

## AACR/HBS/MMRF SUMMIT

# REDUCING DISPARITIES AND DEMOCRATIZING CANCER CARE

## HOSTS & PARTICIPANTS

The Summit's hosts were (clockwise from top left):



- John Carpten, USC
- Marge Foti, AACR
- Richard Hamermesh, HBS
- Kathy Giusti, HBS/MMRF

## BACKGROUND

In mid-2020, amid the beginning of the Covid-19 pandemic and heightened attention on disparities in healthcare, Kathy Giusti and Richard Hamermesh—co-founders of the HBS Kraft Accelerator—asked the CEOs of many of the country's most prominent disease-focused foundations, "What are your top priorities?"

Topping the agenda for these CEOs was "addressing disparities." This led Giusti and Hamermesh to conduct approximately 100 one-on-one interviews with experts on disparities, convene a Leadership Forum of foundation CEOs to discuss best practices, and publish a well-received article in Harvard Business Review titled: "Addressing Demographic Disparities in Clinical Trials," June 11, 2021.

Giusti and Hamermesh realized that a great deal of work had already been done on disparities, largely from a scientific perspective, led by organizations such as the American Association for Cancer Research (AACR). They conceived of a summit to bring together scientific and business experts, using the HBS case study method as a way to surface key issues, and to identify best practices and actionable next steps.

## CONTEXT FOR SUMMIT

The HBS/AACR/MMRF Summit on Reducing Disparities and Democratizing Cancer Care was held virtually on October 21, 2021. It brought together leading thinkers and several of the country's most important organizations working to reduce disparities in cancer.

The Summit featured two real-world, HBS-like case studies—on reducing disparities in multiple myeloma and improving screening for colorectal cancer among Black patients. The Summit also included panels focused on lessons from Covid that apply to cancer and on the role of government. The Summit concluded with a discussion about collective actions to reduce disparities.

Adopting the approach of the HBS Kraft Accelerator, this Summit intentionally had a narrow concentration on one group, Black patients, and two forms of cancer, multiple myeloma and colon cancer. Focusing narrowly avoids boiling the ocean; it leads to identifying best practices that can be expanded to other groups of patients and other cancers and diseases.

## 5 Ideas to Improve Disparities

These ideas, discussed in more detail on page 4, are:

1. GO where the (diverse) patients are. Obviously.
2. KNOW where the patients are, for each type of cancer. This also sounds obvious, but data on where the patients are does not currently exist in one central location.
3. Fund sites with high potential. These are sites with access to many Black patients but without extensive clinical trial experience.
4. Engage patients by building trust.
5. Go beyond trials to collect real-world evidence.

These ideas are best achieved by collective action involving multiple players in the ecosystem.

## OVERVIEW

Disparities in cancer is a longstanding problem. While progress has been made, disparities persist. Per 100,000 people, the death rate for cancer is 173 among Black patients and 153 for white patients.

There has been a great deal of energy and investment focused on reducing disparities, and there are many successful programs. But often programs and activities have been fragmented and underfunded, limiting their effectiveness. To reduce disparities, Summit participants saw opportunities to include more Black patients in clinical trials by improving the site-selection process. Doing so requires sharing data about sites, funding additional resources to assist with patient recruitment, and de-risking for industry the selection of high-potential, community-based sites in catchment areas with many Black patients.

Summit participants also saw a significant need to message to and engage patients to participate in trials and registries, and to engage in important health-related activities like screenings. The most effective engagement will take place at the local level, involving trust agents such as clinicians, pharmacists, religious and community leaders, and other local influencers.

With so many different types of cancer and cancer-related organizations, each organization working alone—as has often been the case—is unlikely to move the needle. Long-term sustained success requires collective action to develop strategies, provide leadership, secure additional funding, and prioritize how best to allocate this funding.

## CASE STUDIES

Two case studies were discussed which surfaced multiple issues in reducing disparities in cancer.

- 1 **Enrolling representative patient populations in registries and clinical research: What's the MMRF's plan for CureCloud®?** This case study focused on the MMRF's efforts to enroll 5,000 patients in its new CureCloud registry, including 1,000 Black patients, using a direct-to-patient (DTP) enrollment approach. Early on, total enrollment was going well, but Black patients represented only 5% of patients. The case looked at ways for the MMRF to boost enrollment of Black patients.
- 2 **Eliminating disparities in screening for colorectal cancer.** Colorectal cancer is the #2 cancer killer. However, it can often be prevented with early screening. But only 6 of 10 Black individuals are screened, which is below the overall American population. The case focuses on strategies to improve screening rates among Black patients and reduce disparities.

## SUMMIT KEY THEMES

### Disparities in cancer is a longstanding problem.

Covid-19 shined a spotlight on disparities, but those with expertise in this area know all too well that disparities are a longstanding problem. Ned Sharpless (NIH/NCI) said, "Health equity research is gaining momentum in the United States." While 20 years ago, disparities existed, the field of health equity research was nascent. Now, said Sharpless, "The field is growing exponentially with great ideas, great scientists, and interesting work. . . The increased interest in disparities research is definitely having an impact."

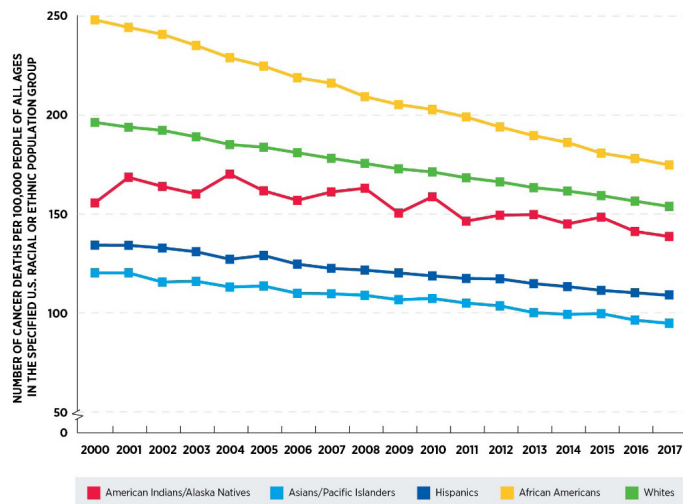
**"COVID-19 AND THE EVENTS OF 2020 HAVE BEEN A CATALYST FOR INCREASING THE VISIBILITY ON THIS ISSUE . . . BUT THIS HAS BEEN A LONGSTANDING PROBLEM AND THERE HAVE BEEN MANY SOLUTIONS IN THE MAKING FOR MANY, MANY YEARS THAT ARE UNDERUTILIZED."**

LOLA FASHOYIN-AJE, FDA

**In the past two decades, progress has been made reducing disparities in cancer.**

As shown below, from 2000 to 2017, the cancer death rate declined and disparities narrowed.<sup>1</sup>

Figure 1: Cancer Death Rate 2000 to 2017 by Race/Ethnicity



Source: American Association for Cancer Research (AACR) Cancer Disparities Progress Report 2020

Among the reasons for this progress are:

- **Attention.** AACR provides an example of the increased attention focused on disparities in the cancer community. In 2000, AACR launched the Minorities and Cancer Research Council (MICR). Over the last 20 years AACR has gone from less than 2% of its members being minority investigators to about 10%. AACR has also held a series of major meetings on the science of cancer health disparities. This level of attention is matched at other organizations such as NCI, the FDA, and in industry.
- **Funding.** Analysis by IQVIA found that in recent years, billions of dollars have been allocated by government and industry to focus on disparities. Over the past five years, NCI’s funding for health disparities research has increased from about \$300 million to \$400 million, which Sharpless acknowledges reflects a shift in NCI’s priorities. Stand Up to Cancer also provides grants aimed at reducing disparities, as do other organizations. In addition, industry is making significant investments to reduce disparities. An example is program by the BMS Foundation to identify and train 50 early-career minority clinicians who will learn about and become experts in cancer disparities, drug development,

and translational research, and then lead initiatives in communities across the country that will help reduce disparities.

- **Policy.** A few years ago NCI changed the rules for applying for a grant. The change requires that organizations seeking grants understand their catchment area and the racial and ethnic composition of their patient population. This policy adjustment has had a significant impact on the behavior and actions of cancer centers.
- **Science.** Biological differences can contribute to disparities. For example, myeloma has translocations where one part of a chromosome changes. The t(11:14) translocation is more common in Black patients. The medicine venetoclax has been found to work in many myeloma patients who have this chromosomal abnormality. Greater use of this treatment could further improve outcomes among many Black patients with myeloma.

**However, despite progress, disparities remain and are still significant.**

As shown in Figure 1, while the cancer death rate has declined and disparities have narrowed, they remain significant. The rate of new cancer cases is similar for white and Black patients, but the death rate for Black patients is significantly higher at 173 per 100,000 people compared to 153 for white individuals.<sup>2</sup>

The case studies showed that:

- The incidence of and deaths from multiple myeloma are much higher for Black patients.
- The screening rate and death rate of colon cancer is much higher for Black patients.

However, despite higher death rates, minorities have been and continue to be underrepresented in clinical research and registries. A participant from a biotech company said that over the past 15 years, about 94% of clinical trial participants in the US have been Caucasian. Recently Pfizer did a retrospective analysis of all of its clinical trials from 2011 to 2020 looking at representation by race, ethnic group, gender, and age. In its oncology trials, the company found that the percentage of Black and Hispanic patients was below the representation in the community.

It is hard to reduce disparities without proper representation of Black patients in trials and registries.

## There are several reasons for disparities in clinical trials and registries.

Among the reasons are:

- **Trials have been concentrated at academic medical centers (AMCs).** Trials have often been conducted at the same AMCs, which have experience and expertise conducting trials, but aren't necessarily in catchment areas with high numbers of diverse patients. Conversely, trials typically haven't been conducted at sites that lack significant trial experience, even if a potential site is within a community or catchment area with a large number of Black patients.
- **Diversity hasn't necessarily been mandated in trial protocols.** Trial funders haven't mandated recruitment of certain numbers of diverse patients. In many instances the diversity of patients in a trial hasn't even been reported, as trials have often lacked transparency.
- **Deep distrust among Black patients.** There has been deep distrust and skepticism among many Black patients about healthcare institutions and trials, causing Black individuals to be reluctant to participate.
- **Lack of targeted recruiting efforts.** Recruitment hasn't been done by trusted sources, in culturally appropriate ways, creating even further distrust.

## Lessons learned from Covid can be reapplied to cancer.

Responding to Covid-19 created a sense of urgency and broad collaboration in the scientific community. There was a central convener—the government, through Operation Warp Speed—and significant funding. There was scrutiny of the clinical trials of vaccines, which put disparities in the spotlight and required companies to enroll representative patient populations.

Also noteworthy was how organizations such as the Ad Council developed national campaigns to increase acceptance of Covid vaccines. These programs followed a process of defining specific audiences, developing an understanding around the barriers, and developing targeted PSAs. These campaigns involved trusted influencers and micro-influencers who have the ability to counter mistrust. The Ad Council also engaged in a “ground game” to train the trainers locally. These local trainers included healthcare professionals, pharmacists, church leaders, and local influencers. The Ad Council also provided toolkits and turnkey content that organizations could use in their own newsletters and social platforms.

Similar approaches could be utilized for multiple cancers, both nationally and locally.

## 5 Actions to Improve Disparities in Clinical Trials

To continue the progress that has been made in reducing the cancer death rate and reducing disparities, Summit participants shared the following ideas and actions to go to the next level in reducing disparities in clinical trials.

1. **Go where the patients are, obviously.** Approximately 85% of cancer patients receive care in community settings, not in AMCs or major tertiary centers. Therefore, to enroll more Black patients in trials, it is necessary to recruit these patients in the community. This could mean working with the NCORP network and with health systems. For example, Ochsner—the largest health system in Louisiana—has about 1,200 patients with multiple myeloma, 40% of whom are Black.
2. **Know where the patients are—for each type of cancer.** Going where Black patients are sounds obvious and easy. But it's not. Going where the patients are does not mean recruiting a diverse, nationally representative patient population; it means recruiting a population that is representative *for each particular cancer*. What is representative for multiple myeloma is different from what is representative for colon cancer.

The problem today is that there is no central data repository showing the number of Black patients with a particular cancer at each possible trial site.

Creating such a catalog or a market exchange would have significant value in helping any organization pursuing a clinical trial—and wanting to enroll a diverse patient population—make site-selection decisions. To create such a catalog will require that all parties—sites, CROs, SMOs, consulting firms, pharma companies, and more—share data, and that this data is centralized and is broadly accessible. The solution may be a public-private partnership. Decisions would need to be made about leadership and sustainable funding.

**“WE’VE ALL GOT A SLICE OF THIS; WE’VE JUST GOT TO PUT IT TOGETHER.”**

ADRIAN MCKEMEY, IQVIA

3. **Fund high-potential sites.** Everyone sees the need to go beyond AMCs to other trial sites, especially sites in catchment areas with large numbers of Black patients that have not previously participated in trials or registries. However, when pharma companies are making site-selection decisions that involve investing

tens or hundreds of millions of dollars, they don't want to take risk by going to an inexperienced, unproven site. They want to use sites that they know have the experience and capabilities to generate high-quality data as rapidly as possible. But this can lead industry to repeatedly select the same proven AMCs, despite the desire to enroll more diverse patients in new, high-potential locations.

What is needed for sites in catchment areas with large numbers of diverse patients, but without significant trial experience, is funding and support to build the necessary capabilities and reduce risk for industry. The type of support that is needed includes infrastructure within health systems and communities such as community health workers, patient navigators, and other resources to assist with patient education, recruitment, and enrollment. Also, one participant called for a higher-level professional role (not administrative) focused on strategy, prioritization, and collaboration across the cancer and healthcare ecosystem.

**“THERE WILL BE RISKS, BUT WHAT CAN WE DO TO BUILD A MODEL WHERE DE-RISKING IS BUILT INTO THE MODEL?”**

JOHN CARPTEN, USC

4. **Engage patients by building trust.** A central theme of the Summit was the need to build trust in Black communities. Just as there has been mistrust for many years, building trust will take years and sustained efforts; it won't occur overnight. It will require communication and campaigns from trusted clinicians, additional healthcare infrastructure and resources, and sustained communication from national and local trust brokers and influencers, including multiple local healthcare leaders, pharmacists, faith-based leaders and other influencers.

5. **Go beyond clinical trials to collect real-world data about what works.** Clinical trials are extremely important. Yet the reality is that even with the best possible efforts, many Black individuals and other underserved populations will never be involved in clinical trials. For this reason, there is a need to collect real-world evidence from communities regarding what works and what doesn't. This includes collecting data from electronic health records, claims data, and other sources. Real-world evidence provides a valuable complement to clinical studies and needs to be part of comprehensive efforts to reduce disparities.

### Collective Action Required

In today's broken healthcare system, meaningful progress won't come about from individual actors attempting to drive change alone. The major ideas and actions discussed—creating a catalog/market exchange for site-selection data, building support infrastructure at high-potential sites to assist with patient education and recruitment into trials, and orchestrating national and local messaging campaigns—will work best if there is collective action.

This collective action includes collaboration between government and industry, researchers and practicing clinicians, academic medical centers and community-based clinics, scientists and business people, funders and marketers. There must be a convener and there must be engaged organizations willing to contribute time, resources, money, and data.

There was optimism that now is the right time for acting collectively to take concrete actions and develop sustainable models that will move the needle on disparities.

**“TO REALLY SOLVE THIS PROBLEM, WE NEED STRATEGIES THAT ADDRESS ALL THESE LEVELS . . . BUT I TRULY DON'T THINK WE CAN DO THAT UNLESS WE HAVE STAKEHOLDERS AND EXPERTS IN ALL AREAS WORKING TOGETHER.”**

FOLA MAY, UCLA

<sup>1</sup>American Association for Cancer Research (AACR) Cancer Disparities Progress Report 2020, Figure 1

<sup>2</sup>Cancer Stat Facts: Cancer Disparities, NIH National Cancer Institute, Surveillance, Epidemiology, and End Results Program (SEER) as of November 3, 2021.

## Participants

- Ken Anderson, DFCI
- Mike Andreini, MMRF
- Silas Buchanan, IE Health Equity
- Catherine Chao, Ad Council
- Ben Colmery, NIH
- Anjee Davis, Fight CRC
- Patrician Doykos, BMS
- Travelle Ellis, Exact Sciences
- Lola Fashoyin-Aje, FDA
- Nicole Gormley, FDA
- Quita Highsmith, Genentech
- Rob Huckman, HBS
- Melanie Ivarsson, Moderna
- Elise James-DeCruise, Ad Council
- Heather Knowles, Moderna
- Fola May, UCLA
- Wortia McCaskill-Stevens, NIH/NCI
- Adrian McKemey, IQVIA
- Edith Mitchell, Thomas Jefferson, NMA
- Randall Morgan, BCAC
- Renee Nicholas, Stand Up to Cancer
- Ajay Nooka, Emory
- Eliseo Pérez-Stable, NIH/NCI
- Jon Retzlaff, AACR
- Brian Rivers, Morehouse School of Medicine
- Andy Schmeltz, Pfizer
- Ned Sharpless, NIH/NCI
- Carmen Sivakumaren, IQVIA
- Anne Quinn Young, MMRF
- Yixian (John) Zang, AACR

