

Executive Summary

Thanks to advances in breast cancer treatment and increased access to early detection, we have seen a 42% overall decline in breast cancer mortality rates since 1989. Yet, Black women in the US are about 40% more likely to die from breast cancer, have a lower 5-year breast cancer survival rate, and are more likely to be diagnosed with breast cancer at a younger age, at later stages, and with more aggressive types of breast cancer compared white women.

Susan G. Komen® conducted landscape analyses in 10 targeted metropolitan areas with the greatest disparity to:

- Understand breast cancer disease burden in each metropolitan area.
- Describe systemic barriers, including social determinants that may contribute to breast cancer inequities.
- Explore community members' and provider perspectives.
- Review Federal and State policies.
- Identify strategies to mitigate breast cancer inequities.

In 2021, Komen published “Closing the Breast Cancer Gap: A Roadmap to Saving the Lives of Black Women in America. Some of the core findings from the reports showed providers often do not grasp barriers faced by Black women; although data show many Black women are being screened, there is confusion about current screening recommendations; and there is a lack of access to genetic counseling and testing in the Black community. Micro-, mezzo-, and macro-level recommendations were offered, including the recommendation to advance clinical trials and tailored treatment focused on Black women.

In response, Komen launched ShareForCures®, a secure, patient-centered breast cancer research registry which aims to engage breast cancer survivors from diverse backgrounds as research partners to facilitate sharing of their data to drive innovative breast cancer research and improve outcomes. To create such valuable datasets for research, we will need to oversample from populations that have been historically under-represented in research, including those from Black/African American and Hispanic/Latino communities as advancing health equity starts with ensuring representation and diversity.

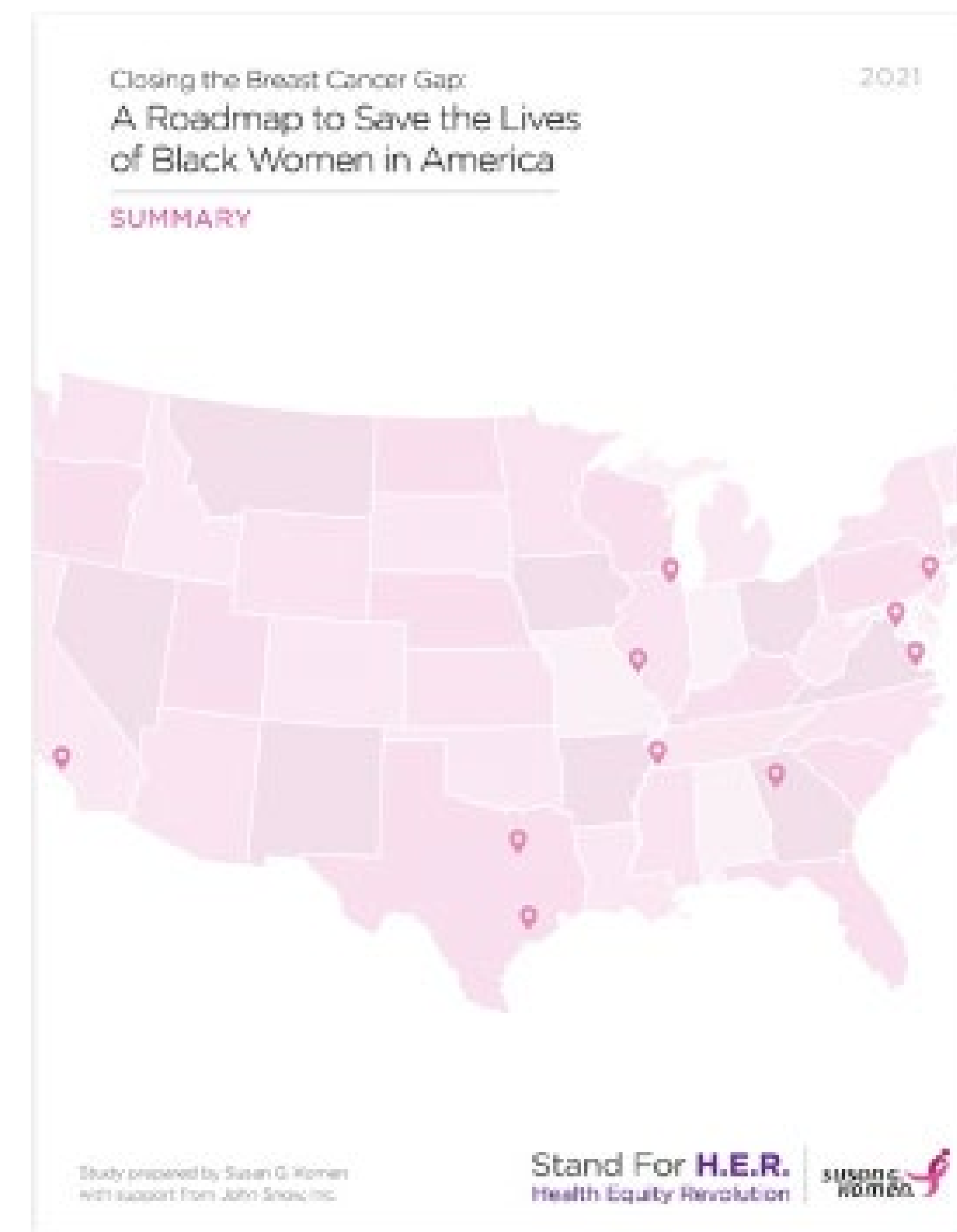
ShareForCures is IRB-approved, open to any adult living in the US and diagnosed with breast cancer. It is easy to join and accessible online. Participants as our partners in research will be invited to consent and share their health data, including their electronic health records, wellness data, and any existing genetic and genomic data that they may already have. Participants will also be asked to complete surveys to provide additional information about themselves. A subset of participants will be selected to provide biospecimen for which genomic information and other biomarkers will be obtained, with priority based on the need for diversity and population representation in data.

It is imperative that there be more racially and ethnically diverse representation in research to ensure that discoveries, treatments, interventions, and prevention strategies are relevant to all populations. Currently, populations not represented in research have not benefited equally from past discoveries as those represented in research. Komen aims to focus ShareForCures' outreach and recruitment efforts to populations that have been historically under-represented in research.

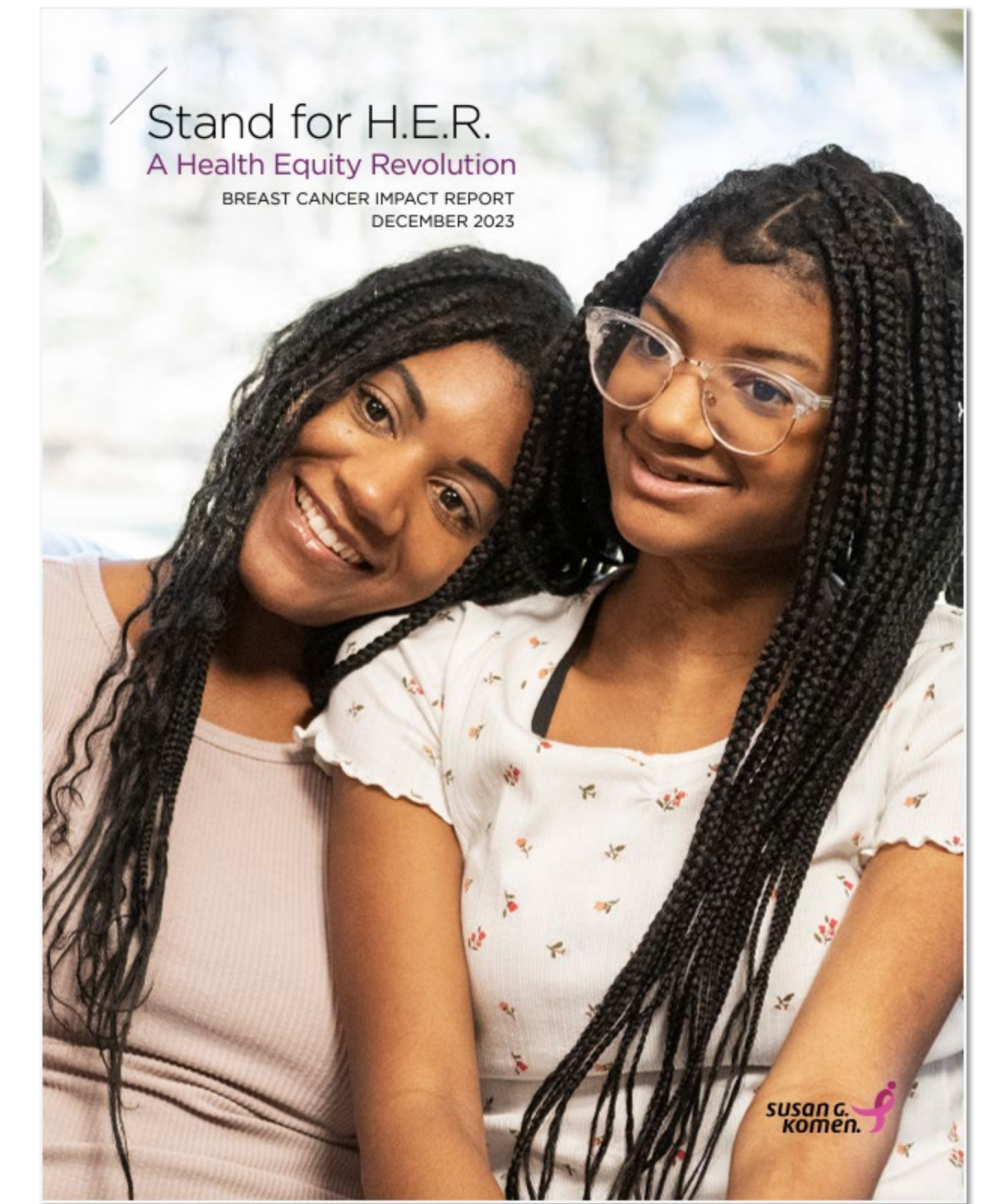
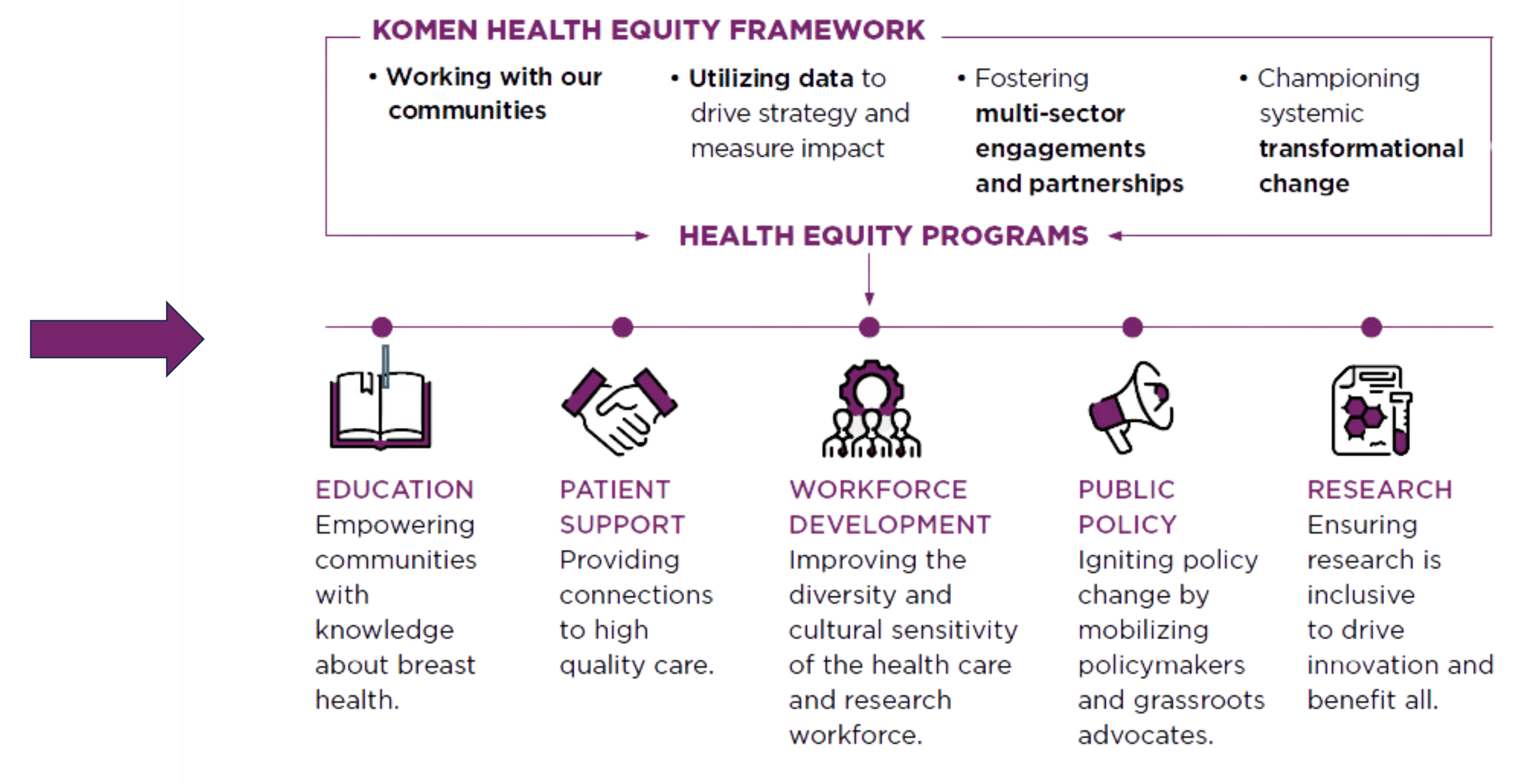
Breast Cancer Disparities Harm Communities
Health disparities and inequities contribute to poor breast cancer outcomes.

- 1 in 6 Americans live in a rural area. In 2020, 32 million Americans lived in counties without an oncologist.
- Black women are about 40% more likely to die of breast cancer than their white counterparts.
- 1 in 3 Hispanic women have no personal doctor and are more likely to be diagnosed with breast cancer at a later stage.
- The increased risk of breast cancer among Black and Hispanic women is linked to risk factors more common in these populations, such as never having children or having them later in life, obesity and alcohol use.
- Breast cancer is the second leading cause of cancer death in Asian American women.
- Only 30% of uninsured women were up to date with breast cancer screening, compared to 54% of insured women.

Stand for H.E.R. – A Health Equity Revolution – The Framework

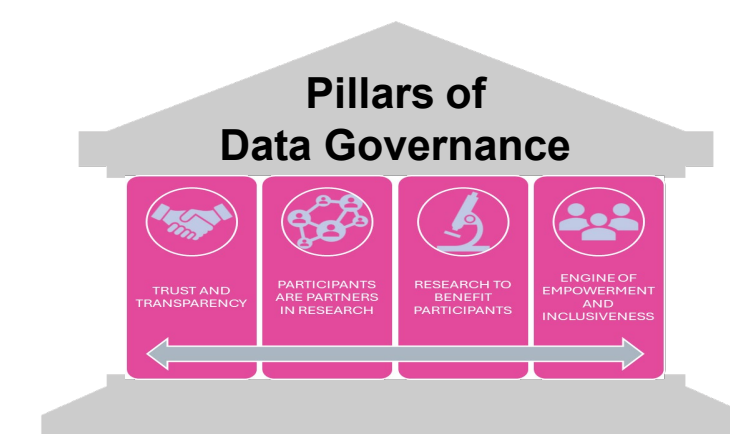


Stand for H.E.R. - A Strategic Approach



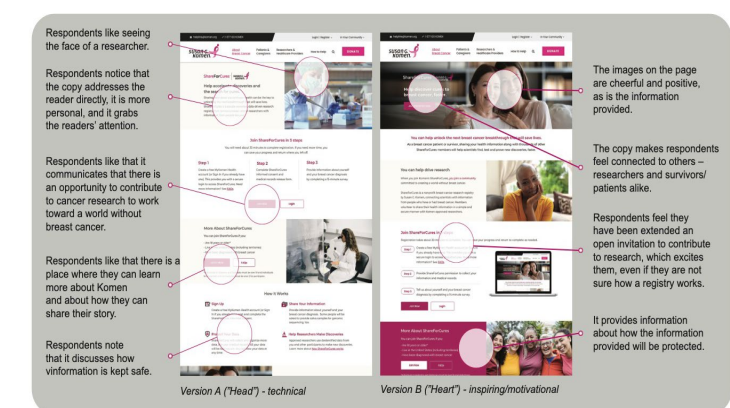
ShareForCures – Breast Cancer Registry – One Mission and Strategies

Engagement in Governance



- Engaging community partners was essential in creating SFC governance.
- Framework for preserving participants' trust and data integrity maximizes benefits and minimizing risks for patients and their data.
- Goal met through external oversight, policies and technology, continuous engagement of advocates, researchers and representation at all steps.

Engagement in Content Testing



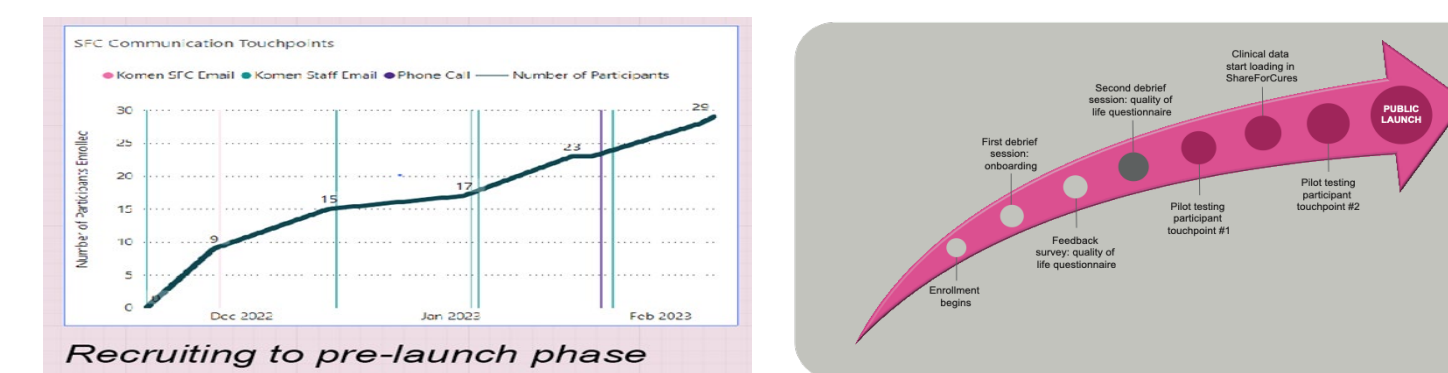
- A/B testing of landing page to get reactions and preference from diverse audience was conducted.
- Testing conducted online – 2 formats: Focus group-like discussion (32 respondents; 22% Hispanic, 19% Black) and Survey (400 respondents; 24% Hispanic and 22% Black).

Engagement of Focus Group



- Diverse group of breast cancer survivors revealed; privacy and data security main concern when considering participation in research, especially for populations experiencing current and historical medical mistrust.
- Patients want to help but know the importance of keeping information secure and private, especially sensitive health information.

Engagement in Platform Testing

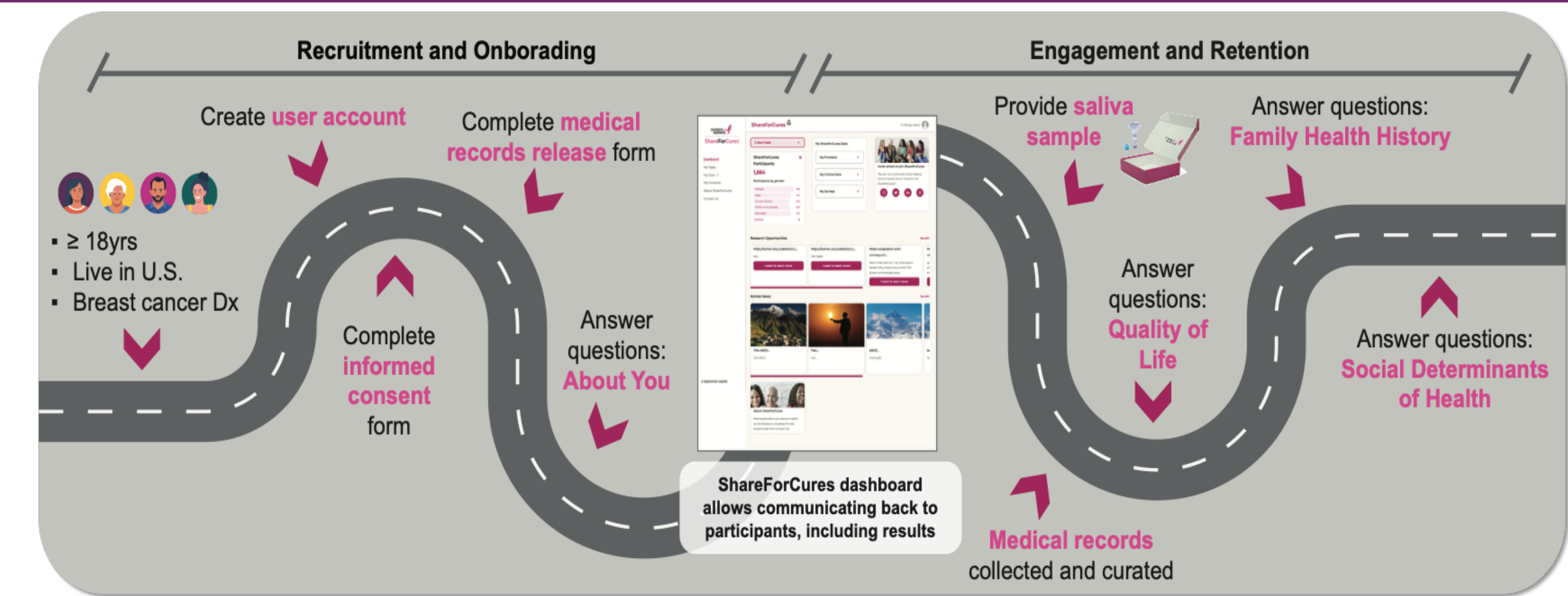


- Pilot participants tested the registry platform and process to join for Pre-Launch.
- 56 signed NDA; 31 joined; and 18 (58%) provided feedback via debrief sessions or questionnaires.
- Patient engagement allowed for the design of an inclusive, culturally sensitive and respectful participant journey.

References

- American Cancer Society, Cancer Facts and Figures, 2024
- American Cancer Society, Cancer Facts and Figures for African American/Black People, 2024
- Surveillance Research Program, National Cancer Institute, SEER 5-year Relative survival rates, 2013-2019, by race/ethnicity, female, all ages, all stages
- Jourquin, J., et al., (2023, December 5-9). Driving diversity in research participation with ShareForCures™, a patient-centered, nationwide breast cancer research registry to improve outcomes [Poster presentation]. San Antonio Breast Cancer Symposium, San Antonio, TX, U.S.A., PO1-17-06.

ShareForCures Participant Journey



Patient Engagement Drives Results

We deployed a multi-prong approach to engaging the breast cancer patient population ensuring that we met patients where they are and how they want to be engaged. The three key patient-centric focuses regarding the development of ShareForCures and the engagement opportunities were:

Inclusiveness

- Approach design with intentionality to respect and recognize the barriers to participation such as limiting eligibility requirements to increase participation and meet patients where they are and how they want to be engaged.
- Fuel innovation by engaging diversity of the patient population at every step, from conception to development to implementation of ShareForCures to benefit all.

Trust and Transparency

- Clear informed consent process, with data uses highlighted.
- Participants can be re-contacted to share updates and new research opportunities.
- Can re-consent for new data uses.
- Confidentiality and privacy is protected with only de-identified data shared.

Participants are Partners in Research

- Participants are actively involved; participation is voluntary.
- Data collection/sharing is free and easy; participants own their data.



Scan to learn more at
komen.org/shareforcures or visit
komen.org/standforher.