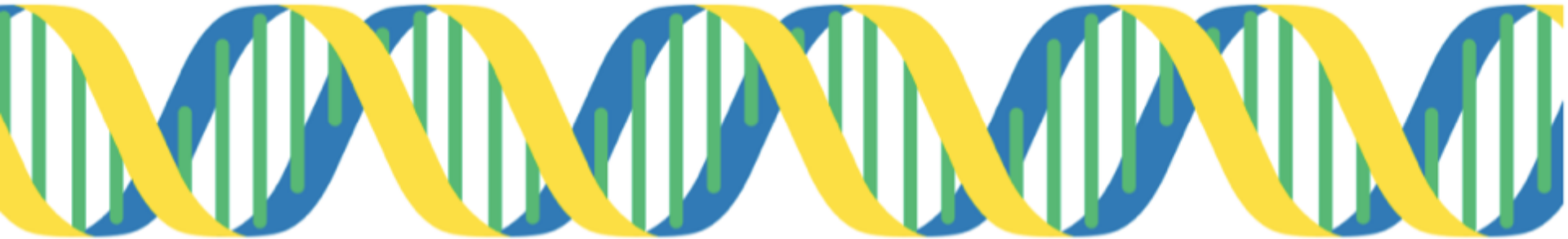
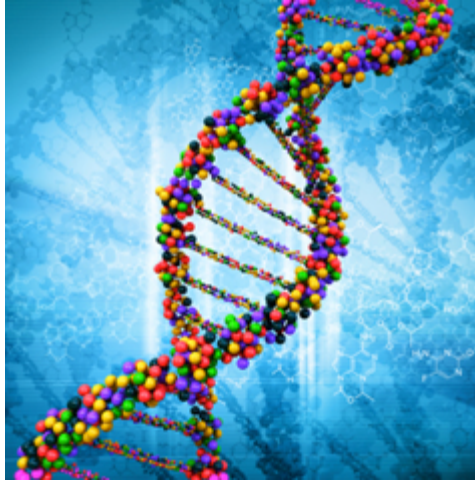


# The Metastatic Breast Cancer Project

June 1 2016



# *What is metastatic breast cancer?*



- Metastatic breast cancer (MBC) is breast cancer that has spread beyond the tissues of the breast
- An estimated 150,000 women and men are living with metastatic breast cancer in the U.S.



- 40,000 people in the U.S. die from metastatic breast cancer each year (7% of all cancer deaths in U.S.)
- Though treatments are improving, metastatic breast cancer is currently not curable

# *The Scientific Need in Cancer Research*



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

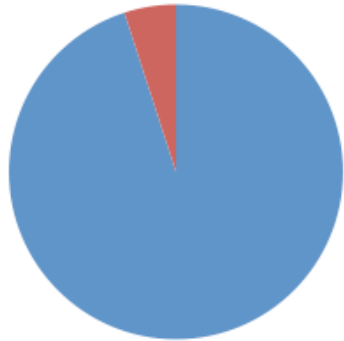


- There's been a lot of progress, but we are still far from the goal
- What will it take to get there? Detailed molecular and genomic characterization of **thousands** of tumor and germline samples along with medical information

# *Some questions we are trying to answer in metastatic breast cancer*

- What are all changes at the molecular level that can lead to metastatic breast cancer?
- What explains why some patients show extraordinary responses to a particular treatment?
- What explains why some tumors never respond to a particular treatment, or why some tumors initially respond but later develop resistance?
- What are some factors that can lead to developing metastatic breast cancer at a young age?
- What are the genes involved in metastatic breast cancer for underrepresented and understudied groups?
- How can we improve the use of genomic information in the treatment of metastatic breast cancer?
- *How can we develop better treatments for metastatic breast cancer?*

# Challenges of Studying Patient Tumor Samples



*Only 5% of U.S. cancer patients are enrolled in clinical trials*



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

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

---



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

# *The Metastatic Breast Cancer Project*

## *MBCproject.org*



Metastatic  
Breast Cancer  
Project

[Learn More](#)

count me in

Do you want to 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 samples, your medical information, and your voice. Together, we can speed the development of future therapies.



BROAD  
INSTITUTE



HARVARD  
MEDICAL SCHOOL

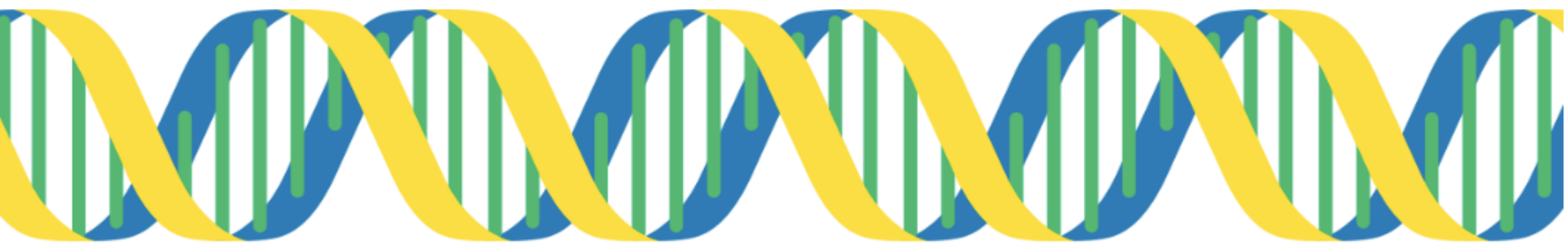


DANA-FARBER  
CANCER INSTITUTE

## 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 (using "genomic sequencing"), researchers can make discoveries to identify new ways to treat metastatic breast cancer.

This information will be securely shared with researchers around the world. It will be invaluable to cancer research for years to come — and ultimately lead to a better understanding and faster advances in the treatment of metastatic breast cancer.



# Become part of the research movement. Have a direct impact on the future.

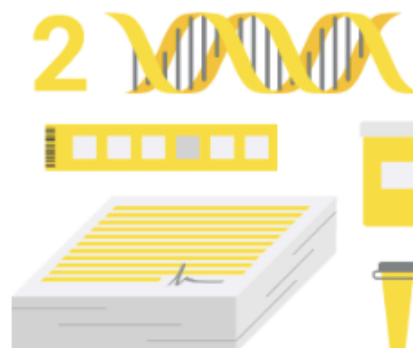
By saying "Count Me In", you will partner with leading research institutes, hospitals, and patient advocacy groups by sharing part of your stored tumor tissue and copies of your medical records.

## 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. Our goal is to perform many different studies within the metastatic breast cancer community, so allowing us to know a little bit about your experience will help us design future



### Step 2. Give us permission to collect your samples and data

When we start a study that matches what you have told us about yourself, 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 will do the rest - we'll contact



### 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



## Join the Movement: Tell Us about Yourself

Complete the form below to tell us about yourself and your cancer. Our goal is to perform many different studies within the metastatic breast cancer community, so allowing us to know a little bit about your experience will help us conduct our current projects and also to design future studies. We will be starting with some focused studies in metastatic breast cancer, and expanding over time based on what we learn from you. We are asking all patients with metastatic breast cancer to say Count Me In and fill out the form so that we can use the information you provide to plan our next studies.

### Contact Info

First Name

---

Last Name

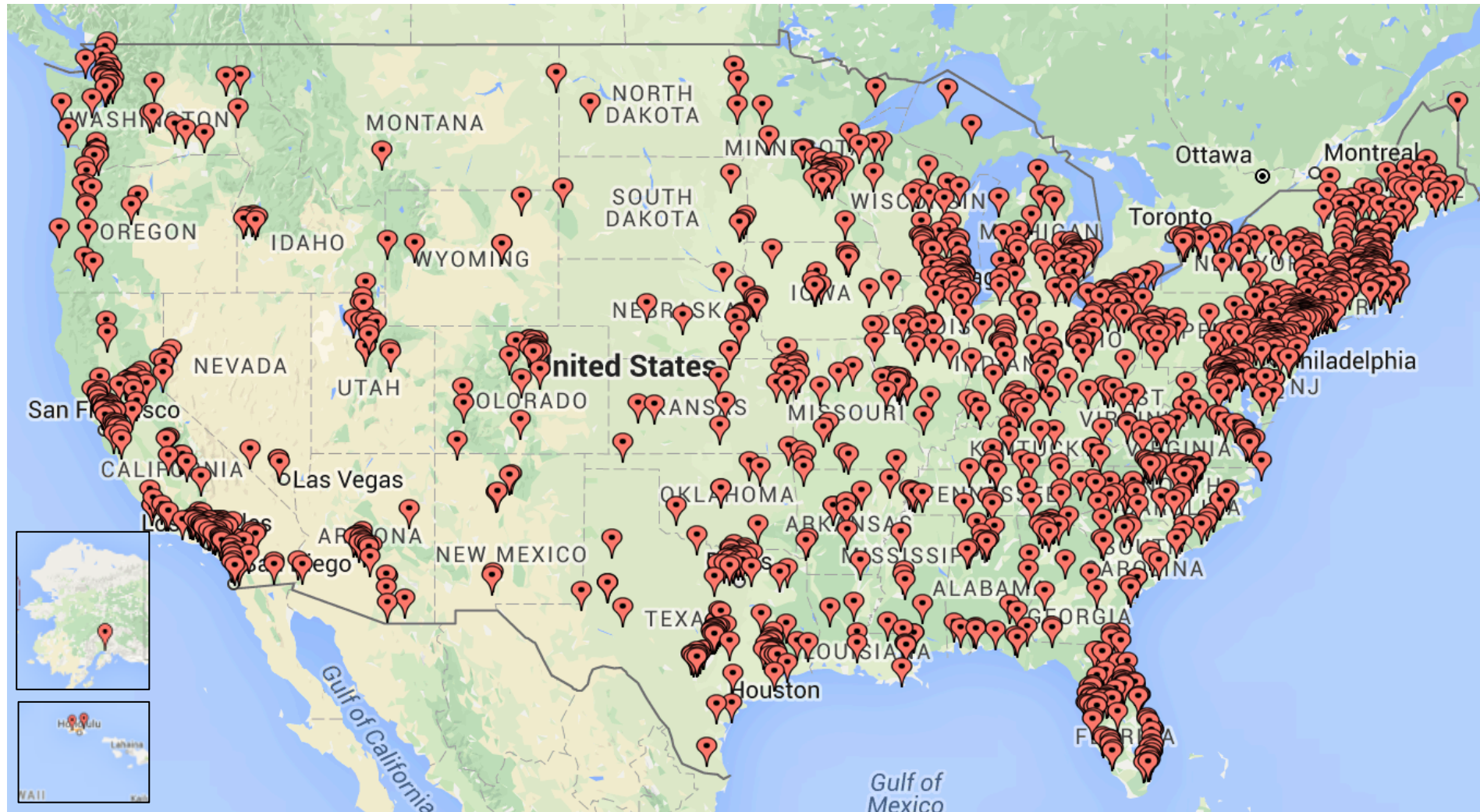
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Email Address

---

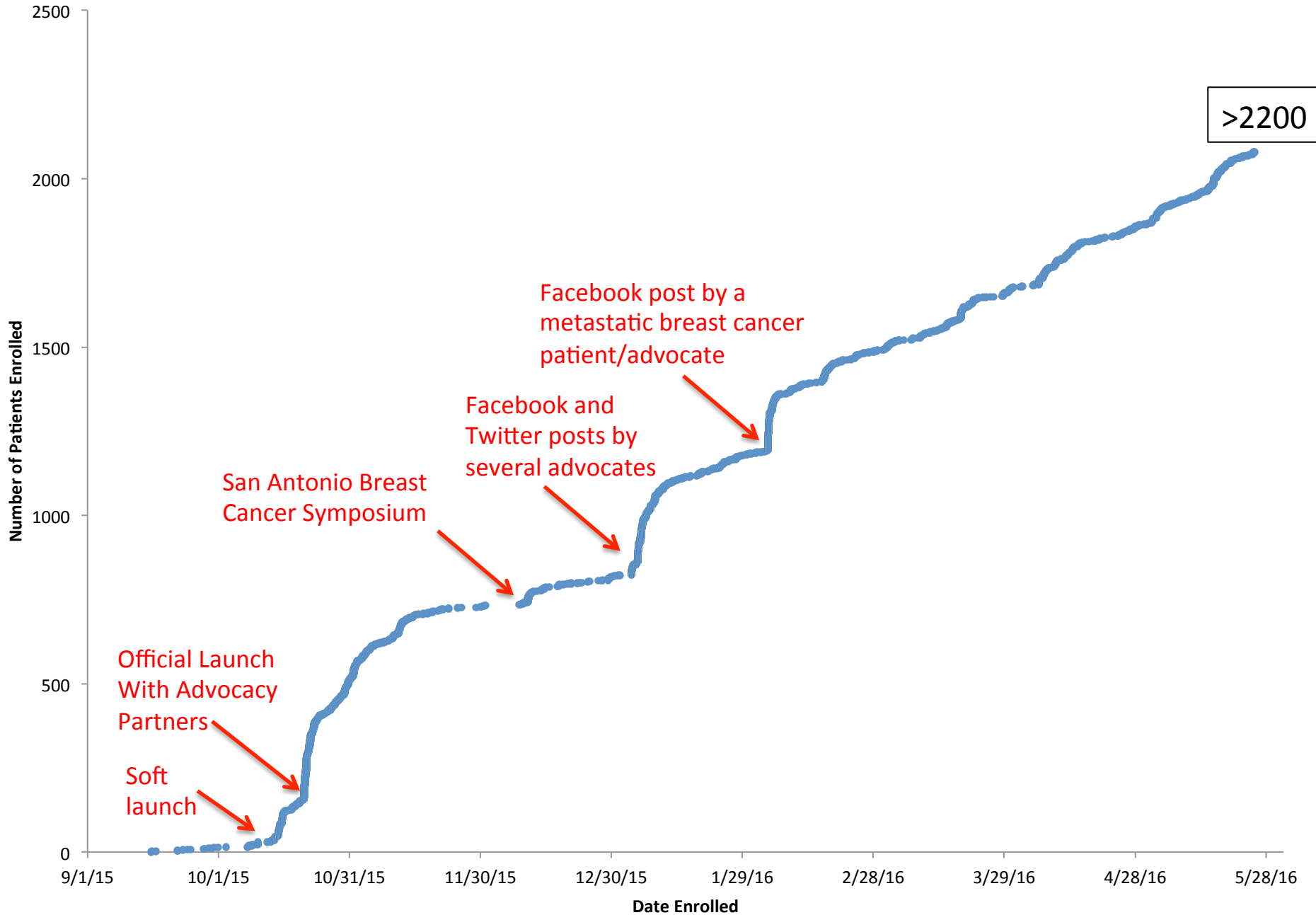
# *The Metastatic Breast Cancer Project*

## *MBCproject.org*



*Over 2200 women and men with metastatic breast cancer from all 50 states have joined the MBCproject in the 7 months since our launch in October 2015*

# Metastatic Breast Cancer Project: Cumulative Enrollment



# *Patient-Reported Data*

**95%** submitted the 16-question survey

**98%** response rate to each question (all are optional)

**6 minutes** to complete

***Detailed patient reported data from >2000 patients***

## *Disease Characteristics:*

- *Dates of initial diagnosis*
- *Date of diagnosis with metastatic disease*
- *ER+, PR+, and HER2+ status*

## *Treatment Response:*

- *Questions about extraordinary responses*
- *Free text about treatments*
- *Date of most recent biopsy*

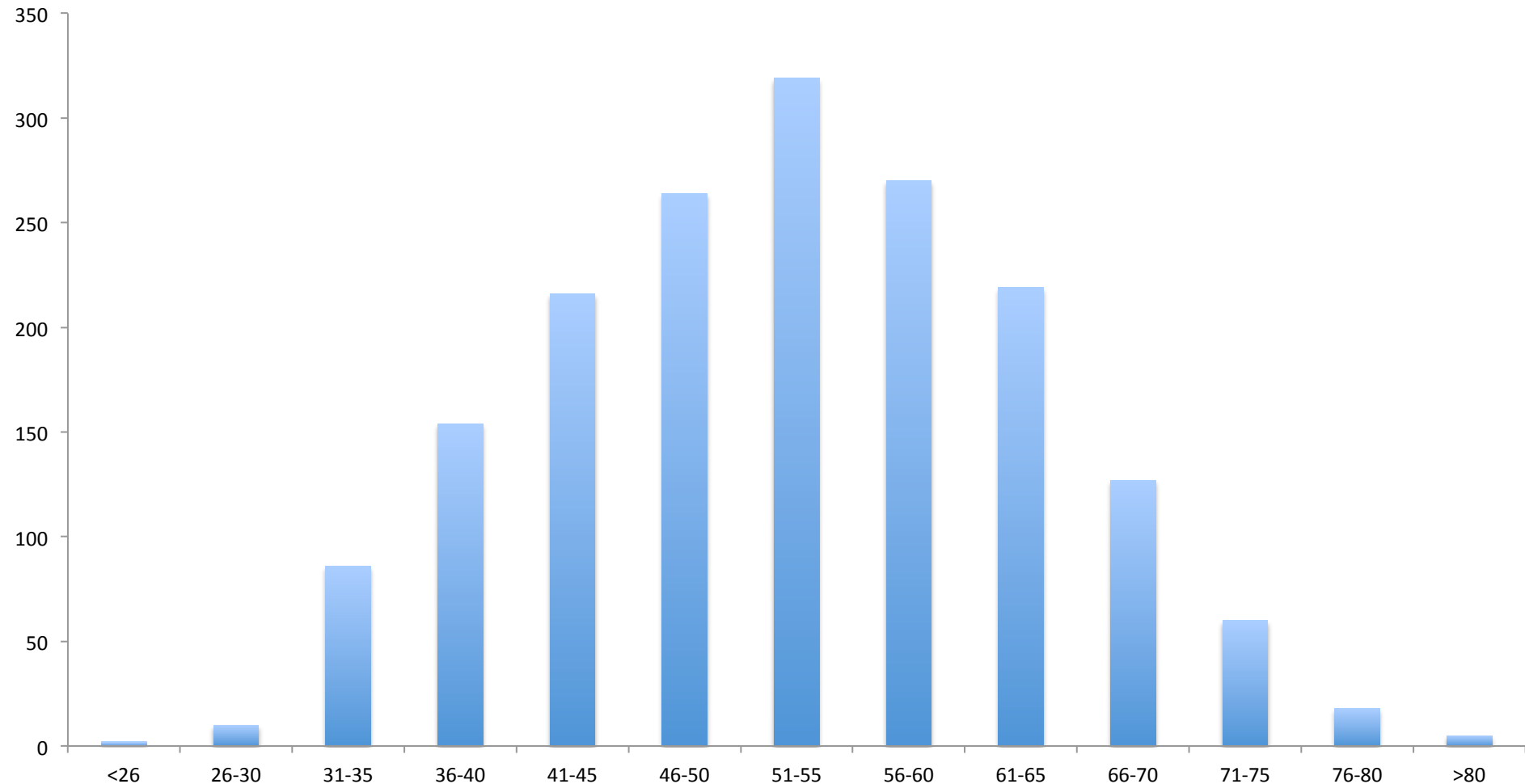
## *Demographics:*

- *Year of birth*
- *Race and ethnicity*

*Free text about anything additional*

The average current age of respondents is 53 years  
(range 24-91)

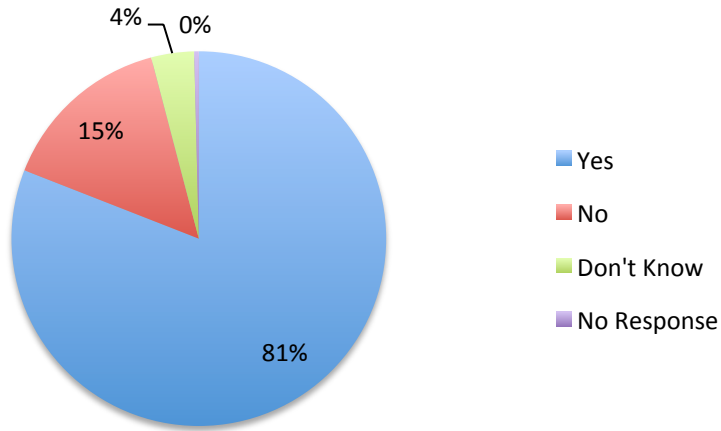
### Current Age of Respondents



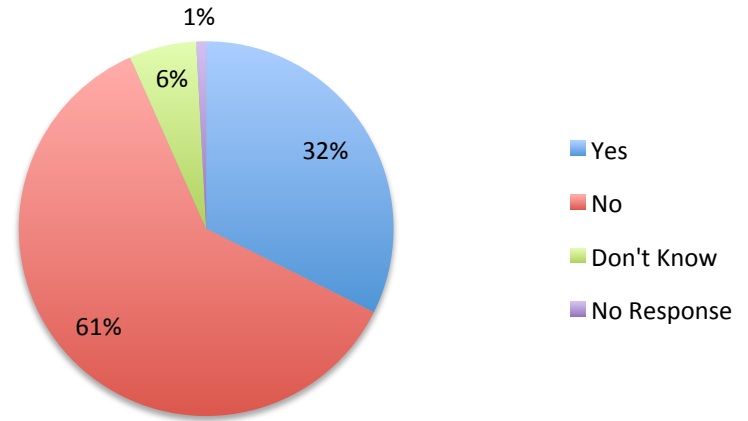
As of April 2016, Based on 1750 responses (99.5% response rate)

Respondents were asked if at any time they had ER+/PR+, HER2+, triple negative, and/or inflammatory breast cancer.

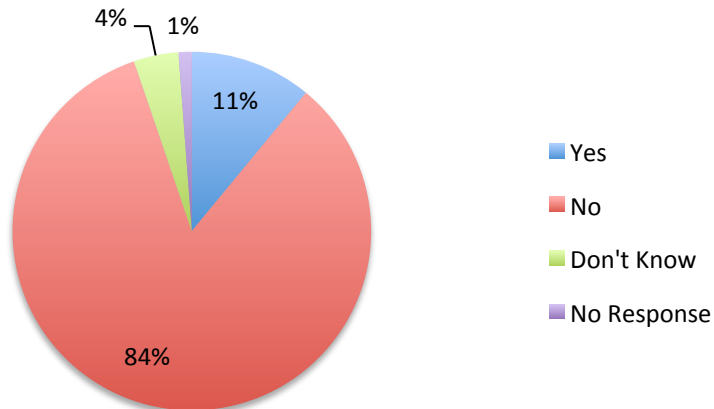
### Hormone Receptor Positive?



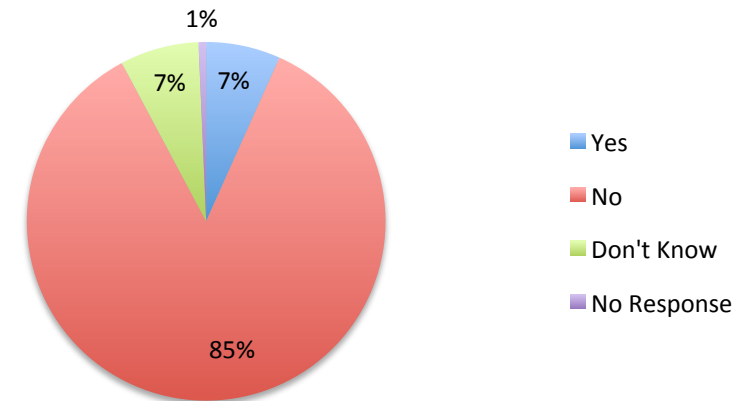
### HER2 Positive?



### Triple Negative?



### Inflammatory?



# *Metastatic Breast Cancer Project: Approach*

## **ONLINE CONSENT**

*Electronic consent form asks patients for permission to obtain a saliva sample, tumor tissue and medical records.*

## **SALIVA COLLECTION**

*Consenting patients are sent a saliva kit and asked to mail back their saliva sample*

## **MEDICAL HISTORY**

*Medical records are obtained by the MBCproject team and centrally reviewed and abstracted*

## **TISSUE COLLECTION**

*Tumor blocks requested from local pathology departments by the MBCproject team*

## **GENOMIC ANALYSIS**

*Molecular characterization of tumor and saliva includes whole exome sequencing (WES) and transcriptome sequencing (RNASeq)*

## **INTERPRETATION**

*Genomic data is interpreted in the context of clinical data (extraordinary response, de novo disease, age, etc) at the individual level and in aggregate across similar patients*

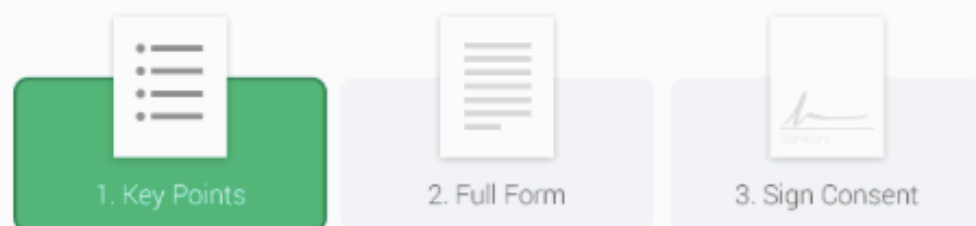
## **REPORTING / DATA SHARING**

*De-identified genomic & clinical data shared widely with research community. Overall progress, findings, and discoveries regularly communicated directly to patients*

# Research Consent Form

## “COUNT ME IN: The Metastatic Breast Cancer Project”

is patient-driven movement that empowers patients to directly transform research and treatment of disease by sharing their genomic data.



---

### 1. What is the purpose of this study?

We want to understand cancer better so that we can develop more effective therapies. By partnering directly with patients, we are able to study many more aspects of cancer than would otherwise be possible.

### 2. What will I have to do if I agree to participate in this study?

Participation requires little effort. You would answer some questions about your cancer and medical care, send a saliva sample to us in a pre-stamped package that



## Research Consent Form

**“COUNT ME IN: The Metastatic Breast Cancer Project”**

is patient-driven movement that empowers patients to directly transform research and treatment of disease by sharing their

*All 2000+ registrants have been sent a link for the online consent. To date, over 1200 patients have signed (>50% consent rate)*

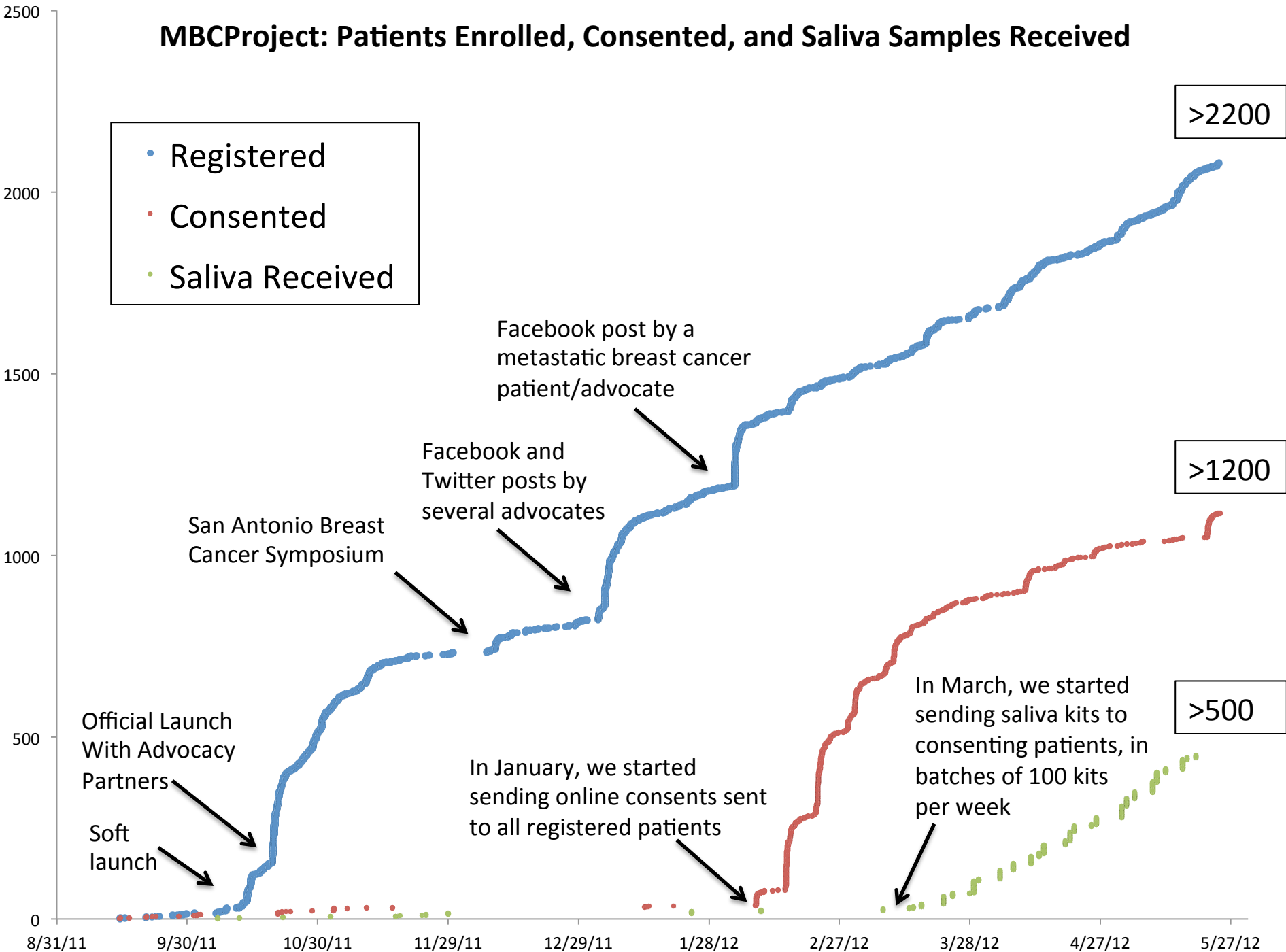
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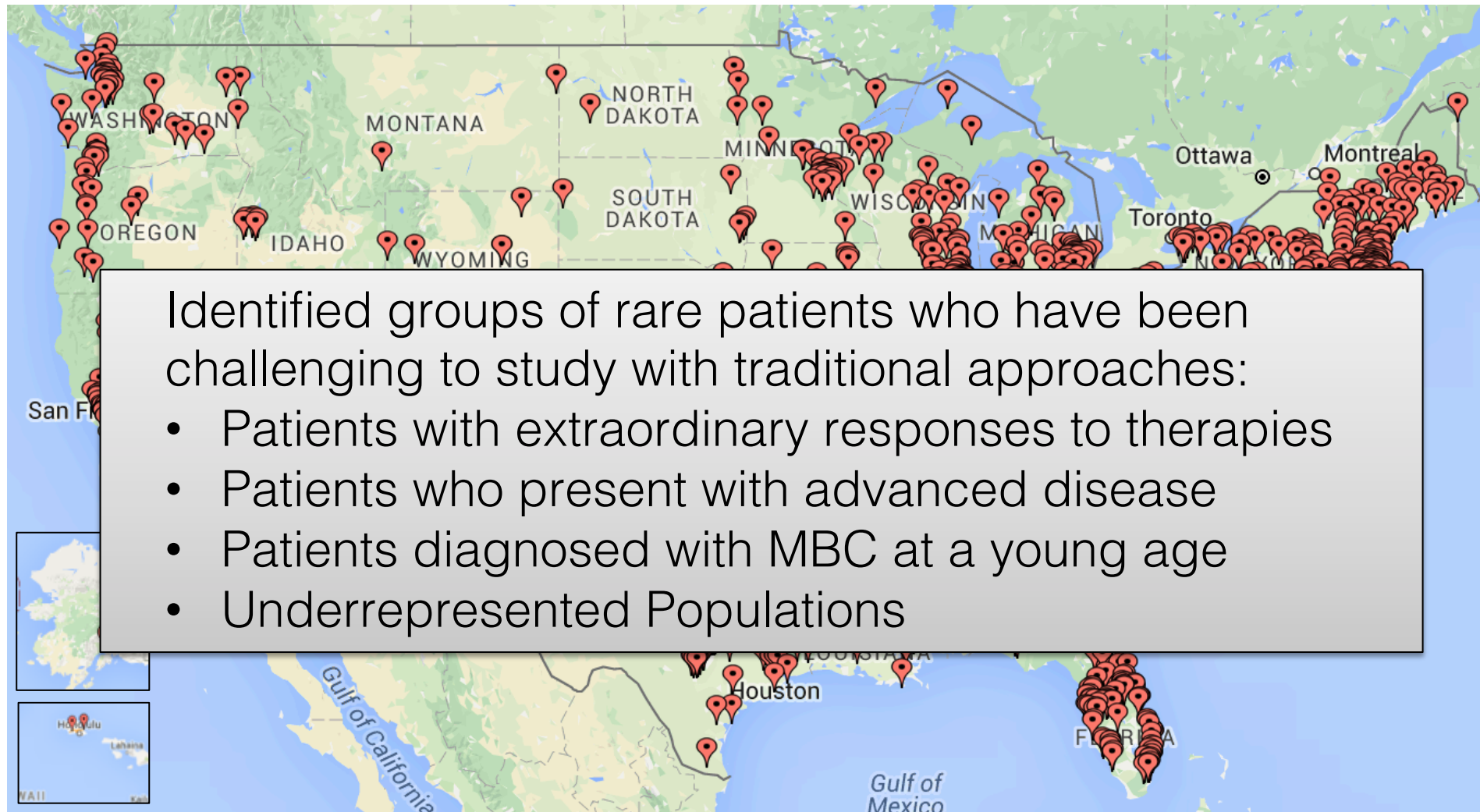
2. What will I have to do if I agree to participate in this study?

Participation requires little effort. You would answer some questions about your cancer and medical care, send a saliva sample to us in a pre-stamped package that

# MBCProject: Patients Enrolled, Consented, and Saliva Samples Received



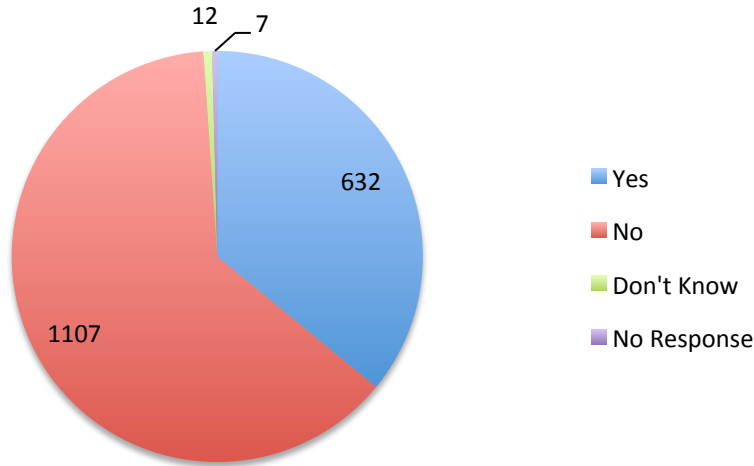
# *The Metastatic Breast Cancer Project Patient Groups to Study*



*Each of these groups is readily identifiable based on the screening questions on the [MBCProject.org](http://MBCProject.org) website*

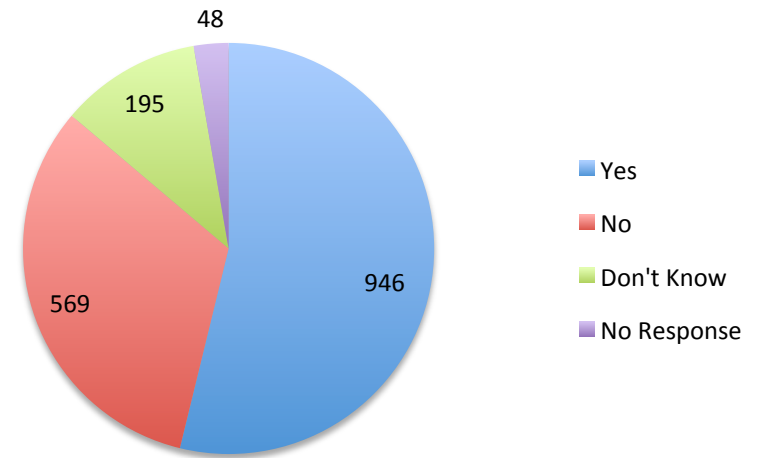
# Studying patients with Exceptional Responses

Any therapy >2yrs?



*99% of those who responded "Yes" provided the drug names*

Any Extraordinary Response?



*98% of those who responded "Yes" provided drug names and additional "free text" details*

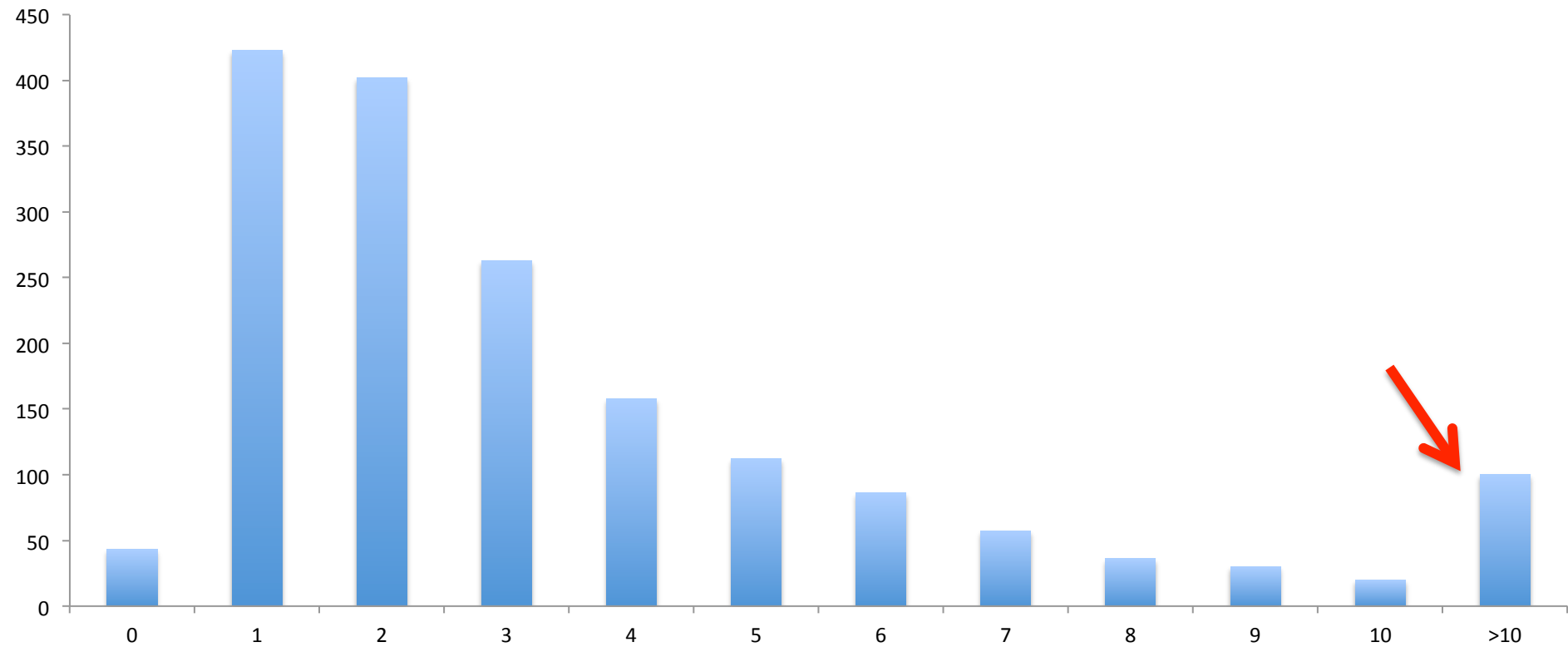
*Hundreds of patients with self-reported long-term and/or exceptional responses identified. For example:*

- Capecitabine (Xeloda): 117*
- Platinums (Carboplatin, Cisplatin) and PARP inhibitors: 63*
- Everolimus: 36*

# *Studying patients with Exceptional Responses*

100 respondents report living with metastatic disease for more than 10 years.

**Years Since Diagnosis of Metastasis**

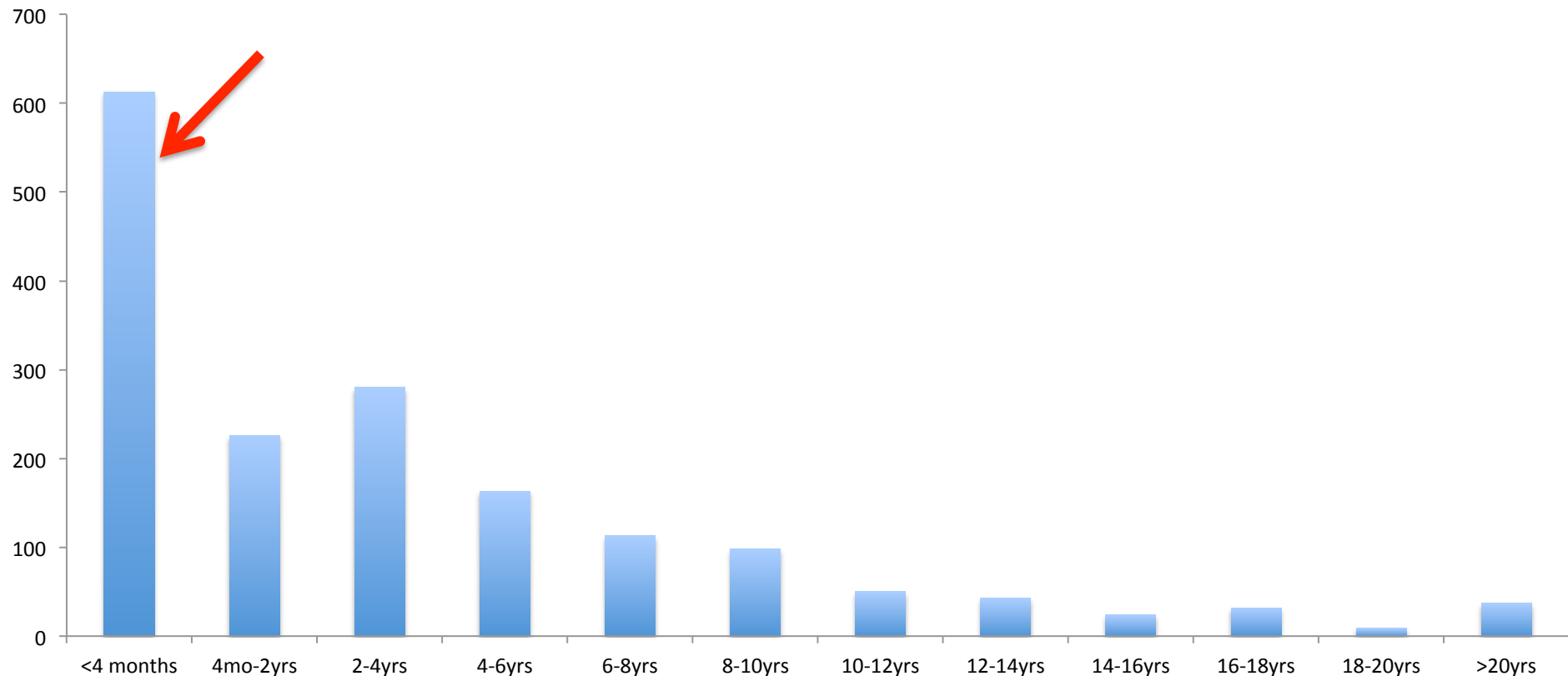


As of April 2016, Based on 1730 responses (98.4% response rate)

# *Studying Patients with De Novo MBC*

613 respondents (36%) report that they were diagnosed with metastatic disease less than 4 months after their initial diagnosis with breast cancer (representing Stage 4 or “de novo” metastatic disease)

**Years Between Initial Diagnosis and Metastatic Disease**



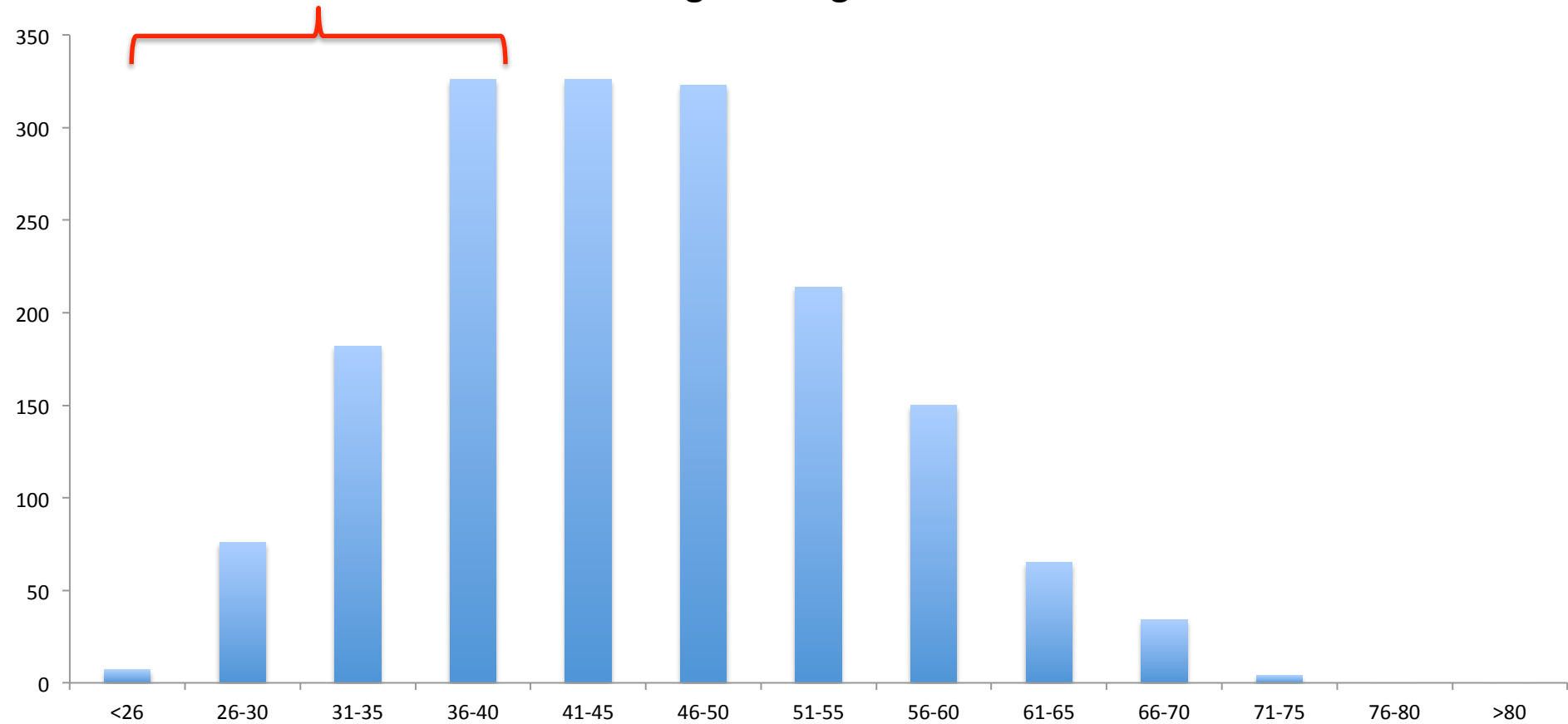
As of April 2016, based on 1688 responses (96% response rate)

# Studying Young Patients with MBC

The average age of respondents when they were initially diagnosed with breast cancer is 45 yrs (range 23-74 yrs)

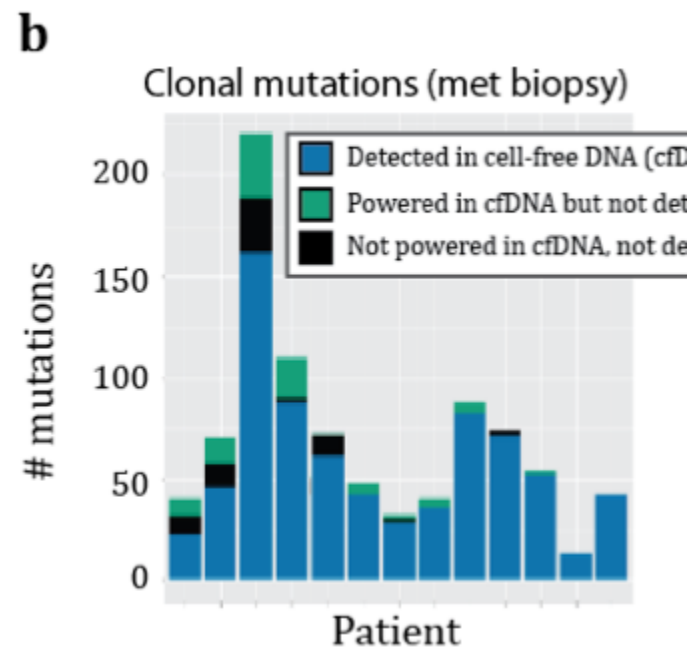
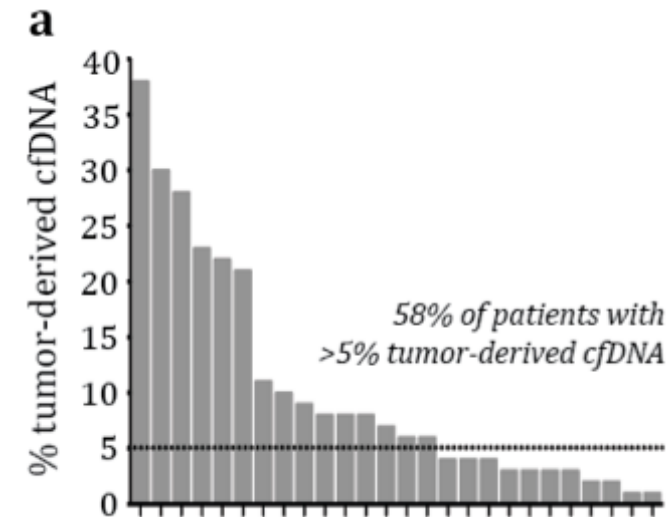
591 (35%) diagnosed before age 40

## Age at Diagnosis



As of April 2016, based on 1707 responses (97% response rate)

# *New MBCProject Initiative: Studying Resistance with Blood Biopsies*



## In Progress:

- IRB Approval
- Blood Draw Kits
- Logistics of blood draw

## Plan:

- Pilot 1 (Summer 2016):
  - Test logistics with ~10-20 patients
- Pilot 2 (Fall-Winter 2016):
  - Send 500 kits
  - Collect 300 blood samples
  - Whole exome sequencing from 100+ samples w sufficient DNA



# A Collaboration with Patients and Advocates



More collaborations  
in the works

*Patients and advocates have been involved from day 1 in conceiving, designing, implementing, testing, and refining this project.*

# *How do we interact with participants?*

- Regular updates through the website and email about status of the project, progress to date, and any discoveries that have been made
- Educational information and videos about metastatic breast cancer research, approaches we are using, and explanations of new discoveries
- Notifications when we are starting to study new groups of patients with metastatic breast cancer
- Feedback about questions and suggestions we receive through the surveys and direct emails – *we're committed to listening to and learning from our patient-partners*

*We are not at present returning individual genomic results  
- but this being worked on*

# #MBCproject on Facebook and Twitter



## The Numbers

2,431,516 Impressions

576 Tweets











60 Participants

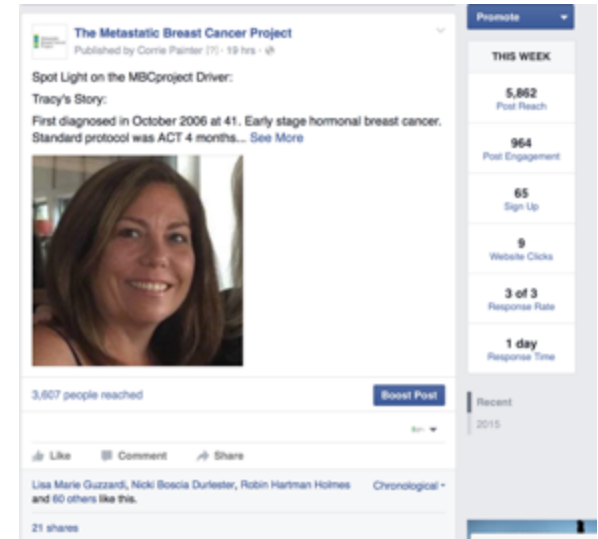
384 Avg Tweets/Hour

10 Avg Tweets/Participant

## The #BCSM Influencers

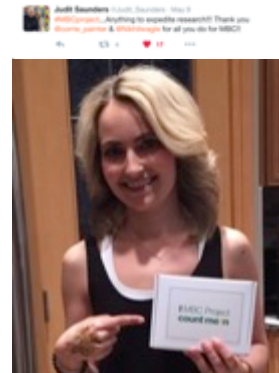
### Top 10 by Mentions

-  @nikhilwagle 191
-  @corriePainter 120
-  @chemobrainfog 55
-  @stales 53
-  @mbc\_project 53
-  @a4breastcancer 19
-  @jamienholloway 19
-  @dr\_dana 17
-  @nickdawson 16
-  @victoryoverbc 16



#BCSM twitter chat: > 2 million impressions; 1 Facebook post: 300 enrollments in 12 hours

# Participants as drivers, not samples



# Online to real life engagement

*The San Antonio Breast Cancer Symposium 2015*



 **BC Consortium** @BC\_Consortium · Dec 10  
Researchers & activists negotiate the future  
of metastatic BC research @corriePainter  
@Nikhilwagle @metup #SABCS15

*MBCproject patient panel and lunch 2016*



One of the most important days of my  
life. Thank you MBC Project.~ Jill  
Haagenson

# Online to real life engagement



# *What the MBCproject means to patients*

“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

“The boy says, ‘Our family could be the key to unlocking a cure for cancer.’”

—Seattle, WA

“I have two daughters and my prayer is they never have to go through what they’ve watched me endure!”

—Clarkston, MI

“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

# *Ideas for Outreach / Expansion*

- 1) Social Media
- 2) Advocacy Groups
- 3) Traditional print media
- 4) Patient Conferences / Meetings
- 5) Patient “Amplifiers” / Community Leaders
- 6) Community Oncologists
- 7) Television
- 8) Advertising

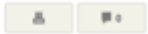
*Major goal for 2016 to increase racial/ethnic diversity in MBCproject participants*



# MBCproject in the News

STAT | KENDALL SQUARED

## Breast cancer patients encouraged to share genetic data in new project



By Andrew Joseph | STAT | OCTOBER 28, 2015

STAT

Cancer patient

FAST COMPANY SUBSCRIBE

6 MINUTE READ | TECHNOLOGY

## #Cancer: Researchers Are Conducting Huge Studies Using Twitter, Facebook

Instead of relying on the small number of patients who go to research hospitals, doctors are recruiting huge numbers of participants online.

DIA ▼ 17773.64 -0.32% U.S. 10 Yr ▼ -3/32 Yield 1.834% Euro ▲ 1.1449 0.85%

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## Researchers Take Aim at Metastatic Breast Cancer

Activists say the deadliest form of breast cancer has gotten short shrift until now

By AMY WESTERVELT  
February 15, 2016



## Facebook, Twitter Helping Boston Institutes Enroll Metastatic Breast Cancer Patients Across US

Apr 27, 2016 | Turna Ray

NEW YORK  
using social m  
around the cou

Within the Me  
online network

## Broad Institute joins White House Precision Medicine Summit with researchers, initiatives to drive health research forward

Paul Goldsmith, February 25th, 2016

The New York Times Magazine

THE HEALTH ISSUE  
THE NEW ANATOMY OF CANCER

01 DOCTOR WITHOUT BORDERS 02

## LEARNING FROM THE LAZARUS EFFECT

Revolutionizing Biomedicine

DONOR IMPACT

## POWER TO THE PATIENTS

Alison Anderson thought she had beaten cancer. Diagnosed with early-



# Acknowledgements



More collaborations  
in the works

*The many advocates and patients who have worked with us over the past year to develop and implement this project*

*All of the patients with metastatic breast cancer who are participating and have contributed their voice to this project*

# *Acknowledgements*

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- Jon Bistline
- Jared Cosulich
- Playground
- Carol Lowenstein
- Kristen Anderka
- Samira Bahl
- Sheila Fisher
- Stacey Gabriel
- Levi Garraway
- Nelly Oliver
- Karla Helvie
- Kate Mulherin
- Bina Venkataraman
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- David Siedzik
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- Shawn Johnson
- Qaren Quartey
- Lee McGuire
- Lisa Girard
- Clare Midgley
- Emily Lipscomb
- Andrea Saltzman
- Stacey Donneley
- Jenny Rood
- Jenn Chen
- Justine Levin-Allerhand
- Elizbeth Frank
- DFCI Advocates
- Eric Winer
- Eric Lander
- Todd Golub

**SUSAN F. SMITH**  
**CENTER FOR**  
**WOMEN'S CANCERS**

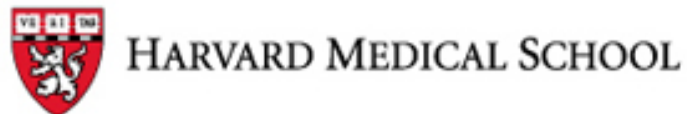
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DFCI / BWH / Broad  
**Center for Cancer**  
**Precision Medicine**

***Thank you!***



DANA-FARBER/BRIGHAM AND WOMEN'S



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*@mbc\_project*