

20  
23



# Translational Science

April 18-20, 2023 • Washington, DC • Washington Hilton

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# From Bench to Bedside to Curbside and Back: Addressing Rare Cancer Health Disparities

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## Translational Science

April 18, 2023  
Washington DC

# Session Learning Objectives

**1**

Delineate unique challenges related to diagnosis, treatment, care coordination, and clinical trial recruitment for rare cancer and associated health disparities

**2**

Gain strategies for effective longitudinal community coalition building to engage with diverse stakeholders (e.g., industry, clinicians, patient advocates, foundation and academia) to address cancer health disparities.

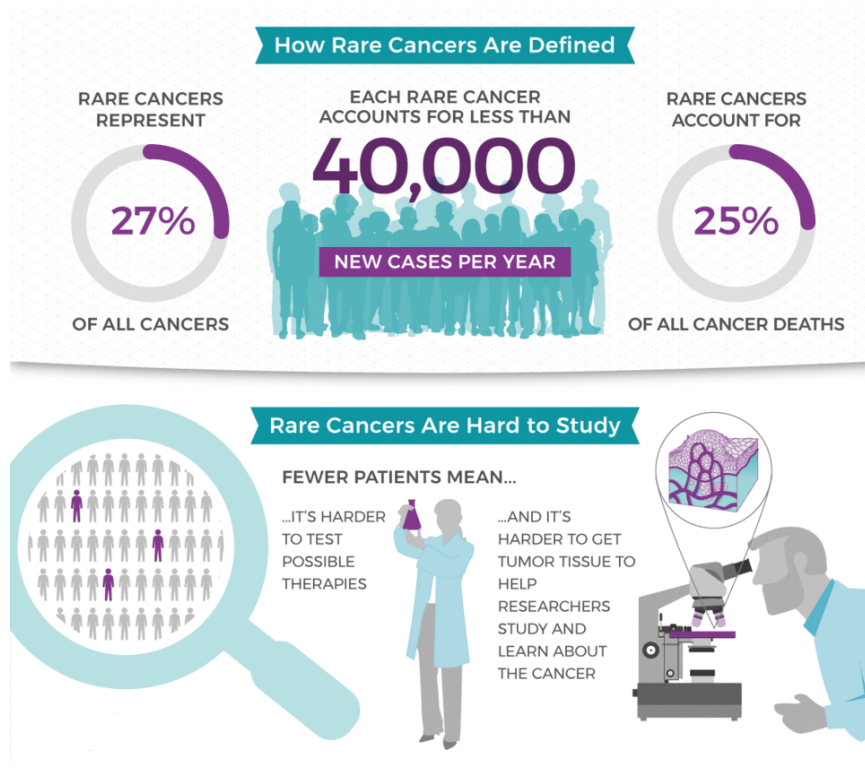
**3**

Gain knowledge of mixed methods and community-engagement principles to develop survey instruments for dissemination.

**Translational  
Science**

# Awareness of Rare Cancers (ARC)

- National Cancer Institute definition: cancers that occurs in fewer than 15 out of 100,000 people each year.





# Rare Subtypes within Common Cancers

- There are around 200 forms of rare cancers
- Diagnostic criteria and standards of care continue similar to common cancers in that organ/type.
- Breast cancer, the most common cancer in women worldwide.
- Recent improvements in treatment options have considerably increased breast cancer survival outcomes.
- However, rare subtypes like inflammatory breast cancer (IBC) representing only 1-6% of all breast cancer cases constitutes **10% of all breast cancer deaths** globally.

## American Cancer Society Reports Breast Cancer Is Now the Leading Cause of Cancer Mortality in Black Women

By The ASCO Post Staff  
March 10, 2022

Breast cancer has surpassed lung cancer as the leading cause of cancer mortality among Black women as of 2019. This news is one of the key findings in *Cancer Statistics for African American/Black People 2022*, published recently in *CA: A Cancer Journal for Clinicians* and its consumer-friendly companion, *Cancer Facts & Figures for African American/Black People*.

Global trends show an alarming race-related mortality gap attributed to:

Aggressive and rare breast cancer subtypes exhibit

- higher incidence
- treatment resistance
- early age of onset

*Huo et al 2017*  
*Fouad et al 2018*  
*Heer et al 2020*

*Esnaola et al 2014 Surg Oncol Clin N Am*  
*Patel et al 2020 J Clin Oncol*  
*Zavala et al 2021 British J Cancer*

# Challenges in Translating For Race Cancer Health Disparities

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### 1. Inadequate accrual of Black patients into practice changing clinical trials

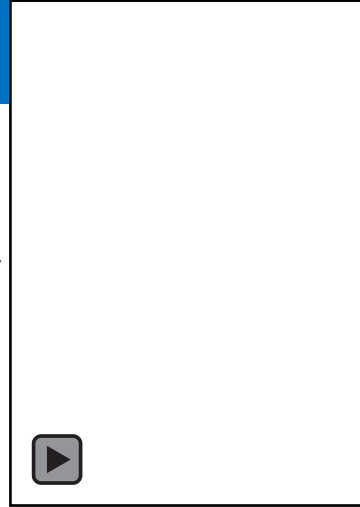
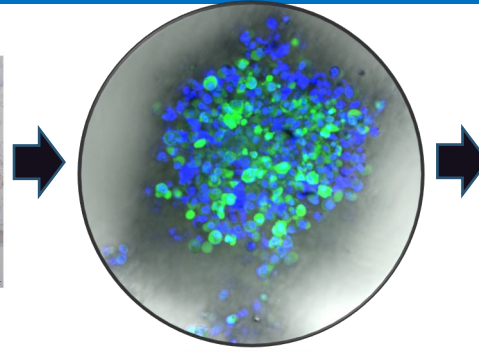
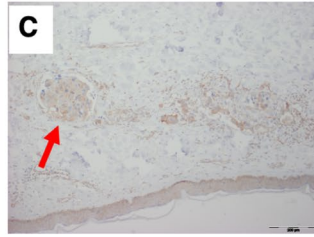
- (KEYNOTE 522) established a higher pCR (65%) with pembrolizumab (P)+neoadjuvant chemotherapy (NACT) in early stage TNBC; however, most participants were W (64%) or Asian (20%) and only 53/1174 patients

### 2. Black patient tissue are under-represented in biospecimen collections

### 3. Lack of Targeted Drug Development based on Biological mechanisms underlying Disparity in therapeutic outcomes.

- No New therapies that address disparity related clinical outcomes of breast cancer patients

# Patient-derived (Bedside to Bench Models)



- No solid tumors like other breast cancers
- Diffuse tumor cell clusters (tumor emboli) collectively migrate and invade the lymphatics
- Disparities in patients- some develop resistance and have poor survival – why (Biological Mechanisms and Beyond)?



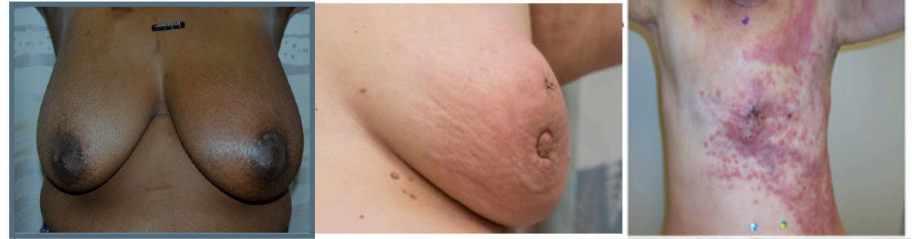
# Challenge: Awareness, Misdiagnosis

## Medical illustrations and terminology

IBC typically based on lighter skinned patients (pink or red breast)

## Access (Urban Rural Divide):

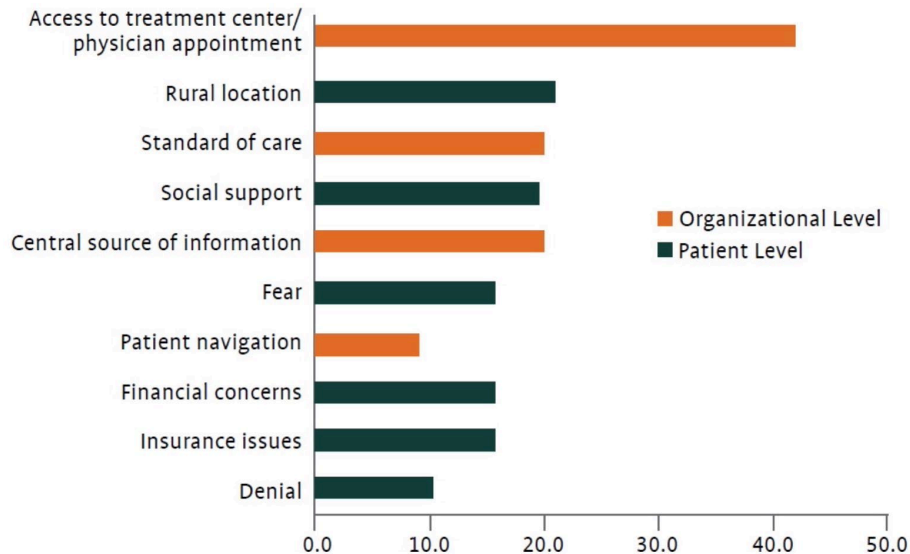
Imaging tests are needed for a timely referral and treatment



**Figure 1.** Representative images of de-identified AA and White patients with IBC- primary (Left, middle); recurrence (Right). Unlike other locally advanced breast cancers, there is lack of a solid tumor mass. It looks like a chest wall inflammation with painful, enlarged breast. The presence of diffuse tumor cell clusters, called **tumor emboli**, in the breast and dermal lymphatics is a classic hallmark and evidence of an efficient path to metastatic dissemination. *Krishnamurthy MDA pathology; Arora, 2017*

# Top barriers identified in a community engaged session

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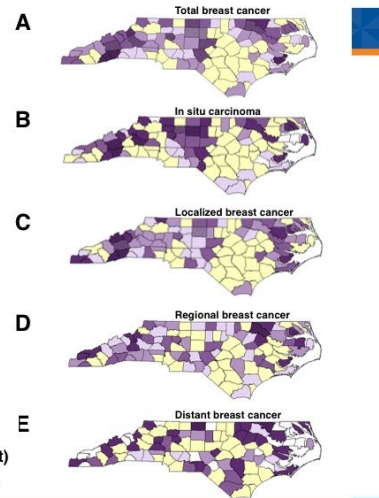
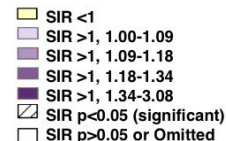


- Challenge North Carolina
  - 100 counties
  - Rural:Urban divide
  - Socioeconomic
  - Racial diversity

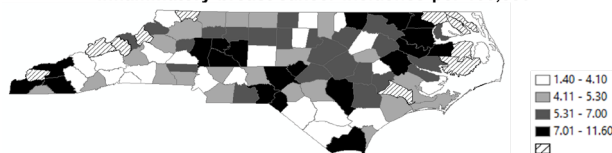
- Standardized Incidence Ratios by County



Gearhart et al., CEPB 2020



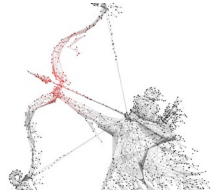
Inflammatory breast cancer incidence per 100,000



# ARC: Advocacy

The story of my diagnoses and how this led to advocacy

Walking on quicksand



# May 2017

**Translational  
Science**

- I woke up with one breast, red hot and swollen.
- Four months and five doctors later, the only thing they all seemed to agree on was it “wasn’t cancer.”
- I went from being told that nothing was wrong to “We are sorry Mrs. Arnold, we missed it. You have Inflammatory Breast Cancer (IBC) and you only have a few months to live.
- Fast forward to a visit at MD Anderson’s Morgan Welch Clinic for Inflammatory Breast Cancer where they thought they could help me possibly live as long as 18 months.

\*\*\*Spoiler alert\*\*\* – I didn’t die. 😊 😊 😊



# Hey, I hear you live in Houston?

- Other newly diagnosed patients were finding me. Many messages started out this way:
  - “Hey, I hear you live in Houston?”
  - “Can we talk, I have never met another women with IBC?”



# Translational Science



# The Power of One



**Our stories only mattered  
to a point.**

**We needed to start a  
charity**

- We started by selecting a research project. The goal was \$30,000.
- We raised the funds in six weeks.
- We realized we could fill a gap, so we formed a charity. Now we have donated almost two million dollars to late stage breast cancer research.

# What I Don't Normally Get to Say

Can I share a fresh conversation?

- Since we are using Inflammatory breast cancer as a model for how to deal with rare cancers or how to address what is viewed as a disease that hit women of color or other minorities, more fatally, can we talk about what we need to do for access of care?
- In my naivety I always view lack of access of care, as not having insurance, (with a few other hurdles throw in) but I realize it is so much more. It can be truly “about your zip code” a quote from Ortis Brawley, past director of the American Cancer Society.



# Only Three Specialty Centers in the US!

- There are only 3 specialty center in the US for IBC.
- The first one opened in 2006 at MD Anderson.
- That was followed by Dana Farber and Duke.
- Even if a person has insurance and even “good” insurance, that does not mean they can be seen at one of these three centers.

# What Should Be Our Goal?

- Can we, advocates as well as medical institutions, lobby to allow for what is referred to in the insurance world as “reasonable allowance”? Meaning funds that would be spent locally could be unitized at specialty hospital?
- Such an allowance could be effective and possibility save a patient’s life, also saving funds in the long run by allowing patients to be free of care sooner and also bring education into the local community via a new relationship.
- Also remember that rare disease education is not commonly taught at yearly conferences, so this is also a win education-wise.

## But wait, there is more....Three simple tips to engage advocates

- Ask them to be a part of your research meetings.
- Invite them to serve on a committee to learn your team's work patterns and needs.
- Then after some trust is built...
  - Ask them to be an advocate on your grant.  
(and not the night before the submission. 😊 )

We want to help, so ask us!

# Advocacy & Fundraising Post-Pandemic

## It is harder? Yes & No

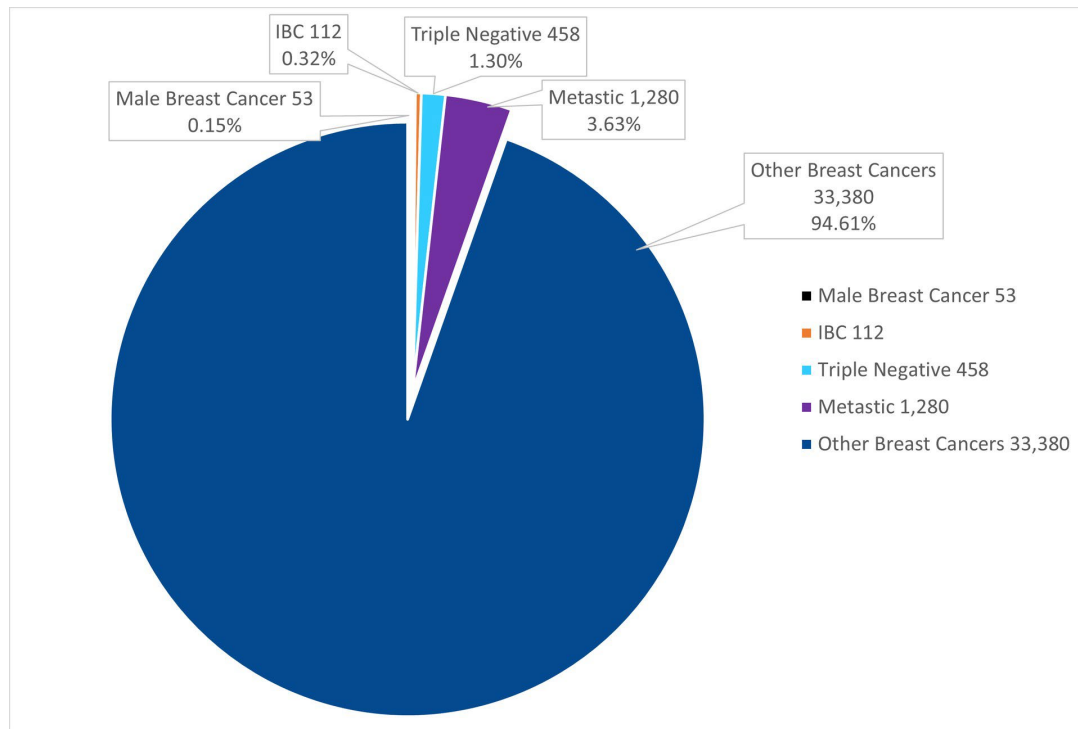
- Not to sound dramatic but “shattered” is the word that first comes to mind.
- As to advocacy, is alive but harder for a new advocate to get engaged. However, there has been a bonus in virtual meeting, allowing the freedom to attend without travel costs.
- As to self-advocating? It has also taken a hard blow. Many rare disease groups are on Facebook and in the last two years, the bots policing conversations have been on high alert, pulling innocent conversations, driving patients away from a place of what could house valuable knowledge shared by fellow patients.
- Dollar Wise? Just think about it, bonds have not done these poorly since 1929, the largest stock market crash in US history.



# Percentage of Breast Cancer Research Funding Regarding Rare Breast Cancers<sup>+</sup>

- “breast cancer” found 35,283 awarded grants
- “metastatic breast cancer” found 1,280 grants (3.6%)
- “triple negative breast cancer” found 458 grants (1.3%)
- “inflammatory breast cancer” found 112 grants (0.3%)
- “male breast cancer” found 53 grants (0.15%)

+The last 20 years of funding+



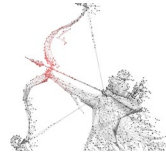
*So, can we move this conversation of advocacy and patient stories to the next level? We know the struggle is real, on either side of the “white coat.” My hope is that we can find a way to make an effective and lasting change.*

*Hope always,*

*Terry Arnold*

*Diagnosed triple negative IBC summer of 2007*

**ARC:**



**Community-Engaged  
Team Science Research Approach**

# What Is Community Engagement?

The Centers for Disease Control and Prevention (CDC) defines **community engagement** as:

- *“The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”*



# Common Language for Community Engagement

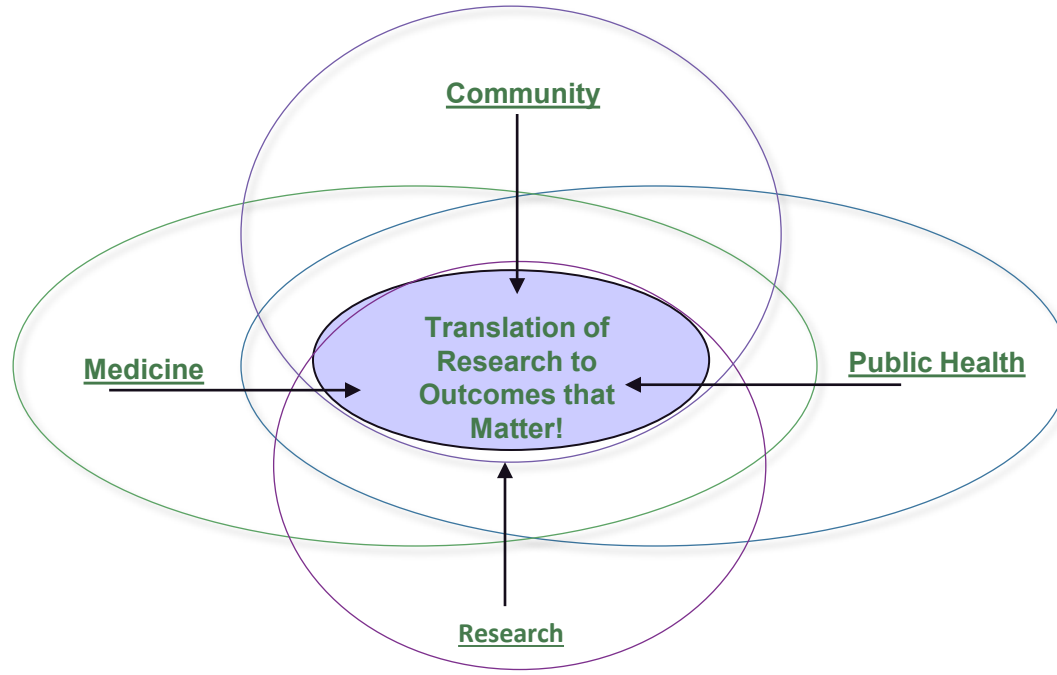
## What's Said:

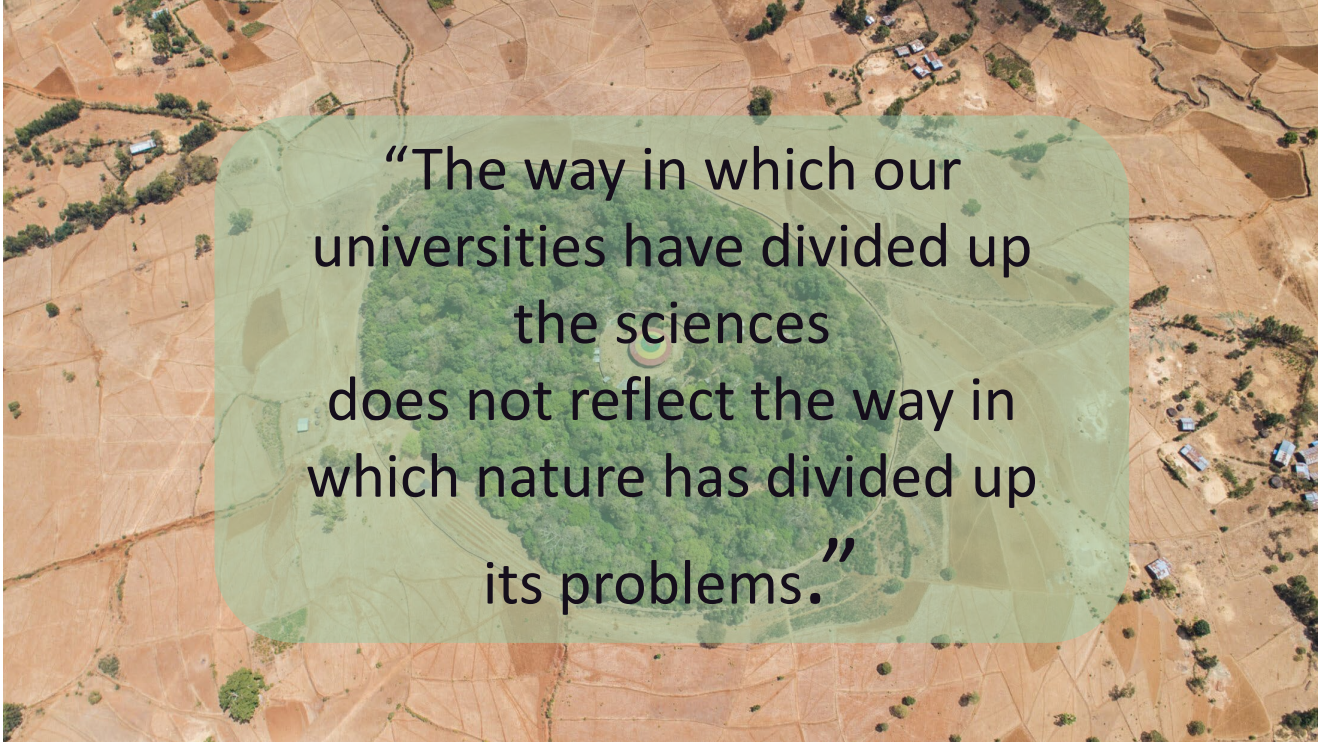


## What's Heard:









“The way in which our universities have divided up the sciences does not reflect the way in which nature has divided up its problems.”

# Why Team Science?

*We need a “smoothie” of disciplines for **many** complex problems*

Disciplinary



Multi-Disciplinary



Inter-Disciplinary



Trans-Disciplinary



- **Convergence** is the process needed to get the inextricable mixture needed to address complex problems.
- **Diverse teams** are necessary for this

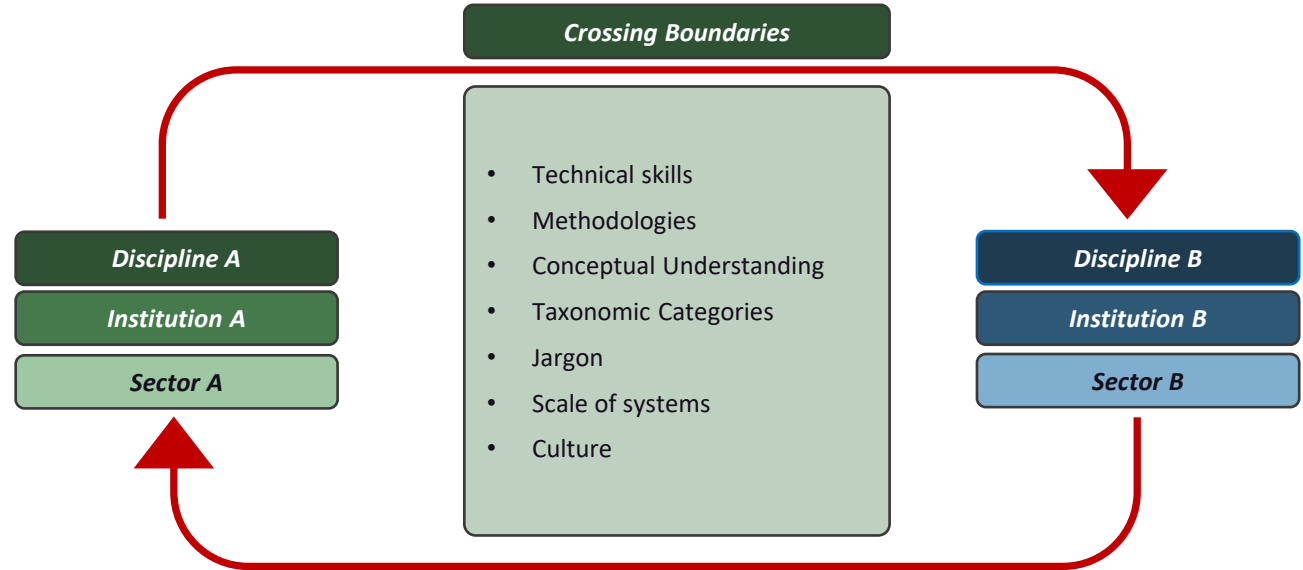
## Translational Science

Team Science is...

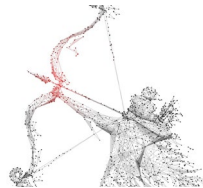
*Collaborative research that spans boundaries*

Science is often learned and practiced using methods, concepts and tools that are specific to that particular discipline (i.e. - Biology, Engineering, Sociology, etc.)

- adapted from Miles MacLeod



# **ARC Survey Study: Overview & Preliminary Findings**



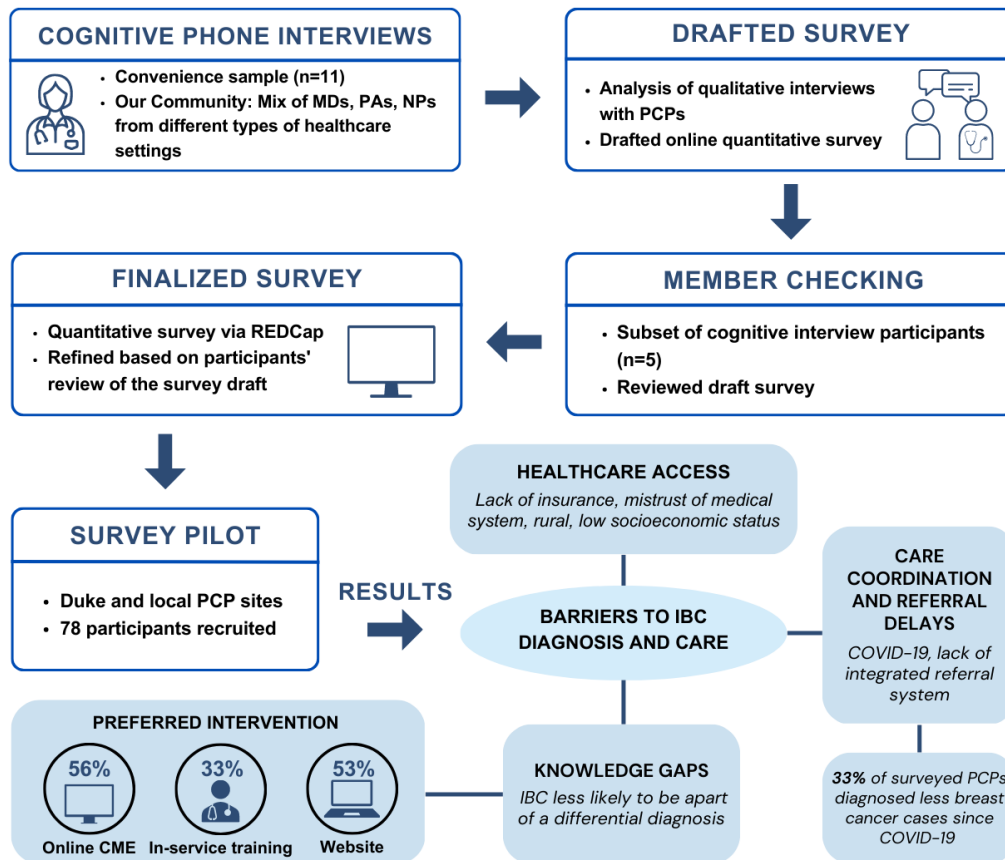
# ARC Survey Study

Formed with feedback from patient advocates, patients undergoing treatments, community stakeholders, cancer foundation leaders, and researchers, clinicians and staff from various national and international universities and medical centers

Target	Goal	Development	Stage 1	Stage 2	Stage 3
PCP	<ul style="list-style-type: none"> <li>Explore PCP experiences to identify barriers and facilitators of identification and treatment</li> <li>Assess knowledge and practices among PCP</li> </ul>	<ul style="list-style-type: none"> <li>Individual semi-structured/cognitive interviews</li> <li>Survey pilot</li> <li>Survey digitization</li> <li>Survey dissemination</li> </ul>	Interviews with Duke/local PCP + Survey local PCP	Survey PCPs statewide	National
Public	<ul style="list-style-type: none"> <li>Assess the current knowledge about RC in the general population, compared to other types of cancers</li> <li>Understand current screening options available and identify barriers</li> </ul>	<ul style="list-style-type: none"> <li>Individual semi-structured/cognitive interviews</li> <li>Survey pilot</li> <li>Survey digitization</li> <li>Survey dissemination</li> </ul>	Interviews with local participants	Interviews with rural participants + Survey participants Statewide	National
Patients	<ul style="list-style-type: none"> <li>To determine factors that impact timing and type of treatment among IBC patients</li> <li>Longitudinally assess how factors impacting delays in care vary over the course of breast cancer therapy</li> </ul>	<ul style="list-style-type: none"> <li>Individual semi-structure/cognitive interviews</li> <li>Survey pilot</li> <li>Survey digitization</li> <li>Survey dissemination</li> </ul>	Interview with Duke/local patients	Interviews with rural patients + Survey patients Statewide	National



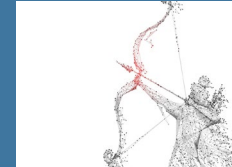
# PCP Survey Development and Launch



FINDING	RATIONALE	POTENTIAL INTERVENTION
Only 1/3 of PCPs self-reported to have suspected a patient with IBC	IBC is rare cancer not encountered by most PCPs	Algorithm for identifying and treating IBC
Majority of PCPs would refer a woman with suspected IBC for a mammogram/ ultrasound	Providers are not sure of type of imaging to order  Mammograms are not completely reliable for IBC	Give guidance on imaging for IBC
PCPs report below average confidence in identifying IBC	Knowledge gaps and a lack of experience in IBC diagnosis are barriers to care	Address knowledge and confidence gaps through CME
Over ½ of PCPs reported online CME modules are the preferred method to learn about IBC	Online continuing medical education modules (CME) can reduce knowledge gaps	Develop and disseminate IBC CME

# ARC: Coalition Building

Translational  
Science



- Basic, translational, and clinical scientists, physicians, and health care providers from Duke and the community
- Patient advocates and community stakeholders
- Investigators and staff from other research universities, industry and foundations
- The IBC International Consortium partners



Review

*Journal of Cancer*

2019; 10(15): 3344-3351. doi: 10.7150/jca.31176

## Perspectives on Inflammatory Breast Cancer (IBC) Research, Clinical Management and Community Engagement from the Duke IBC Consortium

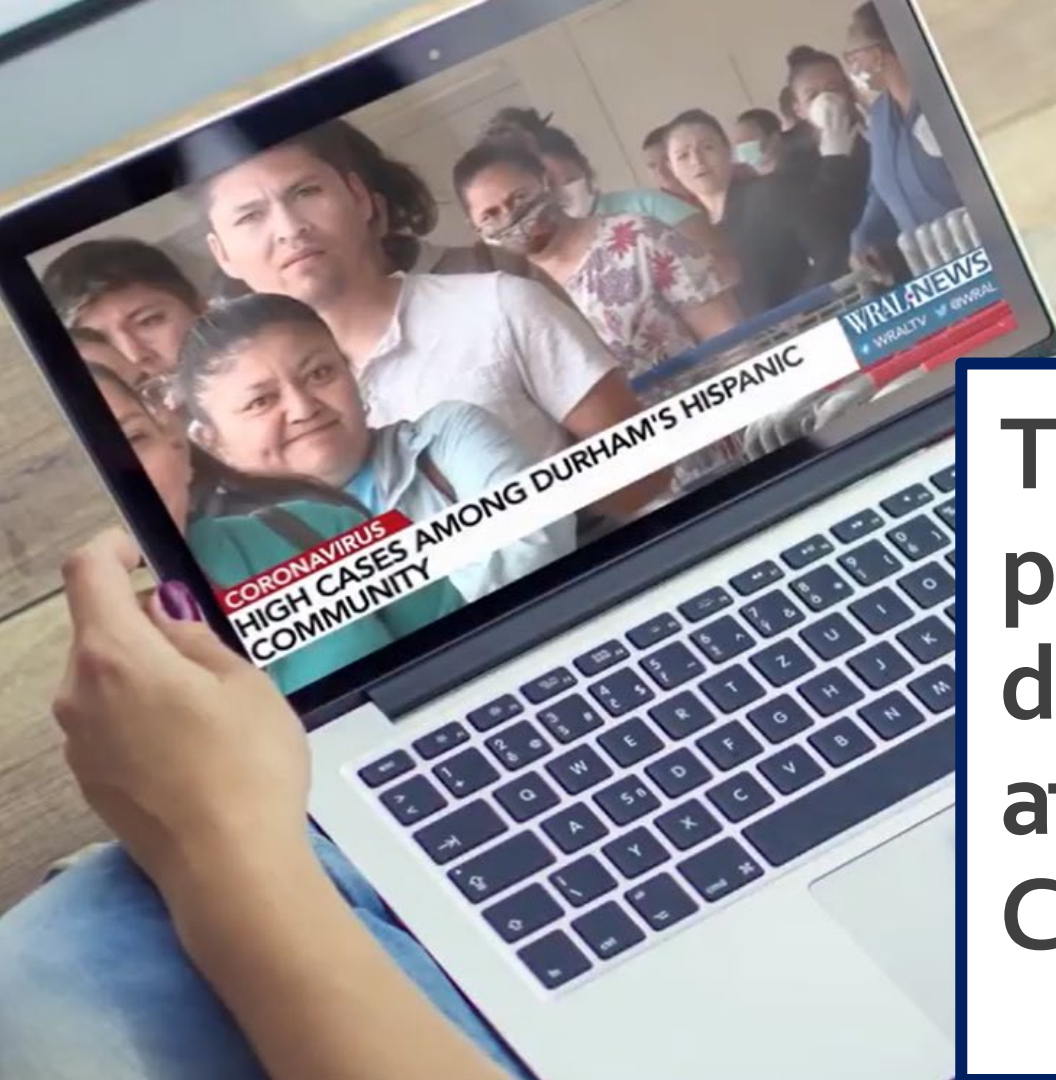
Gayathri R. Devi<sup>1,2,3,5</sup>, Holly Hough<sup>4</sup>, Nadine Barrett<sup>1</sup>, Massimo Cristofanilli<sup>5</sup>, Beth Overmoyer<sup>6</sup>, Neil Spector<sup>1,7</sup>, Naoto Ueno<sup>8</sup>, Wendy Woodward<sup>9</sup>, John Kirkpatrick<sup>1,10</sup>, Benjamin Vincent<sup>11</sup>, Kevin P. Williams<sup>12</sup>, Charlotte Finley<sup>1</sup>, Brandi Duff<sup>1</sup>, Valarie Worthy<sup>1</sup>, Shannon McCall<sup>1,3</sup>, Beth A. Hollister<sup>2</sup>, Greg Palmer<sup>1,10</sup>, Jeremy Force<sup>1,7</sup>, Kelly Westbrook<sup>1,7</sup>, Oluwadamilola Fayanju<sup>1,2</sup>, Gita Suneja<sup>1,10</sup>, Susan F. Dent<sup>1</sup>, E. Shelley Hwang<sup>1,2</sup>, Steven R. Patierno<sup>1,7</sup>, P. Kelly Marcom<sup>1,7</sup>

1. Duke Cancer Institute, Duke University;
2. Department of Surgery, Duke University;
3. Department of Pathology, Duke University;
4. Duke Office of Clinical Research, Duke University;
5. Department of Medicine, Northwestern University;
6. Department of Medical Oncology, Dana-Farber Cancer Institute;
7. Department of Medicine, Duke University;
8. Department of Breast Medical Oncology, University of Texas MD Anderson Cancer Center;
9. Department of Radiation Oncology, University of Texas MD Anderson Cancer Center;
10. Department of Radiation Oncology, Duke University;
11. Division of Hematology/Oncology, University of North Carolina at Chapel Hill;
12. Department of Pharmaceutical Sciences, North Carolina Central University.



**Salud y bienestar para nuestra comunidad Latina**  
Health and wellness for our Latina community

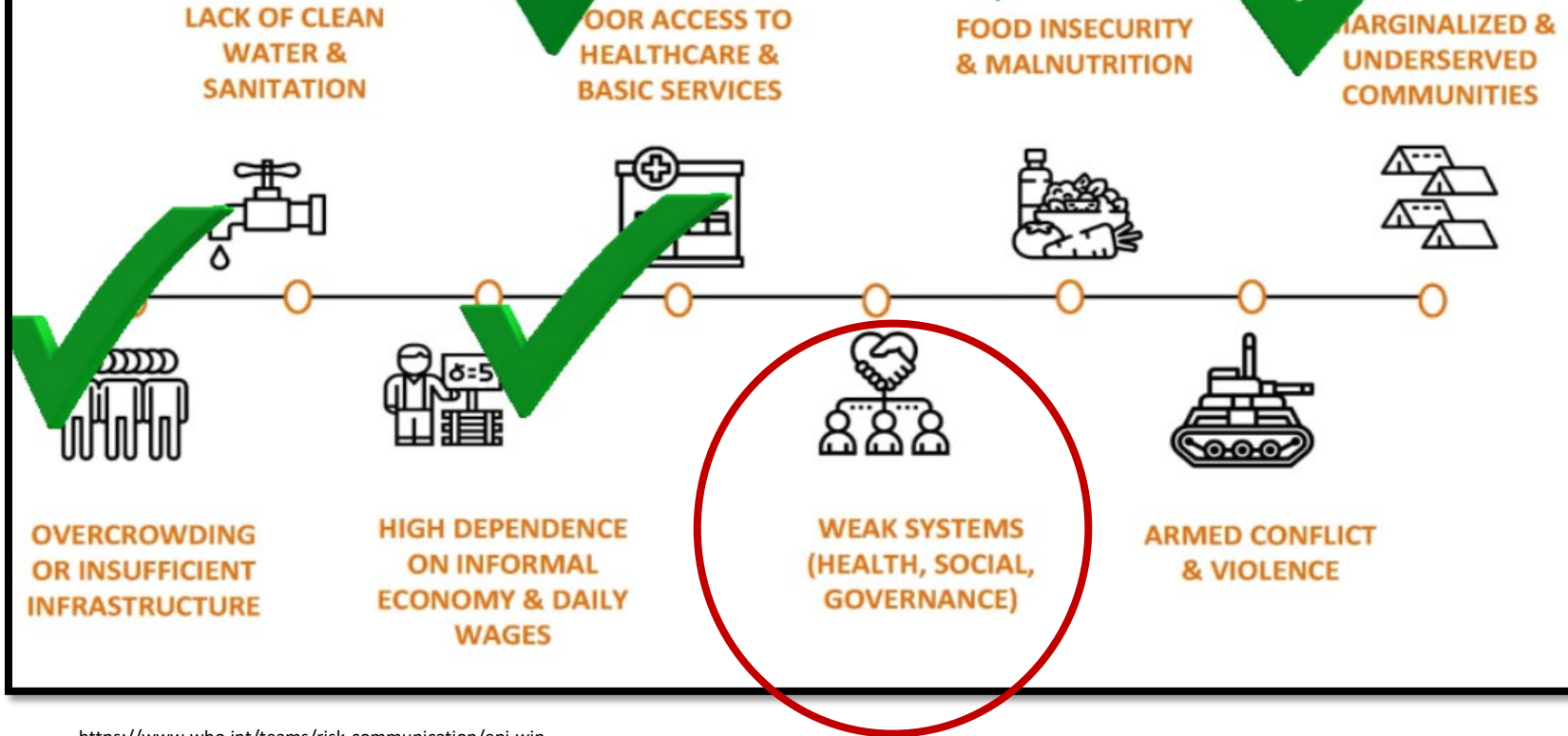
**Viviana Martinez-Bianchi, MD, FAAFP**  
**Duke Department of Family Medicine and Community Health**  
**Co-founder The Latinx Advocacy Team & Interdisciplinary Network for COVID-19**



**The COVID-19  
pandemic highlighted  
deep inequities  
affecting the Latina  
Community**



# Factors leading to increased vulnerability





LATIN-19 was born in March 2020, out of a **collective passion** to support the comunidad latina and amplify its voices



# Los Desaparecidos: Those who have disappeared

Yolanda Guzman, MD  
Senior Assistant Resident  
Duke Internal Medicine Residency Program



- Family fear that their loved ones will not be treated the same due to lack of insurance or legal citizenship
- Language barriers and interpreters were not called to bedside
- Patients thought of as delirious when they were responding in their language
- Patients thought of as unresponsive when they were not addressed in their language-tuning out
- Not identifying next of kin
- Personal biases
- Gaps in health literacy

Identify  
problems

## Take Action

- Collaboration between the MICU leadership and Latin-19 taskforce
  - Updated MICU information pamphlet in English AND Spanish for families
  - Upgrading iPads in patient rooms in the MICU
- Resident tip sheet
  - Spanish interpreter services: iPads, telephone, in-person
  - Chaplain services
  - Empower families





A close-up photograph of a Tabanus (horse fly) perched on a thin, dark twig. The fly's most striking feature is its large, oval eyes, which exhibit a vibrant iridescent pattern of horizontal stripes in shades of red, orange, yellow, green, and blue. The body of the fly is a mottled brown and tan color, with fine hairs visible on its thorax and legs. The background is a soft, out-of-focus mix of green and yellow, suggesting a natural outdoor setting.

TÁBANOS

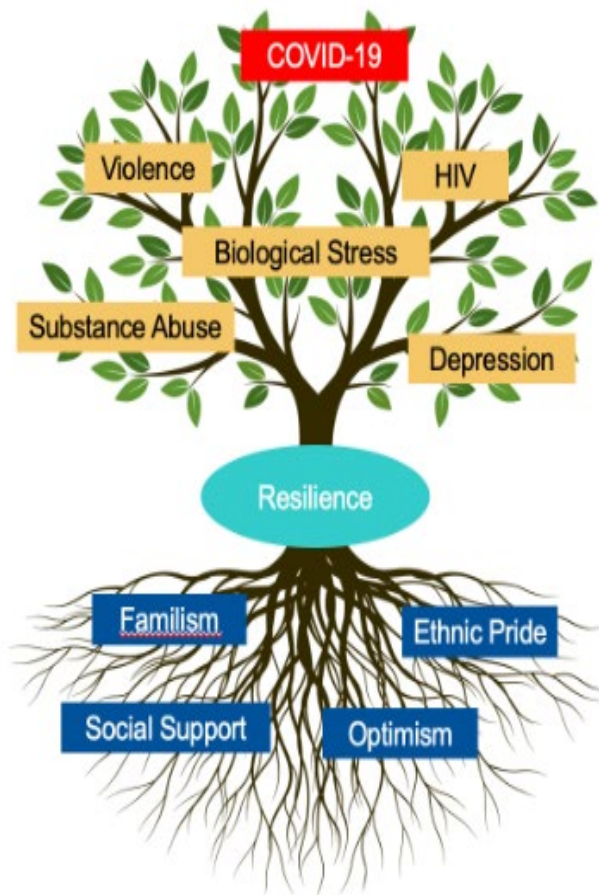
LATIN-19



## Structural & Social Drivers



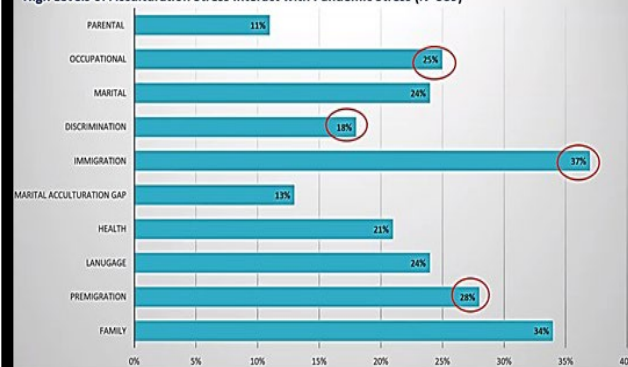
Acculturation stress



Dr Rosa Gonzalez Guarda

## Syndemic Orientation

High Levels of Acculturation Stress Interact with Pandemic Stress (N=389)

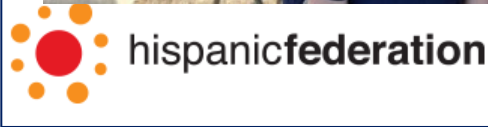




Kate B. Reynolds  
Charitable Trust



free rapid  
COVID tests  
and guidance





## NC DHHS Community Health Worker program



# LATIN-19 Community Consultation Studios

- 1.5 hour **listening session** for health researchers who are interested in getting feedback from community to inform their research
- Community members serve as experts to provide feedback on various aspects of a proposed or on-going research project
  - 6-10 Community members
  - \$50 gift card for time and voice
- Standing roster of individuals who represent diverse communities from LATIN-19 that can be called upon for a CCS
- Eligibility will be based on a common lived experience (e.g., parent of a child in Durham Public Schools)
- Opportunities for CCS in English or Spanish



<http://latin19.org>

# LATIN=19

## Key Initiatives



Multisector,  
Interdisciplinary  
convenings



Mobile testing



Vaccination  
equity



Mental Health



Research



Insurance



Support  
groups



Community health  
workers and navigators



Advocacy



Youth  
Ambassadors



Rural health



Health Literacy



Patient  
Safety & QI

# Why are rare cancers challenging?

## for Patients

- It often takes a long time from the time you think something is wrong to the time when doctors know that you have a rare cancer and what kind of cancer it is.
- It is hard to find doctors who know a lot about your cancer and how to treat it.
- It is hard to know what to do when doctors don't agree on how to treat your cancer.
- You may need to travel far from your home and family to get treatment for your rare cancer.

## for Physicians and Advance Practice Providers

- You may not know what to tell your patient about what to expect with their rare cancer.
- You may not have been trained in how to treat this type of rare cancer.
- It is hard to find an expert in the rare cancer who can answer questions or to whom you can refer your patient.

## for Scientists:

- There may be no information about the rare cancer to give you ideas on which drugs could treat it.
- There may be no animal or cell models of the rare cancer in which to test your ideas.
- There may not be enough tumor samples from rare cancer patients available for your research.
- If you have an idea of a drug that could treat the cancer, it may be hard to find enough patients to test your idea.

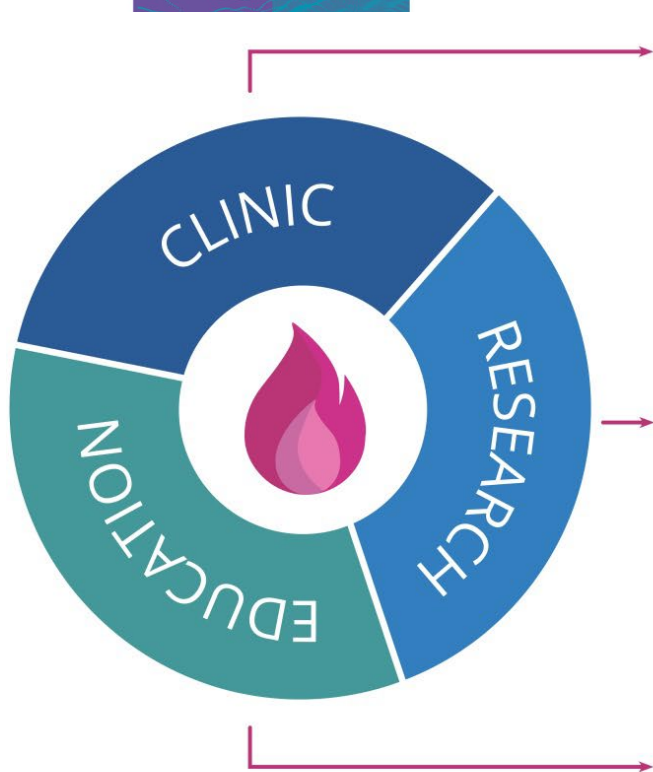
**ARC:**



# **Engaging Trainees and Community Coalitions**

<https://dubox.com/s/m1b34fhtk6mgba0tj83bnox>

# Translating Research into Action for Rare Cancers



Engage primary care providers in our local and statewide communities with a large academic medical center; Improve Knowledge using educational toolkits

Engage with community stakeholders, Connect patients with rare cancer resources and advocacy opportunities

IBC specific program and Clinic: promote and entice novel research and medical education focused on both the clinical care and health equity aspects of cancer diagnosis and referral practice.





Cancer Institute



Gayathri Devi, PhD  
Program Director



Susan Dent, MD  
Clinical Director

## Patient Advocates

Brandi Duff  
Katherine Cooke  
Brenda Denzler



Jeremy Force,  
DO



Rachel C.  
Blitzblau, MD,  
PhD



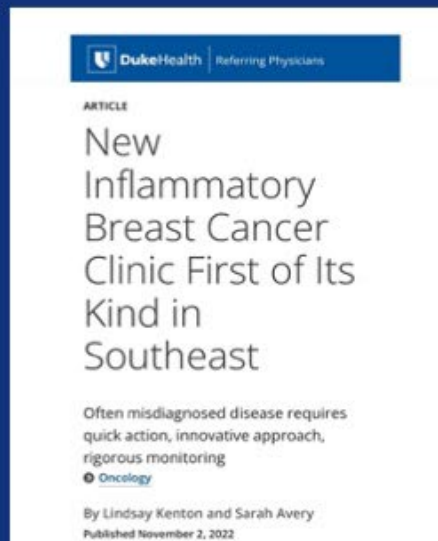
Olga G.  
James, MD



Karen S.  
Johnson, MD,  
MS



Laura H.  
Rosenberger,  
MD, MS



## Rare2Care Trainee Coalition



# THANK YOU!

Questions? Comments?



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**EXTRA  
REFERENCE  
SLIDES**

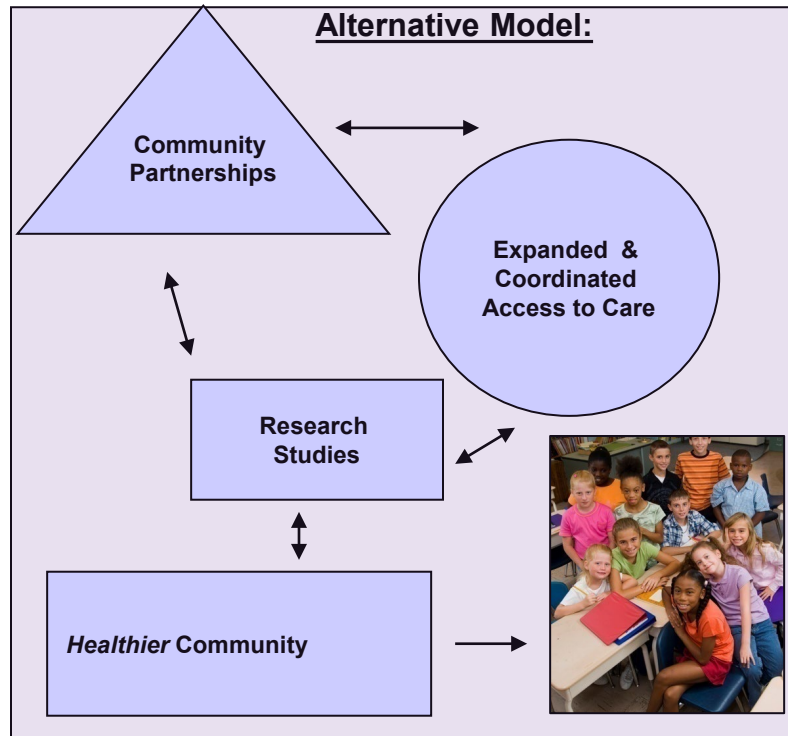
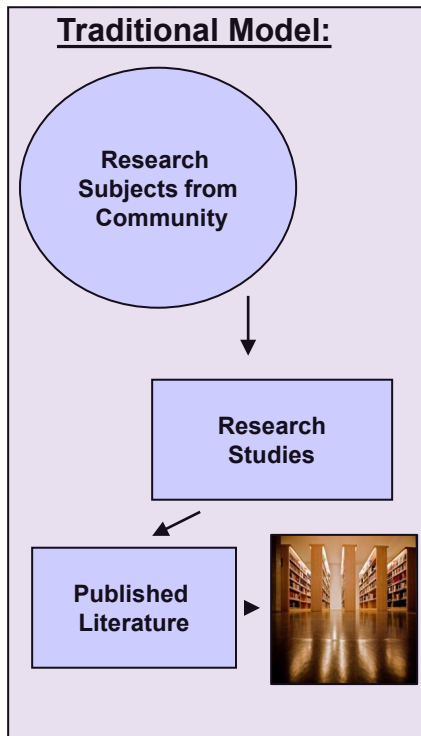
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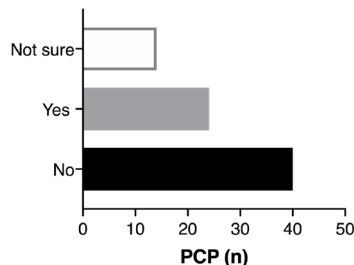
# Attracting Partners to the Research Enterprise



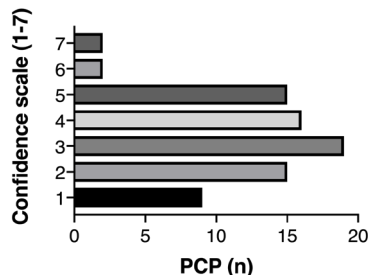
# PCP Pilot Survey Results

## PCP Familiarity and Confidence in Diagnosing and Treating IBC

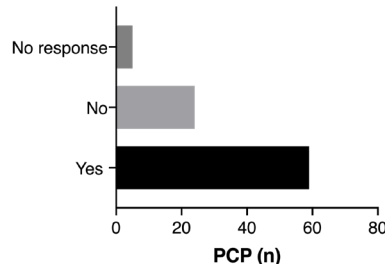
Have you ever had a patient that you suspected to have inflammatory breast cancer?



Confidence on a scale of 1-7



Referral Delays



(A). Only 31% (n=78) reported ever suspecting IBC in a patient.

(B) PCPs reported confidence in their ability to recognize IBC, (mean = 3.3, range 1-7), thereby limiting early diagnosis

(C) Delays in referrals to specialized large clinical centers were reported as a major barrier. 63% of PCPs reported breast cancer referral delays

## What PCPs are Saying: Themes from Qualitative Interviews

*"I have only seen one IBC patient in 30 years. Her case was pretty advanced, and it all happened pretty fast."*

*"Our patient population is what many would classify as underserved. We have challenges with staffing, and resources, and access with our patients."*

*"I have not had enough patients with IBC. I would not have had enough knowledge. I would be afraid of causing them more angst."*

# PCP Pilot Survey Results



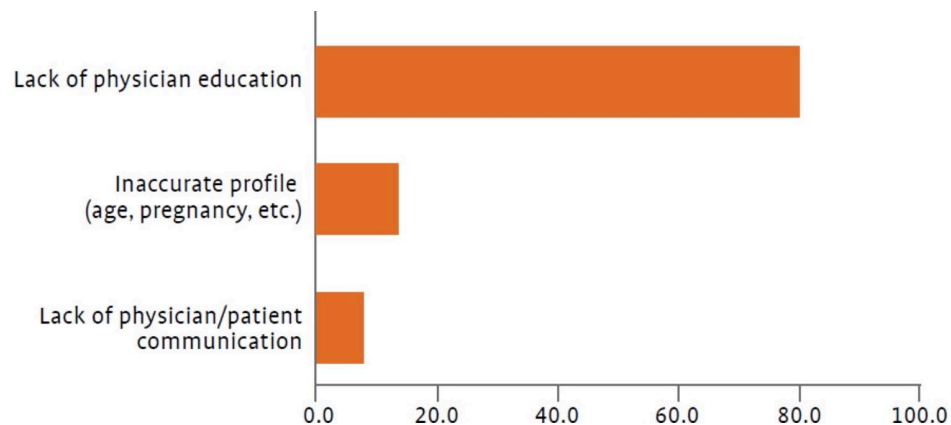
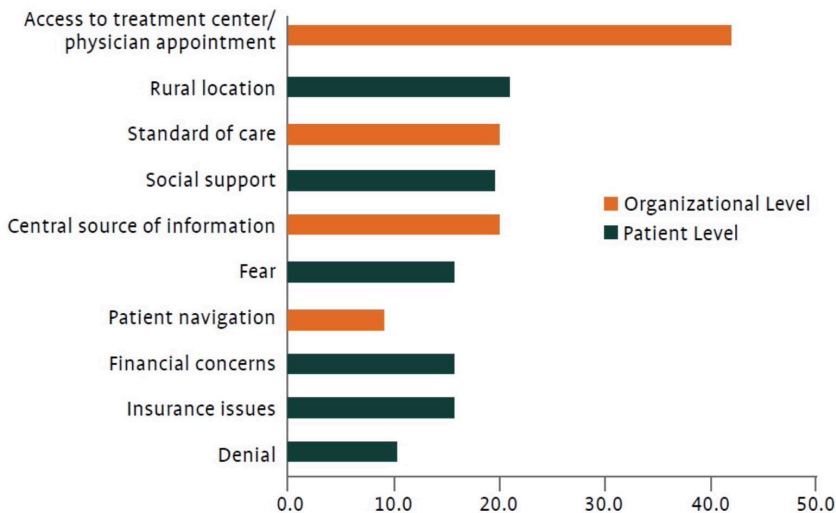
PCP Response to COVID-19 Related Impact on Breast Cancer Care

Characteristic	Categories	% (n)
Change in the number of breast cancer diagnoses made by PCPs since COVID-19	Same number of diagnoses	46.2 (36)
	Lower number of diagnoses	33.3 (26)
	Higher number of diagnoses	11.5 (9)
	Prefer not to answer	9.0 (7)
Percentage of patient visits conducted remotely or via telemedicine since March 2020	<5%	26.9 (21)
	5-10%	24.4 (19)
	11-20%	28.2 (22)
	21-30%	6.4 (5)
	>30%	7.7 (6)
	Prefer not to answer	6.4 (5)
Delays in referrals to diagnostic imaging for breast cancer since March 2020	No, never postponed	30.8 (24)
	<5% delayed	9.0 (7)
	5-10% delayed	21.8 (17)
	11-20% delayed	5.1 (4)
	21-30% delayed	2.6 (2)
	>30% delayed	3.8 (3)
	Unsure	20.5 (16)
	Prefer not to answer	6.4 (5)

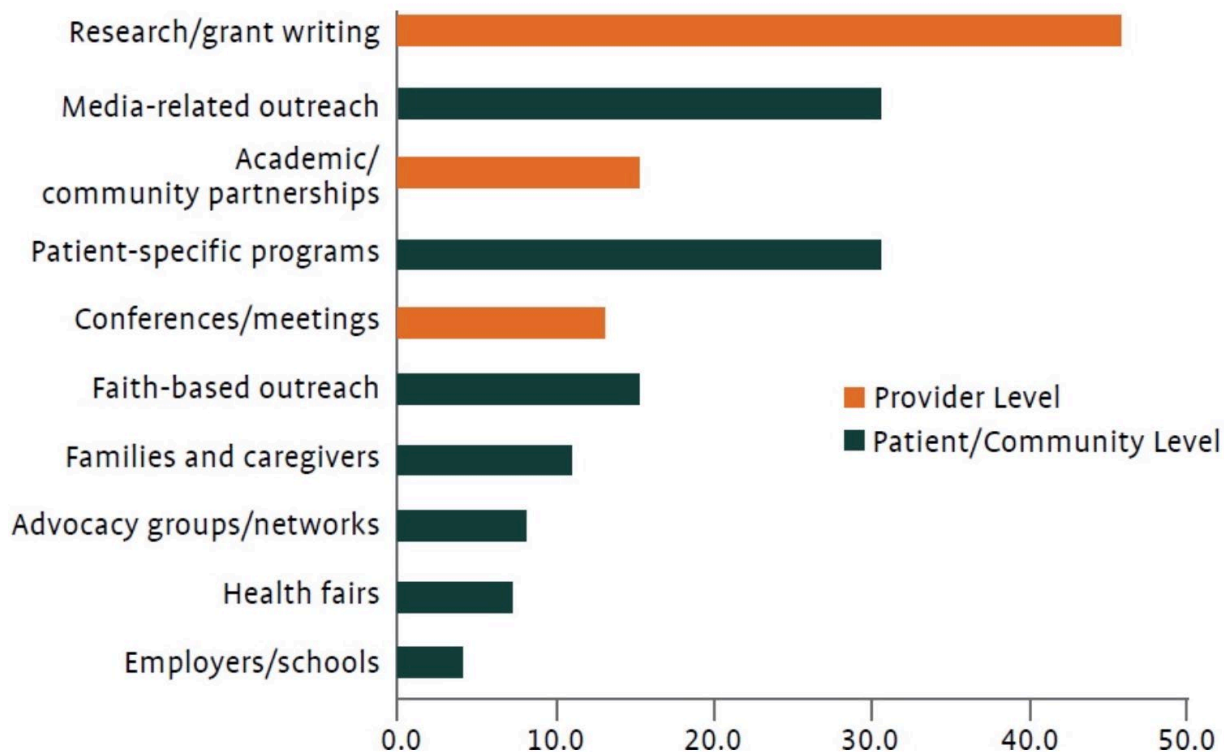
*When asked how COVID-19 impacted screening and diagnosis of breast cancer among their patients, 33.3% (n=26) of PCP reported lower breast cancer diagnoses than pre-COVID-19, and 62.8% (n=49) reported referral delays.*



# Barriers in Rare Cancer Care



# Strategies Identified

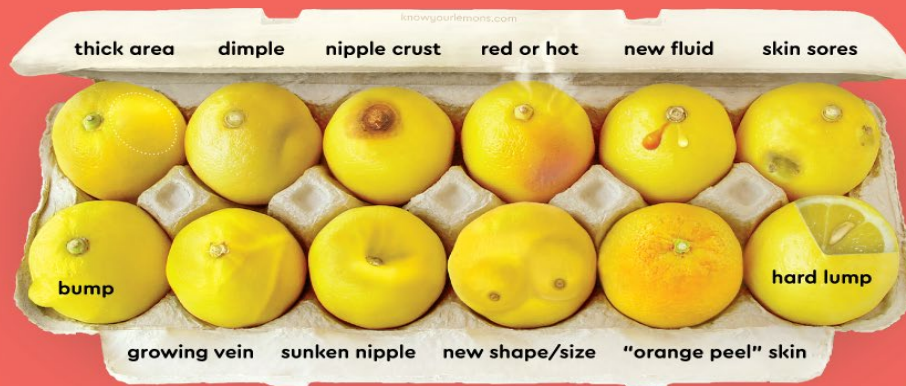


# Primary Care Provider Perspective

- Rare cancer that is commonly misdiagnosed (6% of all breast cancers)
- Firm, enlarged, painful breast with erythema
- Most of us will never see it or diagnose it
- Mammogram and Ultrasound can miss it
- Biopsies (can be difficult to obtain good local anesthesia)
  - High rate of false negatives
- Follow up and continuity are KEY!! (no more than 4-week f/u)

# Know Your Lemons!

What breast cancer  
can look + feel like:



Notice something? Some changes are normal.  
But if the change doesn't go away, be smart and show your doctor.

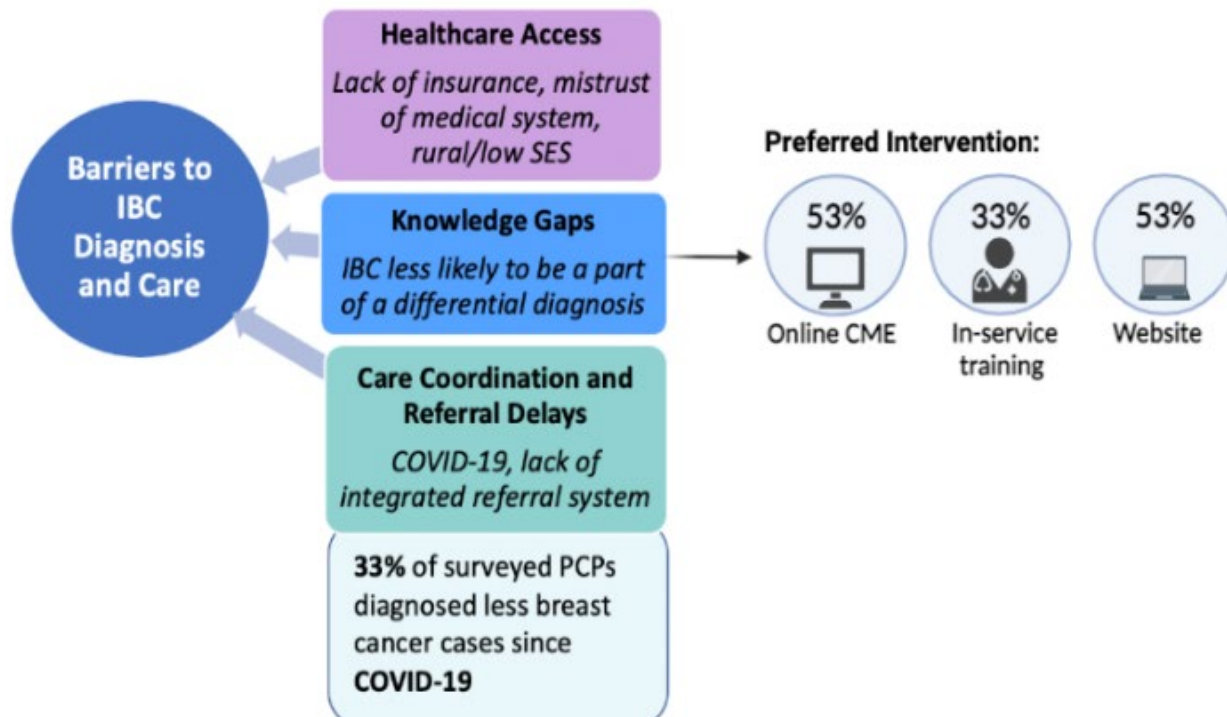


[knowyourlemons.org](http://knowyourlemons.org)



# PCP Pilot Survey Results

## PCP Familiarity and Confidence in Diagnosing and Treating IBC



# Specific Needs

- Engagement with dispersed groups of specialists
- High requirements for diagnosis: Education and testing
- Awareness of rare cancers overshadowed by larger cancer indications
- Distinct capabilities (clinical care, drug development and commercial; patient awareness and recruitment) needed to reach every person with a rare cancer
- A differentiated customer-engagement strategy - *Physicians: Education and awareness. Patient/payer engagement, GPOs*



## Translational Science

*“You see the results of your research in the petri dish or the test tube or in the images. You see the numbers. You see the publications. All is well and good.*

*But all of those things translate into the lives of real people you all too often do not see.*

*People like me and my grandkids (one of whom might possibly not even be here had \*I\* not been here to help out while his mother was pregnant).*

*You need to remember that it's us real people whose lives are impacted in very, very real and important ways by the things you do. I'm so grateful that you do them! THANK YOU!!!!”*

- Brenda Denzler, 10 yr Inflammatory Breast Cancer Survivor (2019)



@4dukeibc

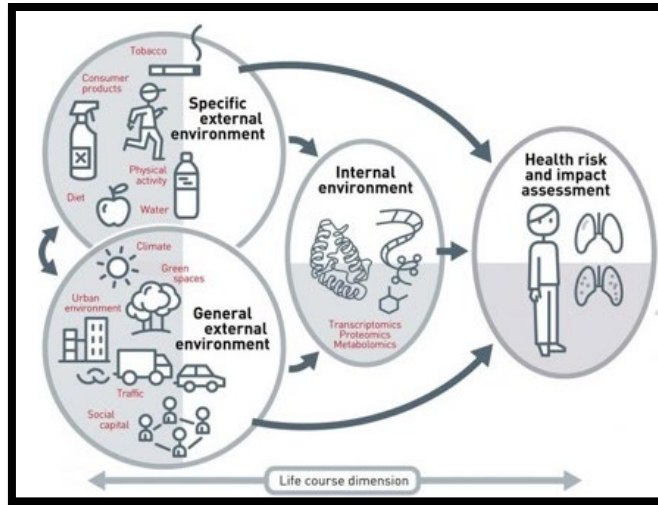
# Engaging Primary Care Providers, an Unmet Need:

- IBC prevalence in rural, underserved, minority and younger populations and the limitations of routine breast screening to identify IBC highlights the significance of **primary care providers (PCP) as often the first point of contact** when patients begin to notice symptoms.
- Professional articles/education often target oncologists and miss the PCP community. It is crucial that PCPs – defined here as physicians (DO, MD) and advanced practice providers (NP, PA) - be aware of and able to diagnose IBC in all members of their patient populations.
- **Continuing education** related to IBC is uncommon, and there is a critical need to be aware that persistent and/or progressive changes in breast appearance warrant medical attention regardless of patient age or date of most recent mammogram.

# Social Elements of Health (SEOH) and Chronic Stress

## Translational Science

## Allostatic Load



Stress hormones, Glucocorticoid  
receptor signaling

Increased inflammatory, oxidative  
stress factors in  
normal and tumor Microenvironment

### Critical throughout lifespan

- Fetal development
- Menarche
- Pregnancy/Lactation
- Mammary gland involution
- Hallmark of Cancer

Neighborhood disadvantage and individual-level life stressors in relation to  
**breast** cancer incidence in US Black women.

Barber LE, Zirpoli GR, Cozier YC, Rosenberg L, Petrick JL, Bertrand KA, Palmer JR.  
Breast Cancer Res. 2021 Nov 22;23(1):108. doi: 10.1186/s13058-021-01483-y.

*Guidi, 2021*  
*Obeng-Gyasi 2021*

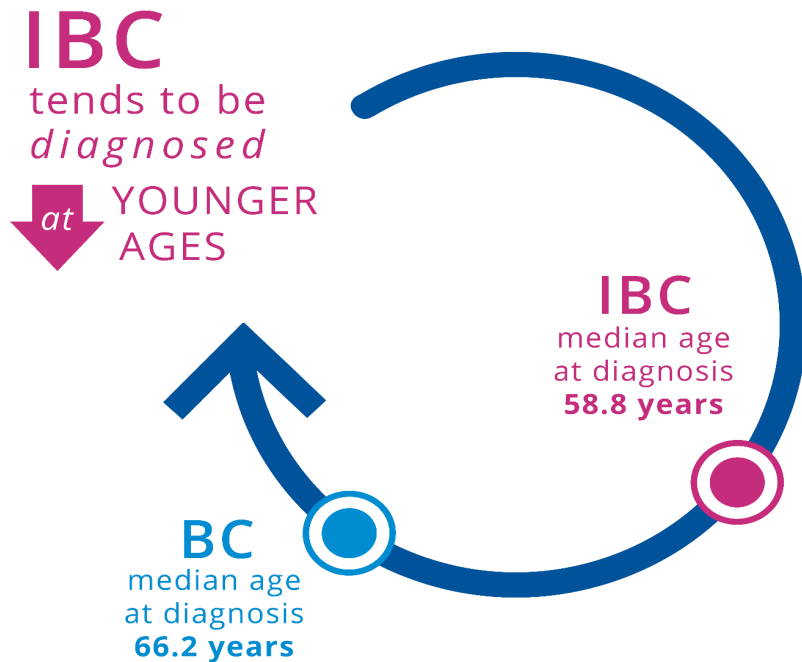
*Hossain, 2019*  
*Barber, 2021*

# Did you know?

African-Americans  
appear to have a  
**HIGHER RISK**  
of developing IBC.



# Did you know?





**Awareness** is critical to the success of any treatment for a rare disease: it can be the perseverance of the people with the diseases that secures access to the right care, given how few physicians have experience in rare diseases.

**Translational  
Science**



**Duke-NCCU Bridge Office**

**Vision:** bidirectional collaborations

**Program Areas & Opportunities**

Interprofessional  
Education

Workforce  
Development

Community  
Engagement

Duke-NCCU  
CTSI Pilot  
Grants



Equity in Science, Medicine, and Health

**Web site:** <https://ctsi.duke.edu/what-we-do/duke-nccu-bridge>



Gay Devi, PhD  
Program Director

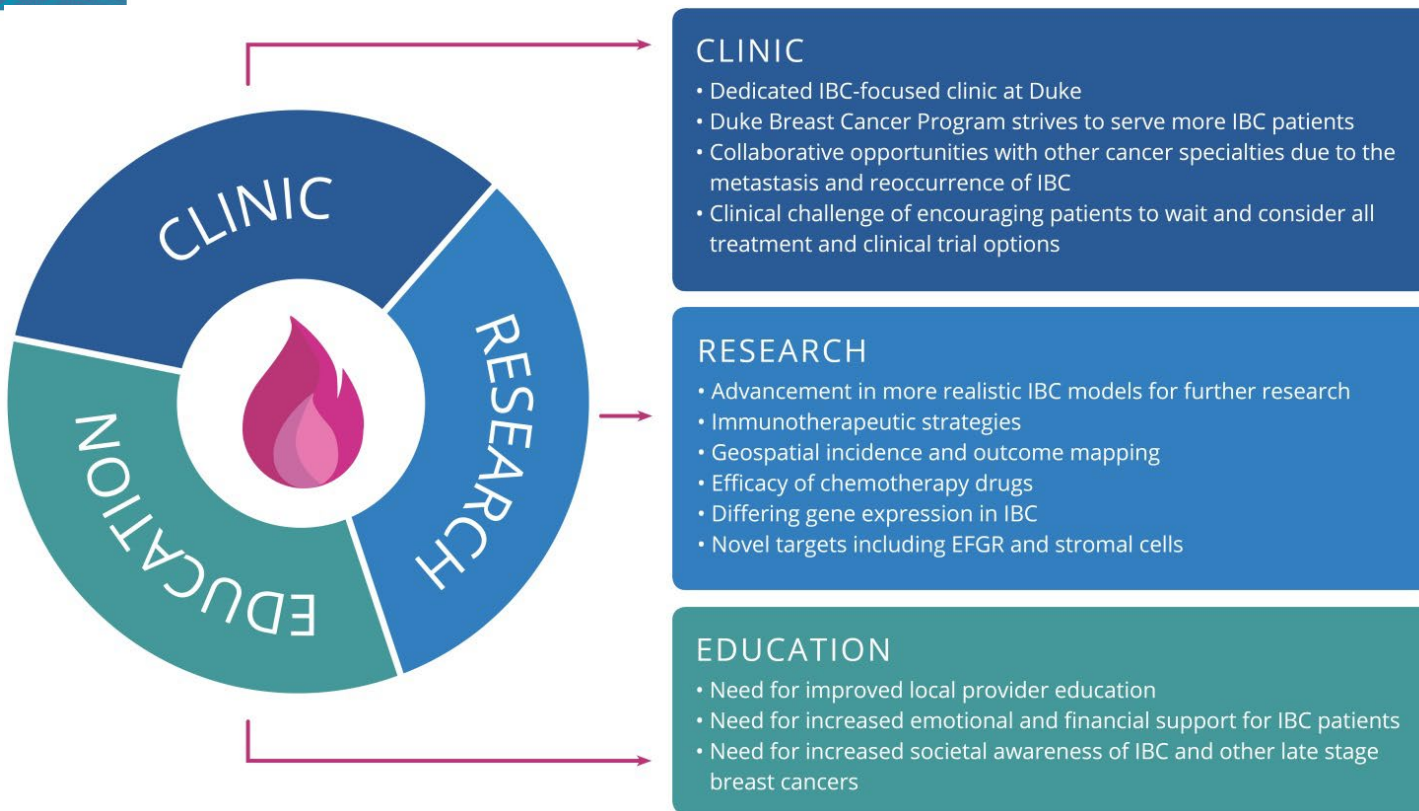


Faye Calhoun, MS, DPA  
NCCU Lead



Lisa Davis, MPh, PhD  
Director, Operations

# Translating Research into Action for Rare Cancers



# Key takeaways ...

- The focus group sessions provided a unique perspective to strategize and develop marketing campaigns to bring awareness to the community and minority populations in the community.
- Many participants were unfamiliar with IBC signs and symptoms, how it is diagnosed, and treatment options.
- To better raise awareness about IBC, participants recommended the use of various social media platforms, promoting more one-on-one education, patient self-advocacy sessions, and changing the perception of the presence of lumps as an indicator of BC

There is a significant need to raise awareness and understanding of IBC in diverse communities.

Partnerships between the community and researchers will facilitate the development of relevant and accessible information about IBC.

Engage all researchers with the community.

Need to develop *culturally tailored* outreach and marketing plans.



- ✓ There is a significant need to raise awareness



- ✓ Important to understand and know how to target diverse communities



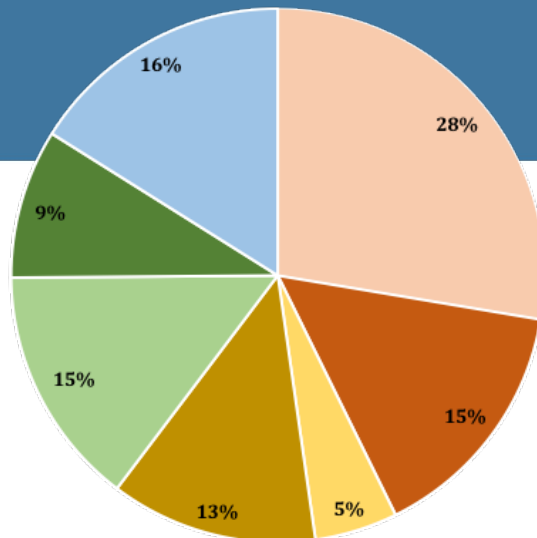
Oncology Issues

ISSN: 1046-3356 (Print) 2573-1777 (Online) Journal homepage: <https://www.tandfonline.com/loi/uoac20>

## Engaging the Community to Improve Patient-Centered Care for Inflammatory Breast Cancer



BY GAYATHRI B. DEVI, PHD, MS; HOLLY HOUGH, PHD; WHITNEY LANE, MD;  
KEARSTON L. INGRAHAM, MPH; LARISA GEARHAUST-SERNA; CYNTHIA SERNA;  
TERRY ARNOLD; AND NADINE J. BARRETT, PHD, MA, MS



Community Stakeholder (Patients, Advocates, Survivors, Other)

Healthcare Provider (Physician, Nurse)

Administrator/Executive

Faculty

Staff

Trainee (Postdocs, Graduate or Undergraduate Student)

Other



<b>Duke University</b>	70
<b>Universities and Hospitals Outside Duke</b>	28
North Carolina Central University	15
UNC Lineberger	4
MD Anderson Cancer Center	3
Northwestern Memorial Hospital	2
City of Hope National Medical Center	1
Dana Farber Cancer Institute	1
Georgetown University Medical Center	1
Shaw University	1
<b>Other Health Organizations</b>	10
American Cancer Society Cancer Action Network	3
Susan G. Komen	2
FHI 360	1
Molecules for Health, Inc.	1
NC BCCCP & WISEWOMAN	1
NC DHHS Department of Public Health Cancer Branch	1
RTI International	1
<b>Community Stakeholders</b>	12
Carolina IBC Survivors	4
IBC Research Foundation	4
IBC Network Foundation	2
Union Baptist Church	2
<b>Other</b>	50
NIEHS, NIH	1
North Carolina General Assembly	1
U.S. Sen. Richard Burr	1
Durham Mayor	1
Unknown	46



# Did you know?

Translational  
Science

Although categorized as a  
**rare disease**, IBC causes



10% of all breast  
cancer deaths.