

## ***79% of Black men know genetic information can improve prostate cancer treatment; yet 33% uncertain or unwilling to share their information with researchers***

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*New survey reveals risky gap between knowing and doing; suggests mistrust of research community persists*

### ***Survey Key findings***

- 79% of Black men know genetic information can help improve prostate cancer treatment options.*
- 75% of Black men know inherited gene mutations can increase their risk for prostate cancer.*
- 33% of Black men uncertain or unwilling to provide DNA samples even if it means finding new treatment options.*
- 64% of Black men report concerns about the privacy and security of their DNA information if shared with medical institutions*

*According to a new survey, Prostate Cancer and Black Men: From Disparity to Discovery, commissioned by Advancing Cancer Treatment and the National Alliance of State Prostate Cancer Coalitions, 3 out of 4 (75%) Black men know that inherited gene mutations can increase the risk for prostate cancer for themselves and their families. And nearly 4 out of 5 (79%) understand that genetic information can help improve treatment options. Yet, despite being well informed of these potential benefits, more than 1 out of 3 (33%) of survey respondents say they are either uncertain or unwilling to provide DNA samples with researchers or doctors even if it means finding new treatment options.*

*With nearly 3 out of 5 (64%) Black men citing concern for the privacy and security of their DNA information, survey findings suggest mistrust of the research community remains a hurdle to bringing diversity to research participation, even when it comes to diseases like prostate cancer that impact Black men disproportionately.*

***Merel Grey Nissenberg, President, National Alliance of State Prostate Cancer Coalitions*** said, *"Black men are at a disadvantage because they are underrepresented in valuable research that could impact their lives and the lives of their family members. Survey data underscores the importance of addressing health information privacy and security concerns to*

*bridge this dramatic health divide and move us from disparity to discovery for all men."*

According to **Channing Paller, MD**, medical oncologist at Sibley Memorial Hospital, associate professor of oncology at the Johns Hopkins University School of Medicine and co-lead investigator of the **PROMISE Registry**, a registry of prostate cancer patients participating in a research study to learn how genetic differences can affect patient outcomes, *"DNA may be a man's most powerful weapon in the fight against prostate cancer. A genetic database built from a racially diverse group of men is a critical step forward in prostate cancer research. We hope to bring personalised medicine to prostate cancer for all men, in the same way the research community has done for women with breast cancer."*

Added **Heather Cheng, MD, PhD**, director, Prostate Cancer Genetics Clinic and associate professor, Clinical Research Division, Fred Hutchinson Cancer Center, associate professor, Division of Hematology and Oncology, University of Washington, and co-lead investigator of the **PROMISE Registry**, *"Black men are disproportionately affected by prostate cancer, with more aggressive disease, and higher mortality rates versus White men. To address these disparities, we need to focus on enrolling and retaining Black men in prostate cancer clinical trials and observational studies—the length and quality of Black prostate cancer patients' lives are depending on it, and the lessons learned can benefit all patients with prostate cancer."*

In the US, the Genetic Information Nondiscrimination Act (GINA) prevents an individual's genetic information from being used to deny them health insurance coverage and from being used to discriminate against them in an employment setting. In addition to GINA, HIPAA protects patient privacy by restricting the sharing of patients' medical information.

If you are a Black man, it is important to talk to your doctor about your risk for prostate cancer and whether genetic testing is appropriate for you.

### **Survey Methodology**

Results of 2023 Prostate Cancer and Black Men: From Disparity to Discovery survey are based on a nationally representative online survey with 250 Black males. The survey was fielded by The PARAGRAPH Project in partnership with their sample provider, Cint. The survey was between August 17 - 21, 2023. The sample size of 285 at a 95 per cent confidence level would equate to +/- 6% per cent margin of error had this been a random sample.

## **About Advancing Cancer Treatment (ACT)**

ACT is a nonprofit organisation committed to improving access to clinical trials for cancer patients and expanding the opportunity for patients to benefit from innovative treatments. ACT support initiatives intended to improve access to precision medicine; improve cancer patient outcomes and experience; facilitate cancer research to hasten the discovery and availability of improved and new drugs and therapies.

## **About National Alliance of State Prostate Cancer Coalitions (NASPCC)**

NASPCC is a national organisation comprised of state prostate cancer coalitions dedicated to saving men's lives and enhancing the quality of life of prostate cancer patients and their families,

*through awareness, education, and public policy.*

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