



## The Metastatic Breast Cancer Project

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**Michael Dunphy, MS**

Senior Manager, Count Me In

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# MBC Impact Series

We won't stop until breast cancer does.

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MISSOURI

# *The Scientific Need in Cancer Research*



- **Ultimate goal:** To understand what drives cancer so that we eventually can interpret every patient's cancer genome, identify the optimal treatments, and anticipate and preempt resistance before it arises



- There's been a lot of progress, but we still have much work to do
- What will it take to get there? Detailed molecular and genomic characterization of thousands of tumor and germline samples along with clinical, pathologic, and radiologic data

# Challenges to Studying Patient Tumor Samples

*Most tumor samples have not been readily available for study*

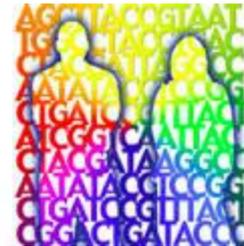
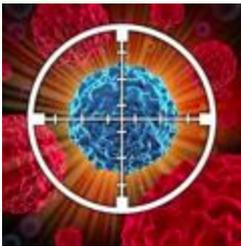


*85% of U.S. cancer patients are treated in community settings*



*Technology, social media, and cultural changes now provide a new opportunity to engage cancer patients and directly partner with them in this research*

*Objective: To generate a publicly available database of clinical, genomic, molecular, and patient reported data in MBC to accelerate discoveries and the development of new treatment strategies*



# The Metastatic Breast Cancer Project



[Data](#)

[Learn More](#)

[count me in](#)

Help transform our understanding  
of metastatic breast cancer.

If you have metastatic breast cancer, join a nationwide movement of patients, doctors, and scientists by sharing your tumor and/or blood samples, your medical information, and your voice. Together, we can speed the development of future therapies.



# *The Metastatic Breast Cancer Project*

Your tumor and medical records  
could unlock discoveries.

The unique genetic information in your cancer could hold the key to rapid advances in cancer treatment. By looking at the DNA in your samples, researchers can make discoveries that will ultimately lead to a better understanding and faster advances in the treatment of metastatic breast cancer. This information will be invaluable to cancer research for years to come.



# The Metastatic Breast Cancer Project

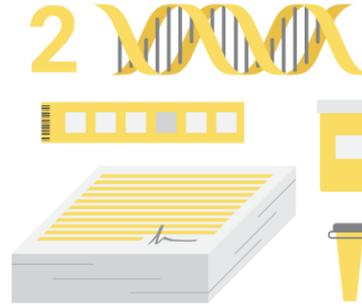
Here's how you can participate



## Step 1.

Tell us about yourself

Click “Count Me In” and complete a simple online form to tell us about yourself and your cancer.



## Step 2.

Give us permission to collect your samples and data

After you fill out the online survey, we will ask you to fill out an online consent form that requests your permission to obtain copies of your medical records and some of your stored tumor tissue. We'll also send you a simple kit to collect a saliva sample. We will send you a separate online consent form that requests your permission to obtain and analyze a sample of your blood. *We will do the rest* – we'll contact your doctors and hospitals to obtain copies of your medical records and a portion of your stored tumor samples.



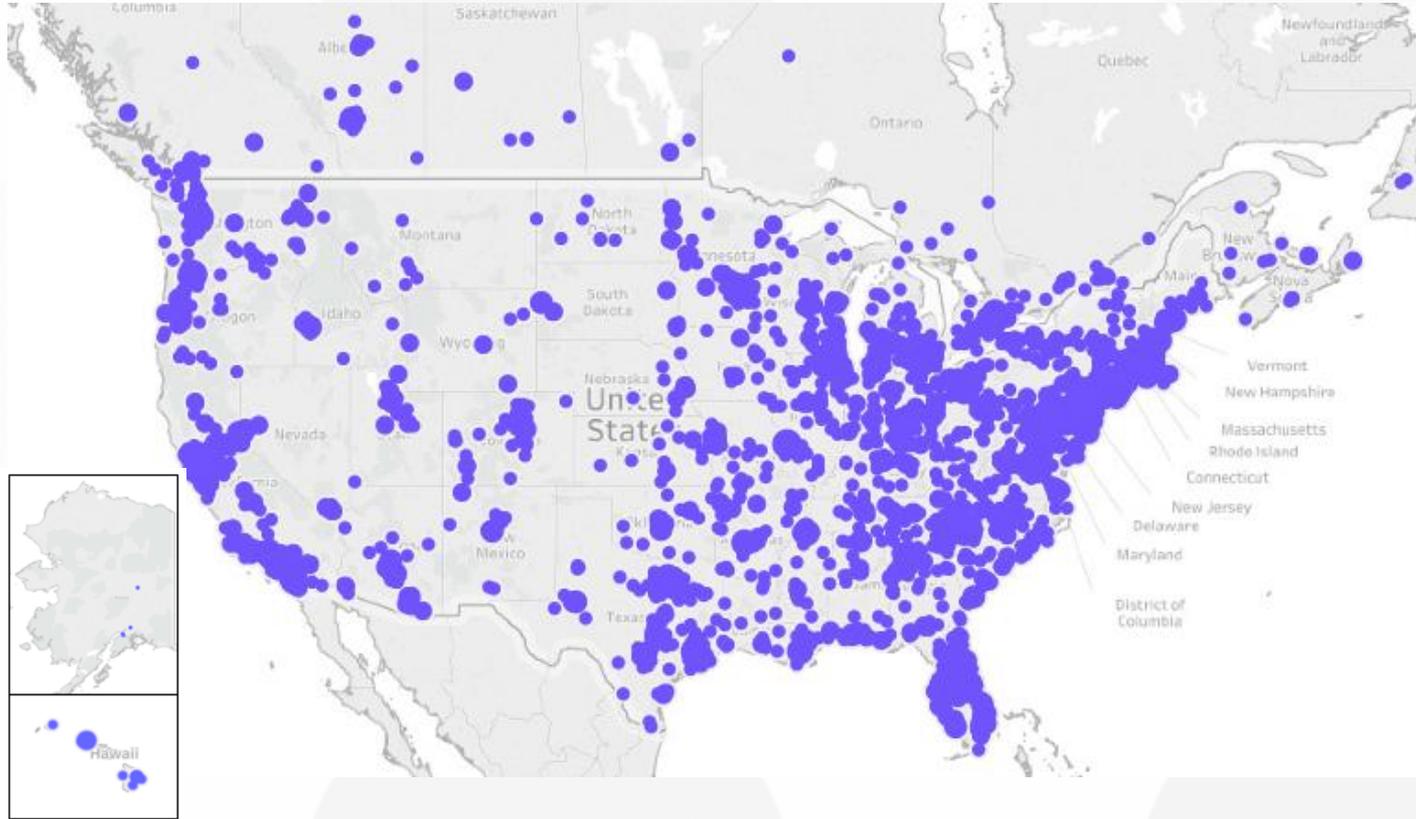
## Step 3.

Learn with us along the way

We are excited to learn with you! Throughout the project, we will provide you with regular updates about the status of the project and share any discoveries that you have enabled us to make. We also may ask you additional questions about your experience to help with future studies – we want to hear what's important to you.

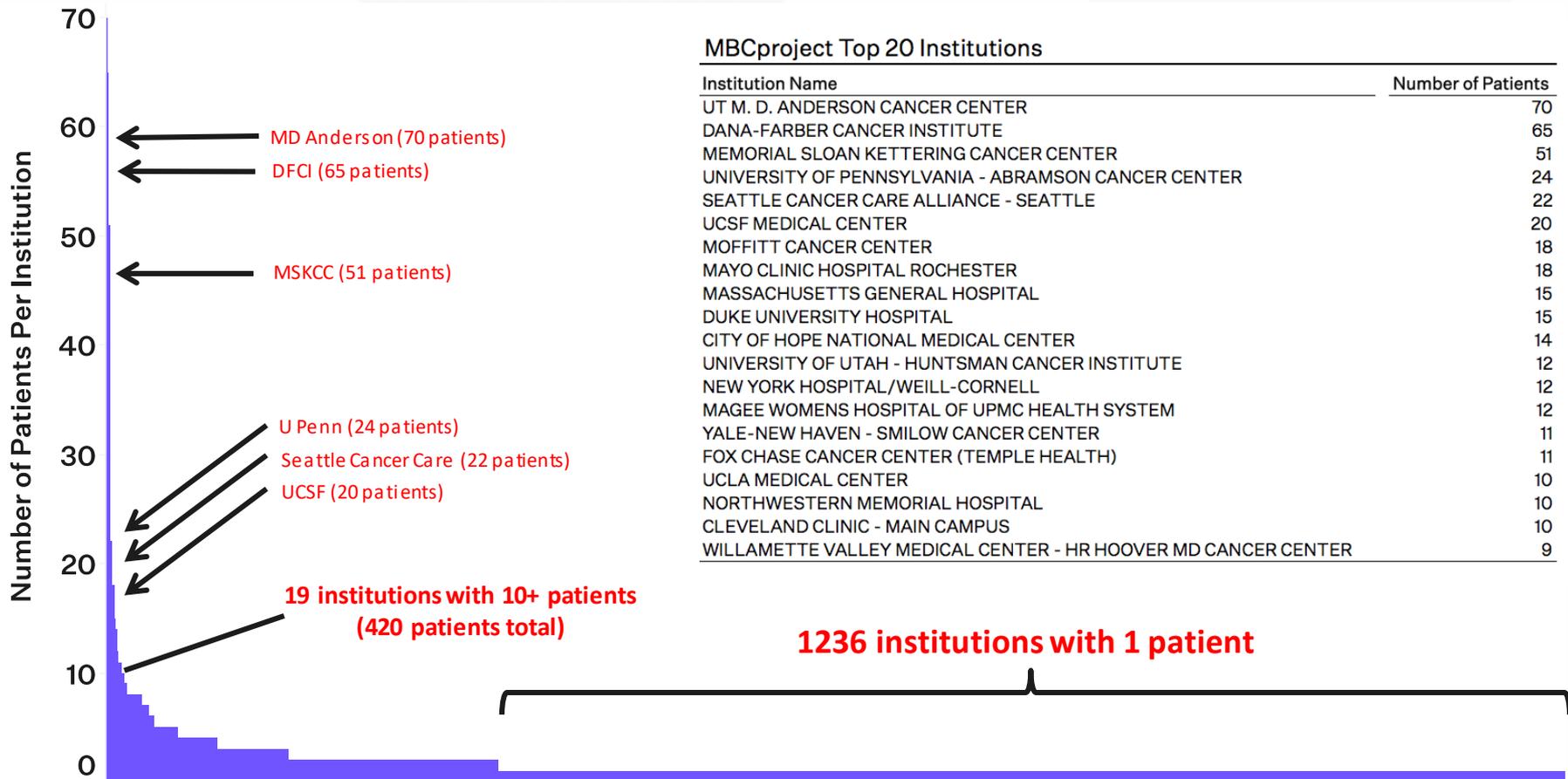
# The Metastatic Breast Cancer Project

## MBCproject.org



Over **5700 women and men** with metastatic breast cancer from all 50 states have joined the MBCproject since our launch in October 2015

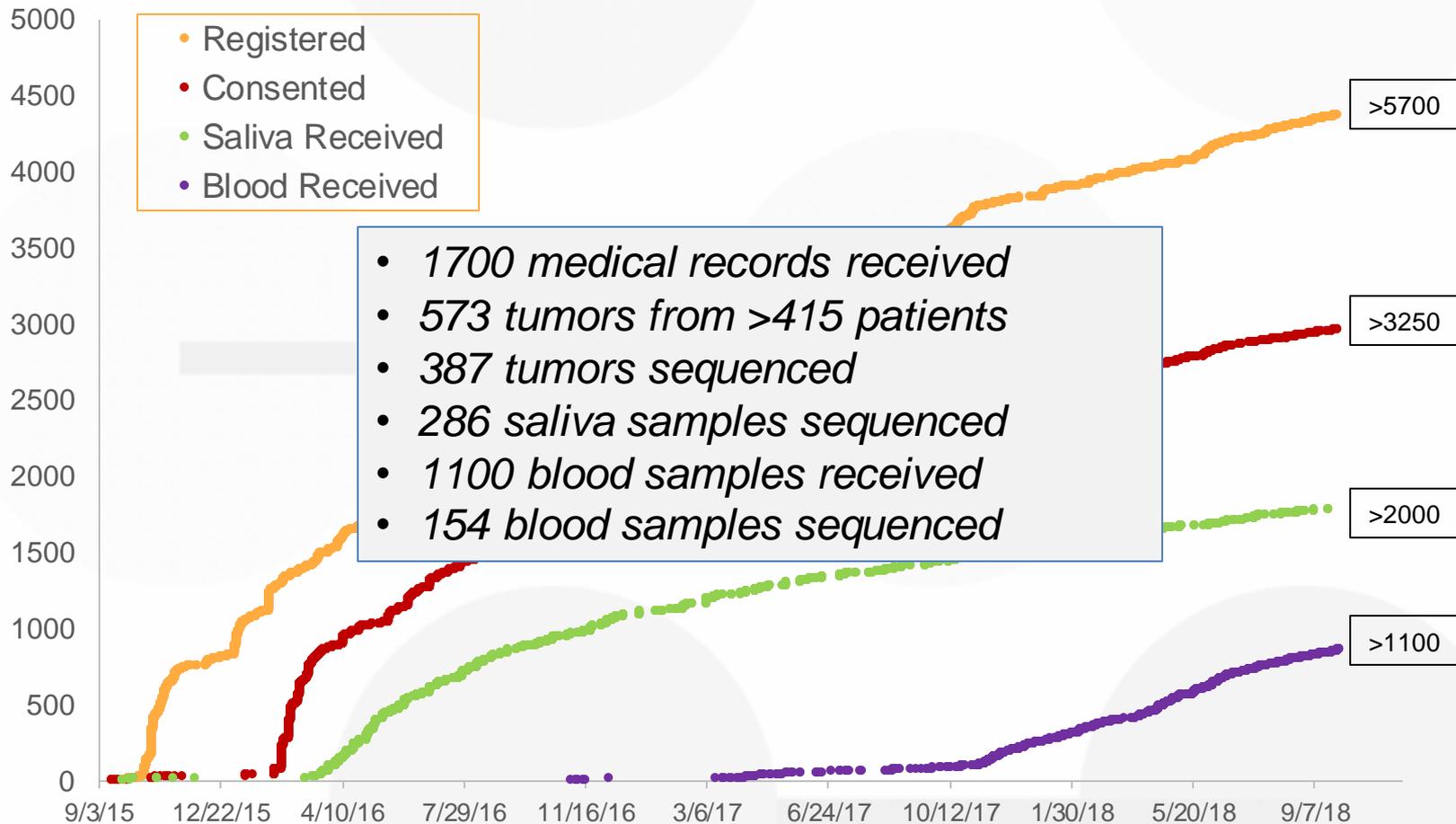
# Over 1700 Institutions Represented



MBCproject Top 20 Institutions

Institution Name	Number of Patients
UT M. D. ANDERSON CANCER CENTER	70
DANA-FARBER CANCER INSTITUTE	65
MEMORIAL SLOAN KETTERING CANCER CENTER	51
UNIVERSITY OF PENNSYLVANIA - ABRAMSON CANCER CENTER	24
SEATTLE CANCER CARE ALLIANCE - SEATTLE	22
UCSF MEDICAL CENTER	20
MOFFITT CANCER CENTER	18
MAYO CLINIC HOSPITAL ROCHESTER	18
MASSACHUSETTS GENERAL HOSPITAL	15
DUKE UNIVERSITY HOSPITAL	15
CITY OF HOPE NATIONAL MEDICAL CENTER	14
UNIVERSITY OF UTAH - HUNTSMAN CANCER INSTITUTE	12
NEW YORK HOSPITAL/WEILL-CORNELL	12
MAGEE WOMENS HOSPITAL OF UPMC HEALTH SYSTEM	12
YALE-NEW HAVEN - SMILOW CANCER CENTER	11
FOX CHASE CANCER CENTER (TEMPLE HEALTH)	11
UCLA MEDICAL CENTER	10
NORTHWESTERN MEMORIAL HOSPITAL	10
CLEVELAND CLINIC - MAIN CAMPUS	10
WILLAMETTE VALLEY MEDICAL CENTER - HR HOOVER MD CANCER CENTER	9

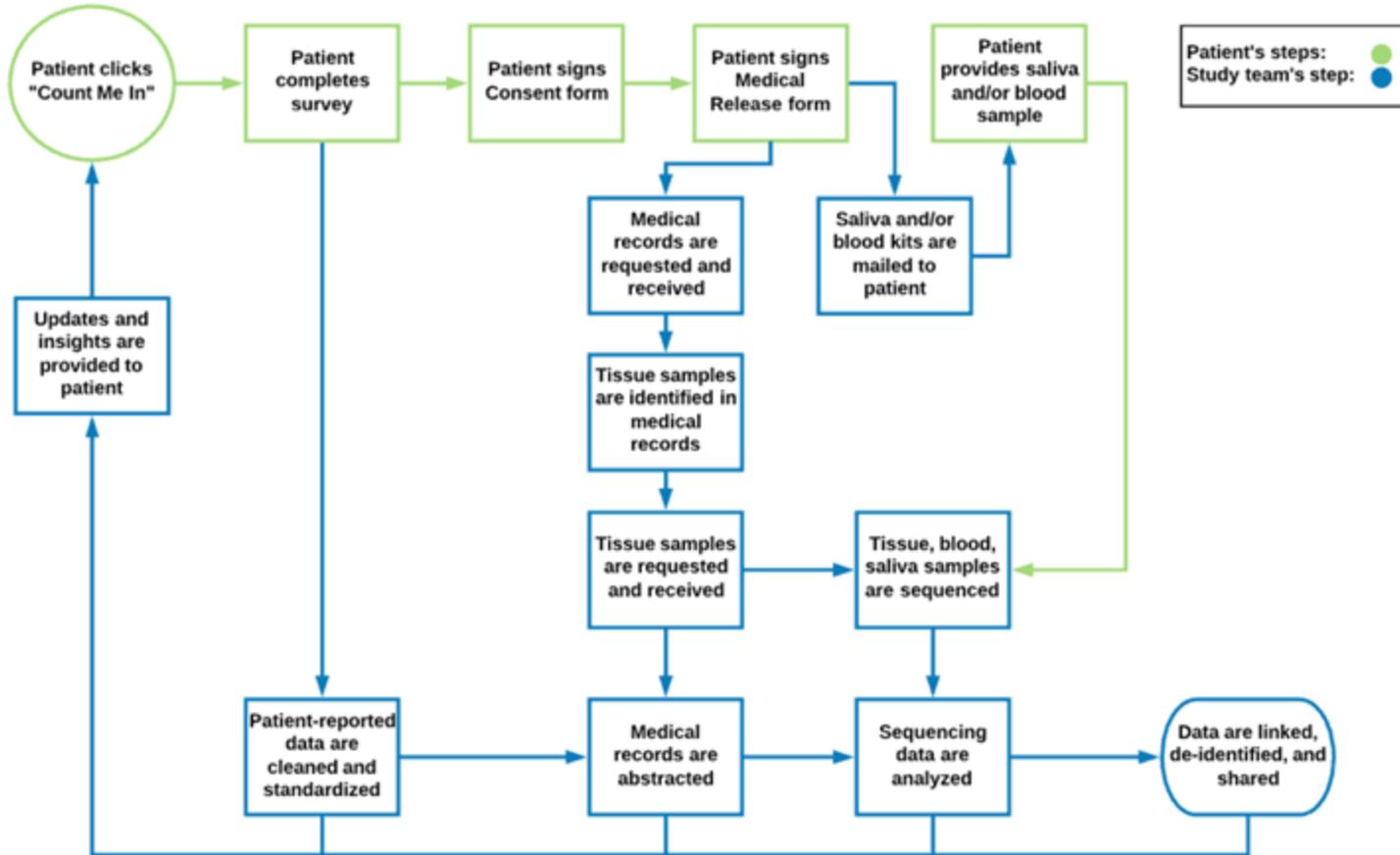
# MBCproject: Patients Registered, Consented, and Samples Received



# Project Processes



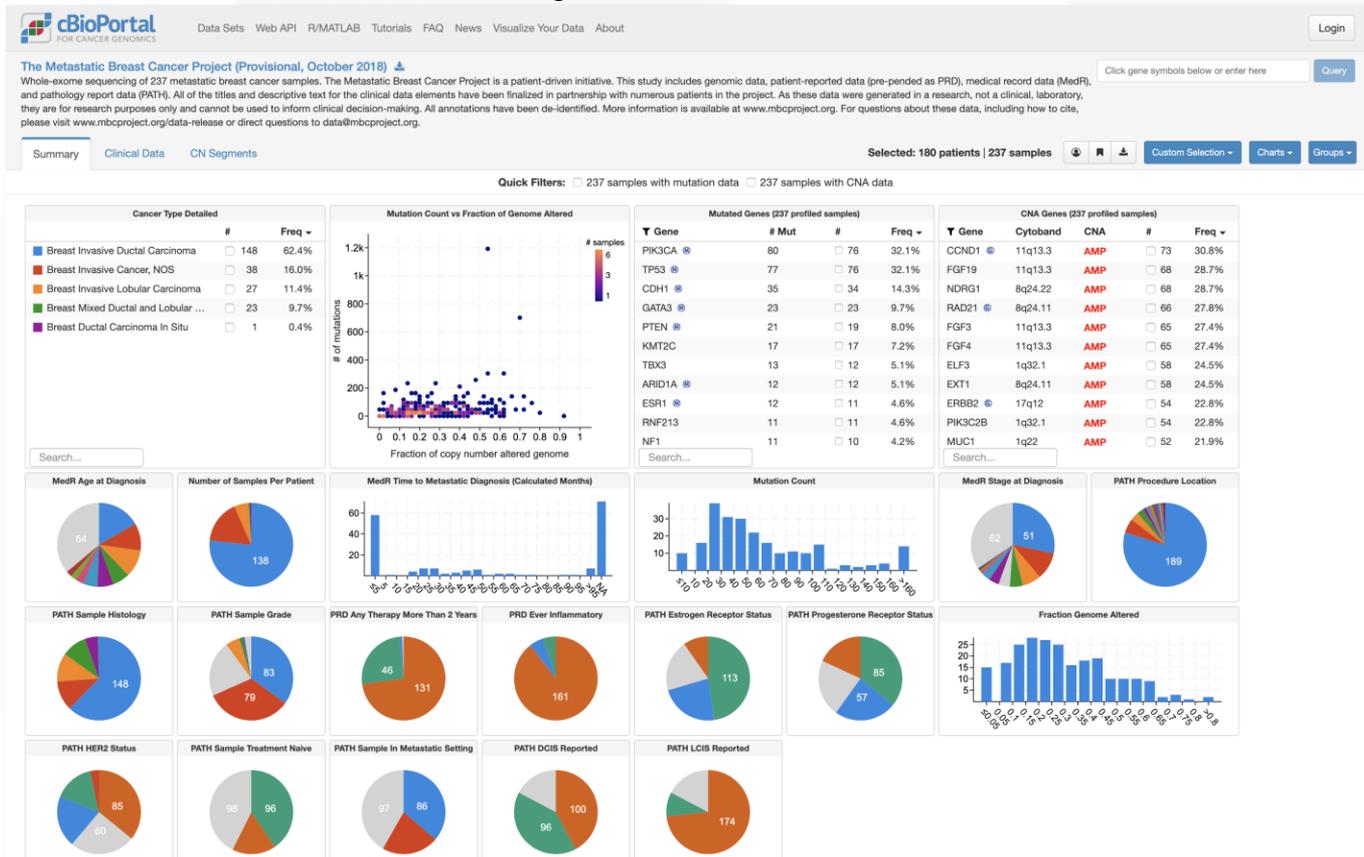
# Project Processes



# Project Processes



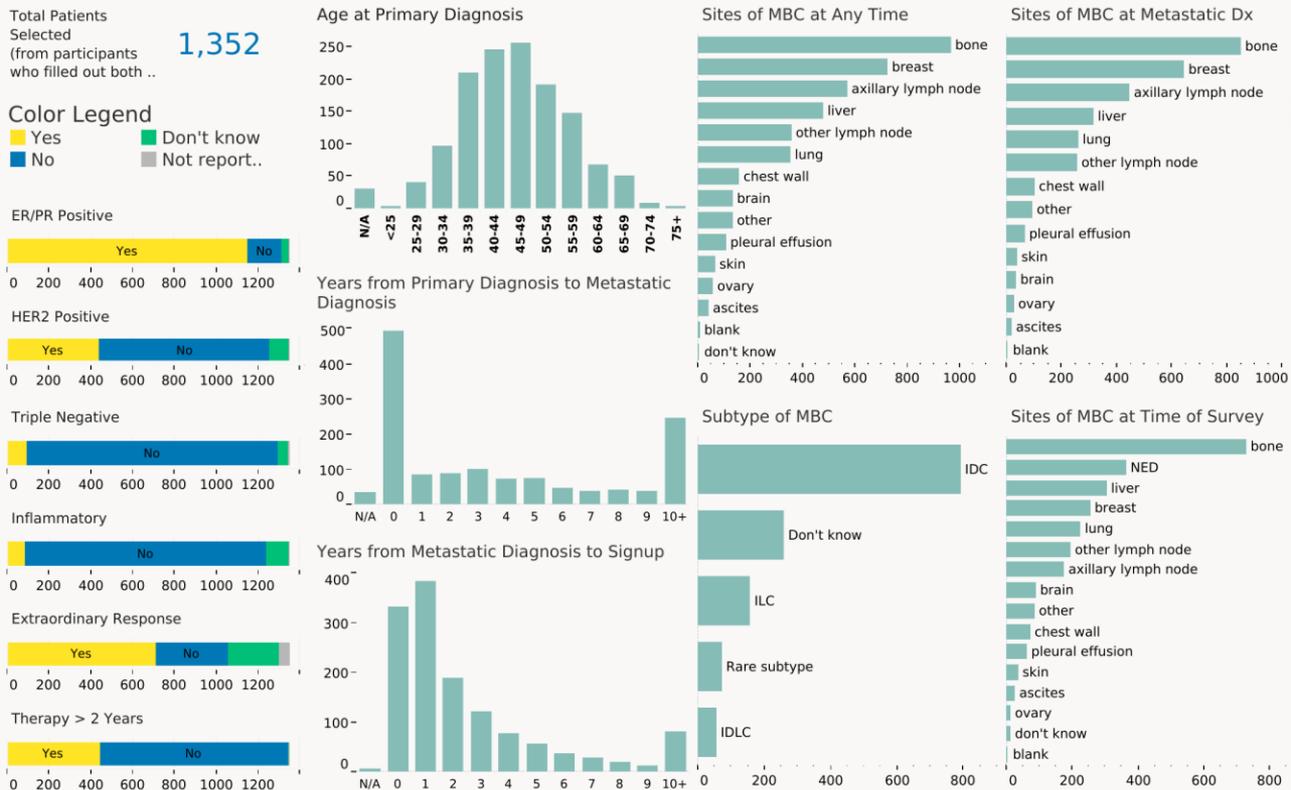
# Publicly Available Data



*Patient-reported, clinical, and genomic data for 237 samples from 180 patients available on cBioPortal through [mbcproject.org/data-release](http://mbcproject.org/data-release)*

# Patient Reported Data

## The Metastatic Breast Cancer Project Patient Data Browser



Survey data from 1,352 patients who completed the intake and follow-up surveys available on [mbcproject.org/data-release](https://mbcproject.org/data-release)

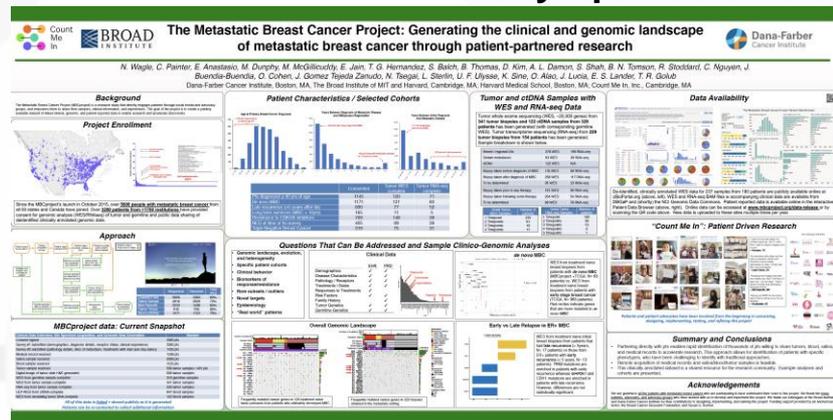
# Scientific Impact

## MBCproject Data on cBioportal.org



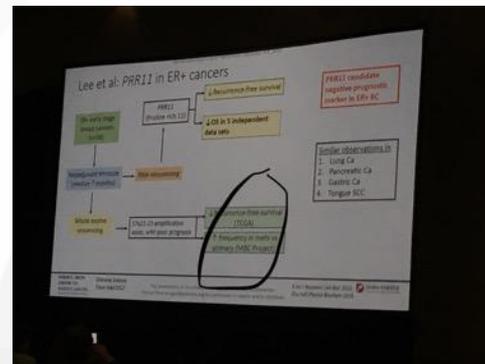
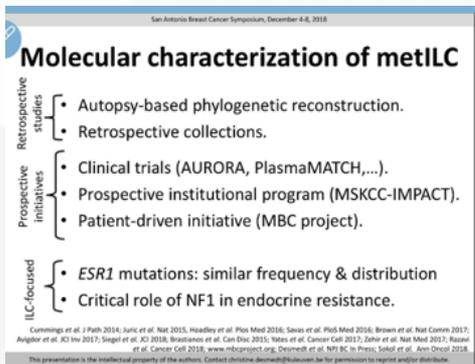
Over 80,000 pageviews in the first year

## San Antonio Breast Cancer Symposium Poster



MBCproject data cited in talks at conferences

**Over 20 Academic publications have cited MBCproject data to date**



# Additional Projects

Angiosarcoma Project

Data Release Learn More Sign In [count me in](#)

## Help transform our understanding of Angiosarcoma.

If you have been diagnosed with angiosarcoma, join a nationwide movement of patients, doctors, and scientists by sharing your tumor samples, your medical information, and your voice. Together, we can develop a comprehensive resource that will drive discoveries about this orphan cancer.



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Esophageal & Stomach Cancer Project

Learn More [count me in](#)

## You can have a direct impact on the future of Esophageal and Stomach Cancer

If you have been diagnosed with esophageal or gastric/stomach cancer, join a nationwide initiative of patients, doctors, and scientists by sharing your tumor samples, your medical information, and your voice. Together we can develop a comprehensive resource to accelerate discoveries that may inform future therapies.



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Metastatic Prostate Cancer Project

Data Release Learn More [count me in](#)

## You can have a direct impact on the future of men with prostate cancer

The Metastatic Prostate Cancer Project is a nationwide genomic research study for men with advanced or metastatic prostate cancer. We seek to generate the most comprehensive database that will be shared with the entire research community to accelerate discoveries.



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Brain Cancer Project

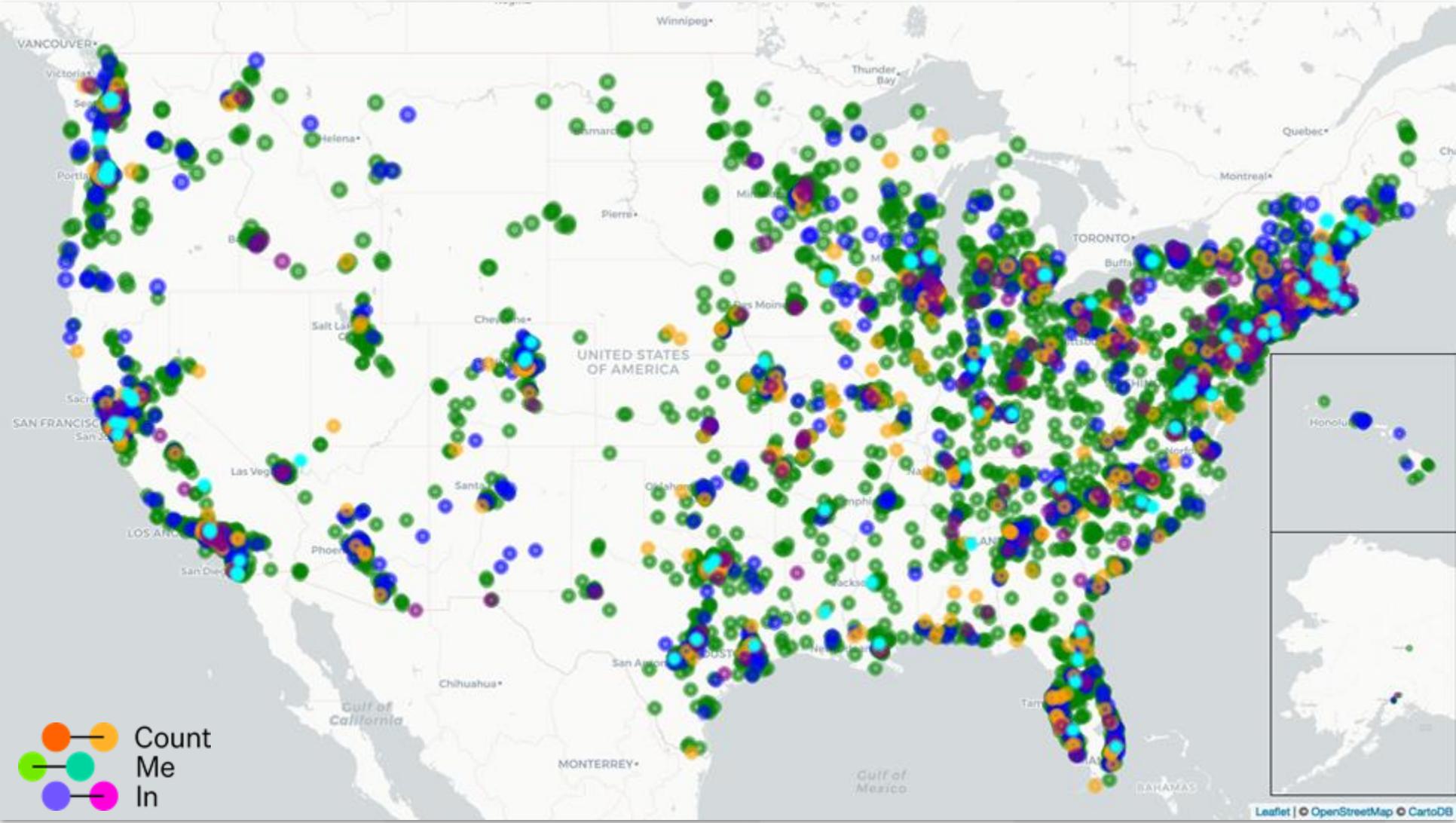
Learn More Sign In [count me in](#)

## Help transform our understanding of Brain Cancer

If you are an adult who has been diagnosed with a primary brain cancer, such as glioblastoma, astrocytoma, or oligodendroglioma, you can join a nationwide movement of patients and their families, doctors, and scientists by sharing your information and your voice. Together we can develop a comprehensive resource to contribute to research that will inform future therapies. The project will be expanding to include pediatric patients soon.



[BROAD INSTITUTE](#) [DANA-FARBER CANCER INSTITUTE](#) 



# JoinCountMeIn.org



Count  
Me  
In

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Patient-partnered research  
is changing the future of  
cancer



"The patient is not an  
afterthought. We're a  
vital part of the  
process."

Michael K.  
Metastatic Breast Cancer Project



"I'm the second  
generation to have  
breast cancer in my  
family. I don't want my  
daughter to get this  
disease."

Sheila M.  
Metastatic Breast Cancer Project

# Patient-Partnered Research



"I want to live and watch my children grow up, but if I can't, then I want to leave a legacy and a cure."

—Houston, TX

"As someone who does not live near a research center and therefore cannot easily participate in trials, I finally feel like I can contribute."

—Lake Tahoe, CA

"Amazing how happy that little box makes you feel! I felt like a 2 year old. Let me help! I feel a sense of pride and belonging because of this."

—Minneapolis, MN

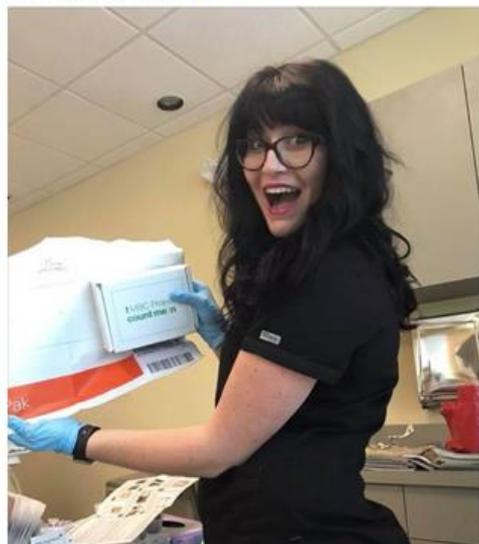
"Giving us HOPE for the future and if not for some of us, for our families."

—Scottsdale, AZ

had his blood draw today for the #MBCProject. Now it is on its #fedex way to the Broad Institute in Cambridge, MA. <https://www.mbcproject.org>



Blood sample coming your way. Thanks to my lovely chemo nurse Madison for the assistance 🙏



Blood biopsy on the way. Love @MBC\_Project @Nikhilwagle @corrie\_painter #MBCstrength



Excited I received my liquid biopsy from @MBC\_Project yesterday & was scheduled 4 blood work today. Count Me In! Thank you for all your hard work @Nikhilwagle @corrie\_painter and to my healthcare team @UCSFCancer . Still going after 3 1/2 years!

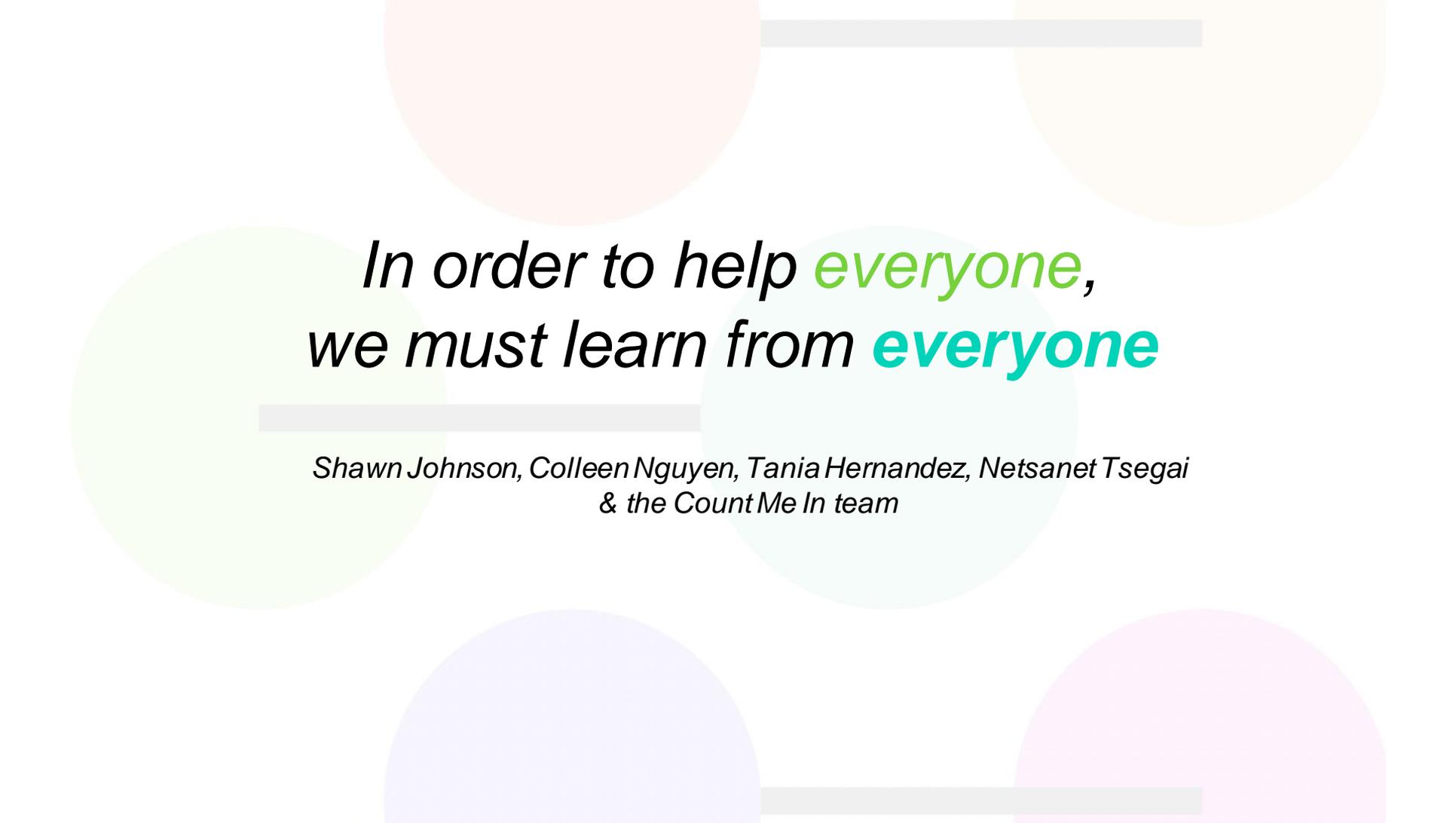


Advancing research possibilities while piloting a potential blood test sample to better understand the mechanics of Metastatic Breast Cancer with the #MBCProject #stage4needsmore #wearedyingforacure







The background features several large, semi-transparent circles in shades of light orange, light green, light blue, light purple, and light pink. Horizontal grey bars are positioned across the top and bottom of the page, partially overlapping the circles.

*In order to help **everyone**,  
we must learn from **everyone***

*Shawn Johnson, Colleen Nguyen, Tania Hernandez, Netsanet Tsegai  
& the Count Me In team*

# Growing the core team

*Colleen Nguyen*



I joined the CMI team a little over a year ago with **the aim of bringing more communities of color to the cancer research table**. As a woman of color, I know that it's a table that our communities have been traditionally omitted from. But with the overall goal to advance our understanding of cancer across the board, it is imperative that everyone is both included in the conversation, and also empowered to *own* a piece of this process.

*Tania Hernandez*



Joining *Count Me In* has **given me the opportunity to invite and include the Hispanic and Latinx community- my community**, in cancer research. In true CMI spirit, we partner with the community to help develop the MBCproject in Spanish, and continue to build it with the diversity and richness of our language and culture to empower patients to participate in cancer research to learn and understand more about this disease

*Netsanet Tsegai*



Community Outreach within CMI is important to me because **I want to help empower individuals and communities to be part of the process and discussion by coming to the table**. Only by bringing everyone to the table will we be able to accelerate treatments for **all** individuals and communities who bear the burden of this disease.

# *Considerations on community engagement in the MBCproject*

- Transparency
- Building trust
- Outreach & education
- Partnerships & collaborations

# Overview of African American participation in MBCproject



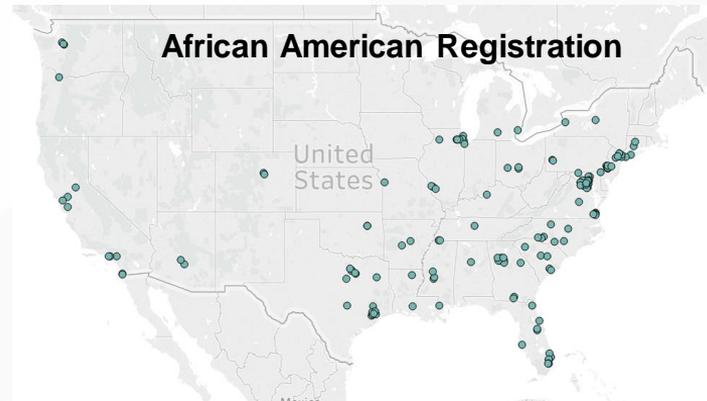
**5471** - Participants registered

**3169** - Participants consented (US/CA)

**+500** - Samples from over 300 participants

**237** - Samples in cBioPortal

**87%** of registered participants consider themselves non-Hispanic white



**155** – African American patients registered

**89** – African American patients Consented (US/CA)

**21** - Tissue samples received

**9** - Samples in cBioPortal

**2.8%** of registered participants consider themselves African American

# *Working With Ambassadors*



Angela Baker



Sheila McGlown



Latonya Wilson



Bridgette Hempstead



Carla Harvey

African American Metastatic Breast Cancer Patient Advocates

# *Working with patients and advocates through an ongoing dialogue*



*Organized and hosted “Clinical Research Across the Color Line”, a one-day symposium in April 2017 at the Broad Institute with patients, oncologists and researchers discussing ways to improve diversity in biomedical research.*

# *Working with patients and advocates through an ongoing dialogue*



*Participated alongside MBCproject Ambassadors on a panel for the MBC Disparities Listening Summit, hosted by one of our advocacy partners, the Tigerlily Foundation, in March 2019.*

# Colleges & Universities

## Project HUMBLE

- First student group pilot at Howard University – the “Howard University Metastatic Breast Cancer Learning Experience”; officially associated with [MBCproject.org](http://MBCproject.org)



## University of Massachusetts, Boston – Phi Delta Epsilon

- Phi Delta Epsilon is interested in engaging further in the new academic year and are contributing to shaping the new campus engagement program



## Roxbury Community College

- Collaborating directly with the Department of Health Sciences at RCC, a volunteer student was recruited who provided project assistance and on the ground presence in developing and navigating outreach on and off campus within the local Boston area.

# Campus Engagement Program

- Learning from past pilots, we've developed a new **Campus Engagement Program (CEP)** alongside the student organizations that we've previously collaborated with
- New pilot periods from 2020-2021
- **Eligibility Requirements:**
  - Existing student organization on campus interested in participating in the *Count Me In* mission
  - This will also require one member of that organization to serve as the CMI contact/campus lead (student-led)

## Development of New Plug & Play Model

- Structured 'curriculum' for the academic year, which can be changed and amended as the pilot progresses

## Key Aspects

- Students can choose how to engage with the program – from month, activity, etc.
- Will be hosting bi-monthly check-ins with campuses to discuss and share experiences with each other
- Aim is to start with Boston area colleges/universities and scale the model over time

# Overview of *LatinX* participation in MBCproject



**5471** - Participants registered

**3169** - Participants consented (US/CA)

**+500** - Samples from over 300 participants

**237** - Samples in cBioPortal

**87%** of registered participants consider themselves non-Hispanic white



**241** - LatinX registered

**117** - LatinX Participants Consented (US/CA)

**17** - Tissue samples from 14 participants

**17** - Samples in cBioPortal

**4.4%** of registered participants consider themselves Hispanic/Latino

# MBCproject in Spanish

## Late 2017

*Project kick-off and initial translations*

## Early - Mid 2018

*Collaboration with Broad community*

- *Landscape analysis of translated resources*
- *Discussions around formality and dialect choice*

## July 2018 - Present

*Formal translations and outreach*

- *Translations completed*
- *Feedback from patients and advocates*
- *Community engagement efforts*



February 2018



August 2018

# Future of the MBCproject in Spanish

## Greater Boston Area

- Faith-based community engagement and general community relationship building planned in 2020, moving forward.

## Puerto Rico

- Help develop materials in Spanish for patients from Puerto Rico.
- Continue to collaborate to obtain feedback on participant materials in the form of surveys and monthly conference call meetings.

## Impact of the MBCproject in Spanish

- **Pilot and foundation** for launching patient-partnered research projects in Spanish in *Count Me In*.
- Learn more about **MBC in the Hispanic and Latinx population**.
- **Increase diversity** of study participants in cancer research.
- **Empower underrepresented groups** to participate in patient-partnered research.

# Conclusions

Go to the patients

- Tap into existing communities – patients

*Patients and researchers can work in partnership to accelerate discovery*

- Start working with patients while designing
- Build messaging with patients
- Take feedback seriously and show it
- Share progress and results



# Acknowledgements

## ALL patients participating

- **Nikhil Wagle**
- **Corrie Painter**
- **Elana Anastasio**
- **Colleen Nguyen**
- **Mary McGillicuddy**
- **Rachel Stoddard**
- **Sara Balch**
- **Taylor Cusher**
- **Beena Thomas**
- **Alyssa Damon**
- **Shahrayz Shah**
- **Rafael Ramos**
- **Tania Hernandez**
- **Netsanet Tsegai**
- **Lauren Sterlin**
- **Fergie Ulysse**
- **Imani Boykin**
- **Brett Tomson**
- **Shawn Johnson**
- **Jamie Holloway**
- **Jim Palma**
- **Samantha Sullivan**
- **Andrew Zimmer**
- **Esme Baker**
- **Simone Maiwald**
- **Rich Nordin**
- **Erin Gwozdz**
- **Jen Lapan**
- **Pegah Taheri**
- **Jordan Doucette**
- **Sarah Winnicki**
- Lauren Ryan
- Max Krevalin
- Dewey Kim
- Jorge Buendia
- Esha Jain
- Sara Semonian
- Miguel Ilzarbe
- Eli Van Allen
- Kristen Zarrelli
- Tania Simoncelli
- Jesse Boehm
- Deb Dillon
- Jon Bistline
- Jared Cosulich
- Playground
- Carol Lowenstein
- Kristen Anderka
- Samira Bahl
- Alicia Wong
- Katie Larkin
- Sam Pollock
- Emily Moore
- Niall Lennon
- Sheila Fisher
- Carrie Cibulskis
- Stacey Gabriel
- Viktor Adalsteinsson
- Gavin Ha
- Greg Gyudish
- Sarah Reed
- Sam Freeman
- Nelly Oliver
- Karla Helvie
- Kate Mulherin
- Levi Garraway
- Bina Venkataraman
- Bang Wong
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- Scott Sassone
- Emily Lipscomb
- Andrea Saltzman
- Stacey Donneley
- Jenny Rood
- Jenn Chen
- Justine Levin-Allerhand
- Elizabeth Frank
- Eric Winer
- Eric Lander
- Todd Golub



The Count Me In Team



# Acknowledgements



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