

# Overcoming Barriers in Conducting a Transatlantic Prostate Cancer Familial Study in Africa: Best Practice from the CaPTC Cohort Study

Iya E. Bassey<sup>\*1,2</sup>, Theophilus I. Ugbem<sup>1,2</sup>, Uwem O. Akpan<sup>1,2</sup>, Stanley O. Anyanwu<sup>1,2</sup>, Enakirerhi E. Glen<sup>1,2</sup>, Rebecca M. Gali<sup>1,3</sup>, Catherine A. Oladoyinbo<sup>1,4</sup>, Abidemi Omonisi<sup>1,5</sup>, Getachew Dagne<sup>1,6</sup>, Ernest T. Kaninjing<sup>1,8</sup>, Nissa A. Askins<sup>1,7</sup>, Motolani E. Ogunsanya<sup>1,9</sup>, Mohammed Faruk<sup>1,10</sup>, Ademola A. Idowu<sup>1,11</sup>,  
<sup>1</sup>CaPTC investigators, Folakemi T. Odedina<sup>1,7</sup>

<sup>1</sup>Prostate Cancer Transatlantic Consortium <sup>2</sup>University of Calabar Calabar, Nigeria; <sup>3</sup>University of Maiduguri, Maiduguri, Nigeria; <sup>4</sup>Federal University of Agriculture, Abeokuta, Nigeria; <sup>5</sup>Ekiti State University, Nigeria; <sup>6</sup>University of South Florida, Florida, USA; <sup>7</sup>University of Florida, Florida, USA; <sup>8</sup>Georgia & State University, Milledgeville, USA; <sup>9</sup>University of Oklahoma Health Sciences Center, Oklahoma, USA; <sup>10</sup>Ahmadu Bello University, Zaria, Nigeria; <sup>11</sup>Ekiti State University Teaching Hospital, Ado-Ekiti, Nigeria

\*Corresponding author: Iya Eze Bassey, email: [iyantui@yahoo.com](mailto:iyantui@yahoo.com)

## ABSTRACT

Conducting prostate cancer research, especially prospective data collection in Africa, has numerous challenges. Some of the difficulties stem from socio-cultural factors that consider sensitive topics about men's health as taboo. Our primary aim was to determine how to overcome barriers in conducting a transatlantic prostate cancer familial study in African males. Key research personnel of the *CaPTC Transatlantic Prostate Cancer Familial Project* were surveyed about their experiences in implementing the study. A mixed-method approach was used for the study analysis and data interpretation. The quantitative data from the survey was analyzed using SPSS version 18 while the qualitative data was analysed based on the principles of grounded theory for emerging themes. A total of 15 key study personnel responded to the survey. About 73% of the respondents reported that the participants requested a home or office visit rather than visit a data collection center. Eighty percent (80%) of the respondents reported that the participants had no preference for interviewer gender. The majority (80%) of the interviewers agreed that answers to questions about participants' sexuality were most challenging to obtain, but with an in-depth explanation of the importance of the study and assurance of privacy, the answers were obtained. The best practice for engaging the community for research include community mobilization through sensitization visits and one-on-one talks, use of community 'gatekeepers', introduction by relatives, assurance of privacy of health data obtained, the use of incentives and a promise to give feedback on the results of the study both on a personal and community level.

**KEYWORDS:** Prostate cancer, community-engagement research, black men, Nigerian men.

**Citation:** Bassey, et al. (2019) Overcoming Barriers in Conducting a Transatlantic Prostate Cancer Familial Study in Africa: Best Practice from the CaPTC Cohort Study. *Cancer Health Disparities* 4: e1-9. doi:10.9777/chd.2019.1001

## INTRODUCTION

In a typical African society, discussion of men's sexual health is not a common practice as most men feel very uncomfortable sharing sexual experiences with researchers. This may be attributed to the need to maintain social status, family respect, spiritual integrity and other cultural factors that men consider sensitive topics about men's health as taboo (Olapade-Olaopa et al., 2014). This, therefore, poses a significant challenge to conducting research on African men's sexual and prostate health.

Prostate cancer research in Africa is growing and has become multifaceted because it has become the number one cancer in men with increasing incidence and morbidity in Black men of African ancestry (Akinremi et al., 2011). Patients often present at a late stage with complications and an earlier age compared to several other ethnic groups (Akinremi et al., 2014). There are several unknowns about prostate cancer risk factors that are specific to Black Africans. Although some similarities have been documented between native African and United States (US) African-American men, there are also significant differences (Odedina et al., 2006). Still, there is a dearth of research data in Africa on prostate cancer (Okuku et al., 2016). So it has, therefore, become imperative that comprehensive research on prevention, early diagnosis, identification of behavioral risk and predisposing factors to prostate cancer as well as health-seeking behaviors of the African men be carried out.

## THE CAPTC TRANSATLANTIC PROSTATE CANCER FAMILIAL COHORT PROJECT

In 2017, the Prostate Cancer Transatlantic Consortium (CaPTC), a US National Cancer

Institute (NCI)-supported consortium, implemented the *Transatlantic Prostate Cancer Familial Cohort Project*. This ongoing project focuses on studying 2,000 West African men. The primary objective of the project is to explore the contributions of behavioral, environmental, and genetic factors in the etiology of prostate cancer among men of West African origin.

The study design for the CaPTC West Africa Familial Cohort study was a cross-sectional prospective study design. Study participants were Black men of Nigerian or Cameroonian origin who lived in Nigeria, Cameroon, or the US. The inclusion criteria for the study were: men of West African origin regardless of a history of prostate cancer; between 35 and 70 years old; and men who provided consent to complete the study survey and provided saliva samples. Using flyers, the participants were recruited in different parts of the selected countries at some settings which included clinics, and wide-ranging community settings such as town hall meetings, eateries, churches, mosques, as well as health events.

Before data collection, ethical clearance was obtained for each study site in Nigeria, Cameroon and the US. The coordinating center for the study was the University of Florida in USA. Participating institutions are Ahmadu Bello University, University of Calabar, Covenant University, Ekiti State University, Federal University of Agriculture Abeokuta, Lagos State University Teaching Hospital, University of Maiduguri, National Hospital Abuja, Ace Medicare Clinics Limited, University of Ilorin, and Lagos University Teaching Hospital in Nigeria. The participating institution in Cameroon was the University Hospital Center Yaounde in Cameroun. Written informed consent was obtained from all the eligible participants before

they were allowed to participate in the study. The participants completed the survey instrument by self-administration or were assisted by a research assistant using the study instrument. English, French or West Africa Pidgin English were the languages used to administer the survey. All participants were given an incentive of either a T-shirt or a monetary incentive tailored to the study sites.

Implementing this study at multiples sites, especially in West Africa, required overcoming several challenges. The specific aim of this study was to explore these challenges and determine best practices on how to overcome barriers in conducting a transatlantic prostate cancer familial study in West Africa.

## METHODOLOGY

This project focused on developing best practices for conducting field research for prostate cancer in Africa. Thus, the study participants were the data collectors of the Transatlantic Prostate Cancer Familial Cohort project, including principal investigators, investigators, research coordinators and research assistants in Nigeria and Cameroon. A structured survey was developed by investigators to collect data from participants. The survey is provided in Appendix I. The items in the survey include: questions on sensitization visits and the methods used; the subjects preference for going to the data collection center for interviews or requesting for a personal visit; the average time it took to fill one questionnaire; participants preferences as pertained to interviewer gender; what questions the participants felt most uncomfortable answering; peculiar challenges the interviewers had while collecting data, how they overcame them, suggestions for best practices;

interviewers suggestions for the best way to engage your community for research; and the best ways to appropriately disseminate results back to participants.

The survey was administered on Qualtrics software. The link to the survey was sent to participants by email. The study data were analyzed using SPSS version 18. Descriptive analyses were used to summarize quantitative data. For the qualitative data, emerging themes were identified from the responses of participants.

## RESULTS

A total of 15 key personnel participated in the study. They were from Ahmadu Bello University, University of Calabar, Covenant University, Ekiti State University, Federal University of Agriculture Abeokuta, University of Maiduguri and University of Ilorin.

## RESPONSES OF DATA COLLECTORS TO SURVEY QUESTIONS

About 73% percent of the data collectors had to carry out pre-data collection sensitization visits. Seventy-three percent of the interviewers also reported that participants requested a home or office visit rather than visit a data collection center. The questionnaire required an average of two hours of personal interview. However, the respondents declared that participant incentives were well worth it. About 80% of the participants had no preference for interviewer gender. Results showed that 80% of the interviewers agreed that answers to questions about participants' sexuality were most difficult to obtain, but with an in-depth explanation of the importance of the study and assurance of privacy, the answers were obtained. About 46% of the participants requested that their

results be typed and given to them personally, 21% requested results be sent as to them as text messages, while 26% requested general results of the study be made available to them in the form of booklets, flyers and orally in town hall meetings. The results are summarized in Table 1.

Table 2 shows the challenges faced while collecting data and successful approaches used by the data collectors to overcome them.

### *Complaints about the bulkiness of the questionnaire.*

This was the most frequent challenge reported by the data collectors (n = 6). Below are typical responses made by the respondents:

“The clients complained of the time taken to respond to the questionnaires.”

“There was difficulty in filling the questionnaire because of the volume.”

This challenge was overcome by initial education about and an in-depth explanation of the importance of the study. Also, the use of incentives and assurance that the results will be communicated back to them both on a personal and community level also helped to overcome this challenge.

### *Time taken to fill questionnaires*

This was another challenge reported by the data collectors (n = 4). This is exemplified by the statements below:

“The clients complained of the time taken to respond to the questionnaires.”

“Finding a time that works best for the participant given that it took about 2.5 hours on average to complete the survey”.

Some of the measures taken to tackle this challenge included making the data collector's schedule more flexible to allow for the convenience of the participants and sometimes the session had to be divided into 2 timeframes.

### *Complaints about the personal nature of questions in the questionnaire.*

The personal nature of questions in the questionnaire posed a challenge to some data collectors (n = 2) as exemplified by these statements:

“They also felt the questions were a bit too personal.”

“The clients complained and said some of the questions are irrelevant.”

Assurance of privacy of their health information as well as an emphasis on the importance of the study were some of the ways used to tackle this problem.

### *Lack of knowledge of ancestral medical history*

One of the respondents complain about the participants “Lack of knowledge of ancestral medical history” as a setback, which resulted in longer time being spent.

## SUGGESTIONS FOR PRESENTATION OF RESULTS OBTAINED FROM THE STUDY

Several of the respondents had different suggestions which included giving personal feedback either as typed reports or text messages delivered to them personally and confidentially by the data collectors as exemplified by these comments.

“The result should be disseminated back personally to the participants in the presence of a health professional.”

“Phone numbers of the respondents through each respondent data collector.”

“Ideally, the results should be typed and formally presented and reviewed with the clients by a medical expert, who can interpret the findings.”

However, some also suggested that public feedback be given as booklets, flyers or oral

communications through the community gatekeeper or town hall meetings as supported by these sample statements

“Go back to those communities where you collected data, work with the community leader or gatekeeper who helped you gain access to participants and schedule a forum in which you can disseminate the outcome. Another alternative is to provide publication of the study to the community at large”.

Variable	Response	N (%)	P-value
Did you carry out sensitization visits?	Yes	11(73.3)	0.012
	No	4(26.6)	
Participants choice of venue for data collection	Data collection center	4(26.6)	0.012
	Home or office visit	11(73.3)	
Length of time for filling the questionnaire	≤2hrs	12(80)	0.001
	>2Hrs	3(20)	
Did participants have a preference or request for male interviewers?	Yes	3(20)	0.001
	No	12(80)	
What questions did the participants find most difficult to answer in the questionnaire?	Questions bordering on sexuality and history of sexually transmitted diseases	14(93.3)	0.0001
	No response	1(6.7)	
What are your suggestions for presentation of results obtained from the study?	Typed and personally delivered	7 (46.7)	
	To be sent as text messages	3 (20)	
	Results of the study should be available as booklets, flyers etc.	4 (26)	

Challenges (n)	Successful approaches to overcome them
Complaints about the bulkiness of the questionnaire (6)	Initial education about and an in-depth explanation of the importance of the study Use of incentives. Assurance that the results will be communicated back to them both on a personal and community level.
Time taken to fill questionnaires (4)	The flexibility of the data collector’s schedule to allow for the convenience of the participants Sometimes the session had to be divided into 2 timeframes

Complaints about the personal nature of questions in the questionnaire (2)	Assurance of privacy of their health information.
Lack of knowledge of ancestral medical history (1)	Exercising patience while waiting for them to remember or confirm with other relatives

## DISCUSSION

To overcome the initial resistance to recruitment and educate the participants about the benefits of the study, pre-data collection sensitization visits are necessary. This involves various approaches including one-on-one visits, rallies, group talks, distribution of flyers, and use of community 'gatekeepers' as well as referrals by close relatives trusted by the participants. Neglecting to do this may result in apathy by prospective participants towards the study. This approach was found very useful by Woods et al. in their study. They noted that 53.1% of the participants in their study were recruited in community settings, whereas 46.9% were recruited in healthcare settings. They also reported that one-on-one recruitment resulted in an immediate 100% increase in client contact and enrollment (Wood et al., 2004). A study by Enaworu and Khutan (2016) also stressed the importance of involvement of family members and friends as a contributing factor to them seeking medical advice; as informal support systems may be a critical part in the decision-making process of men (Jones et al. 2010). It is therefore important for researchers to understand the type of support networks that may influence African men's decision to participate in this type of research.

That most participants requested a home or office visit rather than visit a data collection center may have been due to the participants need for privacy or a need to avoid being labeled and probably stigmatized for identifying with a study involving the prostate. This finding is in concordance with findings by Barber et al., who studied the differences between

black and white men regarding participation in prostate cancer screening and found out that black men were twice as likely to choose a private appointment over mass screening. They also observed that black men tended to participate in preventive activities when they received personal attention (Barber et al., 1998).

The longer duration for a personal interview (about twice the time envisaged) actually constituted a major barrier during the study, and this may have been due to the time taken to explain the questions in the booklet as well as convincing the participants about the need to answer questions they felt were too personal. It was also observed that some of the participants had difficulties remembering ancestral medical history. Therefore, for future studies with similar aims to succeed, the data collectors might consider being more flexible about the place and time of data collection and personal interviews. The use of participant incentives may also encourage participation as participants in the study declared that incentives, though not the primary motivating factor, were worth the time taken for the personal interview. Woods et al., (2004) observed that changing to a more flexible schedule and the use of incentives resulted in a dramatic increase in subsequent enrollment. This was because it showed the participants that the researchers valued their input and time.

Contrary to what has been reported in several health-related studies (Hinchliff et al. 2004; Witty et al., 2014; Hajizadeh et al., 2015; Knight et al., 2017), most of the participants had no preference for

interviewer gender. This may suggest progressiveness in how men view the role of female personnel in healthcare issues relating to men's sexual health. The findings in our study are in concordance with those of another study in Botswana by Letshwenyo-Maruatona, (2017) who reported that gender is of minor importance compared with other characteristics such as competence and confidentiality.

The difficulty in obtaining answers to questions about participants' sexuality and sexual health is a confirmation that discussions of African men's sexuality or sexual history are not common. This may be attributed to the need to maintain social status, family respect, spiritual integrity, and cultural factors that consider sensitive topics about men's health as taboo (Olapade-Olaopa et al., 2014).

From the observations made in the study by the data collectors, it would seem that getting the results back to the participants personally would be a more effective tool in recruitment rather than giving general feedback.

## CONCLUSION

The Transatlantic Prostate Cancer Familial project study survey questionnaire is a very workable tool that has a high acceptance rate among participants. The best practice for engaging the community for research include community mobilization through sensitization visits and one-on-one talks, use of community 'gatekeepers', introduction by relatives, assurance of privacy of health data obtained, the use of incentives, and a promise to give feedback on the results of the study both on a personal and community level.

## Acknowledgments

Funding support for this project was provided by the Prostate Cancer Transatlantic Consortium (CaPTC).

## Conflict of interest

The authors declare that no competing or conflict of interests exist. The funders had no role in study design, writing of the manuscript, or decision to publish.

## Authors' contributions

Dr. Folakemi T. Odedina provided content and reviewed the final manuscript. Iya E. Bassey, Abidemi Omonisi, Theophilus I. Ugbem, Uwem O. Akpan, Stanley O. Anyanwu, Enakirerhi E. Glen, Catherine A. Oladoyinbo, Ernest T. Kaninjing Mohammed Faruk, Ademola A. Idowu wrote the initial draft. Getachew Dagne and Nissa A. Askins did the statistical data analysis. Ernest T. Kaninjing and Rebecca M. Gali reviewed the initial draft. Motolani E. Ogunsanya and Iya E, Bassey reviewed the initial draft and final manuscript. CaPTC investigators provided the data used in the study

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## SUPPLEMENTARY DATA

### APPENDIX I

Questionnaire for Overcoming Barriers in Conducting a Transatlantic Prostate Cancer Familial Study in Africa: Best Practice from the CaPTC Cohort Study: To be answered by ALL Data collectors and Principal investigators

1. Did you go on sensitization visits? Yes or no
  - a. What places did you go to on sensitization visits
  - b. Did you
    - i. hold group talks
    - ii. do a one-on-one sensitization
    - iii. a combination of both?
  - c. What factor(s) influenced the places visited for sensitization and recruitment of clients
  - d. From your own point of view which of the recruitment method gave highest turnout
2. Did the subjects prefer to come to the collection centre or did you have to go to their offices, homes or places of worship?
3. How many people did you invite to your study
  - a. How many refused outright to participate
  - b. How many declined to participate after looking at the questionnaire
    - i. What were their reasons for declining
      - a. Lost interest
      - b. Questions are too personal
      - c. Questionnaire is time consuming
      - d. Other reasons
  - c. How many have you fully recruited
4. What is the average time it took to fill one questionnaire?
5. Did they have any gender preferences for interviewers?
  - They preferred male interviewers
  - They preferred female interviewers
  - They had no gender preferences
6. What questions did they feel most uncomfortable answering? Or what questions did they decline to answer most?
7. What peculiar challenges did you have while collecting data
  - a. how did you overcome those challenges?
8. What are your suggestions for best practices?
9. What are your suggestions for the best way to engage your community for research?
10. What do you think is/are the best ways to appropriately disseminate results back to participants