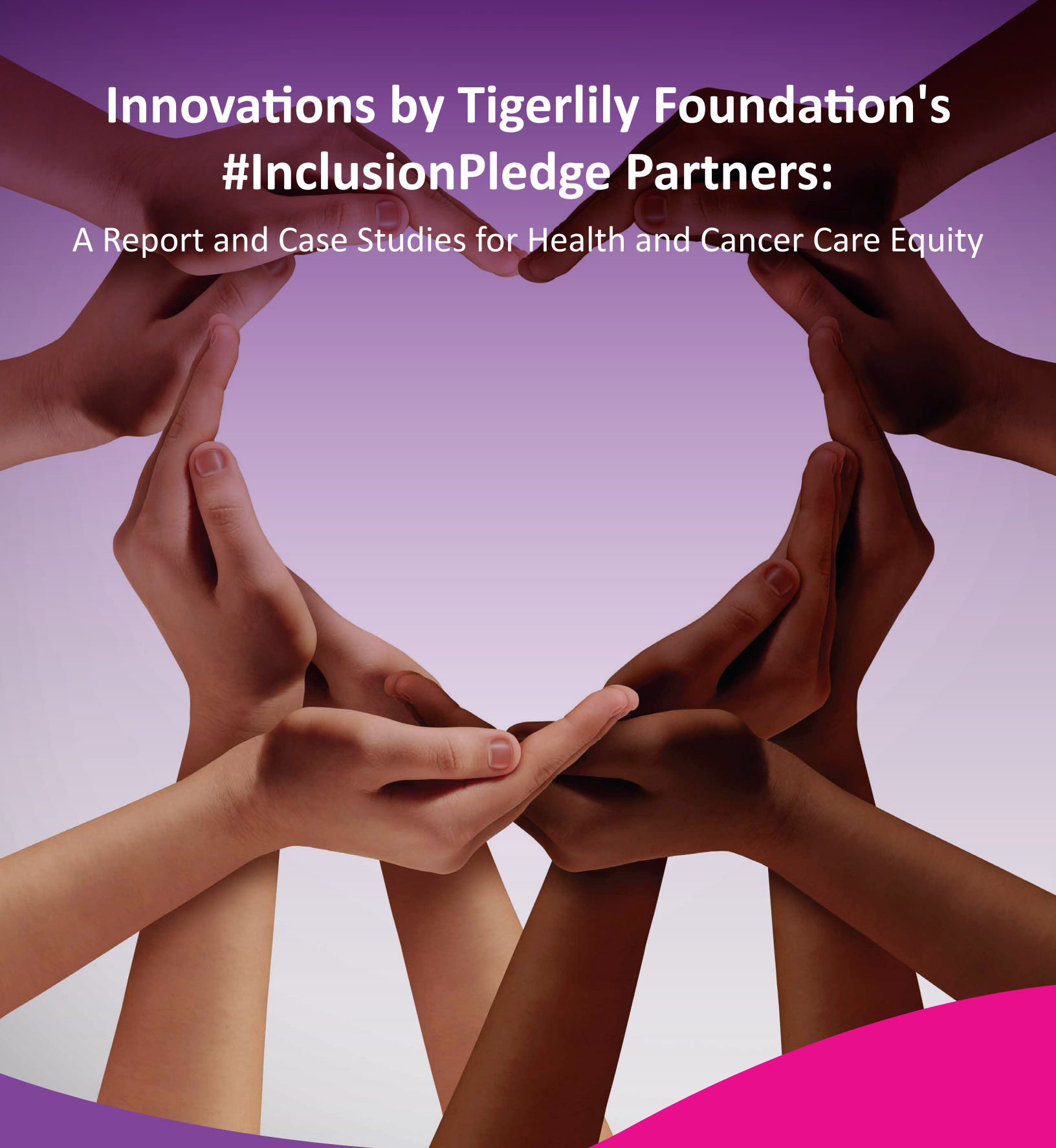


Innovations by Tigerlily Foundation's #InclusionPledge Partners:

A Report and Case Studies for Health and Cancer Care Equity



INNOVATIONS BY TIGERLILY'S #INCLUSIONPLEDGE PARTNERS: A REPORT AND CASE STUDIES FOR HEALTH AND CANCER CARE EQUITY

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LETTER FROM TIGERLILY'S PRESIDENT AND CEO, MAIMAH KARMO

Individuals, organizations, and researchers worldwide are working to find more effective ways of preventing, detecting, treating, and managing breast cancer. Over the past three decades, there have been promising innovations and improvements in breast cancer care. However, breast cancer outcomes are worse for women of color, especially Black women, than they are for white women.¹

The realities of disparities in cancer outcomes by race are sobering:

- In 2022, it is estimated that about one-third of all cancer diagnoses among American women will be breast cancer.²
- Black American women are twice as likely as non-Hispanic white women to be diagnosed with triple-negative breast cancer.³
- Some studies have also shown that Black women often face delays in the diagnostic process compared to white women, suggesting systemic inequities including discrimination and provider bias.⁴
- While the length of diagnostic evaluation itself is longer for Black women, the age at breast cancer diagnosis is younger for Black women. African American women represent 23% of all breast cancer cases diagnosed before the age of 50 compared to 16% of white women. This has been consistent across several decades; a 2002 comparative report on breast cancer racial differences highlighted that more than 10% of African American breast cancer patients were diagnosed before the age of 40 compared to 5% of white patients.⁵
- Black women are 40% more likely than white women to die from the disease—the highest breast cancer mortality rates of any racial group in the United States.⁶

¹ For details on the high cancer burden on Black women, see American Cancer Society. Cancer Disparities in the Black Community, 2022 <https://www.cancer.org/about-us/what-we-do/health-equity/cancer-disparities-in-the-Black-community.html>.

For information on black women's significantly higher risk for triple negative breast cancer deaths see, Southall. J. 2021. Black women are at higher risk for triple-negative breast cancer mortality. HemOnc today. <https://www.healio.com/news/hematology-oncology/20210513/Black-women-at-higher-risk-for-triplegenegative-breastcancer-mortality>

² For specific 2022 estimates see <https://www.breastcancer.org/facts-statistics>

³ See statistics on breast cancer disparities in, "Cancer Disparities in the Black Community", American Cancer Society <https://www.cancer.org/about-us/what-we-do/health-equity/cancer-disparities-in-the-blackcommunity.html> & Armour-Burton, T., & Etland, C. (2020). Black Feminist Thought: A Paradigm to Examine Breast Cancer Disparities, *Nursing Research*, 69(4), 272–279, & Prakash O, Hossain F, Danos D, & Lassak A, Scribner R and Miele L (2020) Racial Disparities in Triple Negative Breast Cancer: A Review of the Role of Biologic and Non-biologic Factors. *Front. Public Health*

⁴ From "Racial Disparities in Diagnostic Delay Among Women with Breast Cancer". Miller-Kleinhenz, J. M., Collin, L. J., Seidel, R., Reddy, A., Nash, R., Switchenko, J. M., & McCullough, L. E. (2021). *Journal of the American College of Radiology*, 18(10), 1384–1393. <https://doi.org/10.1016/j.jacr.2021.06.019>

⁵ Data from the following two articles show the consistent disparities in breast cancer care overtime- (i) Murray Rebner & Pai, Breast Cancer Screening Recommendations: African American Women Are at a Disadvantage, *Journal of Breast Imaging* (ii) Johnson E. T. (2002). Breast cancer racial differences before age 40-- implications for screening. *Journal of the National Medical Association*, 94(3), 149–156.

⁶ From "Patterns and Trends in Age-Specific Black-White Differences in Breast Cancer Incidence and Mortality – United States, 1999–2014." Richardson, L.C, Henley, S.J., Miller, J.W., Massetti G, Thomas C.C. 2016.

The ongoing global COVID-19 pandemic has only deepened these disparities. At the Tigerlily Foundation, we see the direct impact of cancer healthcare inequities in the communities that we serve and are acutely aware of the ingrained historical and systemic issues that need to be tackled to remove barriers to health equity. We also know that a sustained and collaborative effort by a diverse range of individuals and organizations will lead to tangible results in eliminating cancer disparities.

In 2019, the Tigerlily Foundation launched the #InclusionPledge as an online petition to spearhead such a collaborative movement, calling on organizations and individuals to help dismantle systemic barriers to health equity and end disparities for Black women in cancer healthcare and research. The #InclusionPledge is a call to action to have the voices of Black, Indigenous, and women of color (BIWOC) represented in cancer advocacy platforms. To date, the #InclusionPledge has garnered more than 12,000 signatures on Change.org.

In June 2020, Tigerlily added accountability to the #InclusionPledge, inviting signatories and other partners to commit to measurable and meaningful actions towards fulfilling their Pledges. By October 2020, 57 organizations had shared specific commitments to the platform. Since then, Pledge partners have articulated their commitments and taken various actions to fulfill their Pledge commitments.

More than two years since the inception of the #InclusionPledge, in the context of the COVID-19 pandemic and the growth of the Movement for Black Lives since of 2020, we believe the time is right to reflect on the Pledge and its progress. To carry out this vital task of tracking progress, we solicited the guidance of Equity Based Dialogue for Inclusion (EBDI), a diversity, equity, inclusion, and justice (DEIJ) consultancy with expertise in qualitative research. We chose to engage EBDI to help us understand and highlight the accountability journeys of our Pledge partners, and to offer their unbiased expertise on the most promising practices to support health and cancer care equity.



First, EBDI helped us develop a commitment tracker that allows Pledge partners to share their specific Pledge commitments and provide information on their actions towards meeting them, and most importantly, any identified impact. Second, they conducted in-depth interviews with some of our partners to gain insight into the work that has been accomplished, is currently ongoing, and is planned. The latter is the focus of this report, which details the impactful and innovative work our Pledge partners are undertaking to realize greater health and cancer care equity.

Documenting the work that our partners are doing is an essential step in holding our collective movement accountable for what we are doing to expand and accelerate efforts to reduce health inequities. At Tigerlily, this is one of the ways we are restating and reiterating our commitment to listen, learn and continue to place patients and their support systems at the center of what we do. The collection and sharing of the case studies in this report, coupled with the commitment tracker, is our way of embracing the importance of implementing consistent data collection and analytic processes to allow for the dissemination of best practices that organizations can adopt to support the eradication of health disparities for Black and other women of color.

On behalf of Tigerlily's team, I want to extend my appreciation to all our partners that participated in our research journey by sharing their stories. In the next few years, we plan to go through an

annual research process to help track progress on commitments and keep ourselves accountable. Most importantly, we continue in solidarity with every individual and organization working towards eradicating health disparities that affect Black, Indigenous, and women of color in cancer care.

In solidarity,

Maimah Karmo



A NOTE ON THE LANGUAGE AND MEASUREMENT OF EQUITY AND INCLUSION

Tigerlily defines equity as the recognition and acknowledgment of gaps in cancer healthcare for all people regardless of gender, race, ethnicity, nationality, religion, sexual orientation, gender identity, and socioeconomic status; and ensuring opportunities to access cancer healthcare. Essential for achieving health equity is promoting inclusion, which Tigerlily defines as the process of identifying, reducing, and dismantling systemic barriers to health equity. Due to well-documented health disparities in the context of breast cancer, Tigerlily places a specific focus on the impact of equity and inclusion initiatives on Black women.

In our collective work to close health disparities for Black women, equity and inclusion efforts must be measured both in terms of the work's outcomes, and continued commitment to process. Treating equity and inclusion as ever-evolving processes rather than one-time outcomes recognizes that equity and inclusion are attained only when people and organizations continually commit to systems and structures that support everyone, especially people who have been traditionally marginalized.

The best practices for achieving equity and inclusion in cancer healthcare and beyond, however, are emerging. Some best practices are being implemented in local contexts but remain unknown to the larger movement, and still others have yet to be discovered. In this context, the goals of this research and the associated case studies are to:

- Provide an initial overview of the different commitments, priorities, and actions among Pledge partners.
- Identify promising best practices for addressing barriers to cancer care, specifically for Black women and other women of color.
- Identify and explore priority areas for the Pledge's agenda going forward and opportunities for continued collaboration.



Black Women and Cancer Care

Factors such as race, ethnicity, sexual orientation, gender, socioeconomic status and the intersection of these identities, as well as insurance status, and neighborhood location, are at the center of significant barriers to cancer care and health equity for Black women and other women of color. ⁷ In her book, *The Cancer Journals*, Audre Lorde poignantly explains how her experience with liver cancer metastasized from breast cancer is informed by oppressive racist and heterosexist attitudes in seeking care: “Survival isn’t some theory operating in a vacuum. It’s a matter of my everyday living and making decisions”.⁸

Everyday living and decision-making regarding breast cancer management for Black women reside within an inequitable and discriminatory public health system filled with a myriad of barriers. These barriers fall within three categories, system-level barriers, clinical-level barriers, and patient-level barriers (see Table 1). ⁹

⁷ (Footnote ³, Armour-Burton, T., & Etland, C. ²⁰²⁰).

⁸ Quote is from pp⁶⁰. In “*The Cancer Journals*”, Audre Lorde narrates her journey with cancer in a way that highlights the racist and sexist challenges that even women of color with economic freedom face. Lorde, Audre. (1997). *The Cancer Journals*. San Francisco: Aunt Lute Books.

⁹ From “Systemic Barriers to Risk-Reducing Interventions for Hereditary Cancer Syndromes: Implications for Health Care Inequities.” Mittendorf, K. F., Knerr, S., Kauffman, T. L., Lindberg, N. M., Anderson, K. P., Feigelson, H. S., Gilmore, M.J., Hunter, J.E., Joseph, G., Kraft, S.A, Zepp, J.M., Syngal, S., Wilfond, B.S., & Goddard, K. A. (2021). *JCO Precision Oncology*, ⁵, 1709-1718.

Table 1. Barriers to Cancer Care Access for Black Women: Evidence from Literature

System-Level Barriers	Clinical level barriers	Patient-level Barriers
<p>Racism</p> <p>Due to a pattern of systemic and structural racism, Black women have less knowledge about risk reduction options and less access to specialists. Uptake of genetic testing and other cancer care options is also affected by a general mistrust in the health system based on historical medical harm to Black communities.</p> <p>Access and Service Delivery</p> <p>Innovative immune therapies and technology for cancer care remain inequitably accessible. During the current COVID-19 pandemic, there has been a decrease in cancer screening for low-income and ethnic minority groups.</p>	<p>Clinician-specialty and communication with patients.</p> <p>Low-income communities including Black women who are uninsured or underinsured, often do not have access to specialists that provide appropriate recommendations for cancer care. Where clinicians make appropriate recommendations but fail to account for health literacy, they may not adequately convey information in terms that patients understand; therefore the patients may miss out on recommended screenings and follow-ups, including follow-ups on abnormal results.</p>	<p>Financial and geographical</p> <p>Individuals living in poverty are less likely to get early screening and will be diagnosed with advanced level cancers that are more difficult to treat. A six-decade systematic data analysis found that people living in poverty had higher mortality rates than their affluent counterparts. Geographic and financial factors also interact as a compound barrier to care. A Black woman, for example, who lives distant from care, may also be facing financial barriers related to lack of insurance.</p> <p>Lack of information and Transportation</p> <p>Underserved communities such as BIWOC sometimes lack knowledge about screening and how to access relevant services, an important factor and barrier to health equity. Lack of transportation is another barrier that results in missed checkups and appointments for initiation and completion of quality cancer care and treatment therefore may contribute to poor breast cancer treatment outcomes for some BIWOC communities. It's estimated that more than three million Americans miss at least</p>

Table 1. Barriers to Cancer Care Access for Black Women: Evidence from Literature

System-Level Barriers	Clinical level barriers	Patient-level Barriers
<p>Workforce diversity</p> <p>In the United States, less than 3% of oncology specialists self-identify as Black. Black researchers often propose studies focusing on the community and population level to address health inequities. Such studies are less likely to attract funding in a field that prioritizes cellular and molecular science-focused research.</p>		<p>Patient’s beliefs</p> <p>Breast cancer is a difficult disease to cope with as both a patient and survivor. Studies have highlighted the anxiety and fear in African American women as a barrier to care and treatment. Some note that African American women are anxious and afraid to get screened due to fear of the results, fear of death from cancer, and negative previous healthcare experiences.</p>

There is literature that describes interventions aimed to remove barriers to equitable cancer care access in the United States. This report does not cover that literature, however, what we highlight below are the various organizational-level interventions and initiatives that some of Tigerlily’s #InclusionPledge partners are undertaking.

From “Cancer disparities and health equity: A policy statement from the American Society of Clinical Oncology.” Patel, M. I., Lopez, A. M., Blackstock, W., Reeder-Hayes, K., Moushey, A., Phillips, J., & Tap, W. (2020). *Journal of Clinical Oncology*, 38(29), 3439. <https://ascopubs.org/doi/full/10.1200/JCO.20.00642>
 See DeGroff et al. <https://doi.org/10.1016/j.yjpm.2021.106559> (CDC affiliation).

(See Footnote 10)

See (Footnote 10). Also, from “Addressing social determinants of health to improve access to early breast cancer detection: results of the Boston REACH 2010 Breast and Cervical Cancer Coalition Women's Health Demonstration Project.” & Clark, C. R., Baril, N., Kunicki, M., Johnson, N., Soukup, J., Ferguson, K., ... & Bigby, J. (2009). *Journal of women's health*, 18(5), 677-690.

From “Understanding and addressing social determinants to advance cancer health equity in the United States: a blueprint for practice, research, and policy.” Alcaraz, K. I., Wiedt, T. L., Daniels, E. C., Yabroff, K. R., Guerra, C. E., & Wender, R. C. (2020). *CA: a cancer journal for clinicians*, 70(1), 31-46.

From “Breast cancer screening barriers from the woman’s perspective): a meta-synthesis.” Azami-Aghdash, S., Ghajzadeh, M., Sheyklo, S. G., Daemi, A., Kolahdouzan, K., Mohseni, M., & Moosavi, A. (2015). *Asian Pacific Journal of Cancer Prevention*, 16(8), 3463-3471.

(See Footnote 14).

Disparities in barriers to follow-up care between African American and White breast cancer survivors. *Supportive Care in Cancer* Palmer, N. R., Weaver, K. E., Hauser, S. P., Lawrence, J. A., Talton, J., Case, L. D., & Geiger, A. M. (2015), 23(11), 3201-3209.

Research and Case Study Methods

The case studies presented in this report are the product of interviews and in-depth conversations with Tigerlily partners who signed the #InclusionPledge. We identified six case studies that highlight the various actions that partners are taking to address health disparities for Black women. Participants were identified through Tigerlily's database of 57 organizations that made Pledge commitments in 2020. Interview email requests were sent to a broad and diverse cross-section of organizations, including advocacy, pharmaceutical, industry, faith-based, and research institutions.

EBDI consultant, Nyaradzai Changamire, led the interviews with support from at least one Tigerlily staff member. We spoke with representatives from nine Pledge partner organizations:

- a. GRASP (Guiding Researchers and Advocates to Scientific Partnerships)
- b. FORCE (Facing Our Risk of Cancer Empowered)
- c. A Fresh Chapter
- d. Pieces of I
- e. Pink Legacy 50/50
- f. Patient Power
- g. Amgen
- h. ZERO Breast Cancer
- i. Living Beyond Breast Cancer

Our interviews included questions about the actions that partners are taking to advance the #InclusionPledge for Black women, the challenges they have encountered, the impact of their actions on their organizations and the communities they serve, their lessons learned from the Pledge process, and their plans for future Pledge commitments. We specifically discussed Pledge partners' activities in the context of their commitments when they initially signed the #InclusionPledge.

General Findings

Pledge partners are exploring and implementing various strategies, programs, and solutions to address health disparities for Black women with cancer. Table 2 provides an overview of Pledge partners' internal and external initiatives that are being developed and implemented.⁹



Table 2. Sample internal and external initiatives by Pledge partners

Internal initiatives

- Hiring Black women to help facilitate breast cancer education workshops and webinars targeted at Black communities.
- Inviting Black women patients and health experts to join advisory and other leadership boards.
- Investing in staff training on DEI issues to ensure responsive and culturally appropriate cancer advocacy programming for Black women.
- Fundraising for programs that target Black women.
- Developing DEI-related policies and strategies to ensure that organizational leadership set specific goals for achieving DEI (including allocating resources) and specify metrics that program staff will use to measure progress in outreach activities.

External Initiatives

- Developing public-facing materials and content that include diverse racial representation.
- Specifically marketing health information and workshops to the Black community with the help of Black women as facilitators, and making content at health centers, clinics, and churches in Black communities available.
- Organizing and facilitating breast cancer educational workshops and webinars for Black women and other people of color diagnosed with breast cancer.
- Creating and facilitating space for external partners, staff, and founders that share personal stories of self or family breast cancer diagnoses as an advocacy strategy.

All of the Pledge partners with whom we spoke shared the sentiment that, to ensure equitable and inclusive delivery of these initiatives in the communities they serve, the same DEI values need to be reflected internally. In this spirit, some partners have established ambassador or advisory teams with Black women that help design, advise, and review programs for cultural awareness and sensitivity. Lianna Hartmour, ZERO Breast Cancer's (ZBC) Program Director, shared:

"We're putting a specific effort into increasing diversity on our advisory board and inviting several Black women to be a part of that. We have a high representation of Black women on our Community Advisory Board, and we are currently focusing on doing the same for our Scientific Advisory Board. Continuing to make sure that we're prioritizing reaching Black women is an ongoing need and something we're committed to doing."

In other internal initiatives, ZBC and A Fresh Chapter have focused on intentional recruitment and talent acquisition practices that include hiring Black women to be in facilitation teams that reach out to communities. A direct outcome of this intentional recruitment is that their materials have become more culturally appropriate, relevant, and accessible for Black communities. Again, Lianna of ZBC notes,

“Having Black women in our advisory group has been central to making sure that our materials are accessible and relevant for Black communities.”

In addition to making materials more relevant, Black women team members can also help make sure that the materials are effectively distributed to the intended audience. As Terri Wingham, the founder of A Fresh Chapter notes:

“With our Inclusion, Diversity, Equity, and Access (I.D.E.A) team’s three members who are Black women, and taking their suggestions for marketing and word of mouth referrals to our network, has helped us reach the Black demographic.”

Investing in DEI training for staff and leveraging partnerships were also common steps that several organizations have taken in confronting bias and privilege. Organizations like Living Beyond Breast Cancer (LBBC) have engaged a DEI consultant to help them examine biases in hiring practices. Cathy Ormrod, the organization’s Executive Vice President, Strategy & Mission, explained they are developing an additional step to their staff training that disseminates a DEI organizational strategy with metrics for measuring DEI in both internal processes and external programming.

FORCE on the other hand, has anchored some of its initiatives on partnerships with organizations that serve Black women. To gather data on needs assessments for cancer services, FORCE designs surveys to better understand and inform more equitable cancer programs including education and participation in clinical trials. To ensure that the surveys reach and include perspectives from underserved communities, FORCE receives support from partners to share these surveys widely and reach Black women. For example, Dr Sue Freedman, Executive Director and Founder of FORCE explained:



“Through a CDC grant ending in 2024, we started some needs assessment surveys for different populations. We have prioritized reaching Black and Latina women with breast cancer, including some efforts to translate some of our x-ray articles into Spanish. Community partners, including Tigerlily and The Beautiful Gate Cancer Support and Resource Center are helping us spread the word about our programs and surveys to communities of color, because it's really important to us to make sure that they're getting into the hands of the people who are going to most benefit.”



While this report focuses on case study initiatives that organizations are developing and implementing, we also learned of exciting efforts that individuals, independent of organizations, are doing to advance health equity in the breast cancer space. For example, Christine and Julia, the founders of GRASP, share their personal breast cancer experiences at breast cancer conferences and events. They do this to create connections and encourage others going through the cancer experience. They also commit personal time to attending science-centric cancer conferences, intending to contribute to various information-sharing platforms by simplifying the scientific and technical language used at conferences for consumption by the public. Another example that illustrates the impact of independent individual actions is presented in Ashley Dedmon’s story; shared in Case Study Six of this report.

CASE STUDIES

a) Case Study One: GRASP (Guiding Researchers and Advocates to Scientific Partnerships) Intellectual Wrestles, Accountability and Representation in Breast Cancer Advocacy: GRASP’s Story of Advancing Health Equity for Black Women

#InclusionPledge Commitment:

GRASP’s staff will not participate in any advocacy initiative, panels, advisory boards, planning committees, programs, or other events that do not include the experience of people of color.



GRASP brings together scientists working on breast cancer and patients to exchange ideas and learn from each other. Founders Christine Hodgdon and Julia Maués both live with metastatic breast cancer. GRASP’s mission states: “Our patient-led program connects and empowers patients, clinicians, and researchers to exchange ideas and learn from each other so we can drive more meaningful and fundable research and make faster progress to improve therapies that will end cancer.”

Speaking on GRASP’s work, Julia notes, “We learn a lot from the scientists, but they also learn a lot from us.” She calls this exchange of ideas “intellectual wrestles,” where the patients and scientists challenge each other on various issues, including new cancer medicines, emerging therapies, and approaches. Patients and scientists ask each other the tough and necessary questions, therefore promoting better outcomes both ways.

Julia says that patients are the scientists’ biggest cheerleaders, and she knows this since she is a patient herself:

“There's no one that wants them to succeed more than we do because I will die if they don't succeed.”

The Problem: The voices of Black women and other minoritized people are not platformed in treatment and health advocacy contexts

While Julia and Christine (both white women) have, in their own breast cancer journeys, experienced how fulfilling their interactions with scientists are, they have also noted the lack of representation of Black women patient voices in these forums. Over the years, in the various spaces they navigate, they have met people of other identities, including Black women, all of whom experience multiple hurdles with a breast cancer diagnosis. However, they acknowledge that Black women in particular face additional challenges, including limited participation in innovative treatment trials, lack of representation in advocacy panels, and other forms of medical racism that lead to differential health treatment and outcomes.

Julia recalls one specific incident in the fall of 2019 at a breast cancer conference that was pivotal to GRASP's connection with the #InclusionPledge. A Black woman attending the conference brought attention to the lack of racial representation on a panel for research advocacy and health disparities (which broadly impact Black women) in which Julia and three other white women participated. The panel immediately invited the Black woman to join them in the discussion on stage. As Julia tells this story, she recoils at the praise she received afterward from other white women for creating a space for a woman of color. Julia sees such praise as an example of white privilege—being praised for doing the bare minimum of correcting something that should have been done right the first time. She, Christine, and other women pledged to never participate in advocacy panels or other inequitable spaces that do not represent diverse patient experiences.

During a fireside chat hosted by the Tigerlily Foundation at the conference mentioned above, Julia and Christine joined a small group of women in dialogue about the problem of lack of representation of women of color in conference panels. It is then and there that the idea of the #InclusionPledge was conceived. The Pledge grew, amplifying the cause as more people and organizations signed on, made commitments, and took actions to reduce health disparities for Black women. Within the space of breast advocacy, GRASP continues to carve a space for Black women who have not received the same limelight that Julia and Christine have.

The Solution: Actively promote the inclusion of Black women and other women of color in advocacy contexts

GRASP has pledged to not participate in any advocacy initiative, panels, advisory boards, planning committees, programs, or other events that do not include the experiences of people of color. In the two years since making this pledge, GRASP has communicated its commitment to researchers or other people seeking to collaborate and work with them. Their communications highlight the statistics and data on health disparities and, therefore, the value in including and listening to various patient experiences, particularly Black women,



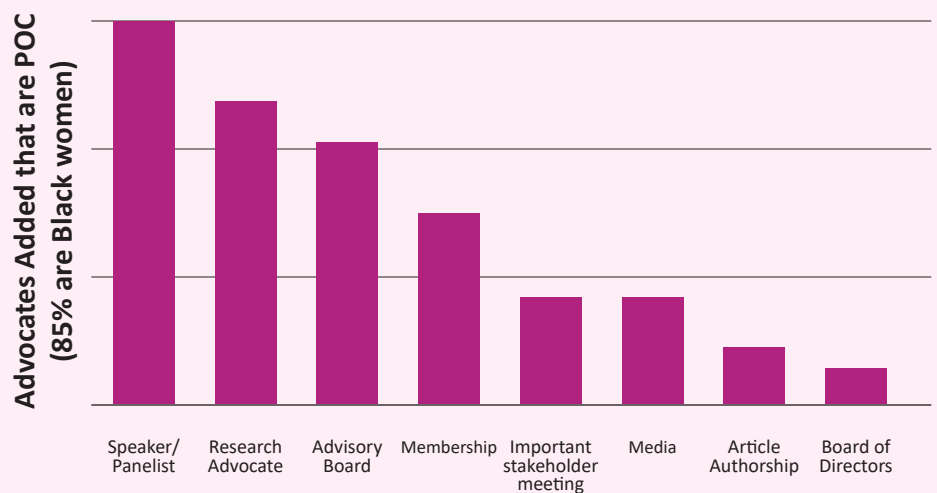
who have a higher breast cancer mortality rate. They encourage collaborators and researchers to add Black patients to panels, boards, and patient advocate groups. Their staff may participate in any breast cancer advocacy initiative on the condition that the platform will include the experience of a Black woman. GRASP additionally offers to recommend or help find a person of color, specifically a Black woman if possible, interested in participating.

GRASP developed a dashboard to track their progress to ensure accountability for themselves and the communities they serve. GRASP has tracked their progress qualitatively and quantitatively for two years now, including during the pandemic shutdown period. Their quantitative data are reflected on their dashboard in a spreadsheet that shows a record of invitations to participate in cancer events, conference panels, article authorship, advisory boards, or cancer advocacy stakeholder meetings. As of November 2021, at the time of our interview, the GRASP founders had received 50 such invitations. Their response was always to request at least one Black woman to be invited

Advocates Added that are POC

Speaker/ Panelist	13
Research Advocate	10
Advisory Board	9
Membership	7
Important stakeholder meeting	4
Media	4
Article Authorship	2
Board of Directors	1

Impact of GRASP Co-Founders' #InclusionPledge



Measuring Impact and Results

GRASP reports that in over 95% of the cases recorded in their dashboard, their request to have at least one person of color represented in the platform to which they were invited (e.g., panels, initiatives, advisory boards) has been received positively. This has resulted in people of color advocates (85% of whom are Black women) being included in various platforms and spaces where they might not otherwise have been included. Where the inviter says they only have space for one person, Julia or Christine will offer to give up their space to have a woman of color take it, knowing that there are likely other white women already in that space.

Next Steps

GRASP plans to expand its qualitative tracking to include negative responses that they often hear related to their Pledge commitment or the Pledge itself. For example, a comment they sometimes hear that diminishes the importance of representation is, “I don’t see color in breast cancer issues; it affects all of us.” To push back against such perspectives, they intend to work collaboratively with other Pledge partners to create a “Mythbusters” series to spread information about the realities of health disparities.

GRASP also plans to track quantitative and qualitative metrics related to their social media posts on health disparities impacting Black women. Julia shared that she would be tracking quantitative data on her Twitter posts on cancer disparities, such as the number of comments and responses she gets. She also plans to analyze the nature of the comments, whether they are positive expressions of support or they are pushing back against the idea of health equity.

CASE STUDIES

b) Case Study Two: A Fresh Chapter (AFC)

Igniting Connections and Empowering Communities: A Fresh Chapter’s Story of Promoting Mental Health for All Cancer Patients, Survivors, and Caregivers

#InclusionPledge Commitment:

1. Ensure at least one Black woman with breast cancer is part of the Inclusion, Diversity, Equity, and Access (I.D.E.A.) team that will include people from different races, genders, stages of the disease, types of cancer, sexual orientations, socioeconomic backgrounds, and religions.
2. Focus outreach and marketing efforts on Black communities and increase the percentage of Black women who participate in their ten-week Ignite Experience program, designed to help people navigate the complex emotions of cancer and find growth, connection, and belonging.



A Fresh Chapter was founded by Terri Wingham and works with cancer survivors and advocates in the United States, Kenya, South Africa, Peru, and India. AFC helps people at all stages in the cancer journey—from survivors to those living with late-stage disease—in developing skills to navigate uncertainty and to redefine and rebuild their lives during and after treatment.

The Problem: Lack of support for Black cancer patients experiencing emotional distress

According to AFC, at least 35% of people impacted by cancer experience significant emotional distress, and more than 50% of those experiencing distress don’t seek traditional in-person and online support groups, which are often organized by a hospital or community group. To address this gap, AFC has programs to help cancer patients, including women of color, deal with the barriers related to emotional and mental health.

The Solution: Increase representation and expand program access

AFC's focus areas for 2020 and 2021 were promoting inclusion, diversity, equity, and access in all programming for cancer patients, survivors, and caregivers. While AFC has been intentional in working with the Black community, they also have, over the years, collaborated with Hispanic, LGBTQ+, Asian American and Pacific Islander (AAPI), and Native American communities. Describing AFC's commitment to engaging all communities, Terri says, "Since 2013, fostering diversity, inclusion, and health equity while building connections across cultures has been in our DNA."

In 2021, AFC launched its Inclusion, Diversity, Equity, and Access (I.D.E.A) team to promote a diverse representation of cancer patients' and caregivers' voices in program design and outreach strategies. The team is represented by alumni volunteers who have previously benefited from AFC's programs. The volunteers are of various ages, backgrounds, races, genders, religions, and other identities. The new I.D.E.A team consists of three Black women, one with breast cancer, and all cancer patients or survivors. The I.D.E.A. team plays a critical role in AFC's programming and overall organizational strategy, especially ensuring that they reach a broad range of communities.

One of I.D.E.A.'s projects was to design two stand-alone 'Empower' workshops, one focusing on life's meaning and purpose and the other on the healing journey. These workshops were piloted in the Fall of last year. AFC's goal for the first quarter of 2022 is to partner with health centers and nonprofits, including those that work with women of color. The workshops will be offered to communities for free by AFC. With guidance and support from its diverse I.D.E.A team, the free seminars will be widely advertised within the Black, Hispanic, AAPI, Native American, and LGBTQ+ communities.

Fulfilling their #InclusionPledge commitment that at least one Black woman is invited to join their new Advisory Board, AFC welcomed a Black woman to the board, Toy Okotete, with the role of providing support, expertise, and strategic thought focusing on her area of personal interest, international development. This board member has been an excellent resource for AFC; the combination of her long-held relationship with the organization and personal experience with cancer as a person of color brings a unique perspective to AFC's health equity programming.

Additionally, one of AFC's core programs is to promote travel for people diagnosed with cancer as part of the journey to rebuild or redefine their lives, whether living with or beyond cancer. This program stalled when COVID-19 hit in 2020, and travel was restricted. Coincidentally, just before the pandemic and as a way to expand outreach to Black, Indigenous and person of color (BIPOC) communities, AFC had already begun working on developing a series of 'Ignite' free virtual workshops, a ten-week experience designed to foster connections among cancer patients, survivors, and caregivers from various backgrounds and living in different parts of the world. Topics included "How to navigate uncertainty," "How to see your challenges from a different perspective," and "How to share your story." One of Ignite's goals was to expand outreach in the Black community using virtual programming. The advent of the pandemic became a strong nudge to scale up virtual programming.



Measuring Impact and Results

On their website, AFC has a page called “Our Impact” with personal stories, radio and podcast interviews, press articles, and video testimonies on how their programs have impacted individuals and communities. One video features a diverse group of people sharing their positive experiences with the Ignite experience in 2021. Participants talk about the networks and relationships developed, the importance of connecting with others, and sharing experiences and knowledge in a virtual space when travel was restricted due to the COVID pandemic.

For equitable cancer outcomes, Terri emphasizes the importance of providing relevant cancer programming. AFC works both in the United States and beyond. Their international reach has provided AFC with unique socio-cultural competence that allows them to be thoughtful and intentional about engaging communities of color and other racial and ethnic groups. When AFC enters a community for any cancer-related work, they involve community representatives and have them at the table from the inception of the engagement. Reflecting on lessons learned from AFC’s international cancer advocacy work, Terri’s shares:

“I think the most important lesson that I’ve learned [from international work] is not to assume that we have the solutions, to really spend time thinking about our programs, not trying to change who we are, but really think about what we offer. How do we offer it in a culturally sensitive and relevant way? And then how do we make sure that our partners are at the table from the very beginning.”

Thanks to their inclusion efforts, AFC now has a critical mass of alumni of color to serve as resources in program design and facilitators. In workshops designed to attract specific demographic groups like Black women, Black women alumni have come forward to be trained as facilitators and lead those programs. “It’s been really powerful to have alumni become facilitators with enough training versus trying to hire all externally,” Terri says.

Furthermore, AFC has developed a diverse peer-to-peer facilitated, extensive, psychosocial support model to assist people in navigating uncertainty. The model of fostering a diverse team of facilitators recognizes that different challenges stem from different contexts. This inclusive model builds capacity for story sharing, life skills, and learning that could be applied to a variety of life challenges, such as the COVID pandemic, cancer, or any loss.



Next Steps

AFC will be exploring ways to create more deliberate partnerships with a diverse group of alumni, nonprofits, health centers, under-resourced communities, and organizations like Tigerlily that are already serving people in historically underserved demographic groups. AFC's 2022 goal is to focus on furthering its outreach in the Black community and expanding its programs to community health centers. In the first quarter of 2022, AFC offered 'Empower' workshops free of charge to various communities through partnerships with health centers or nonprofits.

CASE STUDIES

c) Case Study Three: Facing Hereditary Cancer Empowered (FORCE) FORCEful Actions: Advancing Health Equity and Promoting Informed Decision-Making through Simplifying Cancer-Related Information

1. FORCE will ensure the inclusion of people of color in leadership positions within the organization, including adding additional people of color to the Board of Directors and Scientific Advisory Board.
2. FORCE commits to developing meaningful partnerships with organizations that reach BIPOC communities to assure that programs are culturally competent, representative, equitable, and get everyone who needs information and resources.
3. FORCE commits to focusing efforts on improving and influencing guidelines, policies, and legislation that improve equitable access to quality healthcare and increase patient safety and protection.
4. FORCE commits to increasing "organizational health literacy" (as defined in Healthy People 2030) by striving to equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.



Founded by 20-year breast cancer survivor, Dr. Sue Friedman, FORCE provides accessible education, information, and support on hereditary cancer, including breast cancer, to communities and individuals. FORCE helps people make informed medical decisions and advocates for access to care, better treatment, and prevention options.

The organization's supportive community of peers and professionals ensures that no one faces hereditary cancer alone.

The Problem: Lack of access to expert-reviewed information in marginalized communities

Self-advocacy related to breast cancer and other cancers can be overwhelming due to the technical nature of the field. Additionally, women of color, who bear the brunt of breast cancer disparities, may have limited access to expert-reviewed information to make informed medical decisions.

The Solution: Conceive and execute an organizational strategy that embeds DEI

Dr. Sue, founder and executive director of FORCE, emphasized FORCE's commitment to DEI as a core part of their day-to-day activities. Their work in cancer-related health equity issues focuses on the needs of all historically marginalized communities, including Black women and the LGBTQ+ community.

FORCE has designed and implemented programs that contribute to health equity and fulfill the Pledge's commitments—the progress that they have made is publicized on their **"Our Progress"** page. Below are just a few of the highlights of their significant work.

- **Strategic Plan and Board:** As of October 2021, FORCE was working on completing its five-year strategic plan, a living document that incorporates DEI in all aspects of the organization, including the Board of Directors which was expanded to include two Black people. The expansion of the Board to be as close to a representation of the diverse communities they serve is also intended to hold them accountable to their DEI commitments.
- **Volunteers:** FORCE strives to ensure that their trained volunteers are representatives of the entire community that they serve, including individuals from historically marginalized groups.
- **Community Support Meetings:** Support meetings emphasize DEI and target people of color within the community. FORCE launched monthly meetings for the LGBTQ+ community led by two volunteers who belong to the community.
- **American Sign Language:** FORCE added American Sign Language to their programming for the deaf community and those who are hard of hearing. They are also translating some webinars into American Sign Language.
- **Scientific Advisory Board:** FORCE added people of color, including Black health professionals, to the Scientific Advisory Board.
- **Internal training:** FORCE has sponsored DEI training with staff to promote awareness and understanding of what it means to be an equitable organization.
- **Partnerships:** FORCE has developed partnerships with organizations such as Black Health Matters on campaigns that raise awareness of cancer disparities.
- **Annual Conference:** In their Annual Joining FORCEs Virtual Conference, FORCE added five webinar sessions that specifically addressed health disparities across cancer. Sessions included:
- **I am not white; can I have an inherited mutation?**
- **TALK BACK: Increasing Patient Engagement in Decision-Making**, with a focus on Black women with breast cancer and self-advocacy strategies

A highlight of FORCE's equity efforts is the **XRAY** (eXamining the Relevance of Articles for You) program: Research articles are often technical and not accessible to lay readers, while the media may sometimes sensationalize cancer information. To address this issue, FORCE reviews and summarizes articles, including those related to breast cancer, and provides a relevance score for the research based on the science and accuracy of the media articles. The review includes who the article is relevant to and provides links to any related clinical trials, expert guidelines, and question prompts for users. The website also prioritizes articles pertinent to health disparities of historically marginalized groups and communities.



Measuring Impact and Results

To measure their impact, FORCE collects and analyzes survey data including its volunteer numbers. As of the close of 2021, they were still collecting data specific to #Inclusion Pledge initiatives. However, they highlighted several internal targeted metrics that indicate the successful integration of DEI lenses in their operations. Some of the areas that FORCE is focusing on for data collection include traffic to specific web pages and survey responses for a needs assessment that FORCE is conducting among BIWOC members with breast cancer. As of late 2021, FORCE planned to call on Pledge partners to help promote the assessment, which at the time had collected 75 responses, with a target of 150. They were also planning to do a series of focus groups to inform culturally tailored programs that prioritize Black women with breast cancer.

CASE STUDIES

d) Case Study Four: ZERO Breast Cancer (ZBC) Representation Matters: Designing Culturally Appropriate Cancer Education and Showcasing Black Women's Breast Cancer Stories

#InclusionPledge Commitments:

1. Develop and improve educational materials for BIPOC communities.
2. Increase organizational diversity through recruiting diverse staff, board members, and advisors.
3. Maximize representation by women of color as presenters and participants on ZBC webinars.
4. Increase partnerships with BIPOC communities on organizational campaigns (e.g., Generations Campaign & Advancing Health Equity).
5. Continue equity training for staff as individuals and organizational development.inform health-related decisions and actions for themselves and others.



Zero Breast Cancer (ZBC) is an organization that focuses on prevention and risk reduction programs for breast cancer. ZBC recognizes that social and economic conditions impact individuals' ability to pursue healthy behaviors. They believe that education and empowerment are instrumental to increasing resilience and bringing about change within communities to improve the health of all

The Problem: There are systemic barriers to cancer care

Social and economic conditions impact individuals' ability to live in healthy places and pursue healthy behaviors, creating barriers to cancer care that disproportionately affect women of color. While many disparities are systemic, education and empowerment can increase individual resilience and contribute to broader change that improves the health of all.

The Solution: Emphasize equity and inclusion in program design

In 2020, ZBC hosted four webinars on Advancing Health Equity in Breast Cancer. ZBC ensured that all of them had women of color panelists and three with Black women panelists specifically. Black women, particularly in webinars, were able to speak to issues that disproportionately affect their demographic. These included medical distress, participation in clinical trials, and access to healthy food and exercise.

The ZBC staff consulted with the advisory board to ensure that their educational content was relevant to the communities it was designed for. For example, the Black women on the advisory board gave constructive feedback on posters for the “New Generations” campaign and the other program factsheets. All materials featured a diverse array of stories and images.

ZBC believes that stories are impactful in educating communities about breast cancer and influencing people to act. That is why in 2021, they made an effort to expand the diversity of the stories they share on the blog to include Black women’s stories. Liana Hartmour, ZBC’s Program Director, highlighted two impactful stories on the blog of Black women that connect cancer experiences with disability:

- Cassandra Falby, a psychotherapist who addresses cancer disabilities, shares her story about her work and approach to systemic racism in social justice work on cancer issues.
- Christine Jon’el, a young two-times cancer survivor, a Black woman living with an amputation, shares her story about ableism and racism in breast cancer.

ZBC also recognized that it needed help in reaching Black populations with its educational materials. The organization has two strategies to expand its outreach. First, they engaged the services of a digital marketing firm to revamp their already-extensive social media presence, including Facebook ads to target communities of color. Second, ZBC is exploring collaborations to reach more Black women survivors and their families. Catherine Thomsen, ZBC’s other Program Director, notes that they plan to partner with BIPOC-oriented organizations such as Tigerlily to help them share information on ZBC’s programs.

Measuring Impact and Results

One of ZBC’s motivations for developing partnerships with other cancer advocacy organizations, such as Tigerlily and #InclusionPledge partners, is to get support with 22 of 28 measuring, tracking, and interpreting data on the impact of their work. For example, ZBC distributes educational content such as factsheets via community-based centers. Even though they know how many flyers they share, they have no quantitative or qualitative tool to know who and how many people exactly have collected their materials.

Lianna notes that they have materials at Alameda County Social Services offices, which they know to serve a predominantly Black population. However, they are not sure how to get more details about who is picking up the materials. Lianna hopes that the Pledge partnership will enable them to tap knowledge on measuring impact.



In a progress report, program directors Lianna Hartmour and Catherine Thompson list the following specific changes they have already made, owing to their #InclusionPledge commitments:

- Improved access to health and wellness messages and educational materials.
- Modified survivorship fact sheets to be as relevant to Black women’s experiences as possible by including Black women’s images and stories, and having Black women review the materials.
- Ensured that Black women are represented in Generations posters.
- Targeted communities with a higher proportion of Black women across Marin, Alameda, and San Francisco Counties in California to disseminate survivorship factsheets, 13 Ways to Reduce Your Risk of Breast Cancer brochures and posters, and Girls’ New Puberty bookmarks and hand-outs.
- Highlighted the stories of two Black activists on their blog.

CASE STUDIES

e) Case Study Five: Pieces of I Moving from Awareness to Action—Promoting Breast Density Education for Early Diagnosis and Self-Advocacy

#InclusionPledge Commitments:

1. Pieces of I will continue to bring more voices to the table in order to move from awareness to action on early breast cancer diagnosis. They will expand global advocacy through their campaign "Empower Your Breast Health."
2. Pieces of I will continue to work locally to inspire “boots on the ground” act



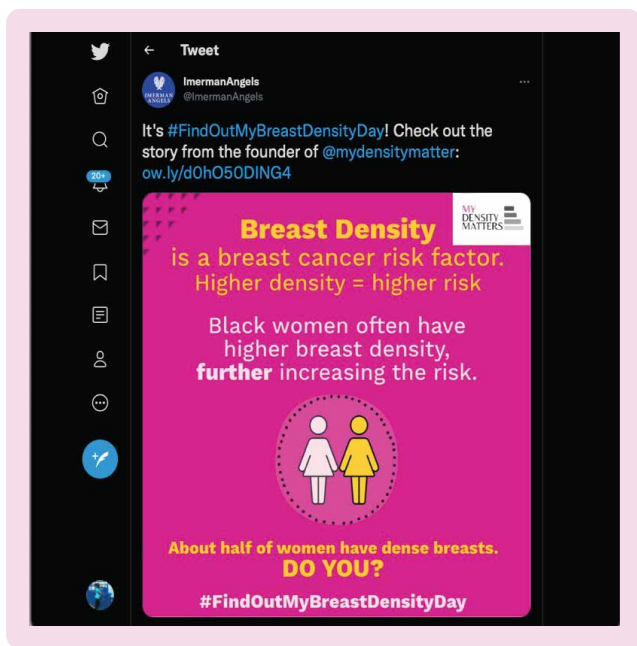
Founded by Susan Leslie Miller, **Pieces of I** helps nonprofits, small businesses, and individuals realize their visions (including breast cancer-related advocacy) by providing focused programs and partnership management. Pieces of I is guided by Susan’s deep 23 of 28 personal belief that every person has something to contribute to this world and must be valued for who they are. The organizational mantra is “Know your value, live your values.”

The Problem: Lack of awareness about risk factors for breast cancer in marginalized communities

Over 40% of women have dense breast tissue, a vital risk factor for developing breast cancer. Some studies have shown that women of color, including Black women, may have more dense breast tissue than other racial groups, further increasing their risk. Most people, including women of color, do not know much about their breast density and do not have the knowledge and skills to advocate for access to screening through mammograms and additional tests as necessary.

The Solution: Engage affected communities through social media and community dialogue

In the past year, Pieces of I's main social impact project was the "Empower Your Breast Health" initiative, inspired by their partner Leslie Ferris Yerger, founder of My Density Matters. Pieces of I and My Density Matters partnered with many breast cancer advocacy organizations, including those that target Black women, to drive an educational campaign on social media. Tigerlily was one of the 25 partners who helped plan and launch the campaign. Some of the messaging included statistical highlights of the racial differences and risks associated with breast density.



Example of one of the Twitter images for the campaign.

Working with community volunteers to mobilize women on the south side of Chicago, Pieces of I conducted listening sessions with groups of women to get first-hand information on access to breast cancer education and services for people who live in predominantly Black areas. With the assistance of a public health graduate student from the University of Chicago and the community volunteers, the Pieces of I team met with a group of women to talk about access and barriers to cancer screening and care. The community volunteers helped with advice on designing guiding questions for the discussion to be culturally appropriate. The conversation brought essential insights into where Black women in that community receive medical information and why some do not go for mammograms or secondary screenings. Insights from this conversation will be used to guide relevant program design.

Measuring Impact and Results

There were more than 700,000 views and tweet impressions across Twitter, LinkedIn, Instagram, and Facebook on the "Empower my Breast Health" launch day alone. While the demographics of the people interacting with the content are not available, the campaign's impact on knowledge sharing and women being compelled to take action is evident in the responses to the tweets. The public attention has also led to more collaborations that focus specifically on health equity and breast cancer awareness. The social media campaign was so successful that it revealed the need for the My Density Matters message and allowed the group to successfully register as a non-profit. Now, My Density Matters, as a registered organization, conducts educational sessions that cover topics such as why breast density matters, how to talk to your doctor about it, and how to navigate insurance coverage. These education sessions have a specific focus on women of color.

Listening sessions were successful in helping Pieces of I and My Density Matters get to know Chicago's Beverly and Morgan Park communities, largely communities of color, and informed future projects in those neighborhoods.

Susan emphasized the limitations of one-size-fits-all programs in cancer equity projects. She recalls her listening session experience and shares a lesson she learned:

"I guess the biggest lesson is, you don't know what you don't know. And you've really got to listen. You just got to ask the questions, sit back and listen to what's happening. We started with the assumption that we would just go and set up our program at a hospital in their area, which would help. But, you know, in talking with the women in that area, they said they don't go to the hospital in their neighborhood but to another outside one. So, I think listening is the one takeaway from that experience. It's got to be about the people that you're trying to serve, and then listen to what their barriers are, don't make assumptions."

Next Steps

The organization is currently building out a community outreach program with ambassadors and volunteers from BIPOC communities. One of their priority areas has the highest late-stage breast cancer rate in Chicago. Referring to the data on health 25 of 28 disparities in cancer care that affects Black women, even relative to other disenfranchised populations, Susan says that it is essential for their programs to be tailored for different communities: "It's not a blanket program, you can have a template, and you can have 70% of the template be applied to everyone, but there's going to be that 30% that's going to be culturally appropriate for a community, that's the part that's going to have to be revised based on where you're going and the needs communicated by the community."

The organization has also developed a corporate wellness program. This is meant to share information about breast density with women in corporate settings. This program will utilize support from other organizations and #InclusionPledge partners that work with Black women, such as Tigerlily, to help with appropriate messaging.

