



ADVANCING HEALTH EQUITY: ADDRESSING DISPARITIES IN PROSTATE CANCER CARE

Developed in collaboration with the AUA and Pfizer Oncology



American
Urological
Association



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ADVANCING HEALTH EQUITY: ADDRESSING DISPARITIES IN PROSTATE CANCER CARE

HEALTH EQUITY

The U.S. Centers for Disease Control and Prevention (CDC) states that health equity is attained when everyone is able to “attain his or her full health potential” and is not “disadvantaged from achieving this potential because of social position or other socially determined circumstances.”¹ The CDC goes on to describe the achievement of health equity in cancer as everyone having the same opportunity to prevent cancer, identify it early, and treat and manage the disease.²

HEALTH DISPARITIES

Health disparities exist when a health outcome is seen to a greater or lesser extent between populations.³ However, some define health disparities more narrowly as “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage,”⁴ or as “differences in health that are unnecessary, avoidable, unfair, and unjust.”⁵

Recently, there has been an increasing focus on advancing health equity, both nationally and globally. In order to advance health equity, health disparities must be addressed. The sources of health disparities are both multifactorial and interrelated; however, race and ethnicity, sex, sexual identity, age, disability status, socioeconomic status, and geographic location, among others, have a significant role.³

To advance health equity in the field of urologic oncology, individual healthcare providers, practices, and institutions must make a conscious effort to understand and address health and healthcare disparities. A number of factors contribute to inequities in prostate cancer care and outcomes. These include genetic differences, differential access to treatment, financial barriers, and lack of participation in clinical trials, among others.⁶ Overall, prostate cancer accounts for 14% of all new cancer cases in the U.S., and 5.7% of all cancer deaths.⁷ Data from the Surveillance, Epidemiology, and End Results (SEER) Program indicate that non-Hispanic black men are 1.7 times more likely to develop prostate cancer and 2.1 times more likely to die from the disease than non-Hispanic white men.⁷ The drivers of these specific disparities are not perfectly understood, but likely are related to modifiable factors, including relatively less access to, and uptake of, prostate specific antigen (PSA) screening⁸ and lack of inclusion in clinical trials, without which, genetic differences that may drive differential response to interventions may not be properly assessed.⁹ The issue of PSA screening was further exasperated by the 2012 US Preventive Services Task Force (USPSTF) recommendation against PSA-based prostate cancer screening. While this recommendation was later reversed in 2018, the consequences are still being felt in prostate cancer care today. In fact, population-based data suggest that black men have lower rates of prostate cancer screening compared to white men,⁹ and black men account for only 5-9% of prostate cancer clinical trial participants, depending on the trials reviewed.^{10,11}

Recognizing the influence that disparities in prostate cancer care have on patient outcomes, the American Urological Association (AUA) collaborated with Pfizer Oncology to assess current practice patterns for those with prostate cancer and identify promising approaches to improve care, particularly among vulnerable populations. This was accomplished by developing and fielding a survey of AUA members and conducting in-depth interviews with three physicians who have spearheaded efforts to address health and healthcare disparities in prostate cancer.

SURVEY OF AUA MEMBERS

To better understand current practice patterns for those with prostate cancer, the AUA fielded an electronic survey to all active, domestic AUA members from July 21, 2021 through October 15, 2021. An 8-member Steering Committee provided guidance on survey content. The survey included a variety of topics, including barriers to care for advanced prostate cancer (APC) patients, methods to identify and manage vulnerable and underserved populations, formal training on health disparities, and awareness of and access to clinical trials for APC patients. A total of 362 individuals responded to the survey. The following infographic presents results from the survey.

Barriers to Advanced Prostate Cancer Care

Most Frequently Reported Factors That Contribute to Variations in Advanced Prostate Cancer (APC) Care

- Comorbidities - 73%
- Patient Compliance/Choice - 70%
- Health Literacy - 69%
- Patient Proximity to Practice - 67%
- Insurance Status - 65%
- Social Support - 64%

Top Ranked Barriers Contributing to Disparities in Treatment of APC Patients

- Financial Concerns - 71%
- Lack of Access to Urologist/Specialist - 53%
- Difficulty Navigating Healthcare System - 52%
- Literacy Issues - 50%
- Lack of Patient Compliance - 47%

N=362
Total Survey Respondents Across 47 States
 239 Practicing Urologists
 68 APP
 42 Residents/Fellows
 13 Practice Admin/Other

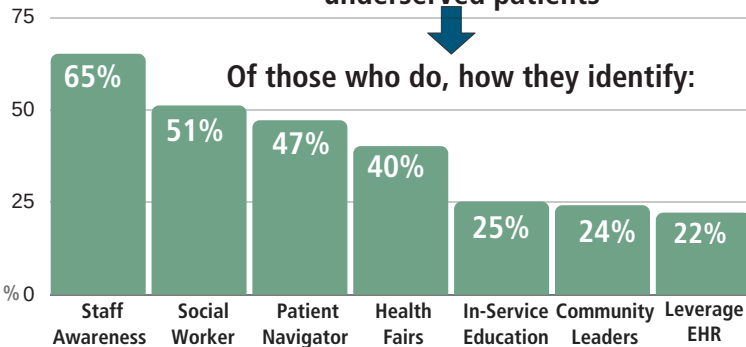
Subpopulations Representing a Moderate/High Percentage of Respondents' Patient Base

- 75+ Years of Age - 92%
- Lower Educational Level - 78%
- From a Rural Area - 65%
- Uninsured - 59%
- Veterans - 59%
- African American - 56%

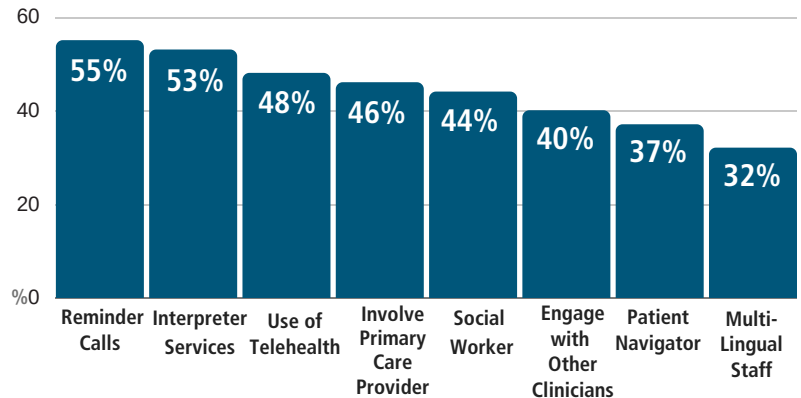
For patients with an initial diagnosis of APC, more respondents perceive lack of screening as very important for those from underserved populations (55%), compared to APC patients overall (40%)

Identifying and Managing Vulnerable/Underserved Patients

25% Of respondents reported their practice does NOT identify vulnerable or underserved patients

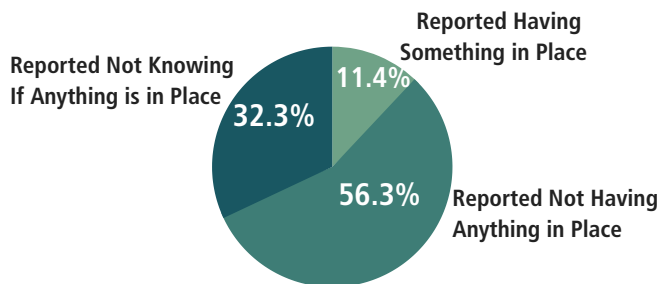


Urology Practices Reported a Variety of Approaches to Manage Vulnerable or Underserved Populations

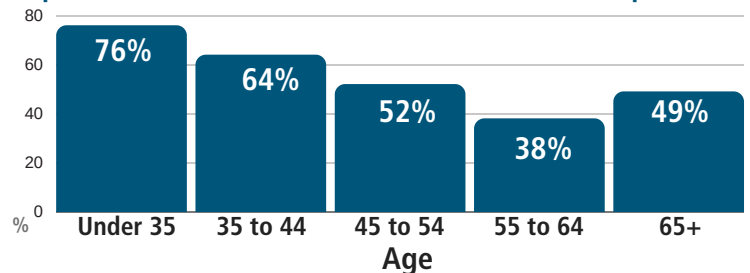


Prevalence of EHR to Manage APC Patients

Does EHR have something in place to address the lack of meeting specific goals/milestones for APC patients?



Among respondents who reported not leveraging EHRs, those who are younger indicate they want EHR trigger warnings in place to alert for unmet milestones for their APC patients



Formal Training on Health Disparities

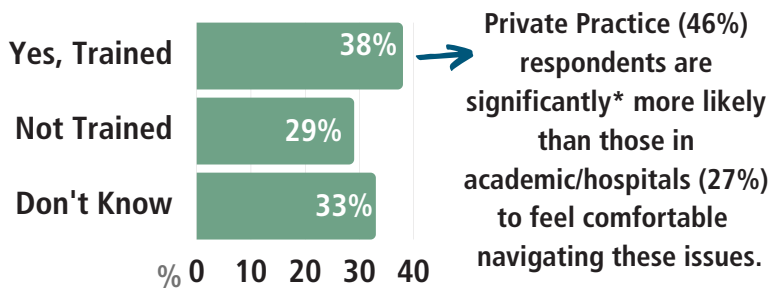
Less than Half of Urology Healthcare Professionals Reported Having Formal Training in Health Disparities



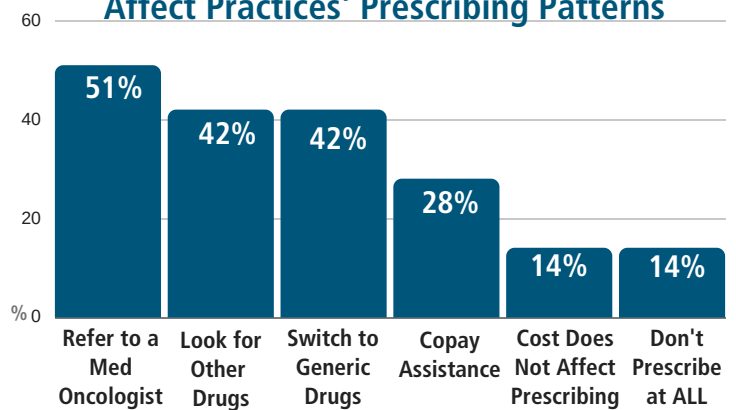
Access Barriers and Use of HUB Services in APC

- **Most frequently reported utilization management issues in accessing oral oncolytics:**
 - Prior authorization - 63%
 - Financial navigation - 37%
 - Copay accumulator issues - 27%
 - Step therapy - 20%
 - Unsure of the specific utilization management issues - 26%
- **Per AUA member surveys, awareness of manufacturer HUB services has increased from 44% in 2018, to 50% in 2021.**
- **Reported Use of Manufacturer HUB Services in 2021:**
 - Prior authorization and appeal assistance - 71%
 - Specialty pharmacy referral - 63%
 - Copay assistance referral - 61%
 - Benefit investigation and copay verification - 60%
 - Payment assistance program - 55%

Respondents Perceptions of their Practices Training to Navigate Financial Hurdles Associated with Oral Oncolytics for APC



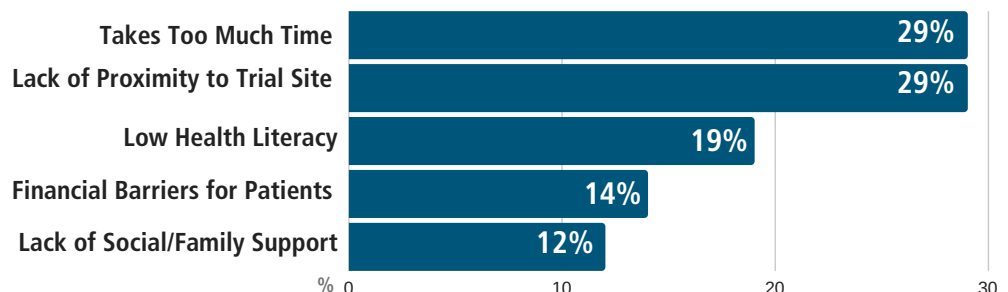
How Cost of Urology Oral Oncolytics Affect Practices' Prescribing Patterns



Awareness of and Access to Clinical Trials for APC

One-third (34%) of respondents indicated they are not very aware of potential clinical trials for their APC patients

Top 5 Factors That Dissuade Respondents From Offering Clinical Trial Opportunities to APC Patients



*Significance testing was performed via Z-Test of proportions at the 95% Confidence Level.

This survey was conducted by Pfizer and American Urological Association (AUA), and conducted online through Survey Monkey from 7/21/21 through 10/5/21. The survey was distributed to AUA membership of 12,206 with valid emails. Results are based on responses from 362 AUA members. These results may not be representative of all urologic practices. Respondents included: 239 urologists, 68 NP/PAs, 42 Residents/Fellows, and 13 practice admin/other.

1. Data on File.

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A DEEPER DIVE: CONVERSATIONS WITH COMMUNITY PHYSICIANS

To identify and highlight promising approaches to address inequities in prostate cancer care and outcomes, AUA staff conducted two virtual interviews with three physicians with extensive experience in this space. These individuals have initiated multiple efforts aimed at improving care for men in their communities, particularly among minorities and low-income populations.

In the first interview, **Dr. Courtney Hollowell** spoke about outreach efforts to men in inner-city communities, building relationships with primary care providers, meeting the challenges of low health literacy, the importance of prostate cancer screening and shared decision-making, and ways to address the financial impact of care for patients. Dr. Hollowell is the Chairman of Urology at John H. Stroger, Jr. Hospital, Cook County Health, in Chicago, IL.

In the second interview, **Drs. Lannis Hall and Arnold Bullock** discussed a variety of efforts to promote appropriate prostate cancer screening. They also spoke at length about barriers to, and benefits of, minority participation in clinical trials. Based at the Washington University School of Medicine in St. Louis, MO, Dr. Hall is an Associate Professor of Clinical Radiation Oncology, and Dr. Bullock is the Alan A. and Edith L. Wolff Professor of Urology.

A FOCUSED DISCUSSION WITH COURTNEY M.P. HOLLOWELL, MD

Courtney M.P. Hollowell, MD

*Chairman of Urology, John H. Stroger, Jr. Hospital
Cook County Health, Chicago, IL*

Dr. Courtney Hollowell currently serves as Chairman of Urology at John H. Stroger, Jr. Hospital, the 450-bed flagship teaching hospital for Cook County Health (CCH). This Level 1 trauma center built in Chicago in 2002 offers a wide range of specialized medical services and maintains a strong commitment to the healthcare needs of Cook County's underserved population.¹² In addition to fourteen community health centers,¹³ CCH also controls Cermak Health Services of Cook County, which is the largest single-site correctional health service in the country serving the healthcare needs of the detainees at the Cook County Department of Corrections.¹⁴ At the heart of CCH's mission is the dedication to care for the uninsured, a group that makes up approximately 45% of the patients who utilize CCH.¹⁵ To this end, the two hospitals under the CCH umbrella now provide more than 50% of all charity care in Cook County,¹⁵ a region that is home to over 5.2 million individuals—nearly 50% of whom identify as either Black or African American, or Hispanic or Latino.¹⁶

Dr. Hollowell graduated from the University of Illinois College of Medicine and completed both residency and fellowship training at the University of Chicago. As such, Dr. Hollowell has dedicated his career to improving the care provided to Cook County residents. In addition to serving as Chairman of Urology for CCH, Dr. Hollowell also works with the Cook County Department of Public Health, a group that is continuously working to address issues of health disparity. Due in large part to his work in this space as well as his expertise in both men's health and prostate cancer care,



“ Healthcare begins long before a patient steps into a hospital. Our goal is to get people thinking about their health and wellness before they ever see a doctor.”

– Dr. Hollowell

Dr. Hollowell was invited to participate on behalf of the Congressional Black Caucus in a review of the Cancer Moonshot Initiative, a program led by then Vice President Joe Biden to identify new ways to prevent, diagnose, and treat cancer.¹⁷ In this role, Dr. Hollowell was able to comment on those patient populations he commonly treats at CCH who could greatly benefit from such a program.

Healthcare Engagement with Minority Patient Populations

In looking at his own patient population, Dr. Hollowell noted that a high percentage of his patients are over 75 years of age and identify as African American or Hispanic/Latino. Many of his patients have lower health literacy and socioeconomic status. Further, a very high and rapidly growing number of his patients are uninsured or underinsured. Dr. Hollowell commented that a surprising number of such patients do not fall into a low socioeconomic status and, therefore, are ineligible for many funding opportunities only available for very low-income patients. While these patients may still have difficulty affording treatment, their options for financial aid are more limited due to their moderately higher socioeconomic status. Dr. Hollowell also treats a large immigrant population, a group that makes up over 20% of Cook County residents.¹⁶

In Dr. Hollowell’s experience, many such minorities are less likely to regularly engage in their own healthcare as adults. Many individuals, particularly men, only seek episodic care for injury or acute illness once they age out from pediatric care. The longer one is out of the healthcare system, the more difficult one may find it to re-enter. In the case of some racial minorities, this is often due to fear or mistrust of the health system itself. Recognizing this as a clear issue within his own city, Dr. Hollowell developed multiple programs aimed at addressing these concerns.

MEN’S HEALTH INITIATIVE

Dr. Hollowell founded the Men’s Health Initiative (MHI) to promote greater understanding of common health conditions among inner-city men. He noted that men, particularly African American men, do not typically seek preventative care. To this end, MHI representatives speak in roughly 100 churches each year on topics of importance to men. They also host a monthly Male Health Forum where they invite local thought-leaders to provide further education to community members on topics of importance to men’s health, including cancer, diabetes, and nutrition. It is the goal of MHI to engage with men in a more casual and less intimidating environment to encourage proactive participation in healthcare.

TOMORROW’S DOCTORS

Recognizing that underrepresentation of minorities as healthcare professionals is a major issue in today’s health system, Dr. Hollowell developed Tomorrow’s Doctors. This school-based program was designed to not only expose children from these underrepresented minority populations to the possibilities of stable careers in science, but also to inspire future professionals who may further address the inequities they may have experienced in their own communities.

Healthcare engagement, particularly via preventative care, has important implications for future health outcomes. While screening efforts aim to identify patients as early as possible in a course of disease, those patients must first be willing to engage with the health system in order to take

advantage of available screening opportunities. Similarly, the health system should offer regular opportunities to promote such engagement. This importance is highlighted, for example, in the case of Black race, which has shown independent association with prostate cancer, particularly diagnosis at a younger age.¹⁸ Not only is prostate cancer incidence 70% higher in Black men compared to White men, but Black men are also twice as likely to die from prostate cancer.⁷

Screening and Prevention

Many patients underestimate the importance of screening and prevention in healthcare—if they feel fine, then that must mean they are healthy. However, many diseases, including prostate cancer, may present with no symptoms whatsoever; yet with prostate cancer, once symptoms do arise, a patient may be beyond the point of curative treatment.¹⁹

PUBLIC DISCOURSE AND OVERCOMING MISTRUST

Healthcare providers are still experiencing the effects of the 2012 USPSTF recommendations against use of PSA for prostate cancer screening.²⁰ Rates of PSA screening, prostate biopsy, and overall prostate cancer incidence declined in the first few years following the 2012 recommendation; healthcare providers have since seen a shift towards higher grade and stage of prostate tumors at the time of detection.⁸ While that recommendation was updated in 2018 to encourage shared decision-making in prostate cancer screening,²¹ Dr. Hollowell noted that one does not change opinions overnight—and one may be hard-pressed to find a patient who won't take you up on an offer not to screen! Consequently, healthcare providers may find it difficult to bring patients who are already somewhat apprehensive about healthcare back into the fold to obtain a PSA test after they were previously told not to screen.

By definition, science challenges previous notions based on new data; thus, ideas about healthcare evolve—that is normal and natural in healthcare, but it isn't necessarily normal for everyone else. When such debate takes place in the public eye, one may create the potential for confusion—or even worse—mistrust. Healthcare providers should be prepared to explain to patients how new information may impact previous recommendations and updates to healthcare protocols.

SCREENING IN LOW-RESOURCE POPULATIONS

It has been shown that screening for prostate cancer is lower in an environment of patients who lack insurance and may have language barriers, lower health literacy, or other social/cultural barriers²²—these individuals may also be more prone to medical mistrust.²³ Conversely, those patients who fall outside those categories are more likely to trust the healthcare system and may expect more of that system²³—insured patients have options, so if they want to undergo screening, they can more easily find a provider to do that. In fact, research has shown in the breast cancer space that insurance coverage is associated with higher rates of screening and lower risk of death.^{24,25,26}

As Dr. Hollowell noted, many of his patients are immigrants. These patients may have entered the US recently and now present with urinary symptoms, which may lead to a diagnosis of prostate cancer. This is not a reflection on the level of care provided by the health system, but an indication of the types of patients who use such safety-net health systems and the barriers to

“ I challenge myself and others to look at how we do things and to be more inclusive. When you're more inclusive you get ideas outside of what may be a very homogenous perspective.”

– Dr. Hollowell

engagement that may be seen in those at-risk patient populations.

In Dr. Hollowell's practice in the early 2000s, he found that roughly 30% of his patients presented with more advanced prostate cancer at the time of diagnosis, which would have been unexpected in a more affluent or well-insured population at the time. Fast forward to the five to six years following more widespread recommendations against screening, and even the institutions serving patients who were well-insured started to notice changes. The number of patients seen for elevated PSA and biopsy or screening diminished dramatically, and the number of patients seen with locally advanced or metastatic disease was on the rise.^{8,20} The non-public healthcare systems started to see numbers on the order of what safety-net healthcare systems had been seeing in patients with barriers to care for many years. Any such barriers to care (either seen in an underserved population or due to recommendations against screening) that result in delays in diagnosis or disease progression may impact treatment decisions down the line.^{27,28, 29}

RELATIONSHIP BUILDING WITH PRIMARY CARE PROVIDERS

In seeking to promote greater access to prostate cancer screening, Dr. Hollowell believes that one must also look beyond just the patient to primary care providers. Currently, screening for prostate cancer is most frequently performed by primary care providers. In his role as Chairman at CCH, Dr. Hollowell has the ability to work with those providers to set the standards for prostate cancer screening within the CCH system. This effort hinges on his ability to work cohesively with primary care physicians and advanced practice providers to establish an open discourse on when and how patients should be optimally screened for prostate cancer and when a referral to the urology service may be appropriate. Such relationships aren't built on quick sporadic interactions—these relationships were established through genuine engagement not only with each practitioner individually, but through interaction on a program level, including training.

An important part of the urology/primary care discourse involves discussion of the unique patient population seeking care through CCH. When reviewing national screening recommendations and data publications with his colleagues, Dr. Hollowell emphasizes the importance of understanding the differences between those patients included in trials and those patients who are seen at CCH. The effects of screening can be very different when comparing populations with barriers to healthcare versus those with greater access. As an example, one of the largest trials to date looking at prostate cancer screening is the Prostate, Lung, Colorectal, and Ovarian (PLCO) Trial.³⁰ The trial randomized over 75,000 men to intervention (screening) or control arms. Of those participants, over 88% were non-Hispanic White, and less than 5% identified as non-Hispanic Black—a group that makes up a large portion of the CCH patient population. This highlights another key issue in addressing barriers to care for minority populations—they are being screened and treated based on protocols from studies in which they are not adequately represented when data show that they are twice as likely to die from prostate cancer when compared to their White counterparts.⁷ Ongoing discussions around the merits of screening highlight the impact that it may have on a population that is not well studied. That, coupled with CCH's own review of the number of patients presenting with locally advanced or metastatic disease, underscores that CCH is treating a highly vulnerable

patient population that could potentially benefit greatly from screening recommendations more appropriately tailored to their specific background.

Health Literacy and Shared Decision-Making

The US Department of Health and Human Services (HHS) defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions.”^{31,32} According to the National Assessment of Adult Literacy, only 12% of Americans have proficient health literacy skills.³³ Research has shown that uninsured adults and those enrolled in Medicare and Medicaid are more likely to fall below proficient health literacy compared to those who are insured through an employer.³⁴ Prostate cancer is very much in the unenviable position of affecting a number of populations also more likely to have lower health literacy—older men, African Americans, and those of low socioeconomic status.^{9,35}

Prostate cancer is a space that very much emphasizes shared decision-making both as it relates to screening and disease management. As such, it is the responsibility of the provider to be able to offer all of the information a patient may need (and in a manner the patient can understand) in order to make important decisions regarding healthcare; this shared decision-making process may be more difficult for patients affected by low health literacy.

LANGUAGE BARRIERS TO HEALTH LITERACY

Many of Dr. Hollowell’s patients have a language barrier that negatively impacts their health literacy. While he noted that many of his patients do not speak English as a primary language, he is quick to note that he treats many patients who are hearing impaired (a trait commonly seen in older populations who are also more likely to experience a prostate cancer diagnosis than their younger counterparts),^{7,36} and such patients experience many of the same issues with health literacy as non-native English speakers. Any sort of language barrier can very much negatively impact patients’ understanding of their health situation and, consequently, their downstream health decisions.

Dr. Hollowell shared CCH’s belief that every patient deserves to be able to communicate in their primary language. Patients deserve the respect of being able to communicate with their physicians in the manner in which they are most comfortable. Further, it is incredibly important that patients are able to also understand the physician. The ability to communicate is essential to the shared decision-making process emphasized in prostate cancer care. As such, CCH has a robust interpreter service available for patients. While interpreters are available on staff, it is not feasible to employ an entire team for some of the less frequently encountered languages. To fill this gap, CCH also contracts with a third-party company that offers virtual interpretation services. While there is no perfect replacement for face-to-face interaction, video calls do allow for greater engagement compared to phone services. Dr. Hollowell noted the potential for a drop-off in communication when speaking over the phone—while also being more impersonal, one may miss certain visual cues that could add value to the discussion. The individuals providing interpretation services are certified to do so and are specially trained in medical terminology to ensure that they are able to effectively communicate information to and from both the patient and healthcare provider.

“You can’t just make recommendations without also providing patients with the tools to succeed.”

– Dr. Hollowell

PATIENT EDUCATION

To further promote greater health literacy, Dr. Hollowell described a CCH initiative to develop a series of videos that provide short vignettes on many of the more common diagnoses and treatments seen in the health system. These two- to five-minute clips may be pieced together to give a basic overview of the patient’s diagnosis and the management strategy being used to treat the condition at a level that patients are able to more easily understand. These clips are recorded by the provider and selected based on each patient’s specific case. While it may be less effort to provide educational materials as a take-home packet or within the visit summary, such materials may be less effective in those populations with literacy issues that may be unable to read at a level necessary to understand the content.

Dr. Hollowell noted that the clips are intentionally designed to be very short and specific in discussion. Longer, more generalized videos would likely contain a great deal of information that may not apply to the patient. This adds an additional layer of educational need on the patient to be able to understand what does or does not apply to his specific situation. Short clips allow the provider to customize the material because multiple focused clips may be “stitched together” to fit each patient in a more tailored manner, thereby reducing the need to discern what is or is not relevant information. This more closely mirrors the in-office patient/provider relationship where discussion is specific to the individual patient. This also provides the patient with additional information from the face of a familiar physician who has an established level of trust with the patient. Currently, this information is provided during the office visit, but it is a future goal to host this material virtually to allow patients to also access the information outside of the hospital setting.

INDIVIDUALIZED PATIENT RECOMMENDATIONS

It must be recognized that as a society, we are more connected than we ever have been before. There is a wealth of information available via the internet and social media, and people regularly access this information. We are often taught that having access to as much information as possible is essential, but this isn’t always the case in healthcare. In many ways, having too much information may be just as dangerous as not having enough information. It can be difficult to glean the reliability and source of information and then have the understanding to interpret that information to apply to a personal situation. Dr. Hollowell shared that he often finds that patients are now beginning to view the internet and social media as an authority. As such, patients may be less likely to believe the physician when provided with information that does not agree with those previously identified sources. Dr. Hollowell emphasized that it is important for providers to explain to patients that their management recommendations are specific for each individual patient. There is no universal way to treat every case of prostate cancer—time is spent reviewing specific patient and disease characteristics before recommending management options. This is not something one will find from an internet search.

Financial Considerations

Many of the recent breakthroughs in advanced prostate cancer care have been through medical treatments.²⁹ The cost of agents used to treat prostate cancer can often far exceed the means patients have to pay for those agents, particularly in minority populations.^{37, 38} It is an unfortunate reality that many patients are faced with a choice between paying for treatment needed to keep them alive or paying for food and shelter. Recognizing this issue, there are now more and more options available to help alleviate some of those costs.

Dr. Hollowell asserted that CCH commonly utilizes medical assistance programs provided by pharmaceutical companies. By design, CCH is a catchment system for patients in need who are uninsured or underinsured and unable to afford treatment without aid. As such, CCH has mechanisms in place to identify resources proactively. Before a patient initiates treatment, the process is already underway. CCH offers several different financial assistance options for patients who need help paying their bills.³⁹ The CCH Financial Assistance Office is available to help patients determine Medicaid and Medicare eligibility and walk them through the redetermination process. Certified application counselors are also available to help enroll patients in plans through the Illinois Health Insurance Marketplace or help them apply for CareLink, a free program to help Cook County residents cover the cost of treatment at any CCH facility. This program is specifically designed to assist uninsured or underinsured patients cover the costs of services at CCH, including clinic visits, lab tests, hospital stays, and urgent or emergency services. Further, CCH may also provide patients information on the Illinois Hospital Uninsured Patient Discount Act, a discount program established to help uninsured residents living in the State of Illinois (but outside of Cook County) pay for their health care services at CCH.

From a financial assistance perspective, often some of the more difficult scenarios are not in those patients living well below the poverty level. Dr. Hollowell sees a number of patients who, while above the poverty level, are living paycheck to paycheck and are less likely to qualify for assistance. Even more difficult are those patients who are not American citizens and may, therefore, not qualify for some forms of financial assistance.

This highlights the daunting nature of healthcare today. It's no longer just about taking care of the patient—it also includes everything that goes along with providing that care. These efforts require a tremendous amount of time, not only for the provider, but also for the support staff. Great strides have been made in identifying and addressing obstacles to healthcare, but much work is still needed in order to ensure that all patients have access to adequate care despite potential racial or socioeconomic barriers.

A FOCUSED DISCUSSION WITH LANNIS HALL, MD AND ARNOLD BULLOCK, MD

Lannis Hall, MD



*Associate Professor of Clinical Radiation Oncology
Washington University School of Medicine, St. Louis, MO*

Dr. Lannis Hall is an Associate Professor of Clinical Radiation Oncology and Director of Radiation Oncology at Barnes-Jewish St. Peters Hospital at Washington University School of Medicine. She graduated medical school from Howard University and completed residencies at Howard University and Washington University. She practices full time in an academic/satellite practice and specializes in delivering radiation therapy to head and neck, genitourinary, and breast malignancies, with about one third of her practice focused on prostate treatment. In addition, Dr. Hall runs the PECaD Clinical Studies Outreach program, which is dedicated to increasing minority recruitment and participation in trials.⁴⁰

Dr. Hall has a diverse practice and patient mix. She estimates that half of her patients are from rural areas, 25% are over 75 years of age, 25% have lower levels of education, and 10% are uninsured or on Medicaid (a percentage that she believes is increasing over time). In addition, about one quarter of her patients identify as a minority (approximately 3% Hispanic/Latino, 14% African American, 2% Asian/Pacific Islander, and 3-5% multiple races).

Arnold Bullock, MD



*Alan A. and Edith L. Wolff Professor of Urology
Washington University School of Medicine, St. Louis, MO*

Dr. Arnold Bullock is a full-time academic urologist practicing at Washington University School of Medicine. He graduated medical school from Johns Hopkins University and completed his residencies in general surgery and urology at Washington University. Having been in the Department of Surgery for nearly 30 years, he now serves as the Alan A. and Edith L. Wolff Distinguished Professor of Urology. Dr. Bullock's urology practice focuses on men's health. The evaluation and treatment of male voiding dysfunction, sexual dysfunction, scrotal problems, and prostate cancer occupies most of his time in clinical practice.

Like Dr. Hall, Dr. Bullock treats a diverse group of patients. He practices at the Barnes-Jewish Hospital near inner city St. Louis and at Christian Hospital Northeast in suburban St. Louis County. He estimates about 20% of his patients are 75 years of age or older. Compared to Dr. Hall, Dr. Bullock has fewer rural patients, who comprise about 35% of his total patients. He estimates about 50% of his patients identify as African American, <5% Hispanic, <5% Asian/Pacific Islander, and <5% Native American. He, too, has seen an increase in those on Medicaid/uninsured, which he estimates comprise 5-7% of his patients. When asked about education levels of his patients, Dr. Bullock said about 20% are of a lower education level.

Washington University School of Medicine, St. Louis, MO

Founded in 1891, Washington University School of Medicine is committed to maintaining a culture that promotes diversity, inclusion, creativity, and critical thinking while advancing the health field.⁴¹ With nearly 1,800 faculty physicians covering more than 76 specialties and subspecialties, Washington University has one of the largest academic practices in the United States.⁴²

Within Washington University, medical staff serve the Barnes-Jewish Hospital and the St. Louis Children's Hospital, as well as more than 60 other clinical sites in both Missouri and Illinois. The Alvin J. Siteman Cancer Center, located at the Barnes-Jewish Hospital, is dedicated to cancer research, treatment, prevention, and community outreach. It is the only cancer center in Missouri to receive the National Cancer Institute's Comprehensive Cancer Center designation.^{43,44} Siteman Cancer Center is home to the Program for the Elimination of Cancer Disparities (PECaD), a community-based initiative with a mission to create a national model to eliminate disparities in cancer education, prevention, and treatment.⁴⁵

Healthcare Engagement with Minority Patient Populations

With Drs. Hall and Bullock working in diverse practice settings where they treat many minority patients, both have a vested interest in promoting health education to minority populations while also engaging in ongoing discussion within the medical community itself on how to more successfully serve such patients.

PROSTATE CANCER COALITION

In response to the 2012 USPSTF recommendations against PSA-based prostate cancer screening,⁴⁶ Drs. Bullock and Hall, along with two other colleagues, founded the Prostate Cancer Coalition (PCC)⁴⁷ to bring awareness to this issue. PCC is an independent group that receives some assistance from Siteman and other health entities, but it is operated by physicians looking to promote appropriate prostate cancer screening. The coalition is region-wide and consists of physicians, survivors, volunteers, and other health professionals.

The goals of PCC⁴⁸ include the following:

- Promoting Smart Screening, an effort based on the American Cancer Society's (ACS) recommendation that men at high risk for prostate cancer (e.g., black men, those with a close family member with prostate cancer prior to age 65) talk with their doctors about the risks and benefits of screening by the age of 45 (or sooner)⁴⁹
- Encouraging frank and informed conversation with health care providers that includes discussion of all options for disease management (including active surveillance) as well as the potential morbidity associated with each strategy
- Developing a better understanding of baseline screening practices of health care providers in the St. Louis region as well as baseline knowledge about high-risk communities in the area
- Determining whether PCC's educational and marketing plans are achieving their goals of increasing baseline knowledge of prostate cancer in high-risk communities, and improving screening practices in high-risk men.

PECaD, the **P**rogram for the **E**limination of **C**ancer **D**isparities, works with multiple stakeholders to eliminate disparities in cancer through community engagement and partnerships, outreach, education, and training. As part of these efforts, PECaD hosts community screening events and develops cancer prevention and awareness materials for the community.

Minority Patient Participation in Clinical Trials

Washington University is one of the largest recruiting centers for clinical trials run by NRG Oncology, one of five national cancer cooperative groups funded by the National Cancer Institute (NCI).^{50,51} Clinical trials allow researchers to evaluate various interventions for the prevention, detection, and treatment of disease. Given that all patients experience disease differently due to many factors, including age, sex, life experiences, and behaviors, among many others,⁵² diversity in clinical trial participation is critical. While current data indicate increased prostate cancer incidence and mortality rates for African American men compared to Caucasian men across the United States,⁷ African Americans continue to be under-represented in clinical research for cancer.⁵³ Further, current screening recommendations are largely based on trials predominantly tracking Caucasian men.^{30,54}

PATIENT BARRIERS TO CLINICAL TRIALS

Previous research has identified many barriers to clinical trial participation in underrepresented populations; these include barriers related to awareness (e.g., lack of education regarding trials), opportunity to participate (e.g., older age, socioeconomic status, racial/ethnic minority status), and acceptance of enrollment (e.g., due to perceived harm, time commitment, transportation issues, mistrust).⁵⁵ As part of the discussion on clinical trial participation, Dr. Hall described the results of a Washington University and Siteman Cancer Center clinical study to assess barriers to participation in clinical trials. The survey included the following domains:

- Mistrust in the healthcare system
- Religious beliefs
- Role overload (i.e., too much to do: competing priorities, both personal and professional)
- Financial costs of participating
- Awareness (i.e., physician discussing clinical trial with patients)
- Benevolence

A total of 250 surveys were completed, with a majority of responses coming from the genitourinary clinic at Washington University. Seventy percent of respondents were men. Results from this study showed that those with a lower annual income (i.e., less than \$35,000) and less education (i.e., high school/partial college) had greater barriers than others to participation in a clinical trial. The two main barriers identified in the study included role overload and mistrust in the healthcare system. Generally, the survey also found that African Americans, those with lower income levels, and those with lower educational attainment tended to have more mistrust in the healthcare system. In commenting on mistrust, Drs. Bullock and Hall noted that historical barriers such as the Tuskegee study, which serves as a glaring example of clinical malpractice that took place nearly 90 years ago,⁵⁶ still play a role in clinical trial participation today.

PRACTICE BARRIERS TO CLINICAL TRIALS

When asked to reflect on the barriers to physicians in running clinical trials, Dr. Hall pointed to expense and staffing needs as primary barriers. She noted that clinical trials require personnel to guide the trials (e.g., research coordinators, data managers) and funding to finance those positions.

“Clinical trials can help eliminate bias and health inequities.”
- Dr. Hall

At this time, there is a shortage of experienced research coordinators in the field.⁵⁷ A third barrier that Dr. Hall mentioned is the time needed for recruitment efforts. Without a person dedicated to recruitment, such efforts fall on the physician, who typically has an active medical practice outside of trial recruitment. Dr. Hall suggested that such time constraints on the physician's part may lead to implicit bias that could further inhibit clinical trial engagement. That is, given the time necessary to screen and provide every patient with adequate information on trial participation, physicians may make fast judgments based on first impressions and, consequently, not offer trial enrollment to potentially eligible patients. Dr. Hall noted that such bias may be reduced through the use of a research coordinator who is able to pre-screen patients for trials.

Dr. Bullock concurred with Dr. Hall regarding such barriers and shared his own experience with lack of time to discuss trials with patients. He echoed that the only way to recruit for clinical trials with a full day of clinic would be to have a research coordinator present the information to the patient before he even enters the room. An additional benefit of a research coordinator is the ability to present trial information differently depending on the audience. For example, if a patient has a higher level of education (college or advanced degrees) and a healthcare background, the discussion will be very different than if the patient has a lower level of education and no experience in the health field.

BENEFITS TO CLINICAL TRIAL PARTICIPATION

In the context of greater participation in clinical trials by minority patients in general, and in prostate cancer trials by African American men more specifically, Drs. Hall and Bullock discussed both direct and indirect benefits to patients. To illustrate indirect benefits, they pointed to a series of trials studying second-generation anti-androgen therapy that indicated either equivalent or improved survival outcomes in African American men with advanced stage prostate cancer compared to white men.⁵⁸ They emphasized the importance of such results, noting that this is a first for any disease site showing better outcomes in African American men. By ensuring that such trials adequately recruit minority participants, we may gain greater insights into both improved management strategies as well as the reasons for such improved outcomes, thereby helping to achieve health equity in this disease space.

Dr. Hall also discussed potential direct benefits of clinical trial participation, suggesting that participants may experience improved outcomes compared to those who do not seek trial-based management options. Drs. Hall and Bullock hypothesized this could occur due to the more robust workup and proper staging during the diagnosis required of clinical trial participation, which would lead to uniform treatment that is specific to the patient's stage of disease. They also noted that if a patient were to relapse during a trial, it is likely to be found earlier, resulting in more expedient treatment initiation compared to those who do not participate in trials.

Noting that poorer outcomes in prostate cancer patients are related to lack of adequate treatment, Dr. Hall pointed to guideline-directed care as another benefit that minority patients receive when participating in trials. Specifically, she observed that the control arm in a clinical trial typically receives guideline-directed standard of care, and the investigational arm is thought to be equivalent to or better than the current standard care. This,

coupled with the focus of a dedicated medical team that is actively engaged in participants' treatment and follow-up, means that outcomes for trial participants may be improved compared to those whose care is provided in the community setting.

Screening and Prevention

Throughout the interview, Drs. Hall and Bullock spoke extensively on their efforts to improve rates of screening for prostate cancer, particularly among African American men. As a backdrop to this discussion, they touched briefly on the lack of formal training on health disparities during their medical school education and noted that many of today's practicing physicians have not been exposed to discussions of differences in health outcomes for particular disease states as part of their formal training. However, they noted that we now have a better understanding of such differences and of how various social factors such as education and income impact health outcomes. As such, they noted that conversations on social determinants of health, which according to some estimates account for as much as 55%⁵⁹ of health outcomes in the United States, are now more common than ever.

Nonetheless, compared to other cancers such as breast or colon cancer, where 76.4%⁶⁰ and 71.6%⁶¹ of age-eligible patients are screened, respectively, only 39% of age-eligible men participated in prostate cancer screening in 2018.⁶² Drs. Bullock and Hall suspect that this is likely due in part to prior recommendations against screening, rates of which steadily dropped in the immediate aftermath of the 2012 USPSTF recommendation, particularly among younger black men.⁶³

When conducted, PSA screening can result in an average of 5-7 year lead time for an earlier diagnosis of prostate cancer, leading to the concern that a reduction in screening will lead to a shift in diagnoses from early stage disease to more advanced stage disease.⁶⁴ In 2018, the USPSTF reversed its 2012 guidance advising against PSA testing, instead recommending individual decision-making regarding testing for men 55 to 69 years of age.²¹ Since then, there has been some increases in screening with PSA.⁶⁵ However, increasing screening, particularly in high-risk populations, likely will require a multi-pronged approach aimed at both physicians and patients.

PHYSICIAN OUTREACH

Drs. Bullock and Hall emphasized the importance of outreach to other physicians to help drive change in behaviors related to prostate cancer screening. Discussing the benefits of screening with medical interns or primary care providers may have a significant impact on future screening practices of the community as a whole. If physicians are reminded to screen for prostate cancer via PSA, it could help to reverse the trend towards more advanced cancers discovered at the time of diagnosis. To this end, Dr. Hall created and sent an informational card to all physicians in St. Louis County, including primary care providers who perform PSAs, that reminds physicians of the importance of screening for prostate cancer.

EHR MODIFICATIONS

In discussing prostate cancer screening, Drs. Bullock and Hall often referenced the tremendous progress made in the area of breast cancer screening. As an example of a method used to increase screening for breast cancer, they described a pop-up message in the electronic chart that is displayed during a woman's appointment if she is overdue for a mammogram (and eligible for screening). Drs. Bullock and Hall lobbied

**"Incorporating the pop-up in EHRs is the most beneficial intervention to increase prostate cancer screening after training physicians."
– Dr. Bullock**

for a similar intervention that reminds clinicians to discuss PSA screening with eligible patients. To date, this functionality has been implemented in the EHR systems of 10 different hospitals and has yielded an increase in PSA screening of an estimated 80%, according to unpublished data cited by Dr. Hall. However, they noted the challenges faced in implementing this PSA reminder system in the EHR, including “competition” for changes to the EHR that were desired by others and the overall length of time required for implementation. While this may seem like a simple update, they noted that the process required more than 18 months to implement. Despite the effort, Dr. Hall and Bullock stated that the PSA screening recommendation in the health maintenance section of the EHR has been a tremendous success. When comparing to results from other time-consuming educational events such as grand rounds and physician dinners, they noted that the rapid increase in PSA screening was substantial across all hospitals in the system and across various demographic groups.

PATIENT OUTREACH

Drs. Bullock and Hall also discussed the importance of engaging men in their own healthcare to empower them to make well-informed medical decisions. As part of their work with PCC, they developed Our Healthy Men, a podcast series that can be found on the PCC website,⁶⁶ as well as on other sites such as Spreaker and iTunes. This podcast focuses on prostate cancer, with each episode going into detail about different aspects of care related to the prostate. They have also begun a weekly radio show. They hope that these weekly shows will also be made into podcasts, which will eternalize them on the internet. It is the hope that such efforts will increase awareness surrounding the risks of prostate cancer and the importance of early detection.

Reducing Financial Barriers

Drs. Hall and Bullock also discussed financial barriers as a driver of disparities in prostate cancer care and outcomes. They noted that while increasing screening for prostate cancer can help identify early stage cancer and improve patient outcomes, many patients may still skip screening due to perceived financial barriers. While setting up free PSA testing in the community (e.g., church, local recreational centers) aids in screening, Drs. Hall and Bullock believe that more formalized programs are needed not only to promote screening, but also to aid patients in obtaining further reflex testing and biopsy, if needed. Again, looking to the example of breast cancer screening, they noted the success of the National Breast and Cervical Early Detection Program.⁶⁷ This program provides free breast and cervical cancer testing to eligible women and includes free diagnostic evaluation like biopsy if the test results are abnormal—yet no such national program exists for prostate cancer. Currently, if a man goes to a free prostate cancer testing site and receives abnormal results, he likely would have to check with local hospitals to see if any charitable funds are available for biopsy and potential further treatment. To address this common issue, California started the IMPACT program (**IMP**roving **A**ccess **C**ounseling and **T**reatment for Californians with Prostate Cancer), which aims to provide high-quality prostate cancer treatment to men with low-income or little/no health insurance.⁶⁸ IMPACT is designed to evaluate and treat patients in their local communities across California. Eligible patients are referred to participating doctors to receive up to 12 months of prostate cancer treatment services with hopes of having improved outcomes.⁶⁹

“Patient compliance and follow-up is related to socio-economic status.”

—Dr. Hall

KEY TAKEAWAYS

Drs. Hollowell, Hall, and Bullock described a variety of interrelated strategies they have used to improve prostate cancer care and outcomes, particularly among vulnerable populations. Although the operational details vary substantially, the strategies include employing community- and provider-based advocacy and engagement to increase appropriate prostate cancer screening; offering tailored education to promote health literacy, enable shared decision-making for screening and treatment, and increase participation in clinical trials; and facilitating use of available financial assistance opportunities and advocating for additional options. Importantly, innovative use of technology has figured prominently in several of these efforts to date.

STRATEGIES FOR ADDRESSING DISPARITIES IN ADVANCED PROSTATE CANCER CARE

Employ community-, system-, and provider-based advocacy and engagement to increase appropriate prostate cancer screening

- Offer community-based outreach that is tailored to men
- Encourage men to be involved in, and take charge of, their own health
- Provide opportunities for free screening
- Educate and collaborate with primary care providers on PSA screening
- Incorporate PSA screening reminders in EHRs
- Educate providers in health and healthcare disparities

Offer education that is tailored as needed for individual patients and provided at the right time in their care journey

- Provide interpreter services to patients as needed
- Develop/use videos and podcasts that offer tailored content on the diagnosis and treatment of prostate cancer
- Promote true shared decision-making by being transparent about changes in screening guidelines and clearly explaining implications of screening (or not) on future care decisions and outcomes
- Systematically assess barriers to participation in clinical trials
- Recruit/fund additional staff positions to promote recruitment and education for clinical trial participation
- Clearly explain the direct and indirect benefits of clinical trial participation, particularly to minority patients

Facilitate use of available financial assistance opportunities so that patients have equal access to guideline based care, and advocate for additional options

- Utilize medical assistance programs provided by pharmaceutical companies
- Assist with Medicaid eligibility determinations and enrollment
- Facilitate enrollment in other available financial assistance programs
- Advocate for creation or expansion of additional financial assistance programs

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