 17 African American (AA) prostate cancer survivors, 8 AA men who have not been diagnosed with prostate cancer, 8 spouses and relatives of AA men who are prostate cancer survivors and 11 health care providers. Focus group facilitators (community PCA advocates) received training from the project's Community-Based Participatory Researcher. Data extracted from the transcripts were organized, coded, and analyzed for recurrent patterns and themes utilizing NVivo qualitative software (© QSR International Pty Ltd. 2020)



*"And I wanted to know what my family life would be like, since because I didn't know anything about prostate cancer. And so I wanted to know if I'm going to be able to please Mama, and all this kind of stuff."* [PCA Survivor]

*"There is a subset of people that you just say the word cancer, and they just fall apart...the fear of death floods the room."* [Health Care Provider]

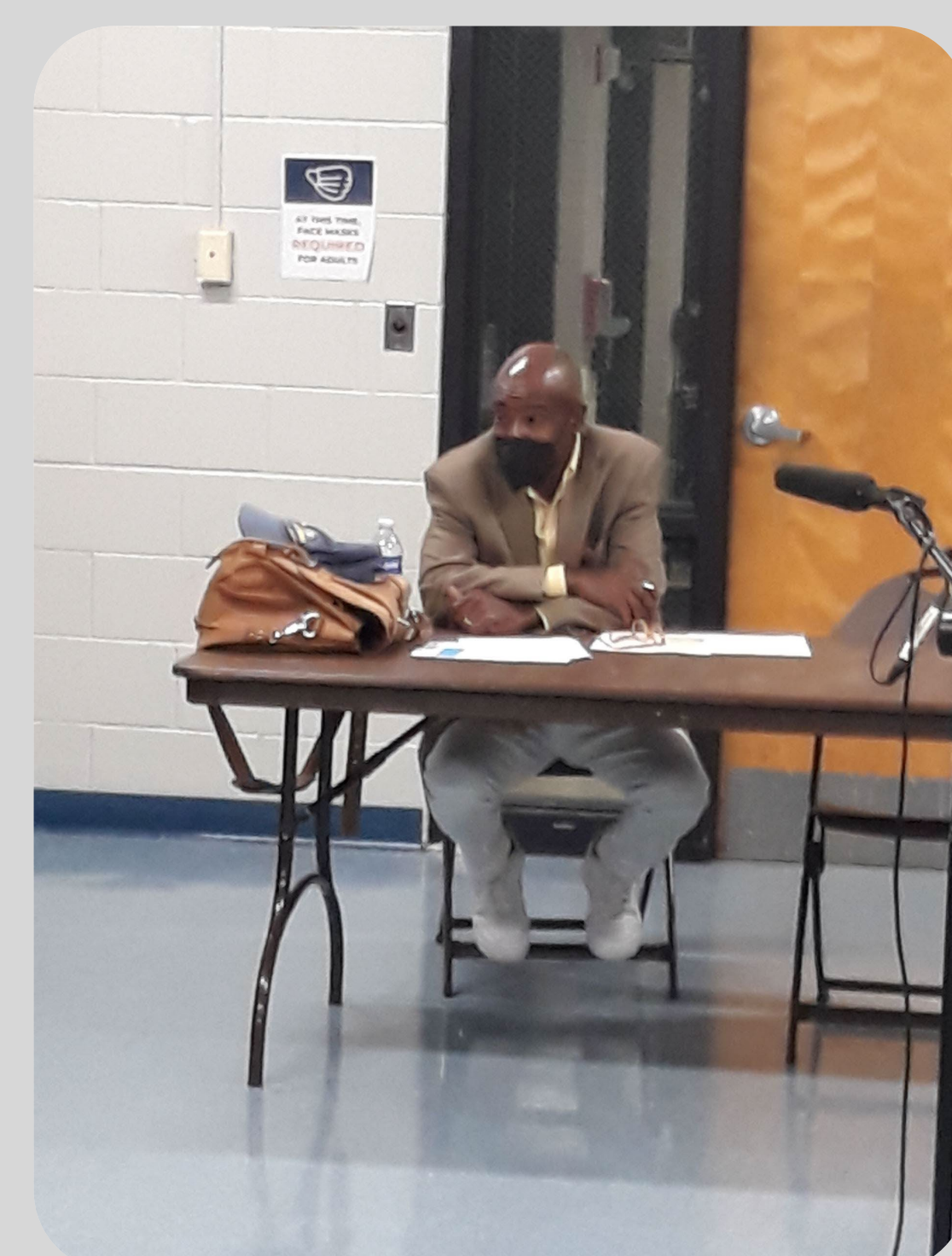
*"You've got to be the one that's going to be able to maneuver through the plethora of information that's out there to find out what works for you."* [PCA Survivor]

*"The frustration of feeling like you're talking to a brick wall. You try to get him to go to the doctor, he won't go... When they finally go to the doctor, it's a tad bit too late."* [Survivor's Spouse]



## Focus Group Reoccurring Themes

Theme	Description
Alternative treatments	Complimentary treatments and medications recommended to or used by survivors
Stage/Biopsy	Biopsy to determine cancer or stage
Causes of PCA	Possible causes of PCA
Clinical definitions	Knowledge of and where to get definitions
Effect on Daily Activities	The effect of treatment/PCA on work or other daily activities
Efficacy of Treatment	How well the treatment worked
Financial Aspects	Financial aspects such as cost of treatment, insurance issues...
Prostate Cancer	When you hear prostate cancer, what comes to mind?
Family History	Other men in family that were diagnosed with PCA
Influence	Who influenced treatment decisions?
Life Expectancy	When you were diagnosed, did you have questions about life expectancy?
Prevention	Measures to prevent PCA.
Prostate Cancer Testing	Ways to test for Prostate Cancer
PSA testing	Having PSA tests
Physician Communication	Perceived relationship with physician who treated the PCA
Sources of Information	Sources of information regarding PCA, treatments...
Support	Emotional or mental health support.
Treatment	Any mention of treatment recommended
- Decision regarding Treatment	What or who influenced decision regarding treatment
- Length of Treatment	How long will the treatment take?
- Side effects	Treatment side effects
Spouse want to know	What the spouse wanted to know about her husband's diagnosis.



*The cost of the treatment that I had selected was outside of the insurance program because they considered it experimental.* [PCA Survivor]

*"And I'd like to stress to them that [impotence] can be treated in 100% patients. Doesn't mean that we're going to return 100% of patients back to a normal sex life, but we can treat it and we can return most of them back to a sex life with therapy."* [Health Care Provider]

*"My grandfather took all the home remedies, and they worked for a minute, but then when they stopped working and he had to go to the doctor, the doctor told him he got here too late."* [PCA Survivor]

*"I don't think that I ever saw anything when I was researching that dealt with emotional or mental health conditioning, when it comes to cancer."* [PCA Survivor]

## Conclusion

The purpose of the focus groups was to determine the most important questions that African American men want to know regarding their diagnosis and treatment options for prostate cancer.

- What are the causes of prostate cancer?
- What are the different tests to diagnose prostate cancer?
- When should I get tested?
- What do "stages" mean?
- What is the life expectancy for prostate cancer?
- Can prostate cancer be prevented?
- What are the different treatments for prostate cancer?
- What are the side effects of each treatment?
- Are there natural or alternative treatments for prostate cancer?
- Should you get a second opinion regarding treatment?
- What are some of the expectations after treatment?
- What can be done for those men who were left impotent after treatment?

These results as well as future focus groups will help us design and develop an artificial intelligent conversational PCA treatment decision aid that is literacy and culturally appropriate for AA men.

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