A Case Study in Anti-Racist Organizing: Closing Healthcare Disparities in Greensboro by Focusing on Structural Racism
Imagine a world where racial disparities in healthcare could be virtually eliminated. Actually, there is no need to imagine because it has already happened at a healthcare center in Greensboro, North Carolina, for Black and white patients with breast and lung cancer.

Think about that: a critical pathway to closing the racial gap in health outcomes in the United States may already exist. All it took to close the gap and improve treatment completion rates for everyone was the tireless work of the Greensboro Health Disparities Collaborative (GHDC), a group made up of community leaders and advocates, public health researchers, and healthcare professionals. Prior to GHDC’s work, white patients were completing their cancer treatment at a significantly higher rate than Black patients, with a gap of 7 percentage points. To be clear, when it comes to cancer, not completing treatment is fatal. This is the little-known story of how this coalition of volunteers, guided by anti-racist principles, community-driven solutions, and authentic partnership, and an unwavering focus on the structural racism at the root of the inequity, got it done.

But first, what is structural racism and why does it matter? The Racial Equity Institute (REI) has come up with the helpful groundwater metaphor to explain structural racism and how it is intricately linked to our biggest social problems. Imagine that you have a lake in front of your house. If you find one dead fish, most of us would analyze the fish. But if you come to the same lake and half the fish are dead, then it probably makes more sense to analyze the lake. But what if there are five lakes around your house and in every lake half the fish are dead? Now it might be time to consider analyzing the groundwater to find out how the water in all the lakes ended up with the same contamination.¹

With this in mind, REI organizers like to point out that structural racism is the problem—it’s in the groundwater—and that the racial disparities and inequity we see in virtually every issue, including healthcare, are the manifestation of that problem.

**Greensboro Health Disparities Collaborative’s Origin Story**

In 2003, a report issued by the National Academies’ Institute of Medicine (today known as the National Academy of Medicine) and commissioned by Congress documented significant and pervasive unequal treatment based on race in the healthcare system across the nation.² Looking over a 10-year period, the groundbreaking 750-page tome found that people of color received lower quality healthcare than whites even when insur-

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Cover Image: A GHDC meeting in 2015. Left to right: Geni Eng, Alex Lightfoot, Cleo Ryals, Kristin Black, Stephanie Baker, and Turner Wiley. (Photo credit: Sarah Cottrell)
ance status, income, age, and severity of conditions are comparable. The report concluded that such differences in treatment contribute to higher death rates for people of color. And these disparities could not be explained by the all-too-familiar narratives that blame people’s behavior, culture, economic status, or genetics. Instead, the study shows, the problem is not with the people experiencing the symptoms, but rather with the system and structure they live in. For instance, although at the time of the study white women were diagnosed with breast cancer at much higher rates than Black women, Black women died of breast cancer at much higher rates. Even now, Black women are still dying from breast cancer at higher rates than white women despite diagnosis rates finally being about equal. Overall, the research indicated that Black women experience problems after having access to the medical system, leading to their higher death rates. In other words, the treatment Black women receive in the healthcare system is a factor in the disparities.

Inspired by the Institute of Medicine report, community organizers affiliated with The Partnership Project, including then executive director Nettie Coad, or “Mama” Nettie as she was known, took up the urgent call to address health disparities in Greensboro. Organizers use a mix of methods to bring people together and push for social or policy change. As Grantcraft describes in its guide to funding organizing for social change, “organizers pull people together, urge them to question their ideas, and support them as they produce and carry out a plan of action.” Being a product of organizing efforts means that the community was embedded in GHDC from the very beginning.

“As a community organizer for 30-plus years, I realized there was a disconnect between community and institutions in regard to dealing with poverty-stricken communities,” said Coad during a presentation to the National Institutes of Health (NIH) about the Collaborative and its work. She explained to the crowd that because of this disconnect programs and approaches are typically designed by those that, “have no knowledge of the community or don’t reside in it. They all come from outside the community, but they are making the decisions. Is this ethical? Is this ok? No, it’s not. But often, [the] community does not have the opportunity to define their own realities. So, we need to look at how to change this.”

Therefore, community members approached public health researchers at the University of North Carolina (UNC) to partner on the issue. Eugenia “Geni” Eng, who was among the UNC researchers interviewed by Coad and would become a founding member of GHDC, offered her expertise in community-based participatory research, an approach that engages academic researchers and community stakeholders as equitable co-investigators and partners. With the help of an initial planning grant from Moses Cone-Wesley Long Community Health Foundation, the work began. The burgeoning collaborative was born with 35 founding members, including 23 community members and 12 medical and health professionals. Mama Nettie was the undeniable soul of the group. Eighteen years later it remains strong—even after Mama Nettie’s death in 2012—and has seen tangible success.
Building Shared Analysis

GHDC was formed as an expressly anti-racist effort. An anti-racist path to social change seeks to upend the root causes of issues—the racism and unequal arrangement of power embedded in our structures, systems, and policies—while embracing transparency and accountability. For GHDC’s success, it is critical that members have the language to talk about racial inequity and a shared understanding how, because of structural racism, institutions and systems can produce the very racial inequities that the Collaborative seeks to change.

Therefore, all members are required to attend anti-racism workshops that offer a historical analysis of the structural and systemic nature of racism present regardless of the social issue whether that be in education, healthcare, the economy, the environment, or another area. Founding members were required to attend the Undoing Racism training presented by the People’s Institute for Survival and Beyond, followed by an additional five educational and five discussion sessions focused on the history of structural racism. In more recent years, new GHDC members are required to attend REI’s two-day Phase 1 Racial Equity Workshop, which similarly offers a historical analysis of the structural and institutional nature of racism.

“It transformed me,” says GHDC member Geni Eng of the anti-racism training. “It really got me to understand that what I had been doing for 20 years was not going to be effective—changing individual knowledge, attitudes, and behaviors was a Band-Aid and not a solution. Instead, what I needed to focus on was systems change. All the social behavioral science theories that I’ve been trained in and been teaching did not address systemic racism and therefore did not help me understand the correlation between...
structural barriers in the healthcare system and race-specific health outcomes. The Collaborative’s work from the beginning was focused on deconstructing the cause.”

The anti-racism training had a similar transformative effect for Black collaborative members too. GHDC member Nora Jones, who later founded the Greensboro chapter of Sisters Network, a national organization for Black breast cancer survivors, admits that she was a little skeptical about spending two full days in a room with 40 strangers talking about racism. “But it really made a big change in my life,” she now says. “I realized how little I knew about racism. All these years, even though I had experienced racism, I didn’t know anything about the history of racism and its manifestations. I did not know anything about systemic racism at that time so was blown away by all that I learned.”

The People’s Institute, REI, and The Partnership Project are all examples of anti-racist community organizers working toward social justice. At the heart of such organizing efforts is “building trusting relationships that are grounded in a common analysis of power and collective action for social change.”  

Collaborative member Christina Yongue noticed the advantage that a shared analysis can offer at the very first GHDC meeting she attended. “What I saw as unique to this group was how comfortable they were to talk and deal with things that are uncomfortable,” says Yongue, currently assistant professor of public health education at UNC Greensboro and who was also a project coordinator and manager of the research projects the GHDC was awarded. “They were comfortable talking about issues of race and racism as well as cancer and dying, and then still able to joke around with each other at the same time.”

Yongue is convinced this dynamic also helps keep the Collaborative focused on the community. “The Collaborative is much more purpose-driven and meaningful about the community it is trying to benefit than what I have seen in professional settings before. Every meeting we were always reminded that African Americans, Black women, were dying. I have been in all Black settings that have that intentionality, but this was a racially diverse group where everyone had that same type of focus to improve health outcomes to Black women and that felt different to me in a good way.”

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Because it is critical that GHDC members have this shared understanding and analysis, no one is allowed to become an official member of the Collaborative without going through REI’s anti-racism training. Members engage in ongoing learning to keep their awakened muscles concerning these issues in shape. As GHDC was forming it lost three members—an academic and two medical professionals⁷—who refused to attend anti-racism workshops.

Leveraging the Expertise of Communities

GHDC did not start with developing a cancer care intervention in mind. Instead, the Collaborative started with the coming together of people who had a common interest in racial health disparities. There were lots of meetings to find out how the Collaborative could address that interest before a project focused on cancer care was even a thought.

In the beginning, members participated in a structured storytelling exercise to explore and understand their collective and individual experiences with racism in the healthcare system. Participants were asked to reflect on how they experienced, observed, or participated in racism within their own local healthcare institution. They also broke into subgroups on the basis of racial or ethnic identity so people could speak freely about their racialized experiences.

The exercise revealed that almost everyone’s lives had been impacted by cancer, specifically breast cancer, either personally, through a family member, or a close friend. As a result, the Collaborative’s first work together focused on racial disparities in breast cancer care. This community-driven area of focus reflected broader trends across the nation. Although survival rates from cancer have increased, Black patients tend to still have the highest death rates and shortest survival of any racial or ethnic group in the United States for most cancers.⁸ One report suggests that Black women are 40 percent more likely to die of breast cancer than white women.⁹ Research suggests that differences of care are a driver of this disparity including differences between Black and white patients in early diagnosis, guideline-concordant treatment, and palliative and supportive care. For breast cancer patients, Black women experienced earlier terminations of chemotherapy. Overall, Black cancer patients report lower levels of shared decision making with their doctors. This might seem like a “system breakdown” or an anomaly, of sorts—but the Collaborative’s structural analysis would point out that really this kind of inequity exists across society. It is indeed the expected, albeit unacceptable, outcome of a society that has racial inequity “baked in.”

In 2006, the Collaborative was awarded a two-year grant from NIH to conduct the Cancer Care and Racial Equity Study (CCARES) to investigate the reasons for disparities between Black and white breast cancer patients. The Collaborative’s community-based

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⁹ Ibid.
participatory research approach to the study ensured that community members had equal standing with academic researchers and healthcare workers. That means that for GHDC the lived experience of community members is as valuable, and informs the work just as much, as the medical knowledge of the healthcare members or the public health lens of the academic members. Therefore, this community expertise was not only at the heart of determining what manifestation of racism would be the focus but also shaped interventions that were developed to solve it.

**Bringing in the Institution**

The GHDC included a medical institution as a fellow collaborator alongside the academics and community members. In Greensboro, that was Cone Health Cancer Center. For change to take hold, it was critical that the institution saw itself as a partner with the Collaborative and its mission, rather than separate from, or even a target of, the Collaborative.

However, getting institutional buy-in was difficult at first. The biggest hurdle was the lack of understanding across the institution that the root cause of the disparities was structural racism. A focus on structural racism means focusing on the systems and policies that lead racism to be baked into an institution. It does not mean that institutional representatives are bigoted or intentionally provided inequitable care. Still, hearing GHDC’s focus on the structural racism of the institution left some physicians of that very institution feeling as if they were being attacked as individuals. Even those who acknowledged that racism exists more broadly, systemic even in nature, were unconvinced that it applied to their own medical institution because they felt personally they were treating all patients the same. That is the pernicious nature of structural racism: it doesn’t matter whether individuals are racist or not. If the system and the policies of the institution were not designed to foster racial equity, then the structure that is formed cannot help but create inequitable outcomes based on race.

“Back in 2003, people were not listening to the [entire] phrase ‘systemic racism,’ instead all they heard was the word ‘racism’ and if you used the word ‘racism,’ you were accusing them of being racist,” says Sam Cykert, Collaborative member and professor of Medicine at UNC Chapel Hill. His medical practice was formerly at Cone Health’s Moses Cone Hospital.

“The defense to that was ‘I take care of everyone equally.’ In these 18 years, there has been an evolution of people who are more willing to listen to the word racism and talk about it and understand that maybe ‘system-based racism’ or ‘institutional racism’ is a thing. And certainly since George Floyd’s murder there has been more receptiveness on the part of healthcare administrators and doctors to have that conversation. But not always.”

When the Collaborative presented data from the institution itself that illustrated a pattern of different care based on race, individuals from the institution began to be convinced. Healthcare members of the Collaborative, like Cykert, who are comfortable speaking in both the language of the medical community and that of anti-racist analysis, also helped to make the case to fellow physicians. Using Cone Health’s cancer registry, the Collaborative was able to examine five years of care and saw that there was a longer length of time between diagnosis and the beginning of treatment for Black patients than for white patients.
patients. Such delays between diagnosis and treatment not only have been found to cause patients unnecessary stress and anxiety but also increases mortality from 1.2 percent to 3.2 percent per week of delay.\(^\text{10}\)

Patient interviews conducted during the Collaborative’s follow-up research uncovered other differences in care based on race. Focus groups showed that for Black patients there were often delays in the hospital’s communication about their care and an insensitivity to their pain—a significant issue for a disease where the illness and the treatment both can come with tremendous pain.

Structural racism can be so baked into day-to-day life that when Black patients were asked if they were treated differently due to their race most said they were not, unaware that they indeed were receiving worse care than white patients, as the Collaborative was able to document.

“When thinking about cancer, if the patient didn’t die then for many people it is often seen as a success. But when you dig in, you find out that patients are having drastically different experiences on their cancer journey,” says Kristin Black, an assistant professor of health education and promotion at East Carolina University, who represented the Collaborative in almost all of the patient focus groups that were part of the GHDC’s preliminary research. “At every point, white people and people of color are being treated differently. To have evidence of that is really startling, and thinking of those stories now still hits me because no one should ever have to experience that.”

**Establishing Trust**

At the start, through in-depth discussions, the GHDC collectively created norms and principles for collaboration, formalized in a document they call the “Full Value Contract,” which all members are required to sign and governs every decision and interaction. Critical for a group with people from such varied backgrounds including race, class, gender, religion, education, and position, the contract affirms “the belief that every group member has value and by virtue has a right and responsibility to give and receive open and honest feedback.”

While the exact makeup and size of the Collaborative has been fluid over the years, a constant that has remained is the strong bond that all seem to share. To achieve this, the Collaborative has dedicated time and intentionality to relationship building. GHDC’s monthly meetings always start with fellowship, where members catch up and talk to one another not about their work together but about life. It is hard not to notice that there is a comfort that overflows in their joyful chit-chat, similar to the kind found when close friends finish each other’s sentences.

“We built this family based on conversations,” says Terence “TC” Muhammad, a community activist in Greensboro and co-chair of GHDC. “Now it feels like the Knights of the

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Roundtable. I am sitting with people who may be the chief oncologist, former head of internal medicine, professors at UNC Chapel Hill. But it doesn’t matter what position you have or degree you hold because this is collaborative work, and we all come to the same table as part of group of people that organized as equal partners.”

In person, this fellowship time together was always over food. The importance of the shared meal is concrete. It acknowledges that some members coming to the meeting may not have the resources for a meal, whether that be money in their wallet or time in their day. Offering food allows everyone who enters the space to be at the same starting point. As a result, sharing meals together helped build the authentic trusting relationships that are needed for collaborative work to succeed, a strong sense of purpose, and lasting commitment. Building similar relationships might look different in communities outside of Greensboro, but the time and dedication needed to foster such trust does not. Now that GHDC has shifted to Zoom, there is no food, but monthly meetings still start off with 30 minutes of unstructured fellowship time to keep relationships strong and build new ones.

Engage With and Learn Through Conflict

Like any collaboration, especially one that values equitable participation and decision making, GHDC’s work has not been without conflict. To deal with conflict, the Collaborative has something they call “pinch moments” or the practice of not ignoring tensions but rather a willingness to discuss and examine tensions as they arise.

“There needs to be a recognition that conflict is part of the process of coming to an understanding together,” says GHDC member Jennifer Schaal, a retired ob-gyn physician and a member of the board of directors for The Partnership Project. “You have got to be willing to work through the conflict and having a mechanism to do that is important. We all need to be open to learning from each other that there are different ways to approach things. If we don’t address those differences the conflicts get worse.”

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One pivotal pinch moment came when the Collaborative’s initial grant proposal to NIH for its study to research healthcare disparities in Greensboro (which later became the CCARES study) received a “non-fundable score” and terse reviewers’ comments. This untactful feedback upset community members who were new to the federal research review process for funding.

In response, community members organized a series of meetings without their fellow academic partners to air their frustrations. These meetings created a lack of transparency within the Collaborative (breaking a key anti-racism principle and Collaborative norm). The tensions required multiple uses of the pinch moment norm to resolve.12

In the end, GHDC held a special meeting to allow academic members to apologize to the Collaborative for neglecting to describe in advance the typical NIH review, decision, and resubmission procedures. Another pinch moment was when some members, in an effort to get a grant proposal in on time, bypassed the Collaborative’s internal committee process that ensures equal input in decision making among community, healthcare, and academic members. The incident caused such a rift that a Collaborative member left, which serves as a constant reminder for the group to lean into their Full Value Contract norms.

However, GHDC’s longevity despite intermittent conflicts over the years helps illustrate how conflict is often part of transformative work and does not have to be feared by funders. Instead, the ways organizations and collaboratives engage with and learn through conflict can help lay the foundation for more authentic communication and collaboration. And that impact is often more lasting than any friction along the way.

**Treating the System**

After the Collaborative documented disparate cancer care outcomes with their CCARES study, they began to work on developing an intervention.13 To develop and implement their intervention, the GHDC partnered with both Cone Health and the University of Pittsburgh Medical Center in order to illustrate that an equity-focused intervention could be successful in two significantly different geographical and healthcare settings. The ACCURE (Accountability for Cancer Care Through Undoing Racism and Equity) project, as it is known, focused on patients with Stage 1 and Stage 2 breast and lung cancer, and was funded by the National Cancer Institute.14 The goal was to test whether a multipronged intervention that changed the systems of care could improve the experiences of Black patients undergoing treatment.

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12 Michael Yonas et al., “Infrastructure for equitable decision-making in research: Methods for community-based participatory research for health.”

13 Kristin Z. Black et al., “It’s like you don’t have a roadmap really’: using an anti-racism framework to analyze patients’ encounters in the cancer system,” *Ethnicity & Health* 26, no. 5 (December 2018): 676-696.

14 While breast cancer kills more Black women than any other cancer, lung cancer was added to GHDC’s work because it kills more Black men than any other cancer. This meant ACCURE looked into the most deadly cancers for Black people and the cancers with the biggest racial disparities in mortality rates.
The intervention was designed to promote the anti-racism principles of transparency and accountability at the community, organizational, and interpersonal levels. Informed by patient focus groups, the intervention had many components at each level, including the introduction of health equity training at the institutions, data tracking on care quality disaggregated by patient race, and race-specific feedback for providers regarding treatments. Nurse navigators who worked to improve communication between the medical center and the patients offered data-informed follow-up to enhance the healthcare system’s accountability to patient needs and also served as patient advocates, taking action where needed. None of the specific components operated alone. (For more detail, see the model above developed by Collaborative member Ida Griesemer, who conducted her dissertation research on ACCURE as a PhD student in Health Behavior at UNC.)

The ACCURE intervention got results, showing that racial disparities in healthcare could be virtually eliminated. Prior to ACCURE, white patients were completing their cancer treatments at a significantly higher rate than Black patients, with a gap of approximately 7 percentage points. Following the ACCURE intervention, the gap nearly vanished, and completion rates for Black and white patients became similar. Black patients saw a completion rate of 88.4 percent, whereas white patients completed treatment at a rate of 89.5 percent. In a system where incomplete treatments had loomed and Black patients faced the brunt of the disparities, this intervention was a watershed.

Part of GHDC’s impact has also been changing mindsets in an institution and across a community, which could not be possible without intention and dedication to the relational work. The realization from medical professionals that bad health outcomes did not have to be about individual patients being noncompliant but a system consistently failing to ensure all patients, regardless of race, get the quality care they need has had ripple effects across the institution beyond cancer care, members say.

**Maintaining Momentum**

Given the baked-in nature of structural racism and its inherent unequal arrangement of power, it is critical to ensure institutions remain committed and diligent to avoid reverting back to business as usual. A strong relationship with a community partner can be the driver of that accountability. GHDC was able to bring about lasting change in Greensboro because of its strong relationship with Cone. Having a community-based effort, like GHDC, to constantly question the status quo, drive priorities, monitor progress, and push the institution to do better is the foundation of the work and any success.

“Trying to have the system accountable to itself just does not work,” says Collaborative member Kristin Black. “Change in Greensboro was enduring because of the relationship the Collaborative established with Cone. That kind of true relationship building that comes first doesn’t happen over weeks or months. Sometimes that takes years while always being clear on why we are together and who the purpose of this work is for. That is how change becomes more sustainable.”

Looking ahead, the Collaborative is committed to this work even if the great many opportunities for further impact can seem overwhelming. There is energy in the Collaborative for an “ACCURE 2,” but what might that look like? So far the funding for GHDC’s work has been minimal—primarily project-based academic research grants. However, the outsized impact that GHDC has been able to instigate despite its limited resources is hard to ignore and begs to be continued. So what could maintaining momentum mean?

It could be as straightforward as tackling racial disparities in other types of cancer care at Cone Health. Or ACCURE 2 could stick with breast and lung cancer care and spread to other cancer centers in North Carolina. Or do both, spreading its cancer care reach both in type of cancer and location. Right now the Collaborative constantly fields interest from other states, which it doesn’t have the resources or infrastructure to pursue. But could
there be a model where GHDC’s insights are shared with other community-based efforts to drive this type of change in cancer centers in communities across the nation?

Perhaps the ACCURE model could move beyond cancer care to other healthcare disparities and diseases. Some members have already begun to think about and work on translating this work to maternal healthcare for instance. What about ACCURE for diabetes or heart disease? Or applying the model to root out disparities that manifest differently for Latinx patients or patients of other racial or ethnic identities?

Or, what if the GHDC approach moved beyond healthcare entirely and tried to chip away at the structural racism in other systems, like, say, education or criminal justice? A cure for the structural racism in any system? Imagine that. The Collaborative wrote a research paper, recently published in *Frontiers of Public Health*, that investigates those types of possibilities.16

**Takeaway for Funders**

Although GHDC’s past success and its dedication to the work ahead are both noteworthy, the virtual absence of private philanthropy over its first 18 years stands out as a missed opportunity. Funders hoping to see lasting impact when it comes to issues they care about cannot ignore groundwater work, like GHDC’s, that tackles the root causes of inequity and disparities, namely the racism embedded in our structures and systems. It is telling that GHDC did not pursue private philanthropy, instead sticking to much more restrictive federal research grants. In part, as a collaborative effort pursuing anti-racism work it could not see itself in the ways that philanthropists often talk about how they support social change. That disconnect is a shame. There is a ripe opportunity for transformative change to happen if more work like this was supported.

*This case study was prepared by The Bridgespan Group for the Greensboro Healthcare Disparities Collaborative.*

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