



Tigerlily
Foundation

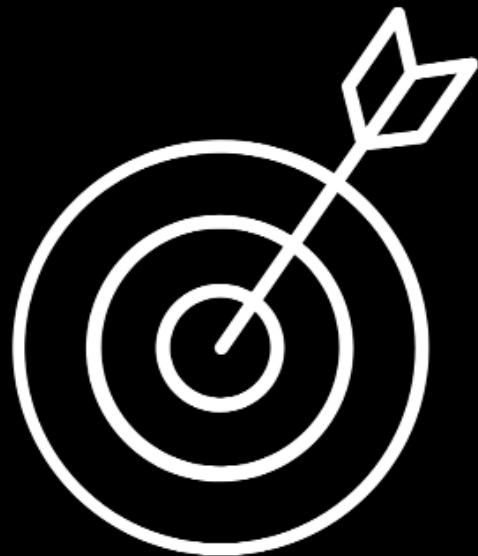
METASTATIC BREAST CANCER
DISPARITIES LISTENING SUMMIT

MARCH 20, 2019 | WASHINGTON, DC

#ListenUpMBC

@TigerlilyCares





LISTENING SUMMIT GOALS

Listen to patients, experts, partners and the community to establish priorities to educate young women of color on MBC.

Demonstrate the importance of access to innovations such as clinical trials and the barriers for young women of color.

Mobilize a network of diverse MBC ambassadors and experts to lower African-American breast cancer mortality rates.

Opening Remarks

Madeline Long Poole



Welcome Remarks

Maimah S. Karmo

I manifest
belief.

I manifest
my power.

I manifest
courage.

I manifest
compassion.

I manifest
truth.

I manifest
a better
world.

Collaborating to Accelerate Impact: Metastatic Breast Cancer Project (MBCp)



Angela Baker
Imani Boykin
Carla Harvey
Sheila McGlown
Colleen Nguyen
Latonya Wilson

Diversifying Clinical Trials & Advancing Access to Innovation

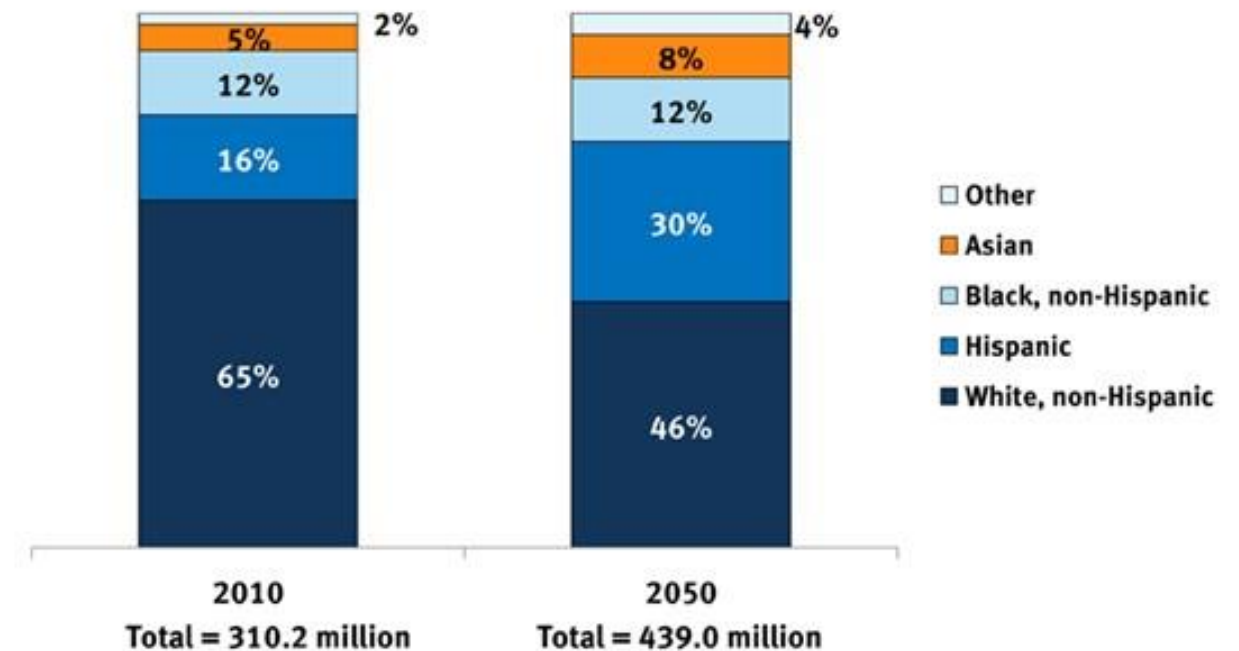
Janeen R. Azare



The Changing Demographics of America

- The U.S. Census Bureau predicts that by the year 2042, racial minority groups will make up the majority of the U.S. population
- Homogeneity in clinical research (clinical trial participation) has long been recognized both as an ethic and scientific issue
 - Limited relevance and generalization of trial findings may contribute to health disparities
- *Will the demographic shifts lead to greater equality?*

Distribution of U.S. Population by Race/Ethnicity, 2010 and 2050



NOTES: All racial groups non-Hispanic. Other includes Native Hawaiians and Pacific Islanders, Native Americans/Alaska Natives, and individuals with two or more races. Data do not include residents of Puerto Rico, Guam, the U.S. Virgin Islands, or the Northern Mariana Islands. SOURCE: U.S. Census Bureau, 2008, Projected Population by Single Year of Age, Sex, Race, and Hispanic Origin for the United States: July 1, 2000 to July 1, 2050. <http://www.census.gov/population/www/projections/downloadablefiles.html>.

Metastatic Breast Cancer: By the Numbers



THIRTY PERCENT

of women who have had early breast cancer will eventually develop metastatic breast cancer^{1,2,3,4}

IT'S ESTIMATED THAT
MORE THAN 150,000
WOMEN IN THE U.S.

are living with

METASTATIC
BREAST CANCER⁵

FIVE-YEAR SURVIVAL RATE
following a
DE NOVO

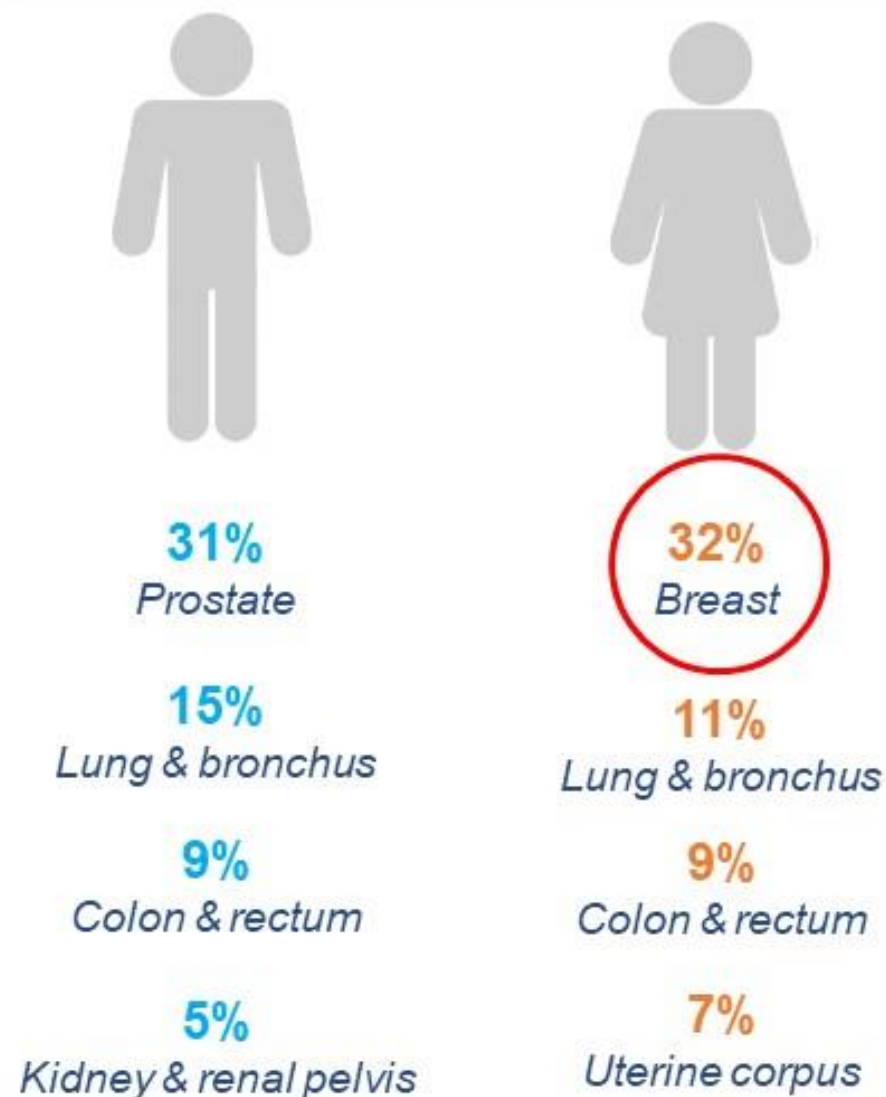
METASTATIC
BREAST CANCER
DIAGNOSIS IS 26%⁵

1. Berman AT, Thukral AD, Hwang WT et al. Incidence and patterns of distant metastases for patients with early-stage breast cancer after breast conservation treatment. Clin Breast Cancer. Apr 2013;13(2):88-94.;
2. Brockton NT, Gill SJ, Laborge SL et al. The Breast Cancer to Bone (B2B) Metastases Research Program: a multi-disciplinary investigation of bone metastases from breast cancer. BMC Cancer. 2015;15:512.;
3. Herrinton LJ, Barlow WE, Yu O et al. Efficacy of prophylactic mastectomy in women with unilateral breast cancer: a cancer research network project. J Clin Oncol. 2005;23(19):4275-86.;
4. O'Shaughnessy J. Extending survival with chemotherapy in MBC. The Oncologist. 2005;10:20-29. http://theoncologist.alphamedpress.org/content/10/suppl_3/20.long. Accessed May 2017.
5. Mariotto AB, Etzioni R, Hurlbert M, et al. Estimation of the Number of Women Living with Metastatic Breast Cancer in the United States. Cancer Epidemiol Biomarkers Prev. May 2017; DOI: 10.1158/1055-9965.EPI-16-0889.

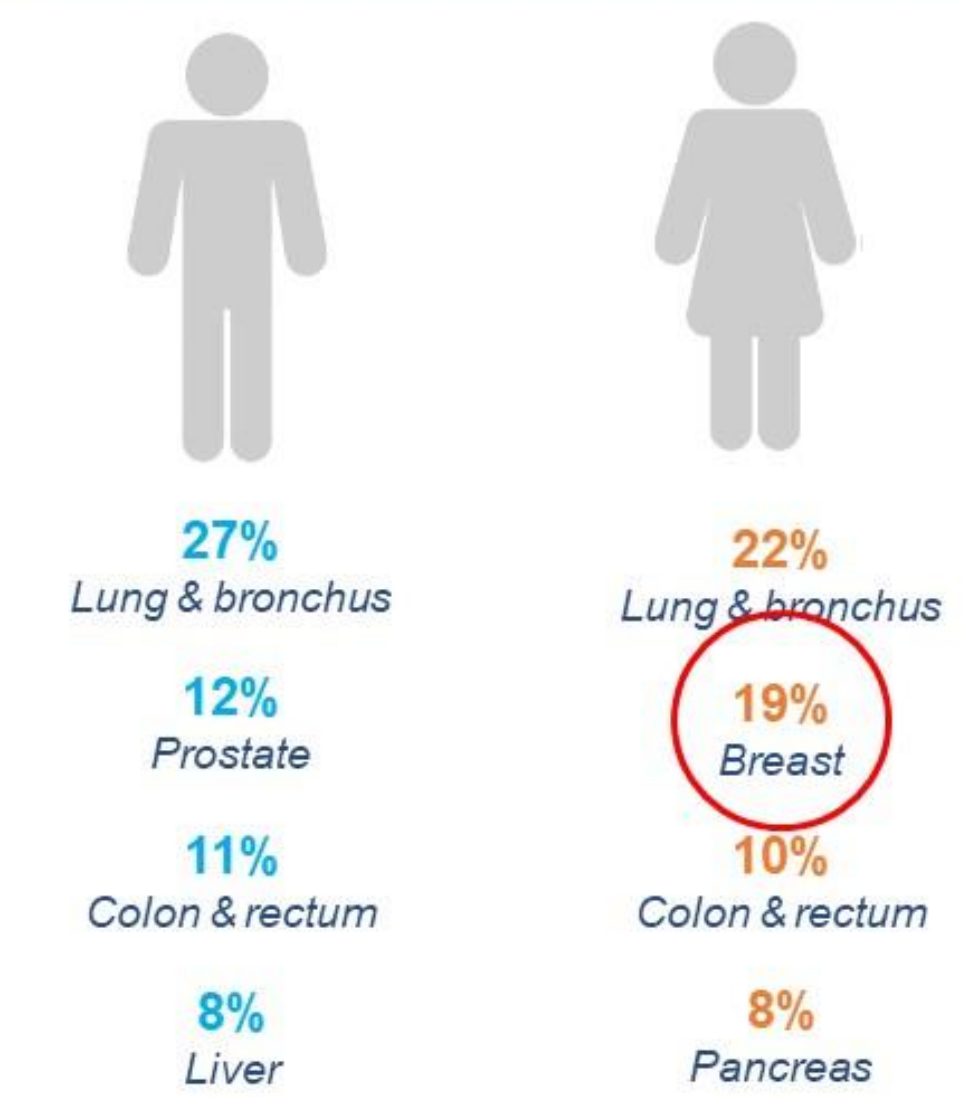
Leading Sites of New Cancer Cases and Deaths among Blacks, 2016 Estimates*



Estimated New Cases

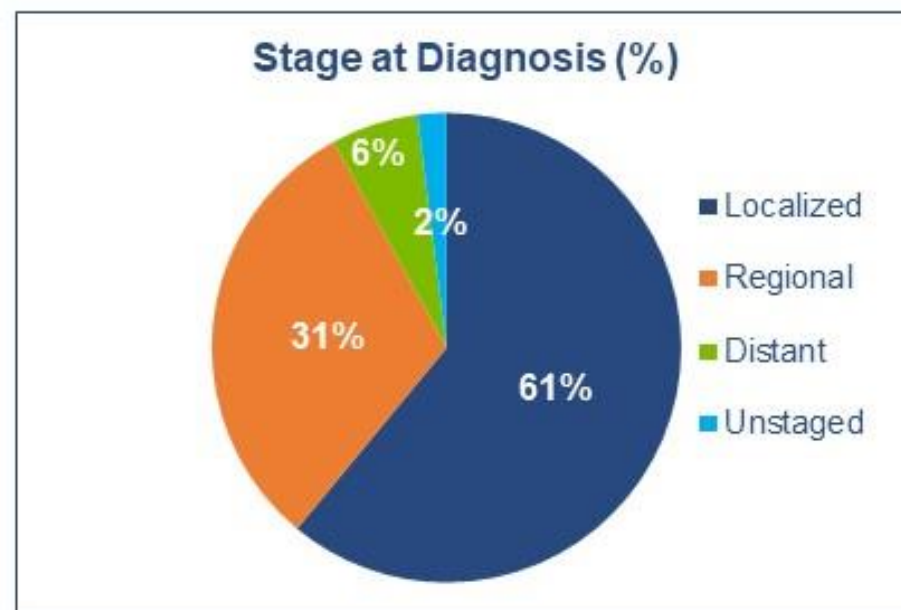


Estimated Deaths

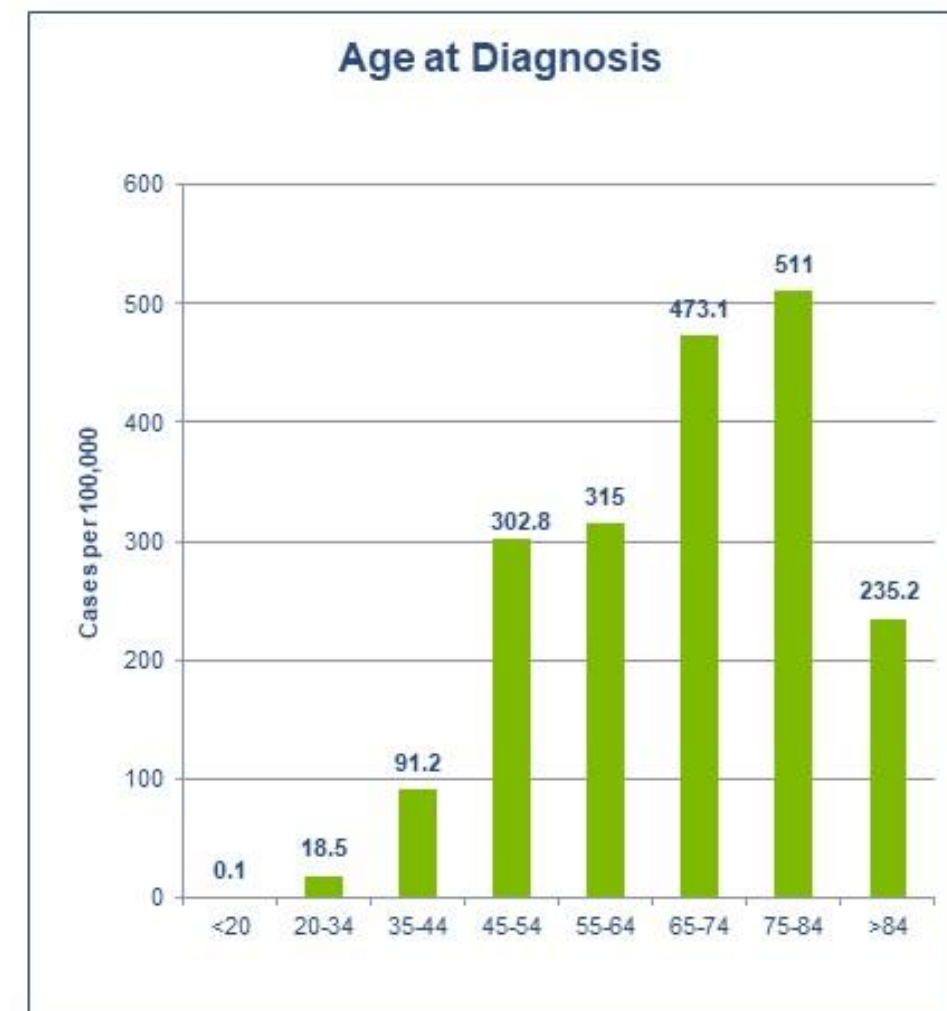


*©2016, American Cancer Society, Inc., Surveillance Research

Breast Cancer: Diagnosis and Survival

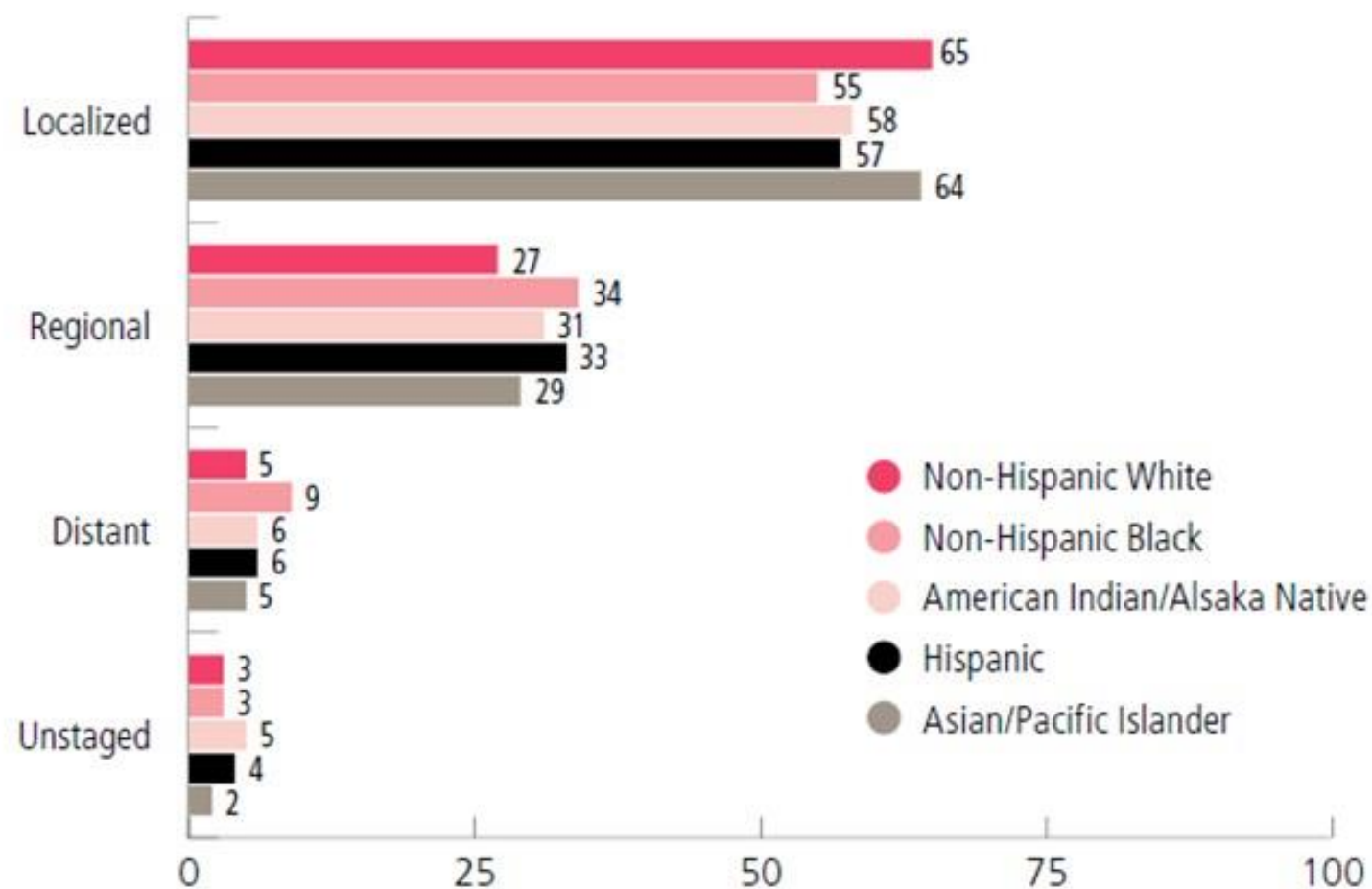


Stage at Diagnosis	5-year Relative Survival
In Situ	100%
Localized	98.8%
Regional	85.2%
Distant	26.3%



Howlader N, Noone AM, Krapcho M, Miller D, Bishop K, Altekruse SF, Kosary CL, Yu M, Ruhl J, Tatalovich Z, Mariotto A, Lewis DR, Chen HS, Feuer EJ, Cronin KA (eds). SEER Cancer Statistics Review, 1975-2013. National Cancer Institute. Bethesda, MD, https://seer.cancer.gov/csr/1975_2013/, based on November 2015 SEER data submission, posted to the SEER web site, April 2016.

Breast Cancer Stage Distribution by Race/Ethnicity

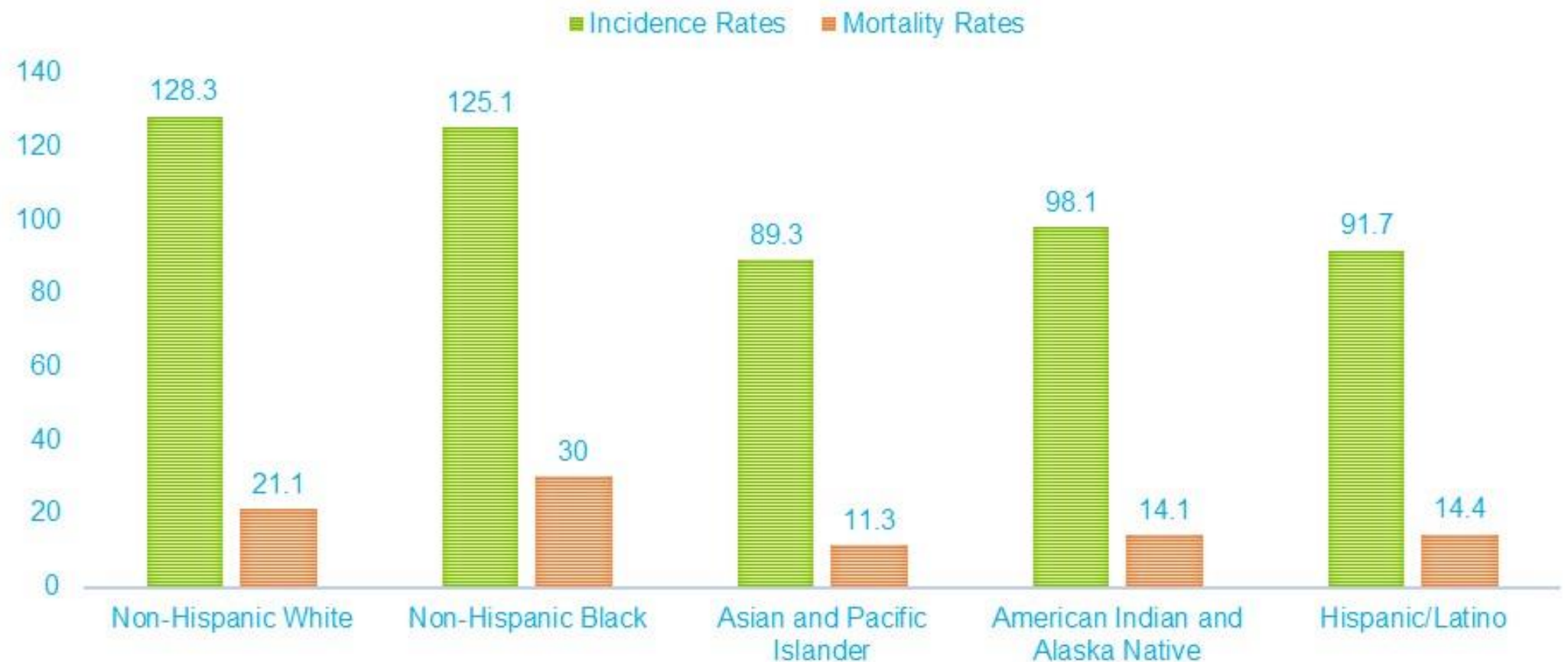


*Based on patients diagnosed during 2007-2013 and followed through 2014. Stage distribution percentages may not sum to 100 due to rounding.

Source: Survival – SEER Program, 18 SEER Registries, National Cancer Institute, 2016. Stage distribution – NAACCR, 2017, American Cancer Society, Inc., Surveillance Research, 2017

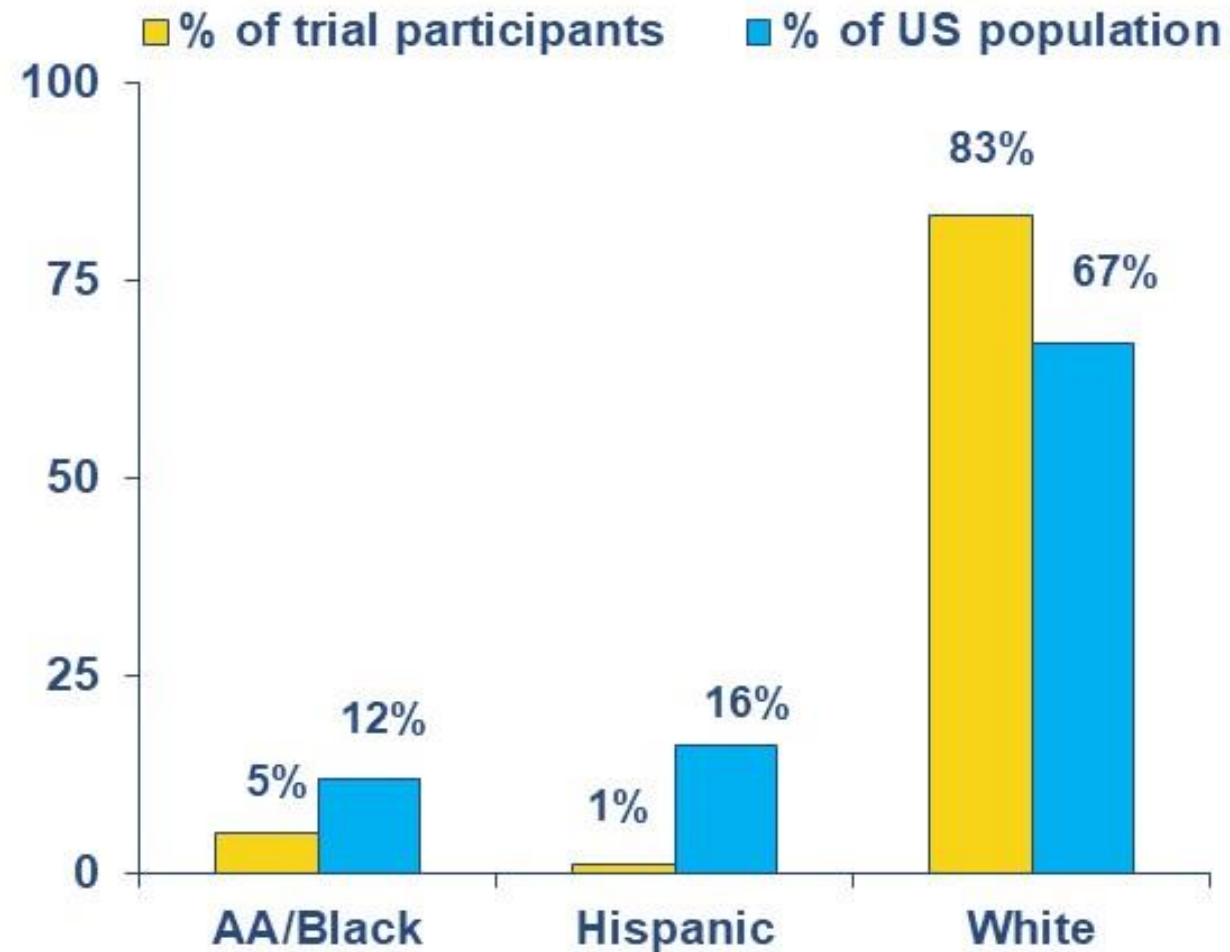
Disparities in Outcomes Between Ethnicities

INCIDENCE AND MORTALITY RATES FOR FEMALE BREAST CANCER BY RACE AND ETHNICITY, US, 2009-2013



American Cancer Society. Cancer Facts & Figures 2017. Available at <https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2017.html>. Accessed June 14, 2017.

Inadequate Diversity in Clinical Trial Participation



Source: FDA, Office of Minority Health. (2013, April 26). Consumers Update: Clinical Trials Shed Light on Minority Health.
AA – African American

Why Diversity in Clinical Trials Is Important?

- Advances in genetic research have shown variations in disease risk, progression and responses to treatments that are associated with specific subpopulations of patients
- Variations of the genes involved in drug metabolism, differ in frequency among ethnic and racial groups
- Helps address healthcare disparities in gender, age, race and ethnic backgrounds (NIH)
- Needed to test for differences in outcomes and to help ensure the safety of therapies (CDC)



Breast Cancer: A Story Half Told

Breast Cancer: A Story Half Told is an initiative by Pfizer in partnership with advocates, patients and healthcare professionals that aims to elevate public understanding of metastatic breast cancer, dispel misperceptions, combat stigma and expand the breast cancer conversation to be more inclusive of metastatic breast cancer.

- **Empowers people with MBC to be storytellers**, capturing their lives through photography,
- The initiative included diverse patients including **Khadijah Carter, an African American** female from New York, and **Esther Garza, a Hispanic** woman from Texas
- Resources also include statistics on **ethnic disparities and public perceptions**
- Since the initiative launch in 2014, the social media reach and website metrics (i.e. page views, visits) represent almost **29.7 million impressions**
 - In 2017, the program will launch its **first male MBC patient** to include men in the conversation



"Additionally, most people believed breast cancer death rates are the same across various ethnic groups.⁹ The reality is that while death rates are decreasing across ethnicities, five-year survival is much lower in certain ethnic groups than in the Caucasian population. African-American women with breast cancer are on average 40 percent more likely to die of the disease than white women with breast cancer. For Hispanic women, breast cancer is the leading cause of cancer death."

Clinical Trial Awareness



Vision

- To make Pfizer the leader in the industry regarding recruitment of a diverse and representative population in clinical trials

Goals

- Drive change internally to encourage teams to consider diversity by design prior to internal governance decisions
- Serve as a single point of contact for teams to enhance diversity in their studies

Mission

- Establish diversity in terms of race, ethnicity, age and gender across our research portfolio as a key scientific variable, which will enable Pfizer to study populations reflective of the epidemiology of diseases we target through our medicines

How Can We Better Engage Patients in Pfizer Trials? Pfizer's "Blue Button®" Program

The screenshot shows the Pfizer Link website. At the top, the logo "Pfizer Link" is displayed with the tagline "Linking you to an online clinical trial community". Below the logo is a navigation bar with links for "Home", "About Pfizer Link", "Sign Up Now", "Clinical Trials FAQ", and "Participant Login". The main content area features a large image of an older man and a young boy fishing together. Text on the page reads: "Welcome to the Pfizer Link Website! Pfizer Link is an online community for study subjects who have completed their participation in a Pfizer sponsored clinical trial. Pfizer Link gives participants access to relevant health information and information about future opportunities to participate in research." Below this is a testimonial section with a quote from a patient and a "Monthly Health Observances" section with links for "February", "March", "April", and "Archives". A prominent "Sign up now" button is also visible.

Blue Button Overview

Pfizer – 1st Pharma to Launch Blue Button to Pilot Giving Patients in our Studies their Electronic Clinical Data

- Feasibility Pilot launched Q4 2014 with a closed study
- Patients access Blue Button through Pfizer Link
- Individualized electronic data provided in XML and PDF format
- Complies with HIPAA, Safe Harbor & Patient Privacy

This screenshot shows a different section of the Pfizer Link website. It features a group photo of diverse people. Below the photo is a large blue button with a white download icon and the text "Click to download". Below the button, there is a paragraph of text explaining the Blue Button program: "The Blue Button signifies that you—as an individual consumer or patient—can get easy, secure electronic access to your own health information in a format you can use. As Americans, we each have the legal right to see and get a copy of our own health information held by doctors, hospitals and others that provide health care services for us. But many of us don't, either because we don't know we can, or because we're not sure what to do with it. Until recently, most medical information was stored in paper files, so it wasn't very easy to access or use anyhow. But all that is changing as America's health care system rapidly goes digital." At the bottom of the page, there is a footer with copyright information and navigation links.

Engaging with patients post participation and returning data electronically could increase clinical research awareness & participation by building trust and therefore getting drugs faster to those who need them

Source: <https://www.pfizerlink.com/>
http://www.pfizer.com/research/clinical_trials/trial_data_and_results/data_to_patients

Frankly Speaking about Cancer Trials Program



*Patient and Caregiver resources on clinical trial participation created by **The Cancer Support Community** with the support of a grant from Pfizer*

- Clinical Trials Fact Sheet (English and Spanish)
- Understanding Clinical Trials: A Guide for Patients and Caregivers
- Refreshing the Dialogue on Clinical Trials Report
- Frankly Speaking About Clinical Trials : A Narrative



Cancer Moonshot Initiative

- President Obama tasked Vice President Joe Biden to lead a National effort to “end cancer as we know it”
- The mission is to make decade’s worth of progress in preventing, diagnosing, and treating cancer in five years
- A Blue Ribbon panel consisting of cancer researchers, oncologists, patient advocates, and representatives from the private sector and government agencies
- Seven areas of focus:
 - Clinical Trials
 - Enhanced Data Sharing
 - Cancer Immunology
 - Implementation Science
 - Pediatric Cancer
 - Precision Prevention and Early Detection
 - Tumor Evolution and Progression

Source: Cancer Moonshot Blue Ribbon Panel Report 2016 Draft (<https://www.cancer.gov/research/key-initiatives/moonshot-cancer-initiative/blue-ribbon-panel/blue-ribbon-panel-report-2016.pdf>)



THANK
YOU

Kimberly Alcantara
Shonte Drakeford
Brandon Garrett
Dr. Lori Wilson



Metastatic Breast Cancer & Me



Ricki Fairley
Keith Gregory
Jasmine Jones
Rev. Dr. Ruth Travis



Metastatic Breast Cancer & The Community

Say Hello, Sweetie.

York Pattie: Favorite Song

Ring Pop: Favorite Color

Starburst: Favorite Book

Skittles: Favorite Vacation

Milky Way: Favorite Food

Kit Kat: Favorite Movie

Lunch

Table Introductions






Jackii Wang
U.S. Representative
Debbie Wasserman
Schultz



Advocating for Young Women



Tammy Boyd
Dr. Regina Hampton
Dr. Sara Horton
Mia Keeys
Dr. Shalewa Noel-
Thomas



Metastatic Breast Cancer & Public Policy

David Lacks, Jr.
Markette Sheppard



Keynote Conversation

Mobilizing Against Metastatic Breast Cancer Disparities

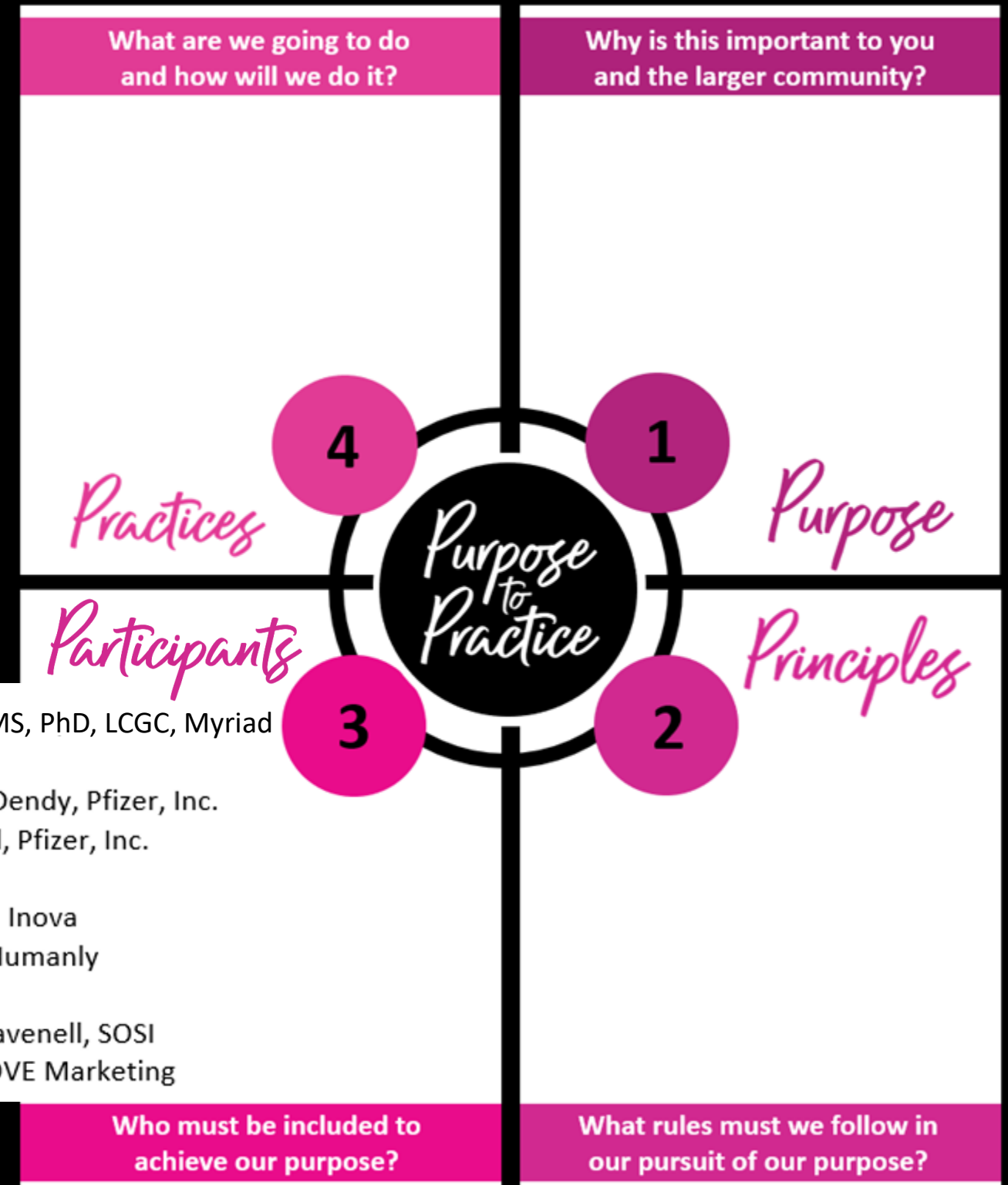
Break Out Groups

Lead Facilitator: Shyrea Thompson, The IRIS Collaborative

- **Group 1: York Pattie**
Facilitator: Janeen Azure, Pfizer, Inc.
Recorder: Beth Burnett, Pfizer, Inc.
- **Group 2: Ring Pop**
Facilitator: Colleen Nguyen, MPH, Count Me In
Recorder: Imani Boykin, Howard University
- **Group 3: Starburst**
Facilitator: Dannielle Patterson, Lilly
Recorder: Coral Jean-Mary, Howard University

Lead Recorder: Irene Rainville, MS, PhD, LCGC, Myriad

- **Group 4: Skittles**
Facilitator: Dionne Jones-Dendy, Pfizer, Inc.
Recorder: Patti Fine Jewell, Pfizer, Inc.
- **Group 5: Milky Way**
Facilitator: Keith Gregory, Inova
Recorder: Lauren Wood, Humanly
- **Group 6: Kit Kat**
Facilitator: Gloria Ward-Ravenell, SOSI
Recorder: Ricki Fairley, DOVE Marketing



 Planning for Impact

What?

So What?

Now What?

Next Steps

Report Outs





Reflection

Maimah S. Karmo



I manifest
love.

Stay Connected



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Closing Remarks

Madeline Long Poole

#ListenUpMBC

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Thank You

Tigerlily Foundation thanks our contributors for the generous support of our Metastatic Breast Cancer Disparities Listening Summit.



Kipp Burgoyne::Photography



HOWARD UNIVERSITY



Donation of Sabika Jewelry gifted by Char Kurihara in loving memory of her sister Lisa Monteleon.