RESEARCH

Standardized Global Behavioral and Epidemiological Measures for Prostate Cancer Studies in Black Men

Folakemi T. Odedina,[1§+*] Camille Ragin,[2§++] Damali Martin,[3] Richard P. Moser, [3] JoAnn S. Oliver,[4++] Alicia C. McDonald,[5++] Elise L. Rice,[3] Jennifer Nguyen,[6+] Frank Chinegwundoh,[7+] Belinda Morrison Blidgen,[8++]Ernest T. Kaninjing,[9+] Mohamed Jalloh,[10] R. Renee Reams[11+]

[1]Department of Pharmacotherapy and Translational Research, University of Florida, Orlando, Florida, USA; [2]Cancer Prevention and Control program, Fox Chase Cancer Center, Philadelphia, PA, 19111, USA; [3]Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD 20850; [4]The University of Alabama, Capstone College of Nursing, Box 870358, Tuscaloosa, AL 35487, USA; [5]Department of Public Health Sciences, Pennsylvania State University College of Medicine, Hershey, PA 17033, USA; [6] College of Pharmacy, Mercer University 3001 Mercer University Drive, Atlanta, GA 30341, USA; [7]Barts Health NHS Trust & Harley Street, London, UK; [8]Department of Surgery, University of the West Indies, Mona, Kingston 7, Jamaica; [9] School of Health and Human Performance, Georgia College, Campus Box 112, Milledgeville, GA 31061, USA; [10]Hopital General De Grand Yoff, Dakar Senegal; [11]College of Pharmacy and Pharmaceutical Sciences, Florida A&M University, Tallahassee, FL, USA;
[+]Member of Prostate Cancer Transatlantic Consortium (CaPTC)
[++]Member of African Caribbean Cancer Consortium (AC3)
[§] Both Dr. Folakemi Odedina and Dr. Camille Ragin are first authors.
*Corresponding author: Folakemi Odedina. Fodedina@cop.ufl.edu

ABSTRACT: Multicenter trans-national studies may be required to understand the complex causes of and solutions to prostate cancer disparities in Black men. In 2014, two cancer epidemiology consortia supported by the US National Cancer Institute (NCI), *the Prostate Cancer Transatlantic Consortium (CaPTC) and African-Caribbean Cancer Consortium (AC3),* formed a consortia alliance to address the disproportionate burden of prostate cancer in Black men. As part of the alliance, this global study focused on developing standardized and culturally tailored data elements and measures for prostate cancer research in these populations. The study objective was achieved by a Consensus Working Group using the NCI–Grid-Enable Measures (GEM) platform. The Consensus Working Group members were assigned to two Special Interest Groups to focus on behavioral and epidemiology topics. Based on crowd-sourcing methodology, the initial standardization decisions were made by each group using GEM. This was followed using nominal group technique to build consensus. Finally, a one-day consensus development conference was held to facilitate the input of the scientific community. The use of the GEM platform, nominal group technique and a consensus development conference resulted in agreement among stakeholders for a recommended set of measures that included 25 behavioral scales and 24 epidemiological scales. The measures developed in this process will facilitate data harmonization and data sharing for multiethnic studies of Black men globally and these measures can be used by other researchers in this area.

KEYWORDS: Prostate Cancer; Black Men, Behavioral Measures, Epidemiological Measures, Cancer Disparity

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INTRODUCTION

Globally, prostate cancer is the second most frequently diagnosed cancer in men and the fifth leading cause of cancer deaths among men (Ferlay et al., 2013). While little is known about prevention and risk reduction for prostate cancer, three risk factors have been long-established: age, family history and African descent (American Cancer Society, 2018). US Black men have been reported to have the highest incidence, highest mortality and lowest 5-year relative survival rates compared to other US racial/ethnic groups (American Cancer Society, 2018). The growing literature supporting the unequal burden of prostate cancer among men of African descent in Africa and the Caribbean underscores the significance of this public health issue (Akang, Aligbe, & Olisa, 1996; Ben-Shlomo et al., 2008; Chinegwundoh et al., 2006; Dawam, Rafindadi, & Kalayi, 2000; Eke & Sapira, 2002; Ekwere & Egbe, 2002; Jackson et al.,1980; Magoha, 1995; Mohammed, Alhassan, Edino, & Ochicha, 2003; Nwana, Mohammed, & Anjorin, 2005; Ogunbiyi & Shittu, 1999; Ogunbiyi, 2000; Oranusi, 2004; Osegbe, 1997; Udeh, 1981; Ukoli et al., 2003)

The multifactorial risk factors of prostate cancer disparity in men of African descent and the need for a unique approach to better understand and address this disease has resulted in many researchers opting for a team-science approach that is multilevel, collaborative, transdisciplinary, translational, and global. Facilitated by the United States (US) National Cancer Institute (NCI) Epidemiology & Genomics Research Program (EGRP), a number of cancer consortia have emerged to effectively address the environmental, lifestyle, and genetic risk factors underlying prostate (Burgio et al., 2013). Two independently led cancer consortia supported by the NCI/EGRP, the *Prostate Cancer Transatlantic Consortium (CaPTC; https://epi.grants.cancer.gov/captc)*, and *African-Caribbean Cancer Consortium (AC3; http://ac3online.org)* collaborated in 2014 to effectively address prostate cancer disparity among Black men.

The CaPTC was formed in 2005 to address the global disproportionate burden of prostate cancer among Black men. CaPTC members focus on studying Blacks who are connected by the Transatlantic Slave Trade, with the goal to explore and quantify the magnitude of prostate cancer morbidity and mortality variance. Additional goals of CaPTC includes the investigation of: genetic and environmental etiology of prostate cancer, using valid and reliable instruments and biomarkers; and the development of ethnically sensitive, targeted approaches that will contribute to the elimination of prostate cancer disparities. The AC3, formed in May 2006, investigates the viral, genetic, environmental, and lifestyle risk factors for cancer in populations of African descent populations in the US, Africa and the Caribbean. The primary aims of AC3 are to conduct multi-centered research studies within an international research network through collaboration, capacity building, and training. In addition, investigators in AC3 aim to translate the study findings to targeted interventions that will reduce the incidence and mortality of cancer in African descent populations.

To accelerate the pace of implementing population-based interdisciplinary research aimed at eliminating the disproportionate burden of prostate cancer in Black men globally, CaPTC and AC3 agreed to a consortia collaboration in 2014. A primary challenge for this large–scale research collaboration is the differences in study measures

employed by consortia investigators. These differences created the additional challenge of pooling of existing data to generate findings that will move the science forward. Thus, the primary goal of this study was to develop standardized global CaPTC-AC3 Behavioral and Epidemiological (CABE) constructs and measures that are culturally tailored for studying prostate cancer in Black men.

MATERIALS AND METHODS

The study objective was achieved by a Consensus Working Group comprising members of the CaPTC and AC3 (Table 1). In addition, an NCI Epidemiology and Genomic Research Program (EGRP) program director and two representatives from the NCI's Behavioral Research Program (BRP) provided their expertise on the Consensus working groups. The Consensus working groups achieved consensus using the NCI Grid-Enabled Measures (GEM) platform, nominal group technique, and a consensus-development conference. For this study, consensus was defined as the extent to which members of the Consensus working groups agree with each other on the appropriateness of the data collection tools and procedures.

Initial standardization decisions through GEM.

GEM is a dynamic, web-based collaborative tool used to gain consensus on the use of common measures for prospective research (Moser et al., 2011). This platform enables a variety of stakeholders to evaluate measures by providing qualitative and quantitative feedback through collaborative workspaces. GEM is a publicly-available resource (see: https://www.gem-measures.org/Public/Home.aspx). The ultimate goal is to achieve harmonized data that can be shared and analyzed. With the support of NCI's BRP's, CaPTC-AC3 virtual workspaces were set up for the behavioral and epidemiological consortia measures to foster standardization of study constructs and measures.

In April 2016, a series of web conferences was conducted to discuss and finalize the methodologies for the initial standardization through GEM, the nominal group technique and consensus development meetings. Web conferences were also used to train Consensus Working Group members on the use of GEM and the nominal group technique process. In addition, Consensus Working Group members were assigned to two Special Interest Groups (SIGs), behavioral SIG and epidemiology SIG. The SIGs were chaired by the CaPTC and AC3 principal investigators (see Table 1).

Table 1: Behavioral and Epidemiology Consensus Working Group.

Behavioral Special Interest Group (SIG)	Epidemiology Special Interest Group (SIG)
Folakemi T. Odedina, PhD (Moderator, CaPTC)	Camille Ragin, PhD (Moderator, AC3)
JoAnn Oliver, PhD (AC3)	Renee Reams, PhD (CaPTC)
Elsie Rice, PhD (NCI)	Damali Martin, PhD (NCI)
Catherine Oladoyinbo, PhD –(CaPTC)	Alicia McDonald, PhD (AC3)
	Mohammed Jalloh, MD (MADCaP)

Following the web conferencing, GEM was used for the initial standardization decisions based on crowd-sourcing methodology. First, the consortia principal investigators populated the GEM

consortia workspaces with their existing consortia study constructs and measures for prostate cancer behavioral and epidemiological constructs. Subsequently, the Consensus Working Group members worked in their respective SIGs to rate and provide critical feedback that drove initial consensus for the CABE constructs and measures. Consensus Working Group members met within their respective SIGs to review all CABE constructs and measures uploaded by the consortia; discussed supporting literature for the measures; conducted literature reviews for additional measures when necessary; and provided recommendations for consortia CABE constructs and measures for prostate cancer. Discussion boards in the GEM workspace and videoconferences were utilized for discussions and notes. The initial standardization was completed on October 2016.

Nominal group technique

Nominal group technique involves the use of expert panels to build consensus. We adapted the nominal group technique methodology proposed by Jones and Hunter (1995) for the second phase of consensus for the consortia CABE constructs and measures. All members of the Consensus Working Group met in person on Nov 8, 2016 prior to the *Science of Global Prostate Cancer Disparities in Black Men conference*, in Orlando, Florida, USA. Prior to the meeting, Consensus Working Group members provided pre-meeting rankings on the appropriateness of data elements for all the CABE constructs and measures on a ranking sheet using a scale ranging from 1 (inappropriate) to 9 (appropriate).

The nominal group meeting was used to forge consensus for the constructs and measures. For the measures, the Consensus Working Group strongly weighed the reliability and validity evidence of the measures as well as cultural relevance of the measures in African Americans (US Black men), Caribbean Black men, and African Black men. The following steps were employed to reach consensus:

1. Presentation of the median scores and ranges of pre-meeting data element ranking, which enabled Consensus Working Group members to assess their initial rankings relative to that of others. With the 9-point scale: scores of 1-3 represented a region where Consensus Working Group members felt that the data element/measurement scale was inappropriate for Black men, 4-6 represented an equivocal region, and 7-9 represented appropriate data element/measurement scale. We concluded that there was strict agreement if all members' ratings fall within one of these three regions.
2. Group discussion of data elements/measurement scales, including discussion of supporting literature.
3. Revision of data elements/measurement scales when necessary.
4. Re-ranking by Consensus Working Group members followed by data analyses to assess agreement.
5. Summary of re-rankings to assess degree of consensus. The process ended with an acceptable degree of consensus by Consensus Working Group members. The scorings were between 7 and 9, indicating strict agreement on the scoring.

After the nominal group meeting, the final consortia CABE constructs and measures were assembled for presentation to the open scientific community.

Consensus development meeting

The final phase of the consensus methodology was the consensus development meeting, which was held on November 11, 2016 during the *Science of Global Prostate Cancer Disparities in Black Men conference*. The consensus development meeting was open to conference participants to facilitate the input of the prostate cancer scientific community. The CABE constructs and measures were presented by members of the Consensus Working Group, followed by discussion, invited comments, and presentation of additional data from the public. Finally, there was a vote to adopt the CABE constructs and measures for the study of prostate cancer in Black men globally.

RESULTS

The goal of this project was to reach consensus for the CABE data elements and measures, which was achieved using the GEM platform, nominal group technique and face-to-face meetings for consensus development. The CABE measures focus on both behavioral and epidemiological measures, including demographic and risk factors impacting prostate cancer. The nominal group members deliberated intensely on items included in the CABE measures and made a decision to be more comprehensive in its approach with the inclusion of items that may impact prostate cancer, including co-morbidities and polypharmacy. It is expected that investigators will choose CABE items that are relevant for their research.

Standardized Global Behavioral Measures for Prostate in Black Men

The CaPTC-AC3 Consensus Working Group reached a consensus on and approved 25 behavioral constructs for the CABE measures (see Table 2). Of the 25 constructs, the measures for the following 15 constructs were based on existing generic instruments in the literature Acculturation (Klonoff & Landrine, 2000; Zane & Mak, 2003), Attitude toward screening (Fishbein & Ajzen, 1975), Cancer Fatalism (Powe, 1995a, 1995b; Powe & Finnie, 2003), Cues to Action (Hochbaum, 1958; Rosenstock, 1974a, 1974b), Health Literacy (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion (2010), National Action Plan to Improve Health Literacy. Washington, n.d.), Perceived Behavioral Control (Ajzen, 1985), Perceived Benefits (Hochbaum, 1958; Rosenstock, 1974a, 1974b), Perceived Health Status (Hochbaum, 1958; Rosenstock, 1974a, 1974b)Perceived Severity (Hochbaum, 1958; Rosenstock, 1974a, 1974b), Perceived Susceptibility (Hochbaum, 1958; Rosenstock, 1974a, 1974b), Subjective Norm (Fishbein & Ajzen, 1975), Shared Decision Making (Rimer, Briss, Zeller, Chan, & Woolf, 2004), Perceived Barriers, (Hochbaum, 1958; Rosenstock, 1974a, 1974b), Religiosity/Spirituality (Carver, Scheier, & Weintraub, 1989; Thoresen, 1998), and Temporal Orientation (Brown & Segal, 1996; Brown & Segal, 1997; Holman & Silver, 1998). It is important to note that these measures had been tailored for prostate cancer research and culturally tailored for Black men in prior CaPTC (Cobran et al., 2014; Kaninjing et al., 2017; Kumar, Yu, Akinremi, & Odedina, 2009; Morhason-Bello et al., 2013; Odedina et al., 2009; Odedina, Dagne, et al., 2011; Odedina, Scrivens, et al., 2011; Ogunsanya, Brown, Odedina, Barner, & Adedipe, 2017) and AC3 studies (Blackman, et al., 2017). Three of the 25 measures were originally developed by CaPTC - Prostate Cancer Information Seeking Behavior (Odedina, Scrivens., et al., 2011), Prostate Cancer Screening Behavior (Odedina, Scrivens, et al.,

2011), and Screening Controversy Scale (Odedina, Segal, Kimberlin, Lee, 2011); two were originally developed by AC3 - Prostate Medical Procedures (Blackman, et al., 2017; Jackson et al., 2010) and Trust of Health Care Providers (Blackman, et al., 2017); three were developed by both CaPTC and AC3 - Knowledge (Odedina, Scrivens, et al., 2011), Medical Care Access (Blackman, et al., 2017) and Prostate Cancer Health (Odedina, Dagne, et al., 2011); and two were new measures developed by the Consensus Working Group Behavioral SIG (Diversity of Residence and Patient-Provider Concordance). The two new measures were proposed by CaPTC and AC3 investigators based on two ongoing qualitative prostate cancer studies, which found two unique themes of racial concordance and socio-demographically diverse residence from interview transcripts.

Table 2. CaPTC-AC3-MADCaP Standardized Global Behavioral Measures for Prostate in Black Men.

Constructs	Description of Measures	Source
Acculturation	Cross-cultural psychology concept that "reflects the extent to which individuals (from a non-dominant culture) learn the values, behaviors, lifestyles, and language of the host (dominant) culture.	Adapted from Acculturation Construct by Zane and Mark (Zane & Mak, 2003) and further refined by the CWG.
Attitude Toward Screening	Positive or negative evaluations about prostate cancer screening.	Adapted from the Theory of Reasoned Action model (Fishbein & Ajzen, 1975) and further refined by the CWG.
Cancer Fatalism	Individual's belief that death is bound to happen when diagnosed with cancer, is a major barrier to cancer detection and control	Adapted from the Cancer Fatalism construct by(Powe & Finnie, 2003) and further refined by the CWG.
Cues to Action	Strategies to inform about and activate prostate cancer screening action.	Adapted from the (Hochbaum; United States. Public Health Service. Division of Special Health, 1958; Rosenstock, 1974a) and further refined by the CWG.
Diversity of Residence	Participants' perception of how diverse their residence is based on socio-demographic factors.	Developed by CaPTC (Odedina, Dagne, et al., 2011; Odedina, Scrivens, et al., 2011) and AC3 CWG for Behavioral Measures.
Health Literacy	The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.	Adapted from the National Action Plan to Improve Health (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2010). National Action Plan to Improve Health Literacy. Washington, n.d.)
Knowledge	Participants' understanding of prostate cancer disease, prevention and detection.	Adapted from CaPTC and AC3 measures (Odedina et al., 2014)
Medical Care Access	Access to medical care and medical care services received	Adapted from CaPTC and AC3 measures (Blackman et al., 2017)

Patient-Provider Concordance	Participants' perception of their similarity to their provider based on race, ethnicity, gender, and age.	Developed by CaPTC and AC3 CWG for Behavioral Measures.
Perceived Barriers	Belief about the potential negative aspects of a particular health action	Adapted from Health Belief Model construct (Hochbaum, 1958; Rosenstock, 1974a) and further refined by the CWG.
Perceived Behavioral Control	Confidence of participants' ability to screen for prostate cancer.	Adapted from Theory of Planned Behavior (Ajzen, 1985) and further refined by the CWG
Perceived Benefits	Belief about the potential positive aspects of prostate cancer screening.	Adapted from Health Belief Model construct (Hochbaum, 1958; Rosenstock, 1974b) and further refined by the CWG.
Perceived Health Status	Perception of overall health in terms of physical, emotional, psychological and social well being. Physical well-being is defined as the absence of disease or infirmity. Emotional well-being includes perceived life satisfaction, happiness, cheerfulness, peacefulness. Psychological well-being includes self-acceptance, personal growth including openness to new experiences, optimism, hopefulness, purpose in life, control of one's environment, spirituality, self-direction, and positive relationships. Social well-being includes social acceptance, beliefs in the potential of people and society as a whole, personal self-worth and usefulness to society, sense of community.	Adapted from Physical, Emotional, Psychological and Social well-being (CDC, 2013; Keyes, 1998; Ryff, 1989; Ryff & Keyes, 1995).
Perceived Severity	Belief about the seriousness of prostate cancer, or leaving it untreated and its consequences.	Adapted from Health Belief Model construct (Hochbaum, 1958; Rosenstock, 1974b) and further refined by the CWG.
Perceived Susceptibility	Belief about getting prostate cancer.	Adapted from Health Belief Model construct (Hochbaum, 1958; Rosenstock, 1974b) and further refined by the CWG.
Prostate Cancer Health	Perceived physical signs and symptoms of prostate cancer.	Adapted from CaPTC (Odedina et al., 2014) and AC3 measures (Blackman et al., 2017)
Prostate Cancer Information Seeking Behavior	Proactive information seeking about prostate cancer.	Adapted from CaPTC measure (Odedina et al., 2014)
Prostate Cancer Screening	Participants self-report on prostate cancer screening activities within the last five years, including the Prostate Specific Antigen (PSA) and Digital Rectal Examination (DRE) diagnostic tests.	Adapted from CaPTC measure (Odedina et al., 2014)

Prostate Cancer Subjective Norm	Perceived social pressure arising from one's perception	Adapted from Theory of Reasoned Action (Ajzen, 1991; Fishbein & Ajzen, 1975) and further refined by the CWG
Prostate Medical Procedures	Participant's recollection of diagnostic and treatment procedures that he has done in the past.	Adapted from AC3 measure (Blackman et al., 2017)
Religiosity/Spirituality	Defined as organized system of beliefs, practices, rituals, and symbols (1).	Adapted from CaPTC measure (Odedina et al., 2014)
Screening Controversy Scale	Knowledge of controversies about prostate cancer prevention, screening, and treatment.	Adapted from CaPTC measure (Odedina, Segal, Kimberlin, & Lee, 2011).
Shared Decision Making (Screening)	Shared decision making involves the patient, provider and family being informed with the best available evidence about options, benefits, harms, preferences and values (Rimer et. al., 2004)	Adapted from Shared Decision Making measure (Rimer, Briss, Zeller, Chan, & Woolf, 2004) measure.
Temporal Orientation	An individual's perception of time as being in the past, present or future (1, 2).	Adapted from CaPTC measure (F. Odedina et al., 2014)
Trust of Health Care Providers	Participants' expression of valuing their providers recommendations relative to their care, including screening and treatment decision-making.	Adapted from AC3 measure (Blackman et al., 2017)

The CaPTC-AC3 Behavioral measures are ideal for studies focused on identifying behavioral factors impacting prostate cancer across the continuum of care; intervention studies to improve prostate cancer prevention, screening, detection, treatment and survivorship in Black men; migration and immigrant health studies; and comparative studies of prostate cancer among ethnically-diverse Black men. Behavioral measures are very important in identifying modifiable variables, which can be targeted to effectively reduce health disparities in minority and underserved populations. According to the Institute of Medicine, the potential sources of disparities in health care occur at individual (personal or provider), institutional or health systems levels (Nelson, 2003). The modification of individual behaviors of Black men with respect to prostate cancer risk reduction, informed decision making for prostate cancer screening, and adherence to prostate cancer treatment and survivorship strategies remains a key weapon to eliminate prostate cancer health disparity in this population. The CaPTC-AC3 behavioral measures are thus important tools in identifying behavioral factors impacting prostate cancer prevention, screening, detection, treatment and survivorship in Black men. In addition, these measures will provide a means of testing the fidelity of intervention programs targeting Black men's behavior. Uniquely, these measures will provide an opportunity to compare behavioral factors among ethnically-diverse Black men globally. The CaPTC-AC3 instrument is provided in the Appendix.

Standardized Global Epidemiological Measures for Prostate in Black Men

The CaPTC-AC3 Consensus Working Group reached a consensus on and approved 24 epidemiological data elements for the CABE

measures (Table 3). For each construct, the measures were either adapted or new measures. *Adapted* measures were from existing instruments of Behavioral Risk Factors Surveillance System (BRFSS), National Health and Nutrition Examination Survey (NHANES), the Southern Community Cohort Study (SCCS), and AC3 and/or CaPTC studies. Baldness was adapted from the Norwood Hamilton Scale (Norwood, 1975). These measures were either generic measures that did not need to be culturally tailored (e.g. demographics, country of birth, smoking cessation, environmental tobacco exposure and anthropometrics) or were already culturally tailored for Black men in Africa, US and Caribbean and had been included in prior AC3 and CaPTC studies (e.g. languages and fluency, sun habits, personal history of cancer, environmental exposures and social environment).

New measures were created from existing instruments of BRFSS and SCCS and were further refined and culturally tailored in order to ensure that the data capture was specific and responsive to the cultural and lifestyle heterogeneity between Black men born in Africa, the Caribbean and US. The reason for choosing the BRFSS and SCCS for adaptation over other study instruments was because (a) the BRFSS and NHANES instruments are already national and standardized instruments established by the Centers for Disease Control and Prevention (CDC 2012a, CDC 2012b) and (b) the instrument from the SCCS (Signorello et al., 2005) is also standardized, was developed for the recruitment of adults from southeastern US, and among existing US cohorts the SCCS has the largest representation of Blacks.

Table 3: CaPTC-AC3-MADCaP Standardized Global Epidemiological Measures for Prostate in Black Men.

Constructs	Description of Measures	Source
Demographics	Participants' age, family status and religion.	Adapted from AC3 measure (Blackman et al., 2017)
Race/ethnicity	Self-defined race as well as self, maternal and paternal ethnicity defined as country of origin and citizenship or immigrant status (for US participants), Hispanic/Latino. Country-specific measures for ethnic groups in, Ghana, Kenya, Liberia, Nigeria, South Africa, Senegal and Trinidad and Tobago are also included.	Adapted from BRFSS (CDC 2012a) and SCCS (Signorello et al., 2005) measures and was further refined by the CWG.
Socioeconomic status (SES)	Subjective social status, community ladders (Adler, Adler, Epel, Castellazzo, & Ickovics, 2000) (Adler et al., 2000) as well as educational attainment, income, employment status and occupation, home ownership and household information including number and relationships with persons living in the household	Adapted from BRFSS (CDC 2012a) and SCCS (Signorello et al., 2005) measures and was further refined by the CWG.
Residency	Participant's current country and duration of residence, it defines whether the participant lived in a rural community, as well as historical residence. Documentation of geospatial coordinates based on participants address are also recommended.	Adapted from BRFSS (CDC 2012a) and SCCS (Signorello et al., 2005) measures and was further refined by the CWG.
Country of birth	Birth country and the number of years lived in that country for participants as well as for mother, father, maternal and paternal grandmother/grandfather.	Adapted from AC3 measure (Blackman et al., 2017)

Languages and fluency	Participant's native language and comfort level speaking their ethnic dialect compared to other languages; as well as measures of fluency and amount of time speaking the country's official language at home, school, work, prayer and with friends for participants living in countries where the official language is their second language.	Adapted from AC3 (Blackman et al., 2017) and CaPTC (Odedina et al., 2014) measures.
Nutrition	Dietary measures as well as a culturally tailored food frequency questionnaire These include participants' dietary intake, food portions described as general plate portions of meat, starches and vegetables as well as a) current intake (past 30 days) frequency and b) average annual intake frequency of: heterocyclic amines based on food preparation methods, dietary fats, meat organs, grains, starchy foods and tubers, lycopene rich fruits, beans, glucosinolate-rich cruciferous vegetables, antioxidant-rich fruits and vegetables, sources of refined sugar such as sweets and sweeteners, non-alcoholic beverages.	Adapted from BRFSS measure (CDC, 2012a) and was further refined by the CWG.
Physical activity	Duration, frequency and intensity for the past year and frequency of strengthening exercises in the past month only.	Adapted from BRFSS measure (CDC, 2012a) and was further refined by the CWG.
Sun habits	Participants' exposure and duration in the sun during the months of summer, on weekdays and weekends as well as sun protection habits on sunny days. Skin pigmentation based on skin tone on the inside part of their upper arm (Ho Chien-Ju, 2015) and latitude obtained from participants' residence location are also included.	Adapted from AC3 (Blackman et al., 2017) and CaPTC (Odedina, 2011) measures.
Smoking habits	Participants' smoking status and history of tobacco use including smoking initiation age, type of tobacco used and frequency of use a measure of Marijuana use	Adapted from BRFSS and NHANES (CDC 2012a, 2012b) measures and was further refined by the CWG.
Smoking cessation	Length of time since last cigarette was smoked	Adapted from BRFSS measure (CDC, 2012a)
Environmental tobacco exposure	Participants' exposure to second hand cigarette smoke at home, workplace, indoor public place or vehicle and includes documentation of in-home or vehicle cigarette smoking policy	Adapted from BRFSS measure (CDC, 2012a)
Alcohol use	Participants' history of alcohol use and includes age of first drink, duration of alcohol use and number of drinks on average as well as for specific alcohol products such as beer, wine, liquor and common alcoholic drinks consumed in Caribbean and African settings.	Adapted from BRFSS (CDC 2012a) and SCCS (Signorello et al., 2005) measures and was further refined by the CWG.
Health care access	Type of health care coverage and method of payment for health care.	Adapted from SCCS measure (Signorello et al., 2005) and was further refined by the CWG.
Personal History of Cancer	Participants' history of any cancer and of recurrence (for men with a history of prostate cancer).	Adapted from AC3 measure (Blackman et al., 2017)
Family History of	Participants' family history of cancer, with responses	Adapted from SCCS measure

Cancer	indicating if sons, daughters, wife, birth parents, full/half siblings, uncles, cousins, maternal and paternal grandparents have been diagnosed with cancer. The specific type of cancer, smoking status and diagnosis before age 50 is also documented.	(Signorello et al., 2005) and was further refined by the CWG.
Medication use	Participants' duration of use of anti-inflammatory and cholesterol-reducing medications in the past year as well as current use and duration of use of urinary retention medicines and other medications.	Adapted from SCCS measure (Signorello et al., 2005) and was further refined by the CWG.
Vitamin and Supplement Use	Participants' past year duration of use of vitamins and supplements including commonly used supplements and herbs to promote prostate health	Adapted from SCCS measure (Signorello et al., 2005) and was further refined by the CWG.
Baldness	Norwood-Hamilton Scale of Male Pattern Baldness at ages 30 and 45 years old	Adapted from Norwood measure (Norwood, 1975)
Anthropometrics	Participants' self-reported weight loss or gain in the past five years, previous heaviest weight, as well as measurements of current weight, waist and hip/buttocks reported in inches in triplicate with notations taken with or without clothing and thickness of clothing Current and previous body shape is measured with a rating scale from Stunkard visual figures for five decades of life from 20 years old to 50 years old (Cheung et al., 2011; Stunkard, Sorensen, & Schlusinger F, 1983)	Adapted from AC3 measure (Blackman et al., 2017).
Personal History of Chronic Conditions and Risk Factors	Participants' history of prostatic diseases and other chronic conditions and age at diagnosis	Adapted from SCCS measure (Signorello et al., 2005) and was further refined by the CWG.
Family History of Chronic Conditions and Risk Factors	Participants' family history of prostatic diseases and age at diagnosis for father and full/half-brother as well as family history of other chronic conditions and age at diagnosis for birth father, birth mother, full/half-sister and full/half-brother.	Adapted from SCCS measure (Signorello et al., 2005) and was further refined by the CWG..
Environmental exposures	Participants' history and age worked as an agricultural/groundsman, pesticide worker or exposure to chemical fertilizers or pesticides used on the farm these measures were	Adapted from AC3 measure (Blackman et al., 2017).
Social environment	Participants' perception of personal social environment such as neighborhood interactions, physical environment and personal safety.	Adapted from AC3 measure (Blackman et al., 2017).

CaPTC-AC3 Epidemiological measures will support research questions that require comparative analysis between US-born, Africa-born and Caribbean-born men whether within the US or between geographic populations in the Caribbean and Africa. Furthermore, the CaPTC-AC3 Epidemiological measures can also be easily adapted and implemented in research studies that also involve Black women since these constructs are not gender-specific. The CaPTC-AC3 instrument is provided in the Appendix.

DISCUSSION

The CABE measures are currently being used as standard data collection tools in multiple countries globally. The CaPTC consortium adopted the measures in March 2017 for the *West Africa Prostate Cancer Familial Cohort Study*, which will recruit 2,000 West African men in United States, Nigeria, Cameroon and England. Supported by the NCI P20 award (P20CA192992), the Geographic Management of Cancer Health Disparities (GMaP) Program award and the Carnegie African Diaspora Fellowship program, this CaPTC study has recruited over 1,000 participants administering the CABE measures in English language and Pidgin English in the United States, Nigeria, and Cameroon. On average, it takes about 1 hour to complete all the measures. In addition to the behavioral, epidemiological and clinical data, the study includes biological data collection in form of saliva and formalin-fixed paraffin-embedded prostate tissue. CaPTC is currently developing a methodology to integrate and harmonize the CABE data with existing CaPTC database of over 5,000 participants.

AC3 adopted the measures for use in an existing US-based multi-ethnic cohort of African descent (Cancer Prevention Project of Philadelphia – CAP3). This cohort is funded by the American Cancer Society (RSG-14-033-01-CPPB) and Fox Chase Cancer Center and includes 946 (female and male) participants. Integration of the CABE measures for the current (N=326) and prospective male participants in this cohort is in progress. Genomic data are currently being generated from DNA collected from saliva and biomarker data are being generated from urine samples. Expansion of this multi-ethnic cohort to two US sites and two Caribbean sites is in development. One Caribbean site in Jamaica will begin in October 2019 and we will recruit 8,000 participants affected and unaffected by cancer (3,200 males and 4,800 females). The second Caribbean site in the Bahamas was established in September 2017 and the first round of enrollment includes 380 Black men unaffected and affected with prostate cancer. Approximately 600 males are anticipated to be enrolled annually. Further expansion of this and other Caribbean sites are planned through supported activities of an NCI P20 award in planning for a Regional Center for Cancer and Cardiometabolic Research in the Caribbean (1P20CA210294-01). In addition to the CABE data, saliva and paraffin-embedded samples (from prostate cancer cases) will be collected for genomic and epigenetic studies.

Data sharing is essential for expedited translation of research results into knowledge that can be used to accelerate the pace of research. The NIH has implemented policies that require investigators to share their data and resources, including the 2003 NIH Data Sharing policy and the 2015 NIH Genomic Data Sharing Policy (https://grants.nih.gov/grants/policy/data_sharing/). In addition, NCI is moving towards methods that will enhance data sharing and encourage the broad sharing of data (beyond current scientific collaborations). The GEM database is one such example, the publicly available CABE measures are easily downloaded and access in different formats to enhance data sharing (Moser et al., 2011).

The CABE measures provide global access to culturally appropriate data collection tools for the study of prostate cancer in Black men. Specifically, the use of standardized and common measures will facilitate data pooling and harmonization across several populations. The long-term impact of the CABE measures is catalyzed progress for prostate cancer disparity research through

harmonized data. For example, the prostate cancer research community will be able to create Big Data from all the studies using the CABE measures. Access to Big Data provides the ability to do analyses that cannot be done with single studies, including exploring the influence of genetic and lifestyle factors on prostate cancer, fostering the identification of genetic changes for cancer growth, accurate prediction of cancer health outcomes, guiding treatment decision making, and predicting behavioral risk factors for cancer. Ultimately, the CABE measures will contribute to the goal of understanding and ultimately reducing the disproportionate effects of prostate cancer in Black men.

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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

Odedina conceptualized the project, participated in the review and development of Behavioral measures, actively participated in the writing of the manuscript; Ragin participated in the review and development of epidemiological measures and actively participated in the writing of the manuscript; Martin participated in the review and development of epidemiological measures and actively participated in the writing of the manuscript; Moser coordinated the GEM platform consensus process and actively participated in the writing of the manuscript; Oliver participated in the review and development of Behavioral measures and actively participated in the writing of the manuscript; McDonald participated in the review and development of epidemiological measures and actively participated in the writing of the manuscript; Rise assisted with the GEM platform consensus process and participated in the writing of the manuscript; Nguyen participated in the review and organization of the Behavioral measures and participated in the review of the manuscript; Chinegwundoh actively participated in the writing of the manuscript; Morrison-Blidgen actively participated in the writing of the manuscript; Kaninjing actively participated in the writing and editing of the manuscript.; Jalloh participated in the review and development of epidemiological measures, and participated in the editing of the manuscript; Reams participated in the review of measures on GEM platform and review of the manuscript.

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