



## **A Population Health Approach to Cancer Genetic Risk Assessment and Health Disparities: Considerations for Healthcare Systems**

Kent Hoskins, MD  
Associate Professor of Medicine  
Director, Familial Breast Cancer Clinic  
University of Illinois at Chicago



UI Cancer Center  
Bench to Community

NO FINANCIAL DISCLOSURES

# Precision medicine approach to cancer screening & prevention: a population health perspective



General population risk



Family history



High risk family  
history

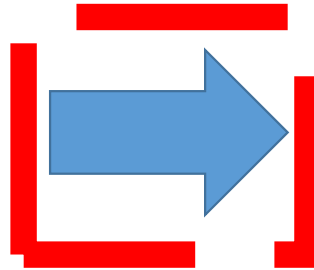


Mutation  
carrier





## Systematic CGRA as a standard component of primary healthcare

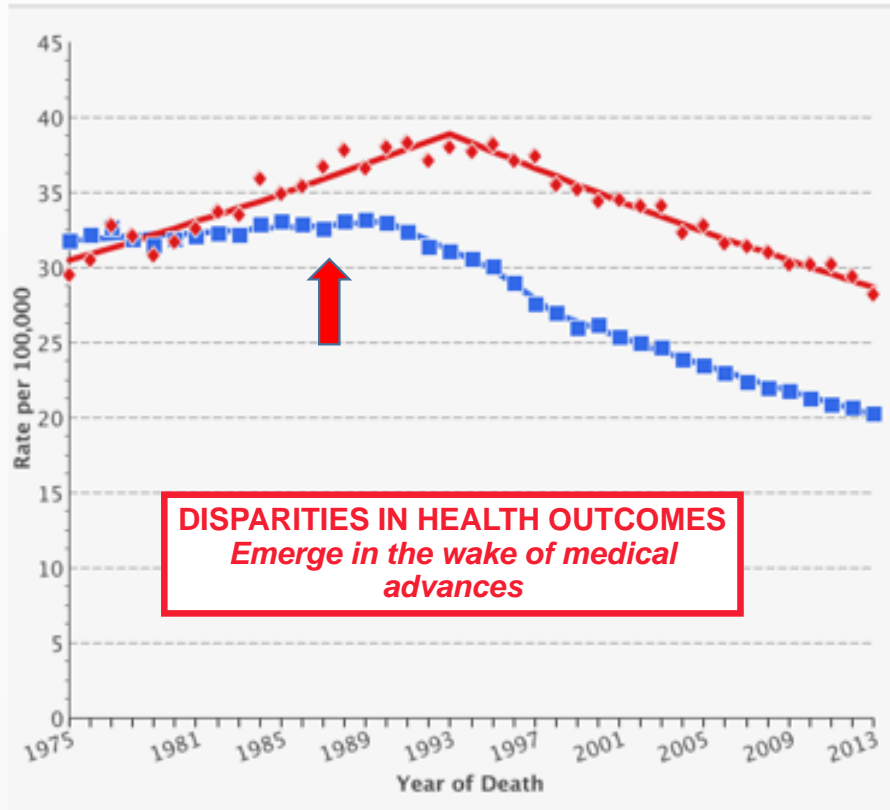


### **CGRA**

Clinics (PCP, OB/Gyn, GI)  
Breast Imaging Centers  
social media

### **Genetic specialist**

## Breast Cancer Mortality in U.S. by Race



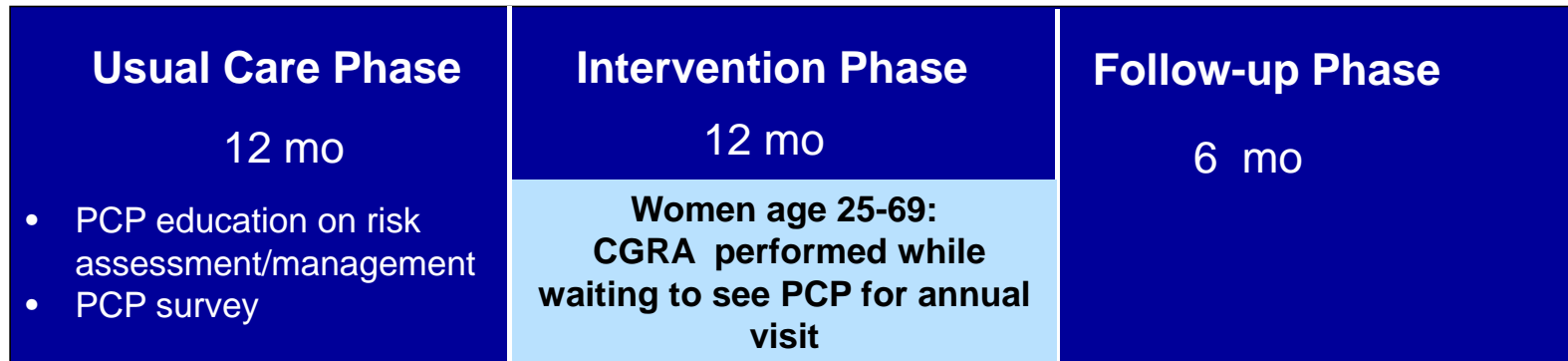
◆ Black (includes Hispanic)

■ White (includes Hispanic)

Source: <http://seer.cancer.gov/faststats/>



## Feasibility of CGRA in Federally Qualified Health Centers to reduce cancer disparities



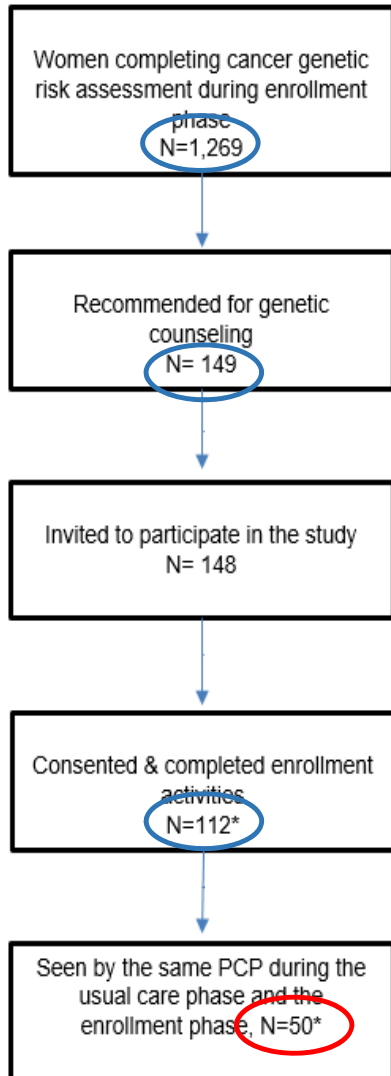
“The USPSTF recommends that primary care providers screen women who have family members with breast or ovarian cancer with one of several screening tools designed to identify a family history that may be associated with an increased risk for potentially harmful mutations in BRCA1 or BRCA2.”

*Moyer VA. Annals of Internal Medicine. 2014;160 (4):271-281.*



### Increased Risk

- Invited to participate in study
- Enrollment survey, Exit Survey
- 2 week post-enrollment interview
- Chart reviews
- 6 month post-enrollment Interview

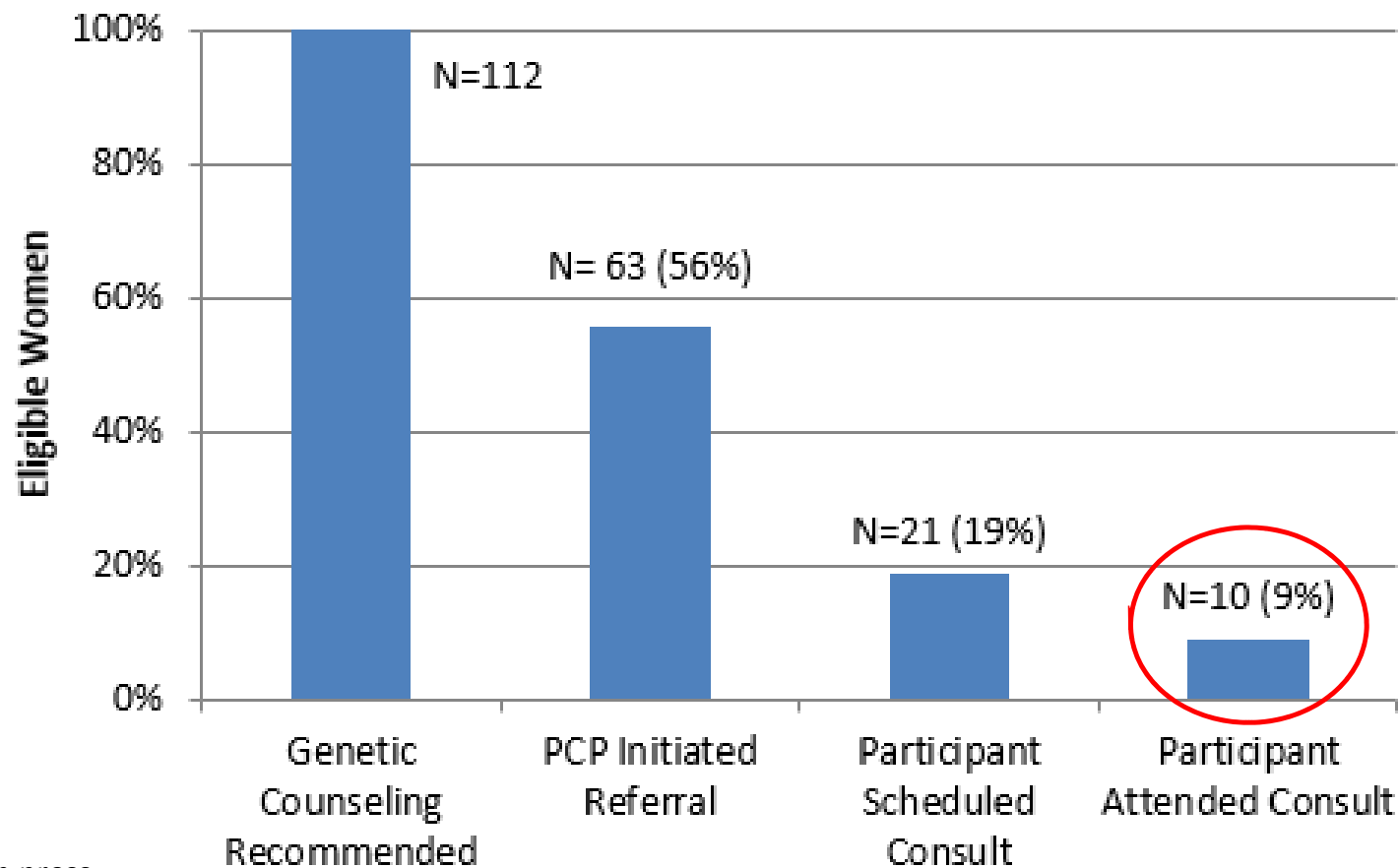


69% African American, 29% Latina  
86% with household income < \$30,000/yr  
85% Medicaid/public aid

CANCER 2018, *in press*

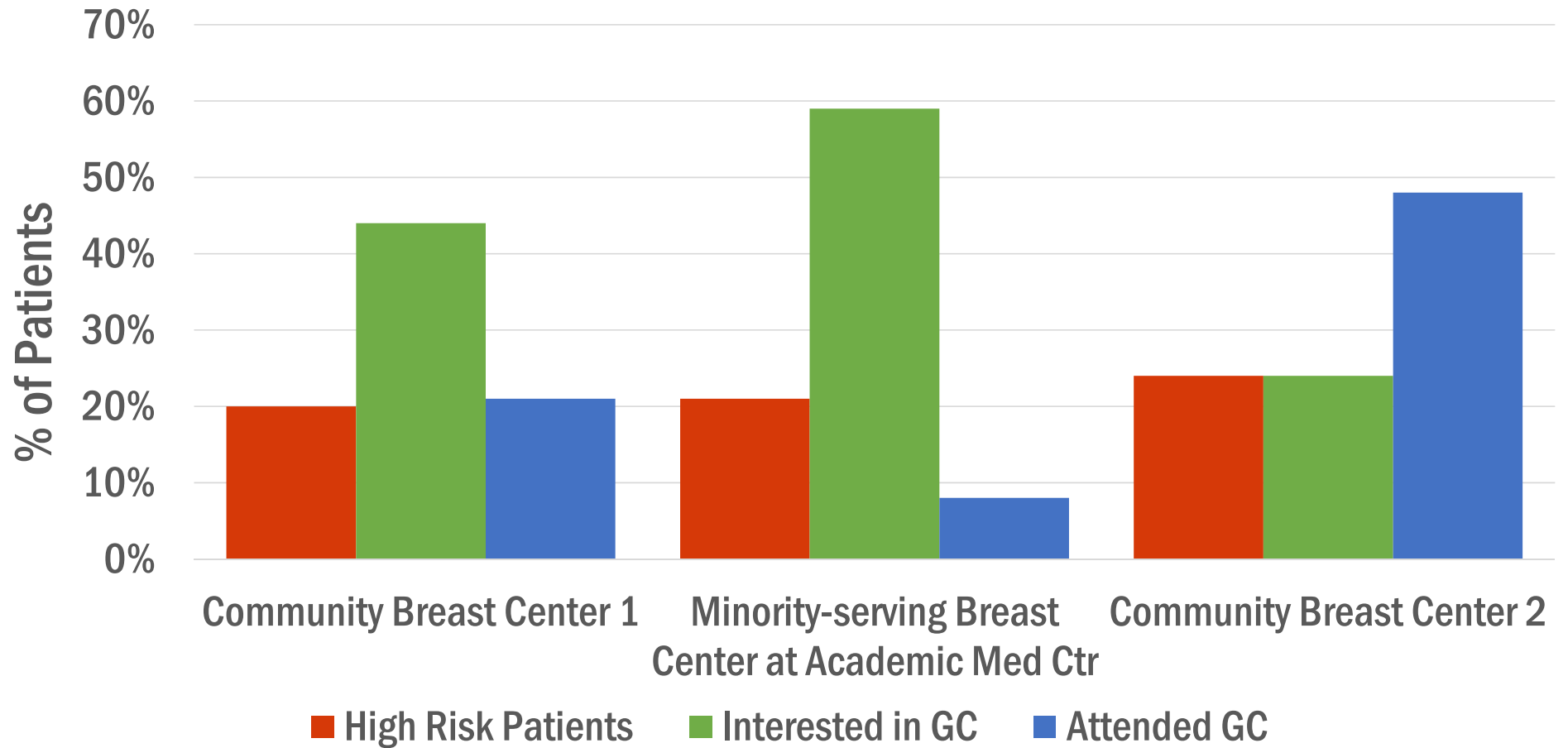


## Rates of referral and attendance at genetic counseling consultation



CANCER 2018, *in press*

## CGRA in mammography centers



Data courtesy of Haibo Lu, CancerIQ®

## Pilot Study of CGRA in a community mammography center

- *97% of women requested to have risk assessment performed*
- *242 women “increased risk” cohort*
- *201 (83%) failed to follow-up for free Genetics consult by APN within 6 months*
- *80 (40%) non-compliant participants returned survey*
- *Reasons for non-compliance:*



## In-depth interviews with 20 African-American women from FQHC study referred for genetic counseling

### THEMES

#### 1. Trust, Relationships, Communication with Providers

Lack of trust and poor communication with providers was prevalent among women. Women often felt talked “about” and not talked “to” by their providers and they desired more comprehensive, honest, and open discussions with their providers so that they could share in decision-making regarding their health.

#### 2. Health Education/ Health Literacy

Due to limited trust in providers, women believed that higher levels of health literacy facilitated relationships and communication with providers because it enabled them to critically assess the information given to them by providers.

#### 3. Health Beliefs

Women acknowledged that many people automatically associate cancer with death but they felt that knowing the status of one’s health was better than not knowing. Women believed in a mind-body connection in regard to health; negative thoughts result in negative health outcomes and positive thoughts motivate women to take measures to prevent negative health outcomes. There was also a general belief that medication caused more harm than good and this belief extended to cancer treatments.

#### 4. Motivators/ Facilitators for Breast Care

Having family members with a history of cancer empowered some women to utilize preventive services and be proactive in their healthcare, while others utilized services due to fear.





# THEMES

## 5. Family

Family and social support were extremely important to women, both in receiving and giving social and emotional support when dealing with cancer. Familial secrecy and nondisclosure of cancer diagnoses were highly prominent among women. Familial secrecy was cyclical, multi-directional and paradoxically associated with guilt or anger.

## 6. Religion/ Spirituality

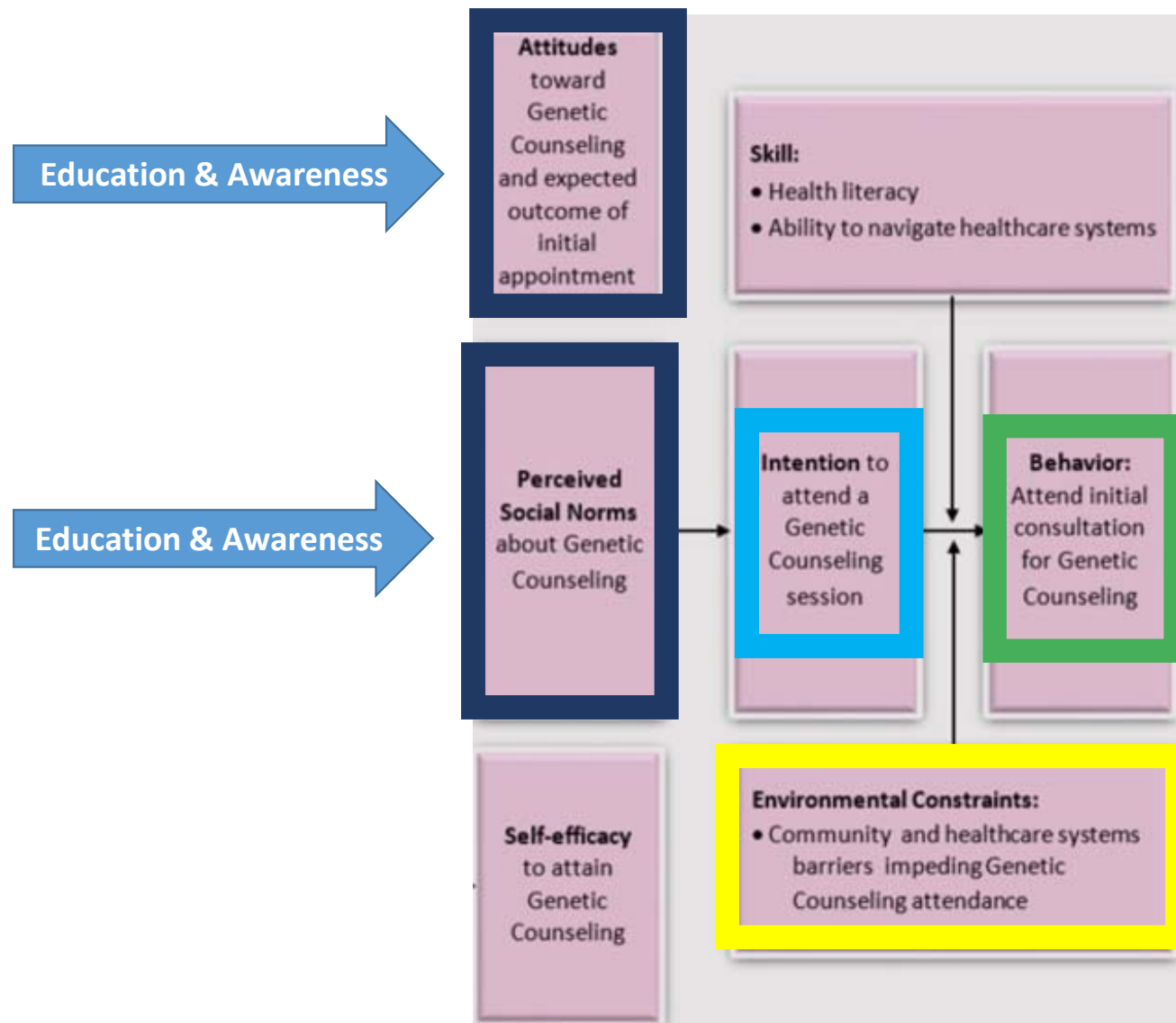
Religion and spirituality played multiple roles in women's health beliefs. Religious/spiritual beliefs and prayer served as: coping mechanisms in dealing with hardships and stress; tools to receive signs or answers in knowing how to act and making decisions; the root causes of positive health outcomes; and the root causes for negative health outcomes (e.g., punishment for prior behaviors).

## 7. Barriers

Barriers related to healthcare and breast health were mostly psychosocial barriers that included: fear of seeing a provider or screening results; guilt associated with cancer diagnoses or the capacity to offer social support to others; and lack of familial or social support. Confusion over mammogram guidelines; lack of healthcare knowledge; discrimination faced within the healthcare system; healthcare system complexity; sub-par or poor healthcare; and lack of insurance or costs were also barriers that women encountered related to their health and healthcare.

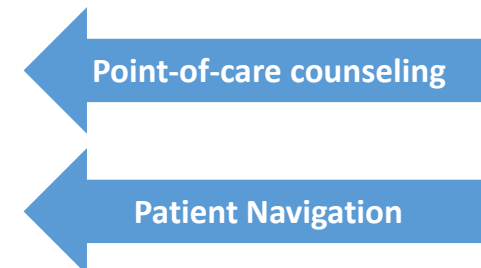
## 8. Genetic Counseling

Many of the women equated genetic counseling with detection or a diagnosis of breast cancer. Consequently, the emotional responses associated with being diagnosed with breast cancer (e.g. fear, embarrassment, denial) were also cited as a barriers to African American women receiving genetic counseling. After learning about genetic counseling, most of the women felt that it was something that would be valuable to them, other women, and potentially their families.



# The Integrative Model of Behavioral Prediction

Fischbein M, 2003

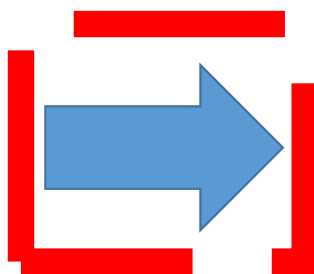


# Critical issues for healthcare organizations that decide to implement CGRA



## CGRA

Financial- business model?  
Location  
Buy-in/training for providers  
CGRA instrument/who will conduct  
Metrics of success  
Integration with EMR



## Genetic Specialists

Who will provide genetic evaluation?  
Where (on-site or off-site)  
Management of high risk patients  
**Coverage for enhanced screening/prevention**  
Training and certification/credential

## A new paradigm for delivering cancer genetic counseling to support CGRA in primary care: “point-of-care genetic counseling”

- “Specialty Cancer Genetic Care” and Primary Cancer Genetic Care”
  - NPs/PAs in primary care clinics/mammography centers trained to deliver “primary cancer genetic care” **in formal collaboration** with a “cancer genetic specialist” at a referral center
  - Complex cases (e.g. mutation-positive) referred to genetic specialist
  - Provides a sustainable business model for clinics
  - Overcomes many of the barriers to accessing genetics care that many underserved and disadvantaged patients experience
  - Increase workforce capacity to provide genetic counseling for cancer risk
  - Current genetic counseling workforce represents major bottleneck to providing population-based CGRA
- 
- Develop a training program in conjunction with City of Hope (J. Weitzel and K. Blazer)
  - National Consortium of Breast Centers developing a certification for Cancer Genetic Risk Assessment



# Acknowledgements

## P50: UIC Center for Population Health & Health Disparities

### UIC

Silvia Tejeda

Beverly Chukwudozie

Ganga Vijayasiri

Melinda Stolley

Dick Warnecke

Hiral Shah

Mylene Remo

Ivy Abraham

Lara Balay

Tara Maga

Kim Vande Wydeven

Diana Moreno

Yejide Awolola

Chicago Family  
Health Center

Loraine Moreno

Maria Rojas

Alicia Carillo

Veena Korah

Erika Searles

### Loyola University

Emily Anderson

### City of Hope

Kathleen Blazer

Jeffrey Weitzel

## P20: GUIDE Cancer Research Training Project

### UIC

Beverly Chukwudozie

Vida Henderson

Angela Odoms-Young

Ravneet Kaur

Ivy Abraham

Tara Maga

Lara Balay

Kariem Watson

Rob Winn

### Governor's State University

DeLawnia Comer-Hagans

Shirley Spencer

Zo Ramamonjiarivelo

Kaylyn Norise

Rupert Evans

Cathy Balthazar

### Storyographers, LLC

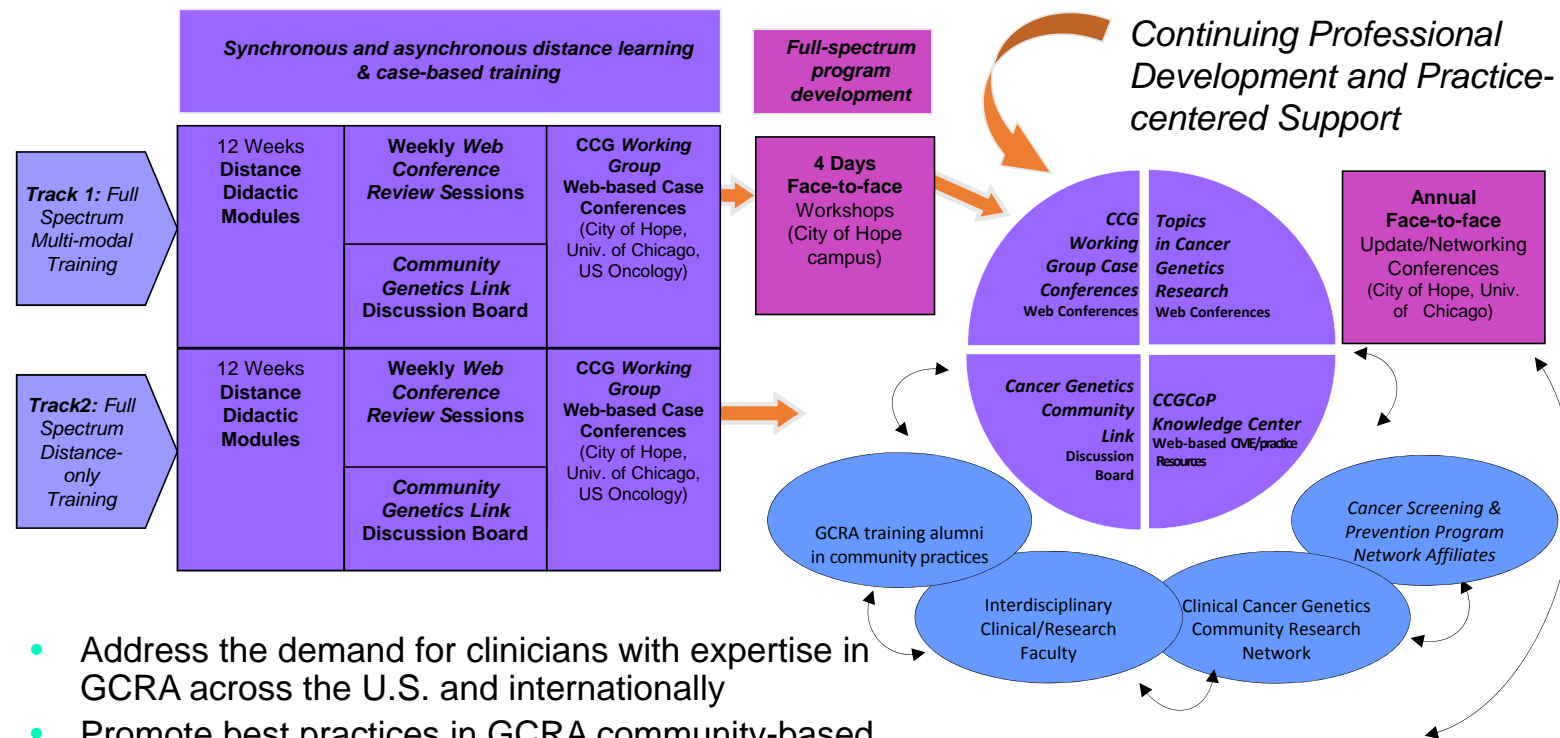
Seed Lynn

Supported by NCI/NIH: P50 CA106743-07, Supplements P50 CA106743-07S1 & S2; 1P20CA202908-01



UI Cancer Center  
Bench to Community

# City of Hope Intensive Course and Clinical Cancer Genomics Community of Practice (CCGCoP) Est. 2001 (NCI R25CA171998)



- Address the demand for clinicians with expertise in GCRA across the U.S. and internationally
- Promote best practices in GCRA community-based collaborations in cancer genomics research
  - Underserved areas/populations a priority
  - Assess longitudinal impact on practice change and patient care

## Conclusions

- High level of interest in receiving information on risk status & options for reducing risk among underserved minority women
- It is feasible to implement population-based CGRA in FQHCs
- PCP adherence to national guidelines for genetic counseling improves with implementation of systematic CGRA, but still not optimal
- Patient adherence to recommendation for genetic counseling is very low even when recommended by their PCP
- Many PCPs expressed limited understanding of genetic counseling, making it difficult for them to effectively counsel women to attend

Now what?

## Summary

- Buy-in from PCPs critical
- Personnel available will determine which model is feasible, the more “POC” the better
- Process for moving patients from genetic risk assessment to counseling is key: each step in the process can effect final uptake
- Remove “environmental barriers” for patients and providers
- Need to address expected outcomes/beliefs that impede intention to attend as much as possible

*Thank You*

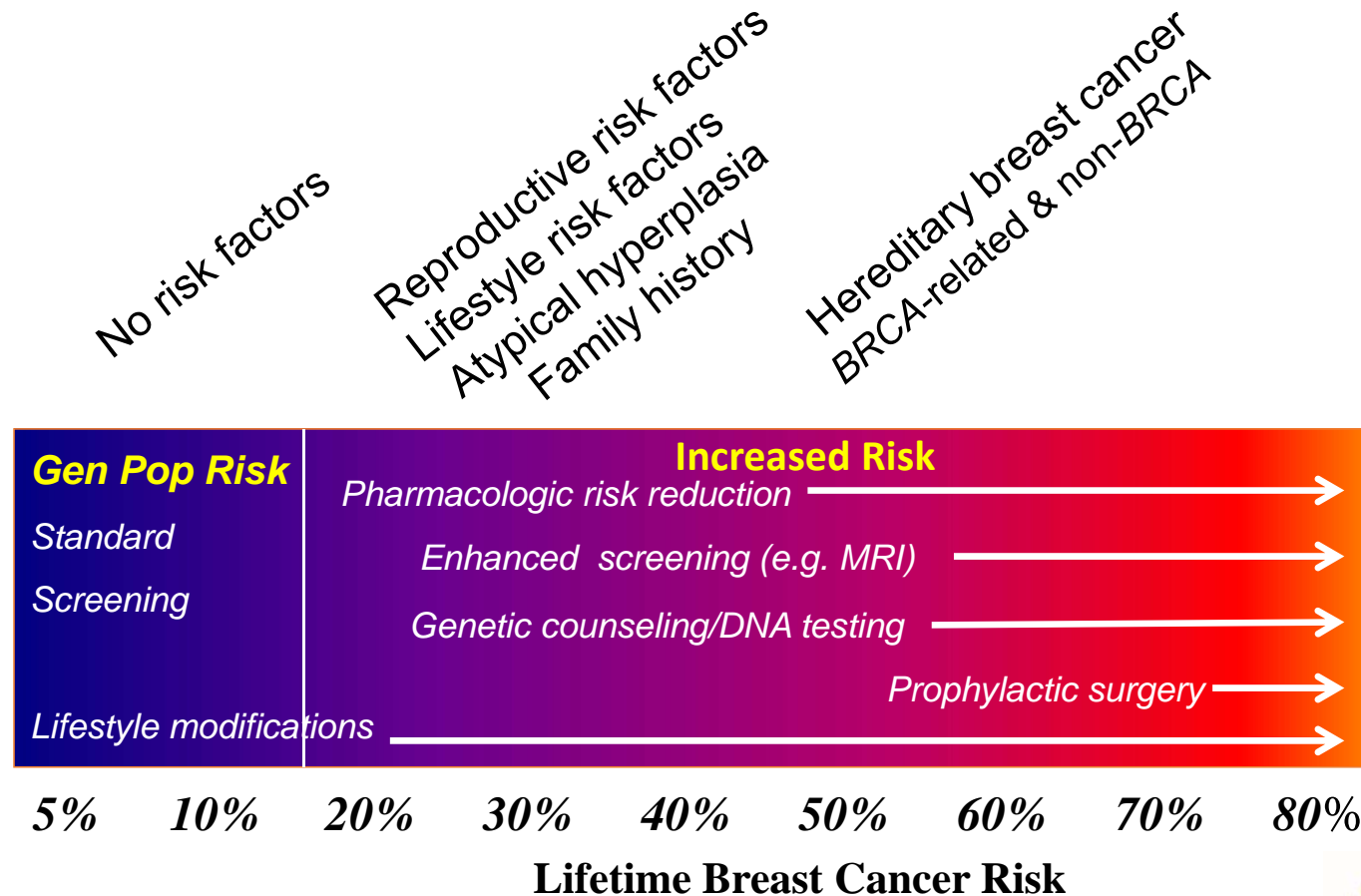


## A Skeptics View of Precision Medicine & Health Disparities

“The enthusiasm for this initiative (precision medicine) derives from the assumption that precision medicine will contribute to clinical practice and thereby advance the health of the public...We suggest, however, that this enthusiasm is premature... Our skepticism about what precision medicine has to offer is predicated on a reading of the evidence regarding social determinants of population health...” Bayer & Galea NEJM 2015

improved clinical practice ≠ improved health for the population

# A Precision Medicine Approach to Breast Cancer Screening & Prevention



# Expanding the Story of Survival

## Faith, Family, and Genetic Counseling in African American Women with a Family History of Breast Cancer

Kent Hoskins, MD

Vida Henderson, PhD, PharmD, MPH, MFA

on behalf of P20 GUIDE Research Team

**GUIDE Project**

GUIDE Project logo  
Governors State University - UI Cancer Disparity  
Education Project:  
Research-Education-Training-Engagement



**UI Cancer Center**  
Bench to Community





UIC

## Breast cancer mortality is higher for African American women than for any other race or ethnicity.



Increasing uptake of genetic counseling (GC) is a key step in reducing racial disparities in breast cancer (BC).



We are developing a culturally-sensitive animated video that provides educational information designed to motivate African American women (AAW) to engage in GC.



Multiple qualitative methods were used to identify barriers, motivating factors, and familial experiences related to BC that impact the desire and ability to access GC.



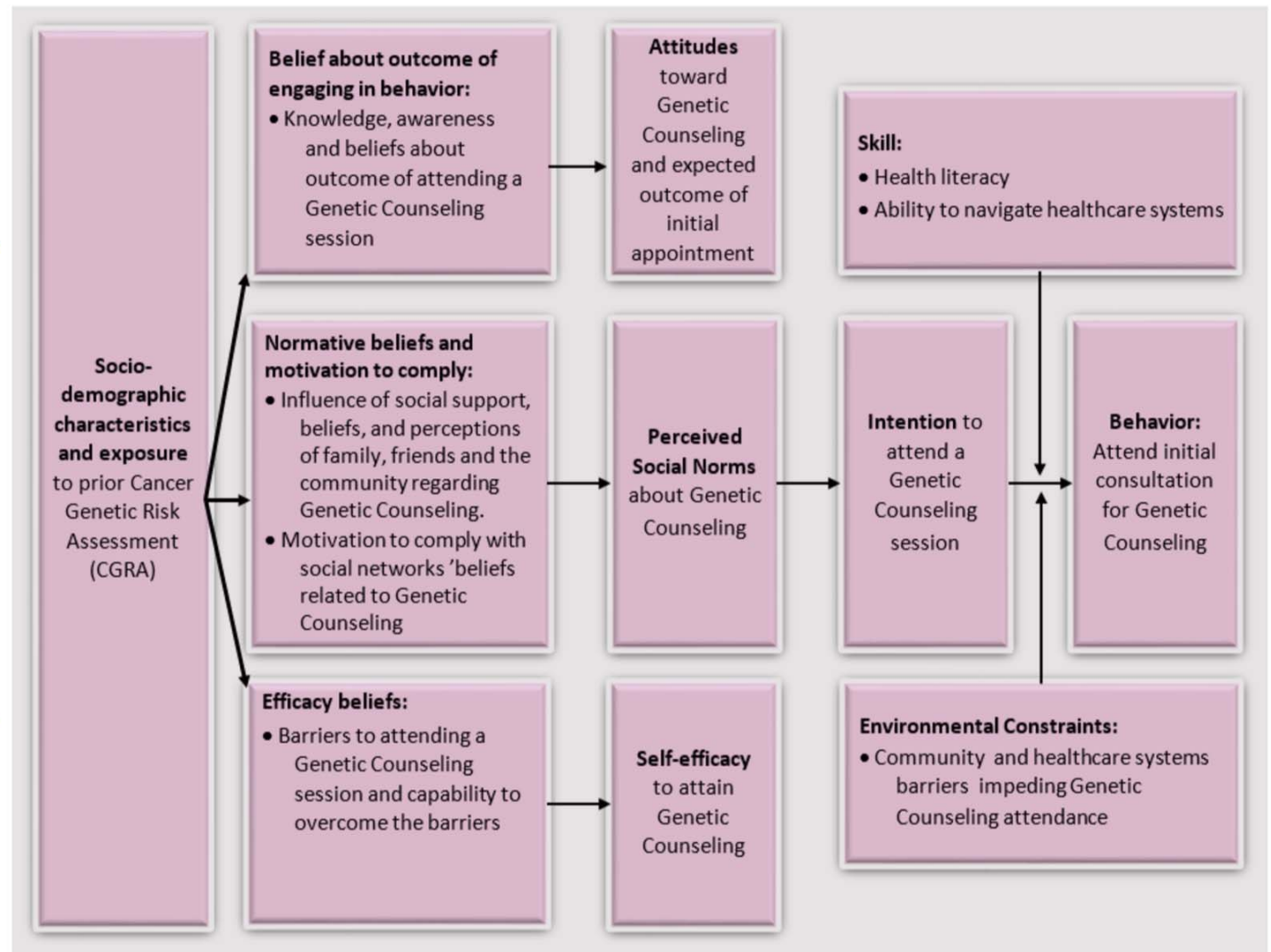
UIC

UI Cancer Center  
Bench to Community



# Integrative Model of Behavioral Prediction

Yzer, M (2012)



# METHODS

Women at high risk for BC, previously recommended for GC, were recruited from FQHC for interviews & story circles



Thematic analysis of both methods was conducted using primary and secondary coding with Atlas & Dedoose software and detailed field notes



A script and storyboards for animated video were produced that incorporated themes and information learned from interviews & story circles



Focus groups with community advocates/organizations, additional women with a family history of BC, and providers are currently being conducted to get feedback on script and story boards that will be incorporated into final video



UI Cancer Center  
Bench to Community

# FOCUS GROUPS



## FOCUS GROUPS

- Community organizations & Advocates
- Providers
- Women with a family history of breast cancer



## REVISIONS

Revise script, animations styles, live action, & look of characters based on feedback



## "FINAL" DRAFT

Film live action, develop music scores, develop final draft of video



## FOCUS GROUPS

Conduct focus groups with same groups of stakeholders for additional feedback on incorporated revisions

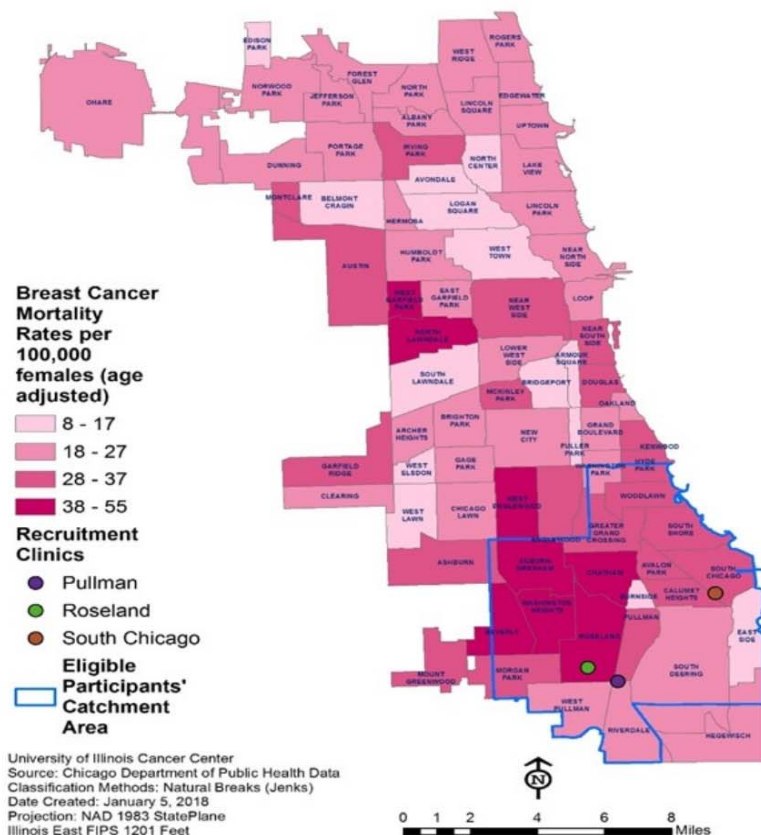


## FINAL VIDEO

Produce final video



UI Cancer Center  
Bench to Community



## Interview Participants

- Interview participants recruited from foundational work in which Cancer Genetic Risk Assessment (CGRA) using a Breast Risk Screening tool was performed at FQHC on south side of Chicago
- Eligibility: AAW 25 to 69 years; no personal hx of BC; received recommendation for GC; consented to be contacted for future studies
- n=61 met eligibility criteria; n=20 participated in interviews
- Interviews were facilitated by interview guide that assessed constructs related to GC in IMBP (attitudes, beliefs, knowledge, perceived social norms, self-efficacy, barriers)
- Conducted May to July 2017

## Story Circle Participants

- 2 story circles were conducted with a subset of women interviewed (n=11)
- Story circle guide was developed that asked women to share different aspects of familial experiences related to BC and GC
- Conducted August to September 2017

## Recruitment



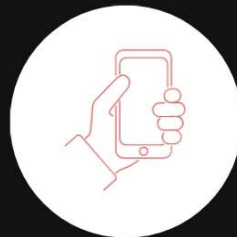
- 25 to 69 at annual well-woman visit at FQHC
- No personal hx of BC
- Never undergone GC, but recommended by PCP
- Minimum sample size of 30
- Consent & baseline survey of predictive measures

## Cancer Genetic Risk Assessment



- PCP receives training on pilot study
- CGRA Performed by clinic staff immediately after check-in
- PCP receives results & individualized recommendations based on national guidelines

## GC Recommendation by PCP & Instructions to Access Video



- PCP decides whether to refer women
- Gives instruction cards for accessing video
- Women complete brief exit survey

## 2-Week Follow Up Phone Survey



- Assessing whether they accessed video and changes in predictive measures

## Provider Survey



- To identify attitudes toward use of video

## NEXT STEPS

# FEASIBILITY PILOT STUDY



# Acknowledgements

## P20 GUIDE & Animation Research Team:

Kent Hoskins, MD

Robert Winn, MD

Beverly Chukwudozie, MPH

Vida Henderson, PhD, PharmD, MPH, MFA

Karriem Watson, DHSc, MS, MPH

Angela Odoms-Young, PhD

Zo Ramamonjiravelo, PhD, MBA

DeLawnia Comer-Hagans, PhD, MS, MBA

Shirley Spencer, PhD, MS

Vickii Coffey, PhD, MSA

Giesela Grumbach, PhD, MSW, LCSW

Carolyn Rodgers, PhD, MPH, MHS, MCHES

Barry Pittendrigh, PhD

Julia Bello-Brava, PhD, JD, MS

Catherine Balthazar, PhD

Rupert Evans, PhD, MPA

Karen Aguirre, MPH

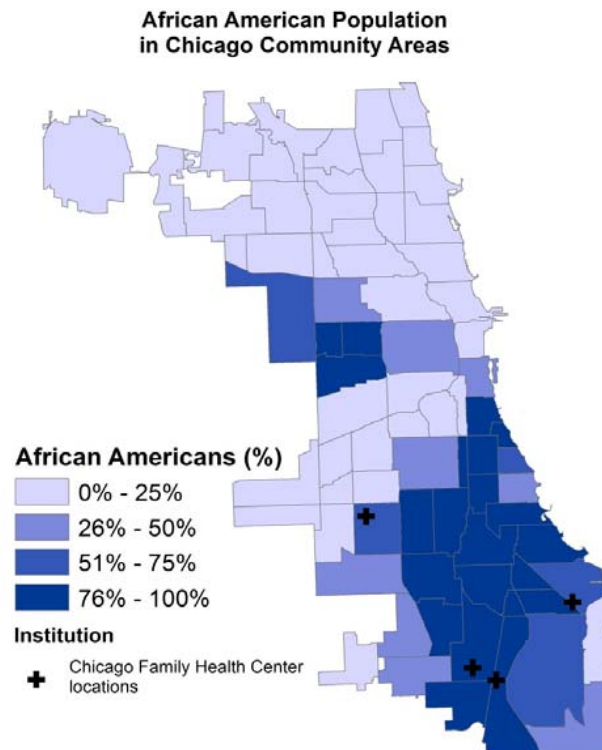
Seed Lyn



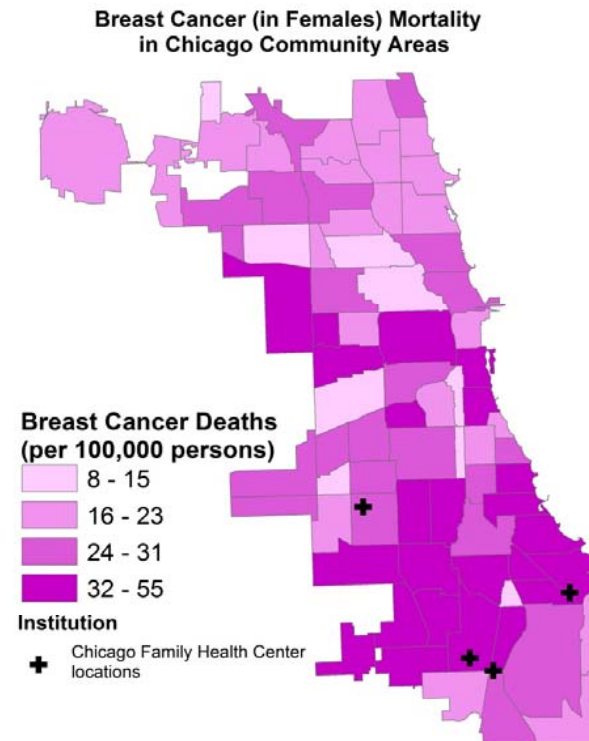
This work was supported by funding from the National Cancer Institute (NCI) P20CA202908.



# Racial Segregation & Breast Cancer Mortality in Chicago



University of Illinois at Chicago  
Institute for Health Research and Policy  
Source: US Census ACS 2007-2011  
Date Created: February 25 2015  
Projection: NAD 1983 StatePlane  
Illinois East FIPS 1201 Feet



University of Illinois at Chicago  
Institute for Health Research and Policy  
Source: Chicago Department of Public Health (CDPH)  
Date Created: February 25 2015  
Projection: NAD 1983 StatePlane  
Illinois East FIPS 1201 Feet



## Why Cancer Genetic Risk Assessment to Reduce Breast Cancer Disparities?

- CGRA for breast cancer should be considered the standard-of-care (USPSTF guidelines)
- Cost Effectiveness analysis: “Additional investments in screening should be reserved for situations in which there are pockets of unscreened women or for ensuring that **all high-risk women are screened.**” Mandelblatt JS, *et. al.* Journal of Clin Oncology 2004;22:2554-66
- Enhanced early detection & prevention measures potential to lower incidence & mortality

## A Skeptics View of Precision Medicine & Health Disparities

“The enthusiasm for this initiative (precision medicine) derives from the assumption that precision medicine will contribute to clinical practice and thereby advance the health of the public...We suggest, however, that this enthusiasm is premature... Our skepticism about what precision medicine has to offer is predicated on a reading of the evidence regarding social determinants of population health...” Bayer & Galea NEJM 2015

improved clinical practice ≠ improved health for the population

## A Slightly Less Skeptical Perspective

*"The enthusiasm for this initiative (precision medicine) derives from the assumption that precision medicine will contribute to clinical practice and thereby advance the health of the public...We suggest, however, that this enthusiasm is premature... Our skepticism about what precision medicine has to offer is predicated on a reading of the evidence regarding social determinants of population health..."* Bayer & Galea NEJM 2015

improved clinical practice  $\neq$  improved health of our population

A precision medicine approach to cancer care has the *potential* to mitigate health disparities, but...

*"Those who cannot remember the past are condemned to repeat it."*

-G. Santayana