

**Supplementary Data  
CaPCaS Interview Guide**

## INTERVIEW GUIDE

Thank you so much for agreeing to participate in our study about prostate cancer care and survivorship. For this interview I will be using an interview guide that provides the questions to be covered. These are not yes/no or short answer questions but are designed to capture your experience with prostate cancer. I will be audio and/or video recording your interview. We have chosen a quiet location for the interview. If there are any disruptions, I will stop the recording and resume when things are quiet again. If at any time you need to take a break, please let me know and I will stop the recording. [Plan for regular breaks as needed or desired.] Do you have any questions or concerns before we begin? [Answer any questions or address concerns before recording begins.]

### 1. Background Questions

- 1.1. Please tell me a little bit about yourself.
- 1.2. Now please tell me about your family. [Prompt: Tell me about your significant other(s).]
- 1.3. How do you identify yourself? [Prompt with: Do you consider yourself American, African American, Caribbean American, or African?] NOTE: They will likely respond with a more specific cultural identity, rather than just "Caribbean American" or "African", such as "Jamaican-American" or "Ghanaian-American."
- 1.4. How do people in your cultural or your ethnic group [*can substitute the name cultural group*] perceive or think about prostate cancer? [Prompts for what group makes sense e.g. family, community, or tribe].
  - 1.4.1. How are your perceptions or thoughts the same as them? [Pause and wait for response to first question before asking next question.] How are they different than them?
  - 1.4.2. How open are they to discussing cancer in general, and prostate cancer specifically?
- 1.5. Where did you first learn about prostate cancer? Who or where did you learn it from?
  - 1.5.1. After you first learned about prostate cancer, did you later gain more information about it? From whom or where did you get it?
- 1.6. Who do you consider to be your primary caregiver(s), that is the person/people who would help you if you needed assistance or would help you make decisions about your health care?
- 1.7. Who is/are your primary care provider(s), for examples doctors or physicians?

### 2. Screening & Diagnosis History

This set of questions will focus on your personal story of your diagnosis, [Including feelings, emotions, reactions, and/or regrets; understanding of the disease, prognosis and treatment options; level of personal/family/physician involvement in diagnosis;]

- 2.1. General question: Please tell me about your diagnosis of prostate cancer.
- 2.1.1. How were you diagnosed? [Prompt: How did you get screened for prostate cancer? ]
  - 2.1.2. What provider(s) gave you your diagnosis?
  - 2.1.3. Who else was with you during your diagnosis?
  - 2.1.4. What was the first thing that came to your mind when you were diagnosed with prostate cancer?
  - 2.1.5. What was your reaction to your diagnosis at that time? [Prompt for feelings, emotions]
  - 2.1.6. How did your relationship with your provider affect your reaction to your diagnosis?
  - 2.1.7. How did your relationship with your provider change after your diagnosis (if at all)?
  - 2.1.8. What was your experience after you were diagnosed with prostate cancer?
  - 2.1.9. What was your later reaction after you were diagnosed with prostate cancer?
  - 2.1.10. How did your access to healthcare affect your diagnosis/prognosis/treatment options?

### 3. Treatment

This set of questions will focus on your process of treatment decision making after your diagnosis. [Including personal/family/physician involvement in treatment decision, types of treatment including non-medical treatments, understanding of treatment and side effects, decisional regrets (if any) about treatment.]

- 3.1. Please tell me about your treatment decision making process after your diagnosis.
- 3.2. Which providers did you see when considering your treatment decision? Prompts:
  - 3.2.1. What were the specialties of the providers?
  - 3.2.2. Describe any referrals your health care providers made to other providers?
  - 3.2.3. Did you discuss alternative treatments (e.g. products, procedures, or activities **instead of** standard medical treatment from urologists, surgeons, radiologists or oncologists) with any of your health care providers? Describe any treatments that were discussed?
  - 3.2.4. Did you discuss complementary treatments (e.g. products, procedures, or activities **in addition to** standard medical treatment from urologists, surgeons, radiologists or oncologists) with any of your health care providers? Describe any treatments that were discussed.
  - 3.2.5. Describe any complementary medicine treatments you took?
  - 3.2.6. Describe any alternative medicine treatments you took?
- 3.3. What prostate cancer treatment(s) did you choose?
- 3.4. What was your level of involvement in choosing your treatment?
- 3.5. What was the level of involvement of your family or significant other(s) in choosing your treatment?
- 3.6. Who did you talk to prior to making your treatment decision? How did that person help you (or not help you) make your decision?
- 3.7. Describe the possible treatment options your provider(s) discussed with you. Prompts:
  - 3.7.1. Was surgery one of the treatment options discussed with you?
  - 3.7.2. Was radiation one of the treatment options discussed with you?
    - 3.7.3. Was watchful waiting/active surveillance one of the treatment options offered to you?
    - 3.7.4. How were the risks and benefits of the treatment options explained to you prior to your making the treatment decision?
  - 3.7.5. Describe your level of satisfaction with the information provided to you prior to your treatment decision.
- 3.8. What was your expectation for the treatment by your provider(s)?
- 3.9. How did the provider(s) meet or not meet your expectation for the treatment?
- 3.10. What was your expectation for the service provided by your provider(s)?
- 3.11. How did the provider(s) meet or not meet your expectation for service?
- 3.12. If you could change anything, what would you change/do differently about:
  - 3.12.1. your treatment experience?
  - 3.12.2. provider?
  - 3.12.3. the process of care?
  - 3.12.4. involvement of others in your care?
- 3.13. Describe any regrets about the decision(s) that you made about your treatment?

### 4. Prevention

This set of questions will focus on your understanding and practices of healthy behaviors prior to and after your diagnosis. [Including level of personal/family/physician involvement in prevention.]

- 4.1.1. What did you know about prostate cancer prior to your prostate cancer diagnosis?
  - 4.1.2. What information did you have about prostate cancer?
  - 4.1.3. Where did you get your information about prostate cancer?

- 4.1.4. What did you know about preventing prostate cancer?
  - 4.1.5. What steps did you take to reduce your risk of developing prostate cancer?
  - 4.1.6. What relationship did you have with your primary care provider?
  - 4.1.7. How did your relationship with your primary care provider affect your prevention behavior?
  - 4.1.8. What are the different ways that you used to prevent prostate cancer, including alternative/complimentary ways (e.g. diet, exercise)?
  - 4.1.9. What were your beliefs about preventing prostate cancer before your diagnosis?
  - 4.1.10. What was your level of access to your health care before your diagnosis?
- 4.2. After your prostate cancer diagnosis:
- 4.2.1. What changed with respect to your health and prevention behaviors?
  - 4.2.2. Where do you now get your information about prostate cancer?
  - 4.2.3. What do you now understand about preventing prostate cancer?
  - 4.2.4. What are you now doing about cancer prevention that is different from what you were doing before your diagnosis, if anything?
  - 4.2.5. How has your relationship changed with your primary care provider since your diagnosis?
  - 4.2.6. How can the relationship with your primary care provider be enhanced?
  - 4.2.7. What do you think should be the ideal relationship with your primary care provider provider?
  - 4.2.8. What are the different ways that you now prevent prostate cancer (including alternative/complimentary ways)? What has changed since your diagnosis?
  - 4.2.9. What are now your beliefs about preventing prostate cancer? What has changed since your diagnosis?
  - 4.2.10. How do you now access healthcare? What has changed since your diagnosis?

## 5. Detection Questions

This set of questions will focus on your understanding of screening for prostate cancer. [Including understanding prior to diagnosis, risks and benefits of screening practices prior to diagnosis, current thoughts about screening, current screening practices, level of personal/family/physician involvement in detection].

- 5.1. Prior to your prostate cancer diagnosis:
- 5.1.1. What did prostate cancer mean to you?
  - 5.1.2. What did you know about prostate cancer screening?
  - 5.1.3. What did you think caused prostate cancer?
  - 5.1.4. How did you feel about prostate cancer screening?
  - 5.1.5. What did you think were the benefits of prostate cancer screening?
  - 5.1.6. What did you think were the risks associated with prostate cancer screening?
  - 5.1.7. What were you doing with respect to prostate cancer screening?
  - 5.1.8. What was the advice your doctor gave you about prostate cancer screening?
  - 5.1.9. How did your significant other(s)/family feel about prostate cancer screening?
  - 5.1.10. What led you to your first screening?
  - 5.1.11. How did your relationship with your provider affect your screening behavior?
  - 5.1.12. Where did you usually get your screening for prostate cancer (setting)?
  - 5.1.13. How comfortable were you where you got screened?
  - 5.1.14. What settings were most comfortable to you for screening?
  - 5.1.15. How was your experience in getting screened at these settings?
  - 5.1.16. What was your lifestyle like in terms of nutritional intake, physical activity, sun exposure, tobacco and alcohol use?

5.2. After your prostate cancer diagnosis:

- 5.2.1. What does prostate cancer mean to you now?

- 5.2.2. What do you now know about prostate cancer that is different from what you knew before your diagnosis?
- 5.2.3. What do you now think causes prostate cancer?
- 5.2.4. How do you now feel about prostate cancer screening?
- 5.2.5. What do you now think are the benefits of prostate cancer screening?
- 5.2.6. What do you now think are the risks associated with prostate cancer screening?
- 5.2.7. What do you now do with respect to prostate cancer screening?
- 5.2.8. What is now the advice of your doctor about prostate cancer screening?
- 5.2.9. How does your significant other/family now feel about prostate cancer screening?
- 5.2.10. What is now your lifestyle like in terms of nutritional intake, physical activity, sun exposure, tobacco and alcohol use?

## 6. Survivorship

This set of questions will focus on your survivorship of prostate cancer [Including understanding of and comfort with uncertainty with prostate cancer, understanding of prognosis, level of personal/family/physician involvement in survivorship, current support/services available for care, challenges/successes related to survivor care, trust in clinicians, experiences with health care and follow-up treatment, experiences with late effects of treatment and second cancers (if applicable), description of quality of life, dealing with recurrence (if applicable), challenges/successes dealing with aggressive disease (if applicable), and challenges/successes dealing with advanced prostate cancer (if applicable).]

### 6.1 How has prostate cancer affected your life?

- 6.2. What does prostate cancer survivorship mean to you?
- 6.3. Describe your original conversations, if any, with your loved ones about prostate cancer:
  - 6.3.1. Were you open with them about your diagnoses?
  - 6.3.2. How comfortable were you discussing all the facts that you knew or understood about your diagnoses?
  - 6.3.3. What made you feel comfortable or uncomfortable in your conversation with family and friends?
- 6.4. Were you provided with any type of resources that helped prepare you for your care after prostate cancer treatment?
- 6.5. What do you know about recent changes in recommendations for prostate cancer screening? What is your reaction to these changes?
- 6.6. What are you currently doing, if anything, about your care after prostate cancer treatment (survivorship care)?
- 6.7. What is the level of your family involvement in your care after prostate cancer treatment (survivorship care)?
- 6.8. What is the level of your physician involvement in your care after prostate cancer treatment (survivorship care)?
- 6.9. What current support or services are available for you survivorship care?
- 6.10. What challenges have you had after your prostate cancer treatment (survivorship care)?  
Probing questions:

- 6.10.1. quality of life?
- 6.10.2. dealing with recurrence (if applicable)?
- 6.10.3. dealing with aggressive disease (if applicable)?
- 6.10.4. dealing with advanced prostate cancer (if applicable)?
- 6.10.5. experiences with late effects of treatment and second cancers (if applicable)?
- 6.11. What successes have you had after your prostate cancer treatment (survivorship care)?
- 6.12. What are currently your experiences with your health care and follow-up treatment?

## 7. Acculturation:

- 7.1 Tell me about the place where you were born and [for those born outside the US] how you came to live in the United States?
- 7.2 How would you describe your cultural identity?
- 7.3 How would you describe your religious beliefs and values? [Prompts: Do you practice a religion? If "YES", what religion do you practice? Do you attend a service? If "YES", then ask, tell me about the ethnic composition (or "ethnicity") of your congregation.]
- 7.4. Do you speak a language in addition to English? (*This can include Creole or Patios*)
  - 7.4.1. If "YES", then ask, what language do you speak at home? Prompt: If they speak more than one, ask which language do you mostly speak at home?
- 7.5 Are you employed outside the home?
  - 7.5.1. If yes, tell me about your work.
  - 7.5.2. Tell me about the ethnic composition (or "ethnicity") of the people you work with?
- 7.6. Tell me about your friends. [Prompt: Where are your friends from?]
- 7.7. Tell me about your diet?
  - 7.7.1. (If not American born,) is your food mostly from your home country a mix with American food, or mostly American food?
- 7.8. What do you do for entertainment? [Prompt: *This can include sports, music, or community events.*]
  - 7.8.1. Who do you go with?
  - 7.8.2. What kind of music do you listen to? [*Prompts would include questions to understand the cultural roots of the music.*]
  - 7.8.3. What kind of sports do you like? (*If they answer "football" clarify whether they are referring to American football or soccer.*)
  - 7.8.4. Who do you attend or watch sports events with?
- 7.9. For the foreign-born black men: obtain information on age immigrated to the US, duration of residence in the US, parental nativity status.

## 8. Advocacy

- 8.1. How would you describe your willingness to discuss your problems with other people? (Do you consider yourself to be an open person?)
- 8.2. Did anyone outside of your medical providers advocate to you about prostate cancer during your experience?
  - a. What kind of information did they share with you? (general information, importance of early detection, treatment options, general support during a hard time, someone who had been through a similar situation)
- 8.3. Do you think advocacy is an important part of the experience of prostate cancer? Why or why not?
- 8.4. Would you like to become a prostate cancer advocate for others in the future?
  - a. What skills and abilities do you have that would make you a good advocate?
  - b. What skills and abilities do you think you would have to improve to become an advocate?
  - c. What would help you reach that goal to advocate?
- 8.5. Would you be interested in being a part of an advocacy training program?