



The Equity Equation

Eliminating disparities in cancer screening will require outreach, availability and cultural consideration

By Melba Newsome

LA SHAWN FORD HAS ALWAYS BEEN METICULOUS about his health. He ate well, exercised regularly and never smoked. But last year, when the 48-year-old Illinois state representative learned that actor Chadwick Boseman had died of colon cancer, he decided to take his health-care game up a notch. In October 2020 Ford scheduled an appointment with his primary care physician for a colonoscopy and, while he was at it, a prostate cancer screening, too.

The colonoscopy came back clean, but his doctor refused to order the prostate-specific antigen (PSA) test, saying Ford wasn't in the recommended age range for screening. Although Ford had no indication that anything was amiss, he found another doctor to help him get the simple blood test.

Men with a PSA level between 4 and 10 have about a one-in-four chance of having prostate cancer. That risk goes to one in two if the level is above 10. Ford's was 11, so high that his physician ran the test again to confirm. This time it registered a PSA of 12.

Black men like Ford are disproportionately diagnosed with, and die from, prostate cancer, says Edward M. Schaeffer, chair of the urology department at the Northwestern Feinberg School of Medicine. "I'm surprised that if you're a Black man and you say to your doctor 'I want to get screened for prostate cancer because I'm at higher risk' that they would say no," he says. "That's kind of shocking to me, but I do see people like Representative Ford in my clinic not that infrequently."

Ford's subsequent blood work and MRI found further irregularities, and a biopsy confirmed that he had prostate cancer. Schaeffer performed a radical prostatectomy to remove Ford's entire prostate gland. Months later he was declared cancer-free.

"My cancer was already in an aggressive stage. It covered a lot of my prostate, but fortunately it was still contained," he says. "If I had not advocated for myself and waited until I was 50, it could have been too late."

His experience illustrates two things: cancer screening can save lives, and cancer screening is not accessible for everyone who needs it. People of color, those of low wealth and residents of rural areas tend to be most vulnerable to screening disparities for reasons that are complex and often interrelated. Cost and lack of access, health illiteracy, implicit bias, and both cultural and structural barriers all play a role, as do disparities in cancer risk and vast differences in how screenings are integrated into patient care. The result is that too many cancers are detected too late, leading to too many avoidable deaths.

According to a report on cancer disparities from the American Association for Cancer Research, people of color receive significantly fewer recommended examinations than white people and are more likely to be diagnosed with advanced disease, lowering their chances of survival. "Cancer screening has huge inequities in this country," says Derek Raghavan, president of the Levine Cancer Institute in Charlotte, N.C. "The screening for breast, colon,

prostate and lung cancer is way below what it should be in the African-American and Latino populations. If we could fix that, we could improve the death rate from cancer dramatically."

ONE SIZE DOES NOT FIT ALL

MEDICAL SOCIETIES AND EXPERT PANELS constantly reassess their screening guidelines in response to new research, using updated models and the most recent data. The result, however, may be confusing and seemingly inconsistent guidelines about who should be screened and how often, leaving many primary care providers unaware of the latest recommendations. It can mean huge variations in how these screenings are implemented—among both individual physicians and large health systems—as well as in how insurance companies reimburse for them. It can also mean huge variations in which patients receive the screenings they need.

Perhaps even more concerning, researchers such as Schaeffer say, is that medical groups often have homogeneous guidelines that do not account for variations among racial groups. With breast cancer, for instance, recent studies indicate that the incidence rate is higher in Black women younger than 45 and among white women older than 60. Yet the U.S. Preventive Services Task Force (USPSTF) and several other medical groups do not differentiate by race and recommend mammography screenings begin at age 50 for those at average risk. This does not acknowledge that Black women tend to have a more aggressive type of breast cancer that strikes at younger ages, argue researchers in a recent report in the *Journal of Breast Imaging*. For this group, those researchers recommend starting annual screening at age 40.

"The data surrounding the disparate incidence of breast cancer in Black women under 40 is compelling and must be considered as we look at cancer screening and diagnosis through the lens of health equity," says Monique Gary, chief medical adviser for Touch, the Black Breast Cancer Alliance and medical director of the cancer program at Grand View Health in Pennsylvania. "The current guidelines are an example of what happens when we 'don't see color.' They potentially place an already vulnerable group at significant risk for greater harm."

Similar disparities exist in cervical cancer. In 2018 both the USPSTF and the American Cancer Society (ACS) were recommending that women between the ages of 21 and 65 get a Pap smear every three years. Women between 30 and 65 were advised to have both a Pap and an hrHPV test, which screens for the presence of high-

risk human papillomavirus—a major risk factor for cervical cancer—every three (ACS) to five (USPSTF) years. As though that weren't confusing enough, the ACS changed its stance in September 2020. Because cervical cancer is so rare in younger women, it suggested testing for hrHPV only and starting at age 25 rather than 21. The reasoning was that getting the more accurate HPV test every five years can reduce the risk of cervical cancer more effectively than a Pap test done every three.

That is troubling for some clinicians, who attribute disparities in cervical cancer incidence and mortality to lower access to screening. The incidence rate of cervical cancer among Hispanic women is 32 percent higher than for white women, and Black women are more likely to die of cervical cancer than any other racial or ethnic group. Limiting screening options could undermine cancer-prevention programs in vulnerable populations. If the new guidelines—which increase the suggested age of first screening—are widely adopted, insurers are likely to change reimbursements to match, something that could further decrease screening rates in the most underserved communities.

As Ford discovered last fall, screening guidelines strongly influence who gets referred for screening and what tests insurance providers will cover for whom. The trouble is that those guidelines are based on clinical trials conducted with subjects who are predominantly white.

Research shows that Black people are at a higher risk of lung cancer even if they smoke less over time, and their inclusion in clinical trials could have a significant impact on any screening guidelines that result. Raghavan points to the 2011 National Lung Cancer Screening trial, which studied more than 53,000 current or former heavy smokers to determine the cost and effectiveness of a form of screening called low-dose computed tomography (LDCT). Fewer than 5 percent of their participants were Black. A European trial on the same topic, the NELSON lung cancer study, also studied LDCT screening with 7,557 participants. The researchers made no mention of people of African ancestry.

Clinical trials investigating the benefits of prostate cancer screening also excluded Black men, despite greater incidence and mortality in this population. These trials, which consisted exclusively of white men, showed little or no benefit from PSA screening. As a result, in 2012 the USPSTF—concerned about overdiagnosis and treatment of small, benign or slow-growing cancers—recommended against using prostate cancer screening for anyone. The organization partially reversed its decision in 2018, recommending instead that for men age 55 to 69, screening decisions should be left up to the individual.

But some researchers are finally beginning to acknowledge the importance of diversity both in clinical trial participation and in establishing more relevant screening guidelines. A 2019 study in *JAMA Oncology* found that fewer Black smokers with lung cancer met the criteria for screening than white smokers with the disease. That is because Black smokers develop lung cancer at younger ages

and at higher rates than white smokers. The researchers found that 68 percent of Black smokers were ineligible for screening at the time of their diagnosis, whereas 44 percent of white smokers were.

The USPSTF cited the study earlier this year as a factor in lowering its recommended screening age for lung cancer, from age 55 to 50, and reducing the number of pack years (years of smoking multiplied by the number of packs smoked per day) from 30 to 20, greatly expanding potential access. Nevertheless, only 5.7 percent of those at high risk are actually screened, in part because of the dearth of screening centers and lack of awareness.

THE COST BARRIER

IMPROVING ACCESS TO, AND AWARENESS and affordability of, cancer screenings is what the Lung Bus was built to do. This 35-foot motor coach is the brainchild of the Levine Cancer Institute and is equipped with an LDCT scanner to serve people in local North Carolina communities with the highest risk of advanced lung cancer. These patients traditionally tend to have high rates of inoperable lung cancer, and they may also face transportation barriers or lack insurance.

**“You can overcome disparities of care
if you really want to.”
—Derek Raghavan *Levine Cancer Institute***



Herbert Buff is one of them. Buff, 58, had smoked for more than 20 years but did not know it was possible to screen for lung cancer. In 2018 Buff went to the clinic in Morganton, N.C., for a routine doctor visit and casually mentioned that he sometimes had problems breathing. His doctor suggested a free screening on the Lung Bus. Buff's quick, noninvasive exam revealed a nickel-sized growth on his left lung that was later diagnosed as stage 1 lung cancer and was cured by surgery alone.

Since its first voyage in March 2017, the Lung Bus has achieved remarkable success in addressing health disparities. “We have used the bus exclusively to screen uninsured and underinsured people and the rural poor,” says Raghavan, noting that they launched their screening program specifically to tackle the accessibility issues they saw in their patient population. They published the initial results in the *Oncologist* in 2020. “Our data show that of the 1,200 people we screened, 78 percent were rural poor and 20 percent were Black Americans. We found 30 lung cancers, of which 21 were at the potentially curable stage,” he says. “You can overcome disparities of care if you really want to.”

Cost factors into other screenings, too. The most advanced, ac-

curate technologies for breast and cervical cancer screenings are more expensive and less accessible. Rural and underresourced areas are most likely to lag in getting the newest technology. Screening guidelines have long recommended HPV testing in conjunction with the Pap test, and randomized clinical trials have shown it results in better detection, fewer false positives and decreased mortality than Pap smears alone. But HPV testing is limited in the communities that have disproportionately high rates of cervical cancer incidence, morbidity and mortality.

Three-dimensional mammograms are another advance that has been more accessible to those with means, despite the fact that doctors say traditional mammograms are still the standard for all patients. The technology, which digitally sews numerous two-dimensional scans into a detailed 3-D image, can detect more cancers with fewer false positives than traditional mammography. But it's only selectively available. According to a study published in *JAMA Network Open*, Black and Latina women, as well as those who have less education and less income, have not been able to obtain 3-D mammography as easily as women who are white, are well educated or have a higher income. Clinics that serve these patients simply do not have the necessary tools. "[The] equipment is more expensive, and it's not available everywhere," says Diana Dickson-Witmer, a breast surgeon and head of the BeeBe Center for Breast Health in Rehoboth Beach, Del.

STRUCTURAL AND CULTURAL BARRIERS

IN THE DECADE since the passage of the Affordable Care Act in 2010, more Americans than ever have gained access to health insurance. Expanded government coverage has gone a long way toward making cancer-screening access more equitable by eliminating many out-of-pocket costs, according to research by the ACS. As just one example, a report in the *Journal of Cancer* in July 2020 found that U.S. states that expanded Medicaid had fewer men with high PSA results, indicating they were getting screened earlier than those living in states that had not expanded Medicaid. In this case, at least, insurance appeared directly correlated to better screening outcomes.

Addressing cost is a good start, says Tomi Akinyemiju, a cancer epidemiologist and associate director for community outreach and engagement at the Duke Cancer Institute. Akinyemiju explores the interconnection of race, ethnicity, income and access to health care and develops outreach strategies for communities in North Carolina. "People in Black, Hispanic or Latinx communities are less likely to have received the screening that they are eligible for," she says. "Affordability ... is a big reason, especially for minorities and those of low income, but there are also other really important dimensions separate from the cost."

Eliminating screening disparities requires tackling structural barriers, Akinyemiju says. These can include knowing the location of the nearest facility, being able to get there and setting up hours that accommodate people with inflexible work schedules.

Education—of risk factors and, consequently, what screening is needed and when—is yet another structural issue. Many people lack basic understanding or a primary care provider to help inform them. When Tanya Weaver, an independent community health advocate, began working to get breast cancer screenings

for underserved Black women in Portsmouth, Va., more than a decade ago, many did not even understand what care they needed or whom they should contact for information.

"Many of the women couldn't even pronounce the word 'mammogram,' and some confused mammograms with having breast cancer because no one had educated them," Weaver says. "When the city sent out informational pamphlets, they were all earmarked for the more affluent areas of Portsmouth."

Even once someone gets past all that, Akinyemiju says, interactions with providers are vital, too. "Do they talk down to you? Do they explain things in language that is easy to understand? Do they answer your questions respectfully and show concern and care for you?" If not, she says, then patients are far less likely to return for future screenings.

That is precisely what Weaver has seen with the women she works with. She arranged free mammograms for them at a local hospital, never imagining they would be derided for taking care of their health. "Many of the women came back dejected and said they would never go back because they felt like they weren't wanted there," Weaver says. "They overheard one person say, 'They keep coming in here with these coupons to get a free mammogram.'"

Today there is growing evidence—medical, epidemiological and sociological—that cancer-related disparities are closely linked to extensive influences known as social determinants of health, which involve the conditions in which people live and work that affect their health risks and outcomes. There is also a growing understanding by clinicians and other health-care providers that helping those most affected will require focused and coordinated social action. Academic institutions and health-care systems around the country are building multidisciplinary programs that prioritize health equity so that the most vulnerable people get the cancer screening tests they need.

One of those programs is at Northwestern, where Ford received his care. Northwestern Medicine's Project HOPE (Health Outreach Promoting Equity) educates local communities in the Chicago area about health disparities, aiming to increase equity in health outcomes. During primary care screenings, doctors now routinely talk with their patients about how they are doing financially and socially. They ask them to describe their living conditions to better understand and address any underlying issues. Ford, now a vocal proponent of regular health checks and of being one's own medical advocate, works with Project HOPE to reach others in situations similar to his.

Today Project HOPE and other programs are identifying ways to help close the cancer-equity gap, in screening and beyond. Patients who have good information, who are treated with respect and kindness, and who have people to help guide them through a confounding process are able to make better decisions, Schaeffer says. "By beginning to identify these different social determinants of health, we can impact this and make a difference," he says. "There are glimmers of hope for continued progress."

Melba Newsome is an independent journalist in Charlotte, N.C., whose work has appeared in *Prevention*, *Newsweek*, *Wired*, *Politico*, *Yale E 360*, *Oprah* and the *New York Times*, among other publications.