



#INCLUSION PLEDGE PLAYBOOK

A step-by-step guide to eliminate barriers in cancer care for Black women, featuring specific and measurable tactics for the pharmaceutical industry.



In collaboration with



FOUNDER'S MESSAGE

Martin Luther King, Jr. once said *"Of all the forms of inequality, injustice in health is the most shocking and the most inhuman because it often results in physical death."*

When I first read those words, said in 1966 before he stepped into the second convention of the Medical Committee for Human Rights, I could not help but think how sad the struggle was back then for people of color to receive basic healthcare, and yet how unfortunate that today, more than 50 years later, those struggles continue.

Because as an immigrant, as a woman, as a woman of color, and as a breast cancer survivor, I have seen firsthand how inequality has negatively impacted the healthcare people like me have received. I have watched friends die because the color of their skin or the size of their bank account determined their outcome. No options. No second opinions. Just one-size-fits-all treatment for people like us.

Because as an immigrant, as a woman, as a woman of color, and as a breast cancer survivor, I have seen firsthand how inequality has negatively impacted the healthcare people like me have received.

After my second round of chemotherapy for breast cancer at the age of 32, I founded the Tigerlily Foundation to educate, empower, advocate for, and support young women affected by breast cancer. From that simple purpose – I call it a seed – the Foundation grew not only to support and educate women around the world on women's and breast health, but also to transform health equity for Black women through advocacy and policy action.

In 2019, the Tigerlily Foundation created the **#InclusionPledge**, stating we would participate only in advocacy initiatives, such as panels, advisory boards, planning committees, and programs, which include the experience of Black women. From there, we expanded the Pledge to include individuals and companies that have a direct impact on the healthcare of Black women.

The **#InclusionPledge** is now a rallying cry and call to action, as the Tigerlily Foundation works with leaders in the breast cancer care ecosystem, including pharmaceutical companies, clinical research organizations, clinicians, healthcare systems, healthcare payor systems and physician organizations and groups, to hold them accountable by taking specific, measurable actions to help end disparities in healthcare. Today, more than 12,000 people have signed the **#InclusionPledge** and more than 90 corporations and institutions have committed to our purpose.

But we're not done. Remember, this is not a moment, it's a movement. A way of life to be sustained. With your help, gone will be the days of health inequality about which Dr. King spoke and continues still to this day. This Playbook is a roadmap for you – as an individual or leader in the healthcare setting – to make specific and measurable changes across the healthcare industry via commitments to end health disparities.

Thank you for joining our movement.

**Maimah Karmo, President and Founder
The Tigerlily Foundation**



PURPOSE OF PLAYBOOK & #INCLUSIONPLEDGE

THE #INCLUSIONPLEDGE PLAYBOOK

The Tigerlily Foundation **#InclusionPledge** Playbook is a roadmap for the pharmaceutical industry and highlights specific, measurable and timebound tactics which can be taken by stakeholders to eradicate barriers in cancer care for Black women while focusing on achieving health equity.

Simply stated, this **#InclusionPledge** Playbook highlights what is possible when pharmaceutical companies commit to transparency, truth, and transformation.

FROM TALK TO TRANSFORMATION: A PATH TO HEALTH EQUITY



THE #INCLUSIONPLEDGE

We pledge to take specific actions to dismantle and eradicate systemic barriers, working to end disparities for Black women in our lifetime.

HOW TO USE THE PLAYBOOK

- In the pages that follow, you'll find information, statistics, actions, and strategies to help educate your company about the healthcare disparities faced by Black women.
- With this knowledge, make a commitment to anti-racism and invest in and develop specific, measurable actions to dismantle systemic barriers, while simultaneously co-creating solutions that will result in health equity for Black women and end disparities in our lifetime.
- As these commitments, strategies, and actions are implemented and socialized, continue to monitor their progress to ensure the barriers to care for Black women are eradicated.

DID YOU KNOW?



Blacks/African Americans have higher death rates than all other racial/ethnic groups for many, although not all, cancer types.
(Source: Cancer.gov)

BARRIERS TO EQUITABLE HEALTHCARE FOR WOMEN OF COLOR

While there are a myriad of barriers Black women face in healthcare, such as health literacy, socio-economic background, and limited access, none are as prevalent as those listed here. The long-term impacts of racism have permeated our healthcare system, and the repercussions continue to lead to health disparities for Black women within the cancer research and the cancer care ecosystem. These factors equate to a 40% higher death rate for Black women with breast cancer. (Source: CDC)

DID YOU KNOW?



Black and Hispanic women have higher rates of cervical cancer than women of other racial/ethnic groups, with Black/African-American women having the highest rates of death from the disease.

(Source: Cancer.gov)

MEDICAL RACISM

A history of racism underscores the American healthcare system.

This racism often persists today, resulting in biased decision-making by medical providers, researchers, and people in a position of power.

Conscious or unconscious, these biases can have life or death consequences and cause psychological and emotional trauma among people of color and other marginalized groups.

Medical racism also results in mistrust of medical professionals by patients due to historical and present-day experiences of harmful and exclusionary practices.

UNDERREPRESENTATION IN CLINICAL TRIALS

Clinical trials for cancer drugs critically overlook women of color and other marginalized groups, and Black women are among the most underrepresented groups. In fact, the Food and Drug Administration reported that only 4% of clinical trial participants are Black and 5% are Hispanic even though Black and Indigenous People of Color, overall, have both the highest death rate and shortest survival rate for most cancers.

Black women are excluded from, or underrepresented in, clinical trials due to exclusionary criteria, oversight by trial organizers and policies that disincentivize participation. Drugs and treatments are then developed without considering efficacy, adverse effects, and other outcomes for Black women.

UNDERREPRESENTATION IN THE HEALTHCARE WORKFORCE

According to the U.S. Bureau of Labor Statistics, in 2020 just 17.4% of workers in healthcare and social assistance were Black, compared to 72.5% white workers. Black women are under recruited and thus underrepresented among healthcare professionals in the U.S. This means that Black patients do not always see themselves represented in their providers, resulting not only in care that lacks cultural and racial sensitivity, but also is a challenge to recruiting and inspiring future Black healthcare providers.

BARRIERS TO EQUITABLE HEALTHCARE FOR BLACK WOMEN

LACK OF ACCESS

Black women are disproportionately affected by socio-economic challenges and psycho-social trauma that limits access to medical care, healthy lifestyle-promoting activities, and support systems.



Psychological

Racism and sexism that increase emotional, mental and physical stress.



Financial

Prohibitive costs of healthcare, including mental health care and medical insurance.



Geographical

Long distance and limited public transportation to reach healthcare locations.



Mental

Impact on family, work, home, caregiving, negatively impacting mental health and increasing allostatic load.



Environmental

Exposure to chemicals, toxins, and other environmental injustices.



Lifestyle

High cost and low availability of healthy foods, combined with safe places to exercise.



Emotional/
Trauma

Limited education, patient advocacy, mental healthcare, case management and other wrap-around social services.



Socio-
Economic

Unavailable or inaccessible specialists and facilities for high-quality treatment and care.

BIASED MEDIA PORTRAYALS

Breast cancer is typically depicted as a disease affecting white women. However, incident rates of breast cancer between white and Black women are nearly identical and, among younger women, Black women have higher rates of breast cancer when compared to white women.

The media and popular culture often reinforce this notion by excluding Black women from decision-making and failing to present images and stories of Black women and other women of color affected by breast cancer.

More representative and inclusive storytelling will help Black girls, women and families learn more about cancer and help all of society gain a greater understanding of the true diversity of experiences related to breast cancer.

BE A PART OF THE **SOLUTION**

Unfortunately, the pandemic has had and will continue to impact health disparities for Black women within the research community and cancer care ecosystem. To continue to accelerate and make an impact, the **#InclusionPledge** is imperative.

To eliminate the barriers listed on the previous pages, people of all races and ethnicities need to come together and pledge to take actions and be a part of the solution. The first step – take the **#InclusionPledge**.

STEP 1

Take the **#InclusionPledge**.

Visit <https://www.tigerlilyfoundation.org/inclusionpledgeforblackwomen/> to take the pledge and commit to at least one action that you and/or your organization will make to bring **AWARENESS** to the issues impacting so many Black women.

STEP 2

Form an interdisciplinary team within your organization, starting with executive leadership, to utilize this document to establish a strategy, set a timeline and **ACTIVATE** your plan.

STEP 3

Don't stop there. Remember this is a movement, not a moment in time. At all steps, let us be a resource for you, including meeting with your leadership team, presenting to your colleagues or working on the DE&I team on tactics and strategy, so that we can **ACCELERATE** the movement.

DID YOU KNOW?



Black women have a less than 5% enrollment rate in clinical trials, resulting in less understanding of physiology and less therapeutic benefit of treatments.

(Source: Cancer.gov)

HOW TO **CREATE & ADVANCE** DE&I INITIATIVES IN YOUR COMPANY

The goal of the **#InclusionPledge** is to hold companies and organizations accountable to take specific, measurable change that improves the health outcome for women of color. By identifying and eliminating the barriers currently in place, particularly in cancer research and the cancer care ecosystem, we will see changes and improvements. While there is no one size fits all approach for companies, Tigerlily is a resource to help you come up with a plan of action best suited for your organization. However, knowing where to start on a DE&I journey can be a barrier in and of itself.

Most companies will find themselves at one of these three levels when they evaluate their DE&I initiatives:

AWARE	ACTIVATED	ACCELERATED
At the AWARE level, an organization is mindful that changes must occur and begins the process to implement meaningful outcomes. This includes both internal and external.	Other organizations may be ACTIVATED , meaning they are familiar with sources of inequalities and are building upon their existing framework by executing commitments, such as partnerships with outside organizations and efforts to increase leadership and organizational staff representation.	At the ACCELERATED level, organizations are capable of influencing policies, programs, and people – both internally and externally – and have taken actions to remove barriers by aligning financial investments with their strategic values.

Before developing commitments, consider these questions to help you assess where there are opportunities to shape your **#InclusionPledge** commitment.

- Where are we when it comes to DE&I initiatives? Is it a one-time initiative or an ongoing process?
- What is the diversity of our leadership team, and is it identical to that of our employees?
- Do our audiences, including customers, employees, community members and peers, believe we are a diverse, inclusive organization?
- Do we incorporate processes to ensure our clinical trials to include Black and Ingenious People of Color (BIPOC)?
- What is the diversity (age, community, socio-economic level, financial, sexuality, etc.) of our workforce?
- Do we provide a safe space for employees to share their thoughts/feelings without retaliation?
- Have we implemented an internal comprehensive diversity and inclusivity commitment, and does this incorporate all company functions?
- Are we recruiting from Historically Black Colleges and Universities as part of STEM recruitment initiatives?
- Is there a communications strategy in place to communicate these commitments across our company?

- Are there financial and human resources to support this commitment?
- Is there an impact assessment plan in place to measure and track these commitments?
- Is there a dedicated person or office to oversee diversity, equity, and inclusion initiatives?
- Are we working with Black and Brown patients and patient advocacy groups to co-create solutions driven by their lived experience and perspectives?

With these questions answered, you'll be able to start down the journey toward the dismantling of barriers to equitable healthcare. Don't forget – as you roll out the actions for your organization, always:

1. Communicate your initiatives and actions both internally and externally to demonstrate to employees, customers, partners, board members and other important audiences that your company takes healthcare equality seriously and is taking steps to ensure all people are treated fairly and equally.
2. Stay with it. Change takes time, focus and resources. Ensure company narratives and investments are aligned with health equality initiatives. Conduct ongoing company-wide town halls and listening summits to keep the topic front and center. Partner with diverse employee groups and outside organizations to keep the conversation going.

SAMPLE ACTIONS & GOALS

Below are examples of plans and actions to eliminate barriers to equitable healthcare for women of color to foster ideation and collaboration:

MEDICAL RACISM

- Design educational content for medical schools – in partnership with advocacy organizations – highlighting awareness of systemic medical racism and strategies for eradication.
- Support advocacy initiatives focused on understanding the experience and perspectives of historically marginalized and racially and ethnically underrepresented people. Work collaboratively to address a shared commitment to advancing science and improving care for those communities.
- Create annual fellow scholarships to identify and illustrate strategies and broadly accepted tools for overcoming medical racism in the clinic.
- Conduct a series of sessions across the enterprise to create awareness, increase understanding and drive action on the topics of racial injustice, the Black experience in the U.S., impact of implicit bias and importance of allyship.

UNDERREPRESENTATION IN CLINICAL TRIALS

- Establish a cross-functional working group within Research & Development to identify barriers to recruitment, enrollment and retention and employ strategies that encourage participation for diverse populations.
- Develop, disseminate, and amplify clinical trial content focused on patients' needs.
- Provide financial support to eliminate barriers to trials by investing in organizations doing disparities work in a strategic, actionable, and measurable way.
- Hire Diversity, Equity, and Inclusion (DE&I) staff for clinical operations.
- Implement Tigerlily training with clinical trial site staff on how to assess bias.
- Partner with Tigerlily and its patient advocates to ensure diversity, equity and inclusion are woven throughout your trial, along with cultural perspective and with a lens to eliminate barriers and improve quality of care and life.

UNDERREPRESENTATION IN THE HEALTHCARE WORKFORCE

- Evaluate, analyze, and evolve hiring practices annually to ensure inclusive practices in attracting, developing retaining and promoting talent. Set collective goal of diversity and inclusion within each corporate function.
- Establish a suite of training materials available on-demand for self-directed learning on addressing racism in the workplace.
- Create Diversity, Equity, and Inclusion (DE&I) committees in every function.
- Set bi-weekly Oncology Leadership I&D "Office Hours," an open exchange to discuss thoughts, ideas, questions or concerns around inclusion and diversity.
- Support initiatives dedicated to addressing disparities in healthcare, particularly underserved communities for STEM education (high school, college, patients).
- Build a cohort of young scientists representing historically marginalized groups to get involved in cancer research by incentivizing and supporting their career development and growth. Fund three scholarships annually.
- Bridge opportunity, knowledge, and equity gaps by connecting students to impactful careers with resources that bring relevancy to learning. Broaden the understanding of and engagement with STEM by providing access to standards-aligned digital curriculum to students, teachers, and parents nationwide with a goal of reaching 1,500 students.

SAMPLE ACTIONS & GOALS

LACK OF ACCESS

Black women are disproportionately affected by socio-economic challenges and psycho-social trauma that limits access to medical care, healthy lifestyle-promoting activities, and support systems.



Psychological

Racism and sexism that increase physical and mental stress.

- Provide semi-annual racial diversity training to provide better patient outcomes.
- Establish safe spaces to allow BIPIC staff to voice concerns, challenges and work collaboratively to create solutions.
- Develop ways to better listen to patients to ascertain their needs, enhance patient/provider communication and offer support.



Financial

Prohibitive costs of healthcare, including mental health care and medical insurance.

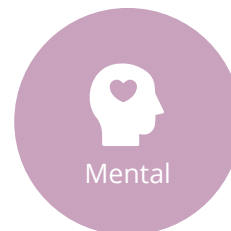
- Create a clinical trials concierge service that will help to defray the cost of traveling, lodging, childcare and other important expenses for patients.
- Offer financial support to patients (out of treatment greater than 12 months) to help alleviate the strain of bills.



Geographical

Long distance and limited public transportation to reach healthcare locations.

- Provide Uber/Lyft vouchers for patients to and from their treatments.
- Provide hoteling near treatment facilities.



Mental

Work and caregiving demands negatively impacting healthcare delivery.

- Offer culturally competent mental health professionals available to staff and patients year-round as a benefit.
- Train staff semi-annually on intercultural communication to improve patient experiences.

DID YOU KNOW?



According to a panel discussion at the **BIO Conference in 2019**, racial minorities make up 39% of the U.S. population, yet clinical trial participation is between 2 – 16%.

At the same conference, it was stated that Blacks make up less than 5% of clinical trial participants.

SAMPLE ACTIONS & GOALS

LACK OF ACCESS (CON'T)



Environmental

Exposure to chemicals, toxins, and other environmental injustices.

- Work with advocacy organizations and elected officials to help create and advocate for political reform around environmental toxicants in underrepresented areas.
- Set a goal to reduce environmental impact affecting women of color by January 2023.



Lifestyle

High cost and low availability of healthy foods, combined with safe places to exercise.

- Donate money to organizations working to provide healthy food delivery 1x per week to patients and survivors.
- Create an exercise series, in person and virtually, for patients and survivors. For those without internet access or encountering geographic barriers, mail exercise and meal plans to their homes.



Emotional/
Trauma

Limited education, patient advocacy, mental healthcare, case management and other wrap-around social services.

- Provide free culturally competent mental health resources to patients.
- Provide staff with training semi-annually to better identify levels of health literacy and know when to provide further education at the level of the patient.



Socio-
Economic

Unavailable or inaccessible specialists and facilities for high-quality treatment and care.

- Establish partnerships with five local hospitals to provide additional trainings, resources, and medical specialists to reach patients who do not have access to high-quality treatment and care.
- Open a small facility in partnership with other centers of excellence in underrepresented neighborhoods.

BIASED MEDIA PORTRAYALS

- Host a corporate "Lunch & Learn" to better understand the needs of patients, publish and implement solutions internally and externally.
- Engage advocates of color in diversity across company programmatic areas to ensure staff is educated on this issue and that external portrayals are improved.
- Ensure company's Black leadership is represented in media relations activities to change the dialogue and promote inclusion.
- Integrate and promote women of color in activities to include media and thought leadership positions.
- Promote the experience of patients of color through diverse patient series and blogs. No less than 25% of experiences to be from women of color.
- Engage and amplify the voices of women of color by integrating more women of color as social influencers, focusing on elevating social change and highlighting disparities. Twenty percent of all patient stories to focus on Black and Brown women.
- Feature women of color with lived experiences from communities we want to serve in to promote culturally accurate corporate public relations campaigns and promotional advertising.
- Co-create a public service announcement with a patient advocacy organization to promote patient empowerment, screening, testing and treatment decision-making.
- If you see someone inaccurately portraying a person of color, say something.

CASE STUDIES

CASE STUDY 1

“Equity” is a core value at a **multinational pharmaceutical and biotechnology corporation**, and it partnered with Tigerlily to sign the **#InclusionPledge** as a demonstration to both internal and external audiences its priority to be inclusive, act with integrity and ensure every person is seen, heard, and cared for. The company also funded medical grants aimed at actively reducing the disparities in care and created resources for both patients and healthcare professionals to help women of color living with breast cancer tackle the barriers preventing them from receiving optimal care.

As part of their **#InclusionPledge, the company made the following commitments:**

- Host “safe space” conversations with patients as experts, engaging their internal DE&I leaders.
- Promote diverse representation throughout their partnerships, suppliers and events.
- Commit to diversity in clinical trials through launching Clinical Trials Center of Excellence and multiple clinical trial workstreams.
- Collaborate with Tigerlily Foundation to host diversity conversations and Town Halls and trainings with internal leadership and staff.
- Highlight its commitment through social media and traditional media opportunities.
- Engage Tigerlily Foundation’s ANGEL Advocates (Black women in communities with the highest disparities in breast cancer) in their disparities initiatives to include ongoing advisory activities.
- Engage Tigerlily Foundation leadership in media spotlight activities and as ambassador to highlight diverse perspectives.
- Issue call to action with partners, suppliers, etc.
- Work to eliminate barriers by developing internal and external solutions.

CASE STUDIES

CASE STUDY 2

A pharmaceutical company headquartered in Indianapolis, Indiana, with offices in 18 countries, is investing to create more jobs and economic opportunity while partnering with Tigerlily to drive social change.

As part of their #InclusionPledge, the company committed to:

- Host diversity Town Hall(s) curated in partnership with the Tigerlily Foundation.
- Work with the Tigerlily Foundation to ensure diverse patient centricity integrated into leadership from product development, protocol development, trial design, marketing and launch.
- Hire Diversity, Equity and Inclusion Corporate lead to implement, track and measure commitments.
- Financially support pilot programs to eliminate barriers for patients in healthcare and clinical trials.
- Conduct landscape assessment and support the implementation of health equity policy across healthcare and clinical trials.

CASE STUDIES

CASE STUDY 3

A research-based biopharmaceutical company in New Jersey and focused on the discovery, development, and commercialization of innovative medicines recognized it needed to do more to accelerate its DE&I initiatives and progress.

It partnered with Tigerlily and developed the following commitments as part of its #InclusionPledge.

- Support development Diversity & Inclusion playbook for pharma to highlight best practices.
- Support policy papers that analyze and provide recommendations for health equity across screening and clinical trials, in order to work to create systemic change.
- Support the #Inclusionpledge campaign through financial investment in organizations with a focus on BIPOC populations and health equity programs.
- Host Town Hall(s) for internal teams with patients as experts.
- Foster an inclusive culture where differences are listened to and leveraged to innovate and achieve health equity throughout entire company.



ACKNOWLEDGEMENT OF **GRATITUDE**

Tigerlily Foundation is grateful to our partners and corporate sponsors, who enable us to continue our mission of supporting young women – before, during and after breast cancer. A special note of appreciation goes to **Gilead Sciences, Inc.** for its support in making the #InclusionPlaybook possible and assisting us on our journey to remove the barriers in cancer treatment and care for Black women.

To learn more about our partners and sponsors, and to become a sponsor, please visit www.tigerlilyfoundation.org/partnership.



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