Health Disparities in Focus

A Series by:

Real World Health Care

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People of color and other underserved groups have faced longstanding disparities in health, health care and health coverage.

Health Disparities in Focus is a recently published series of articles that explores the issue of racial and ethnic health disparities, providing insights from patient support organizations working to address and eliminate these disparities.

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Dramatic Health Inequities Are Pervasive across the United States

A study published by the Commonwealth Fund in late 2021 found that health systems across the United States are failing people of color. According to the study, *Achieving Racial and Ethnic Equity in U.S. Health Care: A Scorecard of State Performance*, Black Americans in nearly every state are more likely than white Americans to die from preventable and treatable conditions exacerbated by lack of timely, high-quality health care.

Even among high-performing states, racial and ethnic health disparities can be dramatic, according to the study. For example, Minnesota's health care system, which has historically performed well in Commonwealth Fund state scorecard rankings, has some of the largest health disparities between white and nonwhite communities. Maryland, Massachusetts and Connecticut are other traditionally high-scoring states where white residents receive some of the best care in the country, but where quality of care is far worse for many populations of color. Similarly, in states like Mississippi and Oklahoma whose health care systems have historically performed poorly for both white and Black populations, white patients still received markedly better care.

According to the study's authors, structural racism and generations of disinvestment in communities of color are chief among many factors contributing to pervasive U.S. health inequities. They note that as the COVID-19 pandemic has shown, people in many communities of color are more likely than members of white communities to live in poverty, work in low-paying, high-contact industries, and to reside in high-risk living environments. Many Black, Latinx/Hispanic, and American Indian/Alaska Native (AIAN) populations then face an unequal health system when they need access to care. They are less likely to have health insurance, more likely to face cost-related barriers to care and medical debt, and more likely to receive suboptimal care.

Commenting on the study, one of its co-authors and Commonwealth Fund's Vice President for Advancing Health Equity, Laurie Zephyrin, MD, said, "The U.S. health care system is not immune from the systemic inequities that plague American society. Our health care is characterized by long-standing disparities in access, quality and outcomes for people of color that were unveiled for many by the COVID-19 pandemic. We can do better, and we can start by tackling systemic racism, ensuring people have the health coverage they need, and resolving racial disparities in care."

Disparities in Health and Health Care: Key Questions and Answers from the Kaiser Family Foundation

The issue of health care disparities is a complex one, with broad implications that are beyond the purview of this blog to cover in their entirety. Experts at the Kaiser Family Foundation have created an issue brief that provides a good introduction to what health care disparities are, the status of disparities and how COVID-19 has affected them, the broader implications of disparities and current federal efforts to advance health equity.

Several key points of the brief are summarized below, and subscribers can click here to read the full brief.

What are health and health care disparities?

- Health and health care disparities refer to differences in health and health care between groups that stem from broader inequities.
- Health equity generally refers to individuals achieving their highest level of health through the elimination of disparities in health and health care.
- A broad array of factors within and beyond the health care system drive disparities in health and health care.
- Health and health care disparities are often viewed through the lens of race and ethnicity, but they occur across a broad range of dimensions.

What is the status of disparities?

- Prior to the COVID-19 pandemic, people of color and other underserved groups faced longstanding disparities in health, health care and health coverage.

How has the COVID-19 pandemic affected disparities?

- Data consistently show that AIAN, Black, and Hispanic people have experienced disproportionate rates of illness and death due to COVID-19.
- Beyond the direct health impacts of the virus, the pandemic has taken a disproportionate toll on the financial security and mental health and well-being of people of color, low-income people, LGBT people and other underserved groups.

What are the broader implications of disparities?

- Addressing disparities in health and health care is important not only from a social justice and equity standpoint, but also for improving the nation's overall health and economic prosperity.

Over the coming year, *Real World Health Care* will explore the issue of racial and ethnic health disparities, bringing you insights from patient support organizations working to address and eliminate these disparities. If you would like to share your organization's story with our subscribers, please reach out to us via email.

Precision Medicine: Eliminating Disparities in Lung Cancer Care

Precision medicine – treatments that are based on an individual's specific genetics and the cancer cell’s genes - holds great promise for lung cancer patients. For all patients, precision medicine is made possible through a type of advanced diagnostic testing called biomarker testing. However, for some racial and ethnic minorities, the promise of precision medicine may be out of reach due to barriers in accessing biomarker testing.

Biomarker testing (also called tumor testing, tumor profiling, or tumor genetic testing) is a way to look for genes, proteins and other substances that provide unique information about a person's cancer and how it grows. It can help determine which cancer treatments are most likely to help and which are not likely to help. It is different from genetic testing, which is used to find out if someone has inherited mutations that make them more likely to get cancer.

In non-small cell lung cancer (NSCLC), there are 37 biomarker-driven treatment options approved for NSCLC patients (as of February 3, 2021) for 9 different biomarkers. Yet in spite of these advancements, lung cancer survival rates are lower for Blacks than whites. Moreover, according to research published in 2021 at ASCO, Black patients get biomarker-tested at a rate more than 10 percentage points lower than that of whites.


Nikki Martin, LUNGevity Foundation

The problem, according to Nikki Martin, director of Precision Medicine programs at LUNGevity Foundation, is that while patients of all backgrounds are largely unaware of the existence of biomarker testing and the possibility of precision medicine treatments at the time of diagnosis, patients from underserved communities face more barriers in accessing biomarker testing, which will connect them to the appropriate targeted treatment, immunotherapy, clinical trial or other appropriate care plan. Lower socio-economic status (SES) patients, including Black/African American and Hispanic Latino patients, experience more barriers early in the diagnosis process. For example, they are more likely to request biomarker testing from two or more doctors. Providers may not recommend testing based on perceived levels of patient-specific factors such as socioeconomic status, age, race/ethnicity and health literacy.

"When new advances are introduced in the field of medicine, we tend to speak about them in a positive fashion," Martin said. "But they are only positive for the people who are able to access them. Unfortunately, new advances often create additional health disparities instead of reducing or eliminating disparities."

Identifying Barriers to Equitable Precision Medicine Access

In 2020, LUNGevity, along with the Association of Community Cancer Centers, conducted a study that included paired clinician and patient perspectives on the use of biomarker testing. The study's goal was to identify barriers to equitable precision medicine access among underserved patients with NSCLC.

Among the clinicians surveyed, most said they would discuss biomarker testing with their patients, however the likelihood of ordering guideline-concordant testing decreased for patients with lower socioeconomic status and health literacy – two groups that are more likely to be comprised of racial and ethnic minorities.

"Our research tells us that people with a household income below $50,000 a year are less likely to have a positive experience in gaining access to biomarker testing and targeted therapies," Martin said.

Among two patient panels surveyed, those in the more racially diverse and lower income cohort were less likely to report receiving biomarker testing and less likely to know of their results if tested. They also reported less confidence in asking their doctor about why biomarker testing was not performed.

"Patients connected to a patient advocacy group like LUNGevity were significantly more likely to receive biomarker testing, suggesting a strong role for patient advocacy groups to help drive guideline-concordant testing among underserved groups," Martin noted.

Breaking the Barriers

According to Martin, the study provided an important data point to support the need to expand and enhance patient education and patient-provider communications related to biomarker testing. To that end, LUNGevity and ACCC have embarked on development of an interventional care sequence plan to increase the rate of biomarker testing for patients with lung cancer in underserved communities.

The interventional care sequence plan is based on the 4R Oncology Model, a four-step cancer care delivery model that focuses on the **R**ight Information and the **R**ight Care for the **R**ight Patient at the **R**ight Time. It includes development of a tool that details the interdependent sequence of events and conversations in the cancer diagnosis and treatment process. The intuitive tool is designed to make it easy for patients to understand where they are in the process. According to Martin, this type of tool has been used successfully in the breast cancer community, and patients consistently rate it highly in surveys.

The tool, developed in conjunction with oncologists and oncology care teams at the sites where it will be deployed, is currently being piloted at three ACCC care centers. Later, a scalable, generalized version will be created for broad implementation at community cancer centers nationwide.

LUNGevity also is developing a series of patient-friendly, plain-language educational materials about biomarker testing and why it's important to wait for test results – which can often take upwards of a month – before determining and moving forward with a course of treatment.

"We want all cancer patients to feel comfortable having these 'care sequence' conversations with their provider and to receive appropriate information geared to their health literacy so they can take an active role in care decisions," Martin said. "We also want patients who are worried about the costs involved with biomarker testing and precision medicine treatments to know that there are financial resources available to help and that they should discuss their financial concerns with their care team's financial navigator or social worker. Cost should never be a barrier to care."

Reaching Underserved Communities

The research and intervention program with ACCC is just one way that LUNGevity is driving awareness of comprehensive biomarker testing among the NSCLC patient community. The Foundation also is spearheading No One Missed, a campaign to build public awareness and empower patients. Later this year, LUNGevity will extend the campaign to specific cities around the U.S. to educate patients and providers about biomarker testing. Each city will have a custom approach to reach underserved populations by working with Black and Latinx community organizations.

For patients who have received biomarker testing and results, LUNGevity created a resource called Lung Cancer Patient Gateway, a user-friendly web portal that offers the latest medical updates and potentially lifesaving resources for people living with various lung cancer markers. Portals will also be available for people with NSCLC who don’t have a mutation and for people with small cell lung cancer. The portal helps patients learn about their mutation, find a specialist, join a variety of online communities, explore clinical trial options, and read up-to-the-minute, curated news and trends.

"We understand that internet access can be a challenge in some homes," Martin concluded. "We encourage patients without reliable broadband access or a home computer to find resources through community centers so they can access this interactive resource to share their stories and learn from the experiences of others just like them."

Are All Gout Patients Getting the Treatment They Need?

More than 9.2 million Americans live with gout, but only 10 percent of people with gout are getting the ongoing treatment they need. The lack of proper treatment is particularly acute among Black patients, who have a 25 percent higher prevalence of the disease but are much less likely to receive the uric acid-lowering therapy that keeps the condition in check.

What is Gout?

Gout is the most common form of inflammatory arthritis and is caused by a buildup of uric acid in the blood. If left untreated, this serious, lifelong disease can lead to permanent bone, joint and tissue damage, as well as heart disease, kidney disease and an overall decline in quality of life.

According to the Gout Education Society, the signs and symptoms of gout almost always occur suddenly, and often at night. They include:

- **Pain and swelling** – usually in one or two joints in the feet or legs, most commonly the big toe. During a gout flare, the intensity of the pain is usually described as excruciating (8 to 10 out of 10).
- **Limited joint function** – After five or more years of recurrent flares, people with gout may develop tophi crystals under the skin and around joints. While generally not painful, tophi can be disfiguring and interfere with normal joint function. The presence of tophi close to bones can lead to bone and cartilage destruction, creating further deformities in the affected joints.
- **Chronic persistent arthritis** – During the early stages of gout, the inflammatory arthritis is intermittent and during the periods between flares, joints may feel and function normally. Years to decades after the initial flare, flares become painful on a daily basis.

Risk Factors for Gout: Myths and Facts

Gout was historically associated with poor dietary and lifestyle habits such as eating rich foods and consuming excess alcohol. As a result, there is a stigma associated with the disease that keeps some people from seeking treatment.

"Many people erroneously look at gout as a self-inflicted disease," says N. Lawrence Edwards, MD, MACP, MACR, board chairman of the Gout Education Society and Vice Chairman and Professor of the University of Florida Department of Medicine. "That creates a bias among providers as well as patients, who think it's their fault and are too embarrassed to talk with their doctor about it. Moreover, because gout has common co-morbidities like obesity, high blood pressure, diabetes and kidney disease – all of which are more prevalent in the Black community – doctors tend to focus on those issues more than gout during patient appointments, thus leaving those patients underserved."

N. Lawrence Edwards,
Gout Education Society

Dr. Edwards and the Gout Education Society point to a list of common risk factors that can lead to gout:

- **Hyperuricemia** – High levels of uric acid (above 6.8 mg/dL) can lead to gout flares. The best uric acid level for a person with gout is below 6.0 mg/dL – regardless of age or gender.
- **Family history** – One in four people with gout has a family history of the disease, yet less than half of people with the disease know it can be hereditary.
- **Age** – Gout can occur in men during their 30s through 50s and in women in their 60s through 70s.
- **Gender** – Gout affects men more often than women – although, once women are post-menopausal, their rates of gout increase almost (but not quite) to the same level as men.
- **Ethnicity** – Some ethnic groups are more likely to get gout than others. This is genetic and varies by ethnicity and other health risks. For example, Hispanics and Blacks are more likely to suffer from obesity, which has been linked to gout.
- **Obesity –** Only one in ten Americans knows that obesity can contribute to an increased risk for gout. Someone with a Body Mass Index (BMI) of 30 or higher is considered obese.
- **Joint injury –** People with previously damaged joints are more likely to have gout flares in those joints.
- **Diet –** Many foods can raise the level of uric acid in the blood, including beer, beef, pork, shellfish and foods or beverages sweetened with high-fructose corn syrup.
- **Medications –** Use of certain medications – especially diuretics or water pills and certain anti-rejection medications used in transplant patients – can increase uric acid levels in the blood.

Barriers to Gout Treatment

While it cannot be cured, gout can be treated – with pain and inflammation medications that can be taken during flares and daily, lifelong uric acid-lowering medications that help lower serum acid levels. During the first few months of uric acid-lowering therapy, patients should see their doctor every two to three weeks, according to Dr. Edwards, who says that treatments typically start with a low dose and then escalate to the most effective dose over time.

Unfortunately, he says, not everyone complies with treatment protocols. He points to a study by the National Medical Ambulatory Care Service which found that only

10 percent of Black patients return for follow up gout-related visits, compared with 82 percent of white patients.

"That follow up is vitally important to make sure patients have their uric acid levels monitored and that they receive the right drug at the right dose to get to the right uric acid level," Dr. Edwards says, noting that unless patients get to that target level, treatment is superfluous. "But between the stigma and embarrassment associated with gout, and the very real barriers of inadequate insurance, lack of transportation, and lower health literacy, some underserved populations aren't receiving the care they need."

The Cost of Gout

As the incidence of gout rises, so do the costs associated with managing the disease – an additional barrier to care for those in lower socioeconomic groups. Direct gout-related health care costs top $12,000 for patients that have six or more flares per year – a sum that is out of reach even for those in higher socioeconomic groups. Elderly and treatment-resistant gout patients can pay upwards of $18,362 to manage their gout.

According to the Gout Education Society, many of these costs can be reduced by understanding the cause of gout and seeking immediate treatment for the disease – right at the first flare.

Financial assistance for gout treatments is available through the HealthWell Foundation. HealthWell's Gout-Medicare Access Fund provides Medicare recipients up to $12,000 in grant assistance with copays for prescription drugs and biologics used in the treatment of gout. Independent of the Gout-Medicare Access Fund, HealthWell also offers travel assistance to all eligible patients living with gout. Through the Gout Travel Fund, the Foundation provides up to $2,500 in assistance for travel related to obtaining treatment for the condition.

Know Your Numbers

Dr. Edwards encourages people who have gout – as well as people who have other conditions that can increase uric acid levels, including obesity, diabetes, hypertension and chronic kidney disease – to know their most recent serum uric acid level. If it is not under 6.0 mg/dL, they should talk with their doctor about how and why to reduce it.

"Gout is one of the most poorly treated chronic diseases," he says. "Only about 15 percent of people with gout stay on an adequate dose of uric acid-lowering medication for their lifetime, which is the treatment period."

He added that the Gout Education Society is conducting outreach and education among primary care physicians (the provider most likely to treat gout in its early stages) to raise awareness of the prevalence of the disease and the need for proper patient intervention, especially for those patients who need advanced treatment.

On May 22, the Gout Education Society will conduct additional gout-related awareness and education efforts in recognition of Gout Awareness Day, an observance the Society created in 2007 to bring more attention to this overlooked disease. Plans this year call for a series of blogs, Twitter chats and Reddit “Ask Me Anything” Q&As (on r/gout and r/medicine) targeted to patients and providers. Visit gouteducation.org for the latest blog posts and follow along on Twitter and Facebook for more details.

Placing Communities of Color at the Forefront of Hepatitis C Elimination

First identified in 1989, the hepatitis C virus (HCV) kills thousands of people in the United States each year. An estimated 2.4 million Americans live with chronic hepatitis C infection, which if left untreated can result in serious, even life-threatening health problems like cirrhosis and liver cancer.

While HCV knows no boundaries of age, gender, race or ethnicity, its outsized impact among communities of color and other marginalized groups are a cause of concern, according to Daniel Raymond, director of policy for the National Viral Hepatitis Roundtable (NVHR).

"When we look at the data for hepatitis C, we see several patterns emerge in terms of disparities among communities of color," he said. "This is especially the case among African Americans, Latinos and Native Americans."

Hepatitis C in the African American Community

African Americans comprise about 11 percent of the U.S. population but account for 25 percent of all hepatitis C cases. Compared with other racial groups, they are less likely to be tested for hepatitis C and less likely to be linked to care after diagnosis. African Americans also are more likely to be deemed ineligible for lifesaving hepatitis C treatment than other racial groups.

Daniel Raymond, National Viral Hepatitis Roundtable

Hepatitis C in the Latino Community

Hispanics and Latinos have faster liver disease progression rates, are more likely to be coinfected with HIV, and contract HCV at an earlier age. They also have a higher HCV mortality rate – nearly two times that of whites.

Hepatitis C in the Native American Community

The American Indian/Alaska Native (AI/AN) community has a higher rate of acute HCV infection and HCV-related mortality than any other racial or ethnic group, along with a higher prevalence of liver disease.

Looking Beyond the Data

Raymond is quick to point out that this data is only part of the story. He said additional societal factors are driving these disparities in HCV risk, testing and treatment.

"Research shows that poverty, homelessness, unstable housing and incarceration can amplify hepatitis C risk," he said. "Communities of color are more likely to be affected by these issues, which in turn, reduces their chances of protecting themselves from hepatitis C and accessing the proper testing and care if exposed or infected. Add to that the difficult or frustrating experiences they may have had with the health care system in the past, and we see a convergence of factors that lead to increased rates of new and chronic infections among these groups."


Adrienne Simmons, National Viral Hepatitis Roundtable

Dr. Adrienne Simmons is NVHR's director of programs. She said communities of color face additional challenges accessing – and affording – care for hepatitis C because they are more likely to be uninsured. Even with insurance, many people face an incredibly cumbersome administrative process that requires prior authorization for treatment. Eligibility requirements vary across insurance companies and can include maintaining abstinence from controlled substances, having a certain amount of liver damage, or receiving treatment from approved specialists. The approved specialist requirement can be particularly difficult for people in marginalized communities who lack access to reliable transportation and can't easily take work absences.

"The hepatitis C advocacy community has been pushing for years for increased access to hepatitis C treatment in state Medicaid programs," she said. "We've made some good strides in this area, with 11 state programs removing prior authorization for most patients. Plus, we've had the Affordable Care Act, which has improved access to care for millions of people in America."

According to Dr. Simmons, evidence of racial and ethnic disparities in hepatitis C treatment has been primarily anecdotal to-date. She hopes future research will illustrate the impact on communities of color.

Implicit Bias Among Providers?

Raymond suggested another factor underlying racial and ethnic disparities in hepatitis C testing and treatment: implicit bias among the provider community. He pointed to recent reports (focused on health care in general, not hepatitis C specifically) that show Black patients are more likely to be deemed negatively by providers, who perceive them as less likely to comply with treatment protocols than white patients.

Raymond worries that these concerns about potential treatment adherence may be unduly amplified among health care providers when considering initiating hepatitis C treatment for African Americans in particular.

"Certain stereotypes may get activated that are unfounded and not relevant to treatment decisions," he said. "Even microlevel biases can reinforce some of the structural disparity factors around access and affordability to create a vicious circle."

Treatments Now More Affordable

Scientists have not yet discovered a vaccine to prevent hepatitis C, but treatments are available, including "direct-acting" antiviral medications that can eliminate all traces of the virus in as little as eight weeks. According to the CDC, current treatments cure over 90 percent of patients with few side effects.

"The cost of these treatments has come down, but out-of-pocket costs for Medicare beneficiaries and commercially insured patients can be significant and out of reach for many," Dr. Simmons said. "People who are uninsured may be able to access treatment at no cost through manufacturer programs."

People with insurance can find financial assistance for hepatitis C treatments through the HealthWell Foundation. HealthWell offers a Hepatitis C Fund that provides up to $30,000 in annual medication copayment or insurance premium assistance for prescription drugs and biologics used in the treatment of the disease.

NVHR: Committed to Supporting Health Equity

NVHR is committed to supporting health equity from both a hepatitis-specific and a broader systemic perspective, to improve the health of those living with or at risk for viral hepatitis.

As an example of their efforts, the organization is currently working with the National Alliance of State and Territorial AIDS Directors (NASTAD) and the National Association of County and City Health Officials (NACCHO) on initiatives to improve the health of people who inject drugs, with a specific focus on racial and ethnic communities that are disproportionately impacted by hepatitis B and C. NVHR will help build a coalition of health departments, community organizations, providers, patients and other partners and will provide technical assistance and training to coalition members around increasing hepatitis C awareness, prevention and testing.

NVHR will also continue advocating for hepatitis C treatment for low-income individuals, many of whom are communities of color, through its Hepatitis C: State of Medicaid Access program.

"Communities of color are a priority in terms of our advocacy, messaging and stakeholder engagement," Dr. Simmons said. "We are a key partner in state and national efforts, and we're encouraged by the health equity strides America continues to make in ensuring nobody is left behind in the race for viral hepatitis elimination."

For additional information about how NVHR is addressing equitable hepatitis C awareness, prevention and testing, visit the NVHR Health Equity web page.

Fighting for Equitable Representation in Alzheimer's Research

Social determinants of health (SDOH) have long-term, far-reaching, and not always obvious ramifications in people's lives, including their risk for Alzheimer's disease and related dementias (ADRD). These disparities were made clear by a 2020 report issued by UsAgainstAlzheimer's and the Urban Institute.

The report found that deep social inequities – in income, health insurance status, education and more – exist in U.S. counties highly impacted by Alzheimer's among Latinos and Blacks. According to the report, these SDOH are "under-recognized and under-appreciated in our national response to effectively treat and prevent Alzheimer's."

The effects of these SDOH are reflected in studies of Alzheimer's prevalence rates, which indicate that 18.6 percent of Blacks and 14 percent of Hispanics age 65 and older have Alzheimer's, compared with 10 percent of white older adults.

Racial disparities continue in diagnosing Alzheimer's. A recent National Institute on Aging (NIA) study found that, although Blacks are 1.5 to 2 times more likely than whites to develop Alzheimer's, they are 35 percent less likely to be diagnosed with the disease when participating in Alzheimer's research studies.

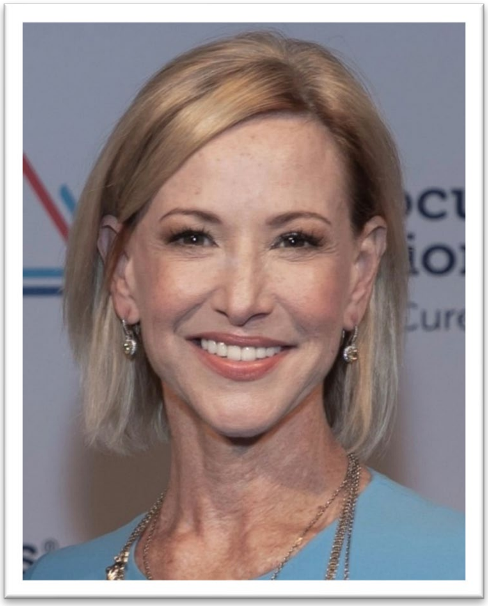
"These diagnosis disparities are only a small part of the story because there are so few Blacks and Latinos engaged in research," said Nancy Lynn, senior vice president, Strategic Partnerships, BrightFocus Foundation. "In fact, they currently make up less than 10 percent of all active participants in ADRD research studies and clinical trials."

A Call for Inclusivity

Lynn estimates that by 2030, more than 40 percent of those with Alzheimer's will be Black and Latino. She said it is imperative for clinical trials to better represent these underserved communities moving forward. BrightFocus, which is currently managing a $36 million global portfolio of over 150 Alzheimer’s research projects, is working to narrow racial and ethnic disparities in Alzheimer's research. One way they are doing so is by removing obstacles minority researchers may face when applying for research grants.

To help more researchers of color enter the Alzheimer's research pipeline, BrightFocus is providing travel fellowships for minority researchers to attend Alzheimer's research conferences and fast-track workshops. In addition to the travel fellowships, BrightFocus is reaching out to Historically Black Colleges and Universities (HBCUs) to make them aware of research grant opportunities.

"The best science and most novel ideas can come from anyone, anywhere, regardless of the researcher's nationality, ethnicity, race or gender," said Lynn, who noted that BrightFocus is working with a range of organizations in government, industry, academia, and local communities to address barriers to participation in clinical research.



Nancy Lynn, BrightFocus Foundation

Brain Info Live

To help raise awareness in underrepresented communities about brain health, Alzheimer's, and the opportunity to participate in research trials, BrightFocus recently launched *Brain Info Live*℠, a series of free, entertaining, interactive online programs customized for diverse communities across the U.S. The Foundation is working with local community leaders and partners to tailor the information and resources in these live-streamed programs to various racial and ethnic cultures. The effort is designed to create a sustained dialogue about Alzheimer's and clinical trials – one that builds trust over time among community members, families, clinicians, researchers, and other health professionals.

"We need to recognize that frightening historic abuses by the medical establishment are not forgotten by communities of color," Lynn said. "To rebuild trust, we need to listen and validate those experiences. We need to *give back* first - information, services, time - before we ask these communities to participate in research. All people want to see themselves represented in the health care setting. Historically, however, most clinical trial recruitment outreach was done depicting white men in white coats standing in front of white boards."

To step away from this model, the *Brain Info Live* programs feature a local "cast" of individuals who reflect the race and ethnicity of others in their community. For example, one early episode targeted to the Boston area featured Mike Kincade of the Massachusetts Alzheimer's Disease Research Center, who is Black and active in local research diversity outreach, as well as Bernice Osborne, a Black woman who shared her experience as an Alzheimer's caregiver successively for both of her parents.

"We work closely with local organizations and community members to help us identify content and approaches that will really provide benefit to, interest, and motivate people from different neighborhoods," Lynn said. "There is no cookie-cutter approach here, even among seemingly homogenous communities. It's clear, for example, that a Latino person who lives in Boston and comes from the Dominican Republic has different and unique cultural touchstones than a Latino of

Mexican background living in San Diego or a Latino of Cuban background living in Miami."

Each *Brain Info Live* session features an "At the Movies" video segment, with clips from multi-lingual films and TV shows with Alzheimer's story lines that are relevant to the topic of the session.

"People learn and develop trust in messaging by being entertained, so the concept of 'edutainment' is central to our efforts and is much more appealing and retainable than a scientific lecture," Lynn said.

Initially launched in September 2021, *Brain Info Live* streams new episodes in various regions across the U.S. every three weeks. Prior episodes are archived for on-demand viewing. Future plans include live events and allowing partners, social services agencies and health care providers to "white-label" the programs for use in their own communities.

BrightFocus also hopes to use *Brain Info Live* as an entry point to on-the-ground efforts targeted to regions in which minorities face high burdens accessing Alzheimer's research opportunities and care. As an example, Lynn pointed to the Rio Grande Valley in Texas, where there is a high prevalence of the disease among Latinos, according to the National Alzheimer's Disease Index™.

"Our goal is to offer long-term, sustained support to these communities, starting with programming through *Brain Info Live*, then moving to memory screenings, clinical trials at local clinics, and additional efforts to make access to care more equitable," Lynn concluded.

BrightFocus Foundation encourages community organizations, social services agencies and health care provider organizations to contact Kait Halibozek for information on how to bring *Brain Info Live* to their constituents.

Cancer Research Belongs in the Community

Studies have shown that cancer disproportionately impacts racial and ethnic minority groups, however, these groups remain underrepresented in cancer clinical trials.[1,2,3] With unique insights into issues facing underrepresented patient populations, the Association of Community Cancer Centers (ACCC) recently developed consensus-driven recommendations to improve diversity, equity and accessibility in cancer research.

The recommendations were released as part of an executive summary report from the ACCC Community Oncology Research Institute (ACORI) Call to Action Summit, a virtual event that brought together more than 120 stakeholders representing oncology programs and practices, research teams and networks, patient advocates, trial sponsors, industry representatives and regulatory agencies.

"The ACORI Summit jumpstarted critical conversations on health equity in cancer care research, including the roles—and responsibilities—oncology programs and practices have to carry out equitable and accessible research," said ACCC Immediate Past President Krista Nelson, MSW, LCSW, OSW-C, FAOSW. "But the most important message we heard was the need to bring the patient and community perspectives into the research process."

Addressing Barriers to Clinical Trial Equity

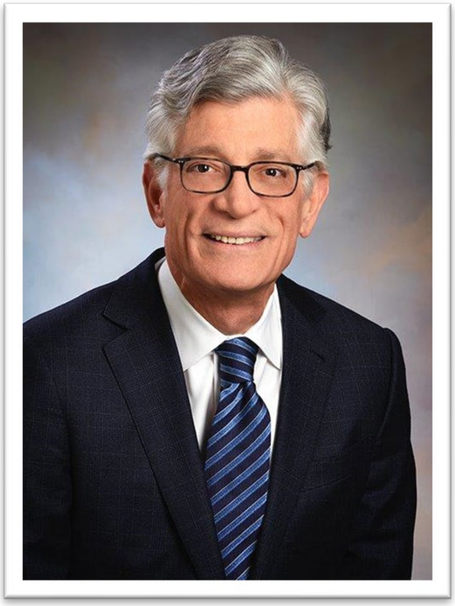
Among other recommendations, the ACORI report asks industry sponsors and others involved in trial design to actively identify and partner with oncology programs serving understudied and underserved patients. It also outlines key action items for oncology programs:

1. Understand the unique needs of their communities, barriers to research participation, and community resources that can help improve trial enrollment and retention.
2. Engage directly with patients and caregivers to embed their experiences and perspectives in the research process.
3. Build capacity to conduct equitable and patient-centered research.

Randall A. Oyer, MD, is medical director of the Ann B. Barshinger Cancer Institute and Oncology Program at Penn Medicine Lancaster General Health and a past president of ACCC. He said community oncology programs and the patients they care for both face challenges ensuring that racial and ethnic minorities and other underserved populations are well represented in the clinical trial ecosystem.

"Community cancer centers may find it difficult to fit clinical trial screenings and discussions into their very busy clinical workflow," he said. "Moreover, their staff may lack adequate training and resources to identify open trials that match the wide range of cancers they care for."

He added that underserved patients – including racial and ethnic minorities – have imposed barriers, including lack of adequate health insurance (underinsurance) and difficulties in traveling to the academic medical centers where most trials take place.


Randall Oyer, Past President, Association of Community Cancer Centers

"Clinical trials must be vetted for safety and effectiveness in patient populations intended to receive the medication or therapy," he said. "When minority groups are not well represented in clinical trials, we don't get to learn about how they fare according to important metrics such as dosing tolerance, side effects and outcomes. Therefore, those patients may not experience the results reported in the trial when following that therapy."

Community Oncology Programs Take Action

Dr. Oyer expanded on the ACORI action items, noting that multiple initiatives are crucial to providing individual patients with equitable, high-quality cancer care – including participation in cancer treatment trials.

"When we involve the communities in which patients live, we have a better understanding of what those patients need," he said. "It also helps create a level of trust among patients and care teams and provides a level of support to help patients manage their care. Patients and their caregivers must be at the center of the entire process so they can inform care teams of their needs and experiences in the medical care system as a whole and with their treatment."

He added that the commitment to equity must start at the top, with clinic leadership providing the appropriate resources, building structured Diversity, Equity and Inclusion (DEI) programs and holding their programs accountable for transparency around health equity outcomes.

At Penn Medicine, where Dr. Oyer practices, leadership clearly communicates the organization's DEI goals, from hiring practices to setting and publishing research inclusion goals. The clinic also takes a race- and ethnicity-blind approach to trial screening.

"We base trial screening on a patient's specific type of cancer and specific stage rather than making assumptions about their trial participation based on race or ethnicity," he said. "At the same time, we construct support systems that make it possible for all patients to enroll in and complete the trial."

While Dr. Oyer said he is encouraged by the inclusivity actions being taken by community cancer clinics, he encourages patients to advocate for themselves as well by seeking information about clinical trials from their physicians and organizations like ACCC.

"Ask your doctor if there's more you should know about your cancer – if there's a clinical trial available," he suggested. "Clinical trials are a key part of high-quality cancer care and with the development of treatments targeted to specific molecular and genetic anomalies, trial participants have up to a 50 percent chance of positive response. In many cases today, clinical trials are a patient's best first option instead of a last option."

About the ACCC and ACORI

The Association of Community Cancer Centers (ACCC) is the leading education and advocacy organization for the cancer care community. Founded in 1974, ACCC is a powerful network of 28,000 multidisciplinary practitioners from 2,100 hospitals and practices nationwide. As advances in cancer screening and diagnosis, treatment options, and care delivery models continue to evolve - so has ACCC - adapting its resources to meet the changing needs of the entire oncology care team. For more information, visit **accc-cancer.org**.

ACORI, the research arm of ACCC, was created in 2021 to close the gap in cancer research by establishing clinical trials as a standard of care in treatment plans and to help achieve equitable cancer care delivery for all patients. To do so, ACORI is focused on making sustainable changes in the way that clinical trials are created, practiced, and discussed in the communities they are representing. Learn more about ACORI and the Executive Summary **here.**

References:

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Driving Equity in Gout Care

Throughout 2022, *Real World Health Care* is covering the issue of racial and ethnic health disparities. This week, we explore the topic through the lens of gout, a type of arthritis that has a higher prevalence among racial and ethnic minorities, especially Blacks, than whites.

Michael Spigler, vice president of patient services and kidney disease education, American Kidney Fund (AKF), shared insights on the special challenges facing those living with gout and how AKF is working to address disparities in access to gout care.

The Gout-Kidney Disease Connection

Real World Health Care: Tell us how the American Kidney Fund supports the gout patient community through programs, services, education and research.

Michael Spigler: Given that kidney disease can cause gout and that gout may also lead to kidney disease, it is important for the American Kidney Fund to educate our community about how the two diseases are related, helping to improve overall health outcomes. One out of 10 people with chronic kidney disease have gout, and an even higher percentage of people with gout have kidney disease. Many people with kidney disease have uncontrolled gout, which can make kidney disease worse and lead to other complications.

AKF's educational campaign Goutful, helps patients develop an understanding of their risk for gout, its relationship to chronic kidney disease and the necessity of treating gout as a chronic disease, rather than a series of acute episodes. Goutful, a blend of the words "gout" and "doubtful," debunks popular misconceptions about gout and helps chronic kidney disease patients understand their risk for gout. The campaign fills an information void for patients, who often face significant stigma because gout is commonly misunderstood and misperceived as being caused by overindulgence.


Michael Spigler, American Kidney Fund

The campaign includes a range of resources for renal professionals and patients, including a "Myths & Facts" quiz to debunk many of the misconceptions about gout. The campaign also features a wealth of online information to support and educate patients, including original videos and information to help people navigate conversations with a doctor. More campaign information and a variety of resources are available at KidneyFund.org/Gout.

Take Gout Seriously

RWHC: What are some of the biggest challenges people with gout face in terms of accessing proper care, complying with treatment protocols and affording their treatments?

MS: One of the biggest challenges people with gout face is that gout is often not taken seriously, although it can be excruciatingly painful. The patient is sometimes blamed for the condition because it is perceived to be a result of the patient's choices, but gout is not a patient's fault. Gout attacks, also known as flare-ups, may occur when the body creates too much uric acid or cannot properly clear uric acid. There may be certain foods patients should limit if they are prone to gout, and certain foods may help decrease the level of uric acid in a patient's body, but diet alone is not a cure. People with gout who follow a healthy diet may still need medicines to prevent gout attacks by lowering the level of uric acid in their body.

In terms of complying with treatment protocols, gout is often poorly managed for several reasons, including a lack of adherence to treatment guidelines by health care providers, lack of adherence to therapy by patients, and differences between a provider's and patient's perspectives regarding treatment. A key barrier to gout management for many patients and their care team is the perception that gout is an acute condition that requires treatment only during a painful flare. Often, gout patients feel their care team is not taking their chronic symptoms seriously, which dissuades them from being compliant with the treatment plan provided by their care team.

In regard to affording treatments, gout patients spend more than $11,000 each year to manage their health problems. By contrast, people with no chronic illnesses spend less than $2,000 annually on health care, on average. Treatment of chronic gout may require multiple medications, which ultimately leads to a combined economic burden. Additionally, flares in patients with refractory gout significantly affect patient work productivity and social activities. This can lead to employed patients missing work due to gout attacks.

Controlling Gout

RWHC: Why is it particularly important for people with gout, who may only experience a couple attacks a year, to comply with medication protocols?

MS: Gout, especially chronic gout, isn't just painful – it can also lead to serious health problems if left uncontrolled, including kidney disease and kidney failure. Living with gout pain can be emotionally distressing because it affects your ability to walk, work and carry out normal tasks. It is also important for patients to talk with their doctor about the impact that gout has on their emotional health and to ask about ways to cope. Additionally, chronic swelling and tophi, meaning clumps of urate crystals that form on most joints and cartilage, can lead to permanent damage and deformity. In the worst cases, patients may need surgery to fix or replace damaged joints.

When you have both gout and kidney disease, treating gout can be difficult because some medicines, such as NSAIDs, are not safe for the kidneys. Some of the most common medicines for acute and chronic gout should be adjusted or avoided when you have kidney disease. Additionally, some people with kidney disease take medicines that may increase their risk of gout. For example, water pills and beta-blockers, two common medicines for high blood pressure, can contribute to gout attacks. Taking too many medicines or taking certain medicines at the same time can be dangerous, so it is very important for patients to talk with their doctor about the medication protocol that is best for them.

Addressing Racial Disparities

RWHC: How is the American Kidney Fund addressing racial disparities in gout?

MS: Since its founding over 50 years ago, the American Kidney Fund has focused on improving health care access and outcomes for populations underserved by our health care system, including people of color. AKF was founded to make access to lifesaving kidney care possible, and the need for our programs has grown exponentially over the decades as the U.S. kidney disease population has exploded. Health equity is a through-line in all our efforts, including the Goutful campaign, to help those most at risk receive the quality care they deserve. We recognize more needs to be done so that everyone can have the same opportunities to live healthier lives, from driving early detection and accurate diagnosis in at-risk communities, to increasing patient diversity in clinical trials to be representative of the audience that the medications will seek to treat. However, it is about more than access. To truly improve kidney health outcomes in our country, we must address the inherent bias and racism within our health care system, as well as the socioeconomic factors that directly impact kidney health outcomes.

In all of our education efforts, we ensure that we produce culturally competent materials that also adhere to health literacy standards. We also deploy specific targeting to reach communities most at risk for certain conditions, to ensure our education expands beyond those already engaged in our community.

We also consider the role of social determinants of health in patient outcomes. These determinants include economic stability, education access and quality, health care access and quality, neighborhood environment and social and community context. To support economic stability and health care access, our Health Insurance

Premium Program has been helping support patients in need. In 2021, amid the pandemic, our program not only helped more than 70,000 low-income kidney patients stay insured, it also made kidney transplants possible for more than 1,889 dialysis patients or about 7 percent of all kidney transplants performed in the United States. Without AKF's help, these patients would not have been able to afford transplants. Compared to the overall U.S. population, those that AKF helps are disproportionately from historically underserved communities. In 2021, over 60 percent of our grant recipients were people of color.

We also worked closely to develop bipartisan legislation with Reps. Lisa Blunt Rochester (D-DE) and Brad Wenstrup (R-OH) – called the Coordination, Accountability, Research and Equity (CARE) for All Kidneys Act – focused on addressing the disparities in communities of color and communities underserved by the health care system that can lead to kidney disease. The CARE for All Kidneys Act would create a national action plan that brings together key stakeholders, including the National Institutes of Health (NIH), the National Institute of Diabetes and Digestive and Kidney Diseases at NIH and the Centers for Disease Control and Prevention to address health disparities in kidney disease. The bill would support initiatives like expanding ongoing kidney disease research and addressing lower kidney transplantation rates in underserved communities. The CARE for All Kidneys Act is a vital first step in addressing the inequities that exist in our health care system for Americans of color and those in rural communities with kidney disease. We need every American—regardless of race, ethnicity or the neighborhood they live in—to have access to comprehensive and affordable diagnosis and treatment options that address kidney disease and related diseases like gout.

AKF also continues to support innovation and research in the kidney disease community, including helping increase diversity in clinical trial recruitment. We hope one day a cure will be discovered for patients with gout.

Editor's Note: Financial assistance for gout treatments is also available through the HealthWell Foundation. HealthWell's Gout-Medicare Access Fund provides Medicare recipients up to $12,000 in grant assistance for copayments for prescription drugs and biologics used in the treatment of gout. Independent of the Gout-Medicare Access Fund, HealthWell also offers travel assistance to all eligible patients living with gout. Through the Gout Travel Fund, the Foundation provides up to $2,500 in assistance for travel related to obtaining treatment for the condition.

Alzheimer's Association Calls for Diversity in Clinical Trial Participation

Access to health care and the opportunity to achieve optimal health should not depend on where people live, their socioeconomic status, or their race and ethnicity, but as the COVID-19 pandemic has shown, that is not always the case.

COVID-related disparities served to shine a light on other areas of health disparities as well, including clinical trial diversity. In the case of Alzheimer's disease, for example, difficulties recruiting traditionally underrepresented groups has a significant impact on researchers' ability to develop therapeutics and care models that work for people of all ethnic and racial backgrounds.

The Alzheimer's Association seeks to change that paradigm, with several initiatives designed to address obstacles, reach out to underserved communities and make clinical trial recruitment more equitable across diverse populations.

"Scientific discoveries should translate into improved health outcomes for all people, in all communities," said Carl V. Hill, PhD, MPH, Chief Equity, Diversity and Inclusion Officer, Alzheimer's Association. "Without representative participation in trials, it is impossible to get a complete understanding of how treatments will be safe and effective for everyone."

Benefits of Clinical Trial Participation

In addition to accelerating progress toward treatments, prevention and a cure for Alzheimer's, participating in clinical trials can translate into tangible benefits for individual patients, according to Dr. Hill. He noted that people involved in clinical trials tend to do somewhat better than people in a similar stage of their disease who are not enrolled in clinical trials, regardless of whether the experimental treatment works.

"Patients can get access to potential treatments before they are widely available," he explained. "They can take advantage of expert medical care at leading academic medical centers, often free of charge. Plus, they can take a more active role in their own health care through general health checkups that are often a regular component of trials."

Carl Hill, Alzheimer's Association

To help those living with Alzheimer's find a clinical trial for Alzheimer's and other dementia, the Alzheimer's Association launched TrialMatch, a free matching service to a continuously updated list of more than 700 studies, including drug and nondrug trials. Studies can be flagged with languages in which they are available, and users can filter studies by their preferred language.

Obstacles to Clinical Trial Participation

Dr. Hill pointed to several obstacles keeping racial and ethnic minorities from being well represented in clinical trials, some of which have their genesis in long-standing mistrust of medical research.

"Black communities, for example, have passed-down memories of the heinous Tuskegee syphilis trial, forced sterilizations, and Baltimore's 1930s redlining initiative, the latter of which impacted health care access and outcomes for generations," he said. "Researchers and the health care system as a whole must therefore work on building trust before they can start to convince African Americans of the benefits of trial participation."

Even when unwarranted, fears over racism or discrimination from doctors and medical staff prompt some racial and ethnic minorities to delay seeking Alzheimer's care. A 2021 study found that more than one-third of Black Americans (36%), two-fifths of Native Americans (40%), and nearly one-fifth of Hispanic Americans (18%) and Asian Americans (19%) believes discrimination would be a barrier to receiving care. They are also less confident that they have access to health professionals who understand their ethnic and racial background and experiences, supporting the need for more diverse representation among health care providers.

Still other challenges to participating in Alzheimer's clinical trials are logistical in nature, including access to transportation, distance from clinical trial locations and ability to take time off from work or family duties.

"Researchers should receive funding from NIH and other sources to better understand how these local, logistical obstacles make it difficult to apply a one-size-fits-all solution," Dr. Hill said. "They also need to re-evaluate trial exclusion criteria, which have the potential to restrict the participation of those disproportionately affected by Alzheimer’s or another dementia, like Latinos and African Americans."

Outreach Builds Awareness and Recruitment

The Alzheimer's Association is leading two major clinical trials with a strong focus on diverse participation. The New Ideas study is recruiting 2,000 Latinos and 2,000 Blacks to investigate the impact of brain amyloid PET scan on clinical care outcomes, including diagnosis and treatment. The U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER) study is a two-year clinical trial studying the effects of multi-component lifestyle interventions on risk of cognitive decline in a diverse population.

"Together, these studies should provide valuable insight into how a patient's knowledge of their Alzheimer's hallmarks and risk factors affect how they manage their health," Dr. Hill said. "Will they take better care of their cardiovascular health? Will they go see their doctor more frequently? Research shows that when people can get their hypertension under control, progression from mild cognitive impairment to severe dementia slows down."

The two trials are actively recruiting, and the Alzheimer's Association is conducting community-based outreach through its 70+ chapters across the country, as well as through strategic partnerships with more than 20 national and countless local organizations, to get the word out in culturally relevant and appropriate formats.

Noting that partnerships at a national level translate into more effective community engagement, Dr. Hill said the Alzheimer's Association is working with the African Methodist Episcopal (AME) Church on a five-year program to disseminate free Alzheimer's and dementia-related information, resources and referrals to its two million members. It also is working with the National Association of Hispanic Nurses to develop culturally responsible and language appropriate content. A complete list of the Association’s national partners can be viewed here.

"People are more likely to participate in clinical trials if they are invited by a trusted individual from their community," added Dr. Hill.

A Critical Moment

Later this month, the Alzheimer's Association will host its International Conference, the most influential international meeting dedicated to advancing dementia science. This year, the Conference will have a special focus on health disparities and health equity, with a daylong workshop Addressing Dementia Risk Through Social Determinants of Health, co-sponsored with the CDC. The workshop will bring researchers and practitioners to increase understanding of how the conditions in which people live, learn, work and play affect dementia risks and outcomes.

"This is an exciting time in health equity research, but issues remain complex," Dr. Hill concluded. "We are at a critical moment in which more intentional inclusion in Alzheimer's and dementia research can help to change the course of a devastating disease and benefit generations to come.”