



# Breast Health Navigation: Is it Possible to Bring Order Out of Chaos?

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# Outline

- What's the problem?
  - Navigating the Health Care System
    - The Chicago experience
  - Breast Cancer Disparities in Chicago
- A possible solution
  - Outreach navigation and education
  - In-reach navigation
- Top 5 lessons learned



# What's the problem?

The Chicago experience



# The System is Broken

- The only public hospital in Chicago **has stopped** screening women for breast cancer.
- Capacity is not able to meet the need.
  - Wait times for getting a screening appointment are getting longer at many hospitals.
- Programs are disjointed and not comprehensive.
- Many are left out, many choose to not have services at all.





# Broken System: Example

- The Illinois Breast and Cervical Cancer Program.
  - Provides free mammograms and Paps to uninsured women in Chicago/Illinois
- What happens when a cancer is found?
  - Case managers enroll her into Medicaid under the Treatment Act.
- What if she is undocumented?
  - Hospitals who see Medicare patients have provide charity care.
  - The hospitals who see the uninsured and undocumented will end up paying for the treatment or refer to the county hospital.



# The System is Not so Easy for Uninsured U.S. Citizens

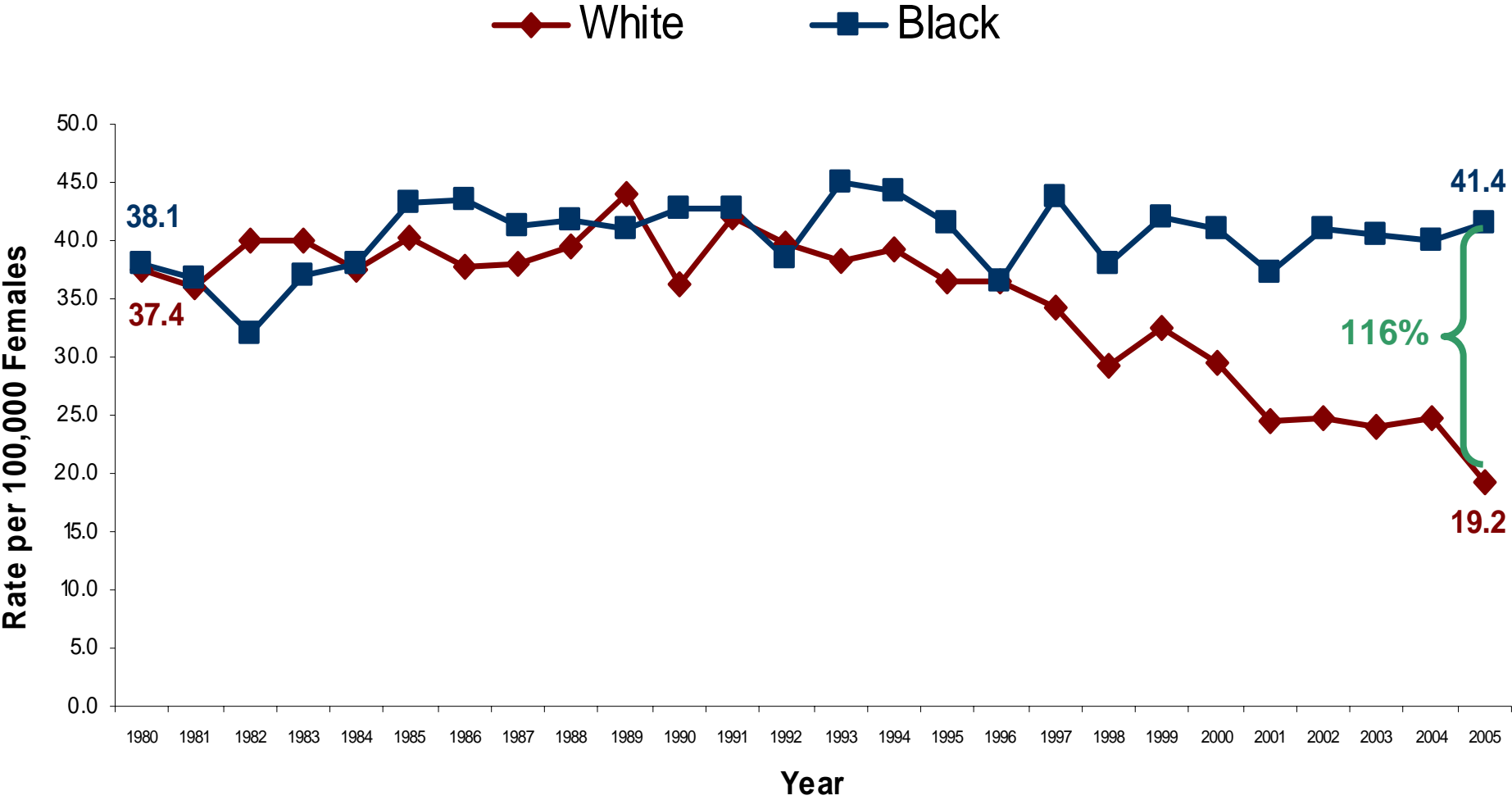
- The Treatment Act is not comprehensive.
- A woman can get treated for Breast Cancer, but if she needs to be treated for underlying chronic conditions...
  - She's ONLY eligible to receive treatment related to the breast cancer.
  - She must pay for her other ailment treatments out of pocket
    - If she could not pay to be treated before she had breast cancer how will she pay for it after the diagnosis?



# What's the problem?

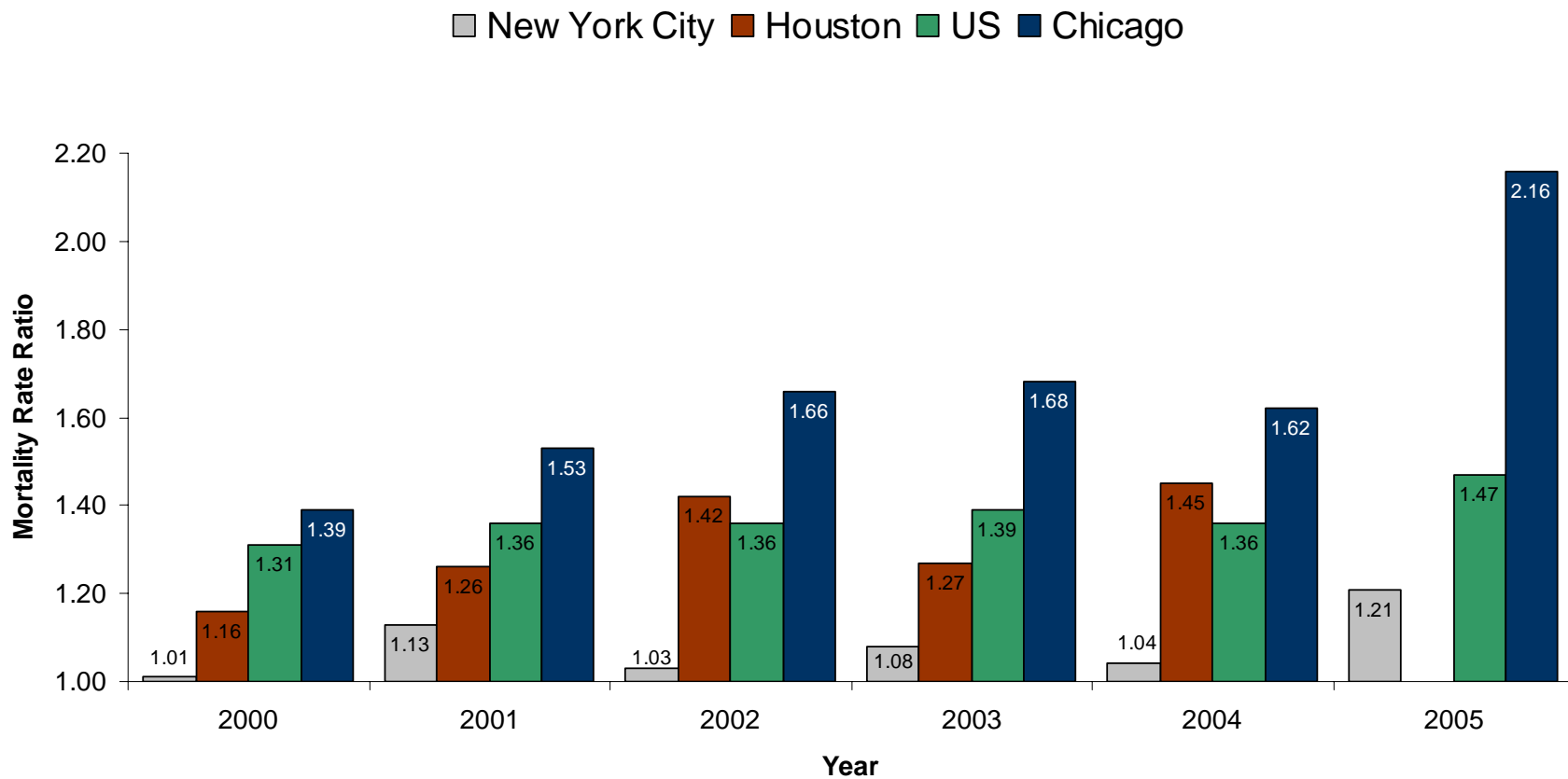
## Breast Cancer Disparities in Chicago

# Black and White Breast Cancer Mortality, Chicago, 1980-2005





# Black:White Rate Ratios for Breast Cancer Mortality, New York City, Houston, US and Chicago, 2000-2005





# Use of Mammography

- Often we use self-report as a measure of utilization and/or need...
  - But studies are clear that self-report is not accurate.

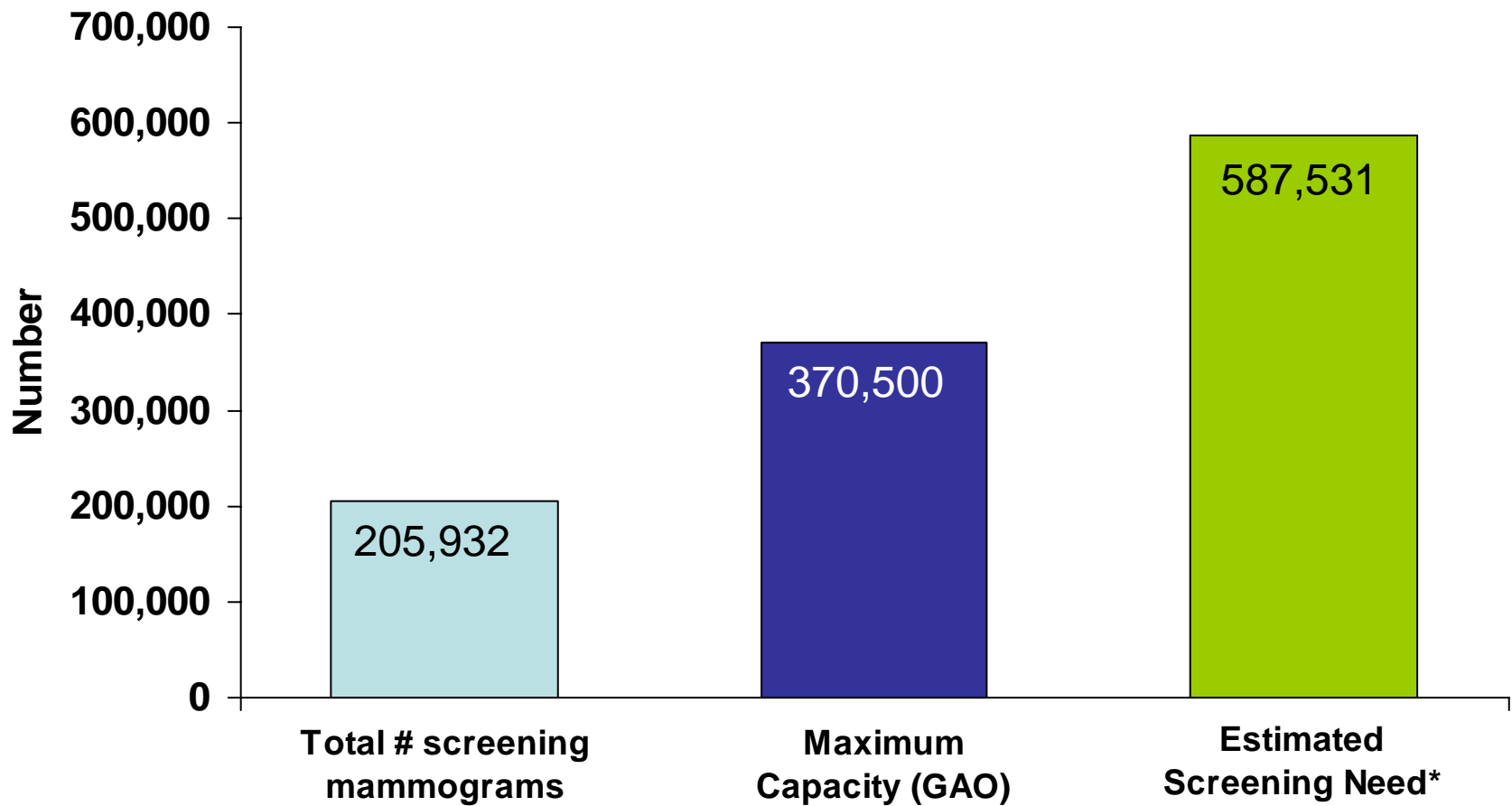
Table: Meta-analysis results observed vs. adjusted mammography use in the last 2 years.

Rauscher, et al. *Cancer Epidemiol Biomarkers Prev* 2008; 17(4)

	Reported Use	Adjusted Use
White	72%	58%
Black	68%	37%
Hispanic	61%	28%



# Screening Capacity In Chicago (2007)



\*Estimates of need based on 2000 US Census of women over 40 yrs old



## In Addition...

- Obtaining a diagnosis for breast cancer is difficult for any woman.
  - Mammograms are hard to interpret.
  - Mammograms do not detect every cancer.
  - There are many necessary medical appointments needed in order to diagnosis a cancer.
    - And many areas where a woman can get lost in the system.





# A Possible Solution

## Patient Navigation

- What is Navigation?
- Helping Her Live~Outreach Navigation
- Sinai's Clinical Navigation



# Navigation

- A navigator is the bridge between the health care providers and the patients.
  - Typically, a navigator comes from the community s/he serves.
  - Wants to help his/her community.
- The purposes of any of navigation includes:
  - Link women into a medical home.
  - Reduce loss to follow-up.
  - Improve timeliness of services.
  - Eliminate barriers to making appointments.



# Types of Navigators

- Outreach Navigator
  - Meets clients where they are in the community.
  - Promotes early detection.
  - Links people into a medical home.
  - Promotes programs for low or no cost cancer screening programs.
- Clinical/Diagnostic Navigator
  - Resolves abnormal findings in a timely manner.
  - Eliminates barriers to making diagnostic appointments.
  - Provides support during and after procedures.
  - Obtains comparison films or medical records from other facilities.



# Types of Navigators - 2

- Oncology/Treatment Navigator
  - Eliminates barriers to making treatment appointments.
  - Provides support and information.
  - Links to social support programs and/or agencies to assist with wigs, make up.
- Financial Navigator
  - Removes the financial barrier.
  - Determines eligibility and financial needs for assistance programs.
  - Enrolls patients into programs to pay for relevant medical services.



# Patient Navigation Activities

- To facilitate screening, diagnosis and treatment of breast cancer in a timely manner.
  - Meet people where they are to talk about breast cancer.
  - Schedule appointments.
  - Support women at doctors' offices or during procedures.
  - Ensure that women receive their results.
  - Walk patients from place to place.
  - Eliminate any controllable barriers.
  - Educate patients.
  - Facilitate patient centered care.
  - Acquire outside comparison films or records.
  - Assist in obtaining referrals.
  - Support the family.



# Why We Need Navigators

- Minority and poor women have additional barriers to receiving medical care.
  - Child care, transportation, seeing loved ones die from breast cancer, fear, misconceptions, unfair treatment when they do go to receive medical services, medical deserts and the list goes on...
- The system is a maze and staff are often overburdened in some facilities.
  - Diagnosing/Treating breast cancer is difficult.
  - People get discouraged and frustrated and give up.



# Timeliness Disparities: Inadequate Communication of Results

- Black women receive inadequate communication of mammography results compared to White women.
- Black women are more likely to receive results in-person than White women.
  - Jones, et al. *AJPH*, 2007; 97.



# Timeliness Disparities: Diagnostic Testing

- Diagnostic testing (after abnormal screening):
  - ~1/3 of Black women were without a diagnosis after 3 months, and ~1/4 were without a diagnosis within 6 months.
    - Kerner et al. *Prev Med*, 2003; 37.
- White women initiate diagnostic testing twice as fast as Black women
  - Black women 15 days vs. White women 7days.
- White women reach a final pathologic diagnosis faster than Black women
  - 74 days for Black women vs. 59 days for White women.
    - Elmore et al; *Med Care*, 2005; 43.



# Disparities in Stage & Survival

- Black women have fewer Stage I cancers than White women.
- Survival rates for Black women are lower at every stage of diagnosis than White women.
  - Chu, et al. *Cancer*, 2003; 97.



# Timeliness Disparities: Breast Cancer Treatment

- More minority women have treatment delays of 1+ month compared to White women.
  - Gorin et al. *Arch Intern Med*, 2006; 166.



# Why is timeliness so important?

- A delay of 3 months can decrease survival by 12%.
  - Richards et al. *Lancet*, 1999; 353.



# Helping Her Live:

## A Local Outreach, Education and Navigation Program

Addressing Breast Cancer  
Disparities **Outside** of the Health  
Care System



*Gaining Control of Breast Cancer  
Tomando Control Sobre El Cáncer Del Seno*



# Baseline Survey

*Mar 2008 – Jun 2008*

- Twelve interviewers surveyed 2,200 women
- Age  $\geq 40$  yrs living in Humboldt Park and North Lawndale
- About mammography history, access to services, barriers to care
- At numerous different venues:
  - Humboldt Park – 120 different venues
    - *Grocery stores, Senior facilities, Community Based Organizations*
  - North Lawndale – 64 different venues
    - *Local businesses (e.g., Walgreens), Senior Facilities, Laundromats*



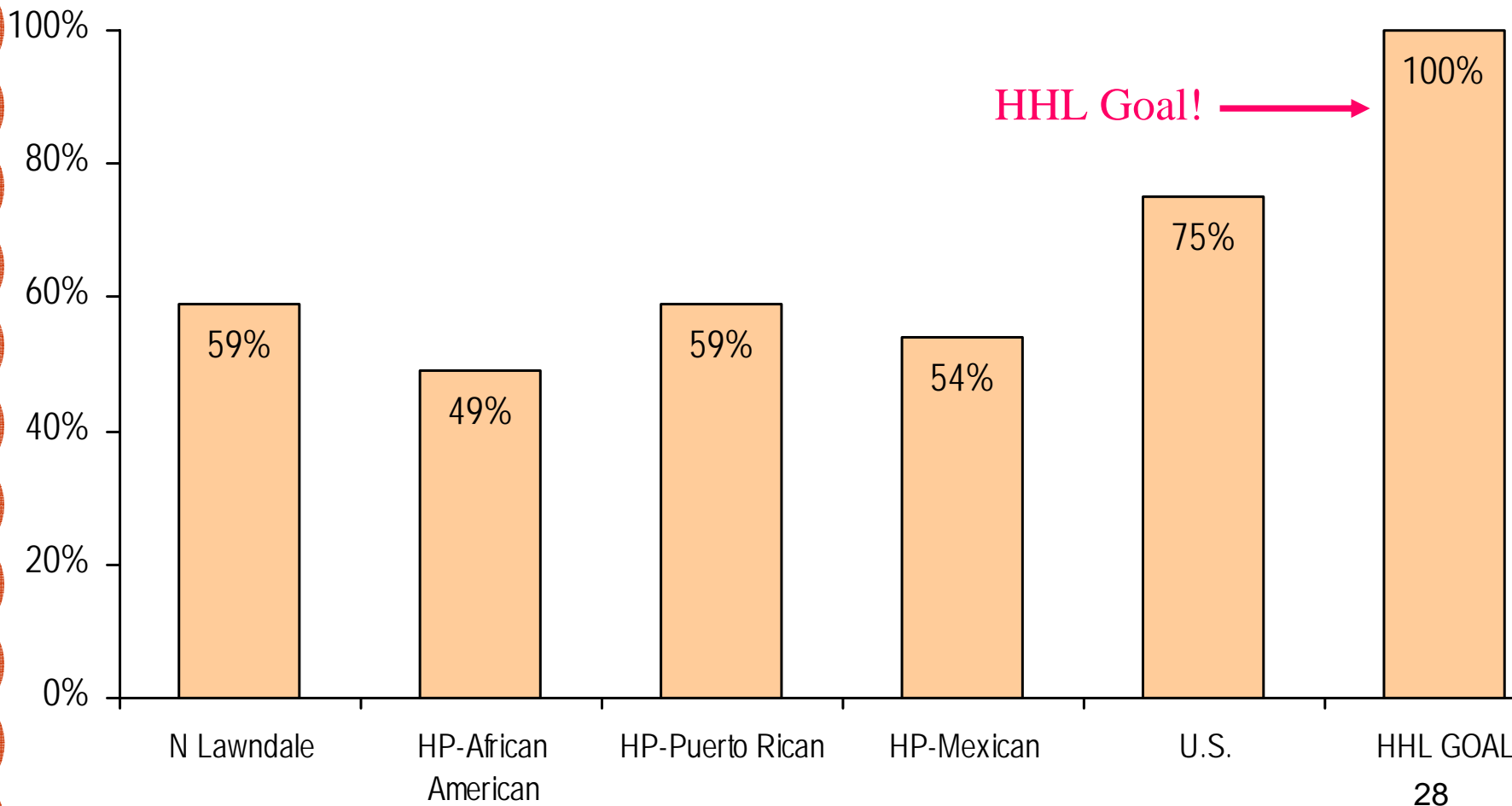
# Survey Results

- 70% of the women surveyed had insurance (compared to 86% of the US).
  - The Mexican community reported that only 50% of women had insurance.
- Yet most women (94%) report having a usual source of care.
  - Thus were able to obtain referral for a mammogram.



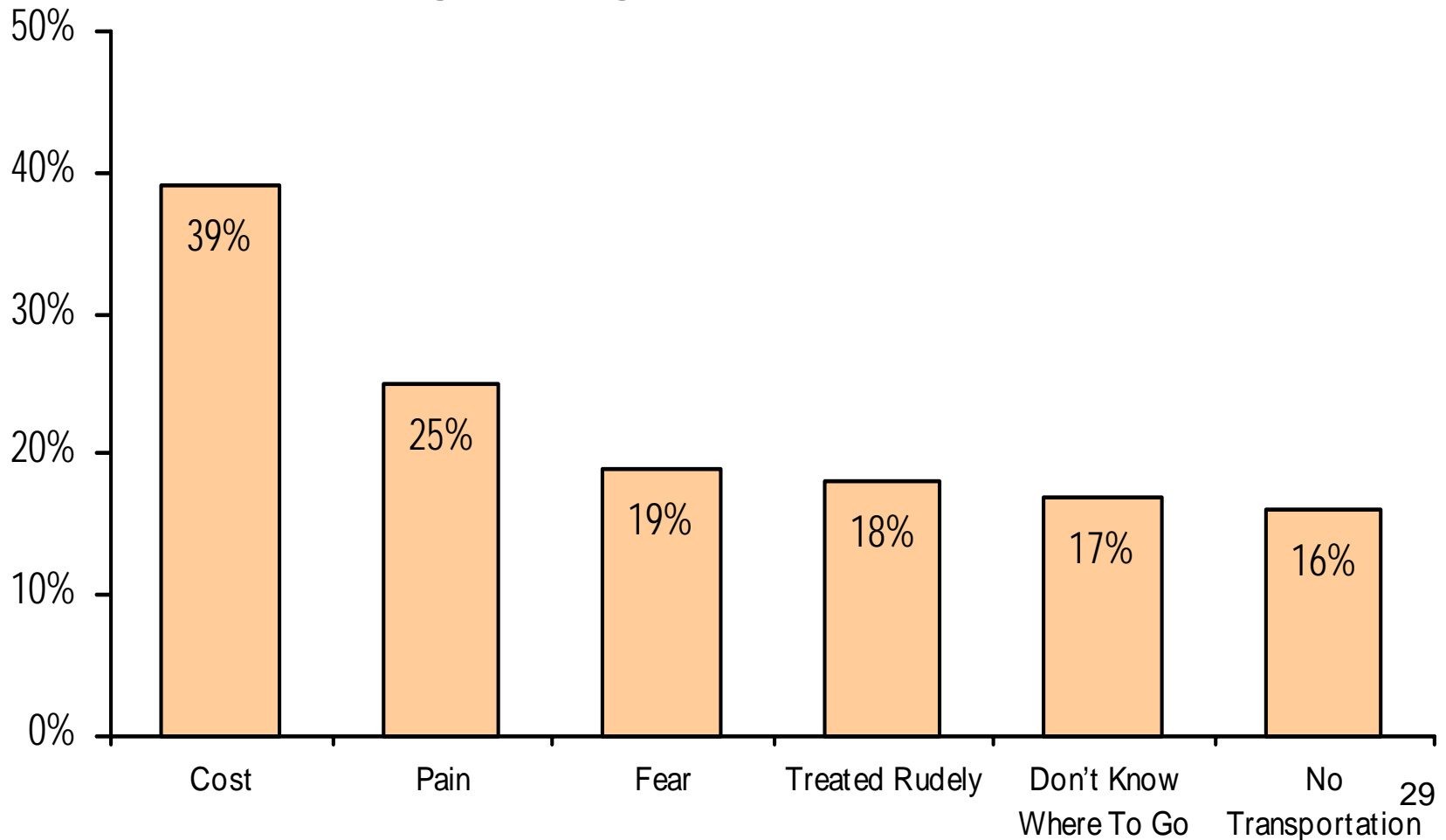
# Are women getting screened routinely?

*Proportion of women who were screened in the last 2 yrs*





# Among those who NEVER had a mammogram, TOP REASONS for not getting one





# Helping Her Live Goals

- Be an effective MODEL of *community navigation* in low resource settings
- Reduce disparities and improve overall breast health outcomes for all women in these two Chicago communities
- Increase routine mammography and timely receipt of results, resolution of diagnostics and access to treatment, when needed \*

\* Most measurable and feasible for 3 yr project



# HHL Program:

## *Two Primary Activities*

- **Client Services**
  - Navigating them thru services
    - Providing transportation
    - Ensuring timely follow-up & receipt of results
    - Reminders
    - Same day services
- **Outreach**
  - Navigating women from the community TO services
    - Engage with the Community.
      - Through workshops, community events/forums...
    - Build Partnerships with other organizations.



# Evaluating Client Services

*Oct 2008 – Oct 2009*

- 1105 HHL Clients
  - 420 PCP appointments
  - 189 mammogram appointments
  - Mail bus cards/set up transportation van~177 visits
  - Go with women for their appointments~72 visits
- Client Profile:
  - 78% are  $\geq 40$  yrs
  - 54% are uninsured
- Requests come mostly from Outreach (76%)



# Outreach Activities

*~We go where the women are*

- Workshop Presentations
  - At women's homes, public places (e.g., libraries), senior facilities, churches, etc...
- Variations of the Workshop
  - Health Fairs
  - Canvassing women where they live on main thoroughfares
  - Community Events
    - Puerto Rican Parade (June 2009)
    - HHL Walk as part of Open Streets (Aug 2009)
    - Community Forums (Oct 2009)



# Outreach Evaluation: *Workshops*

- 258 Breast Health Awareness Workshops
  - 2,642 Workshop Participants
  - ~ 21% requested HHL Services
- Workshop Participant Profile
  - 90% (n=617) are  $\geq 40$  yrs; about half (53%) are uninsured
  - 21% never had a mammogram and about half had a mammogram within the last 2 yrs
- Women gain knowledge about cancer risks, importance of routine screening and timely treatment.



# HHL as a Model for Other Community Navigation Programs in Chicago

- Workshop training for other navigation programs.
- Client database and management.
- Evaluation and tracking forms.
  - All of the programs are local and receive Avon funds.



# Navigation

Addressing breast cancer disparities from within the health care system



## *Navigating to Better Breast Health At Mount Sinai Hospital*

*Please call 773-257-1875 to speak with one of our Navigators*

*We can help by:*

- Navigating through the hospital to your appointments*
- Providing one-on-one support in English or Spanish*
- Helping make appointments for breast health services*
- Providing breast health education*
- Assisting you in obtaining prior mammogram films*
- Participating in community outreach*

*With a generous award from the Avon Foundation we can assist you with all of your breast health needs including appointments for:*

- Mammograms*
- Ultrasounds*
- Breast biopsies*
- Breast cancer treatment*



A proud member of Sinai Health System

**Don't delay!**

**We are only a phone call away!!**

**Call us at 773-257-1875**



# What We Knew Before Navigation Began.

- The death rates of breast cancer were high, and our hospital serves predominately Black and Latino women.
- The follow-up and timeliness rates were unacceptable.
  - 13% of those with Suspicious findings did not return for a diagnosis at our site or any other facility.
  - 23% did not receive timely treatment.
- The no-show rates in our mammography center were over 40% every day.

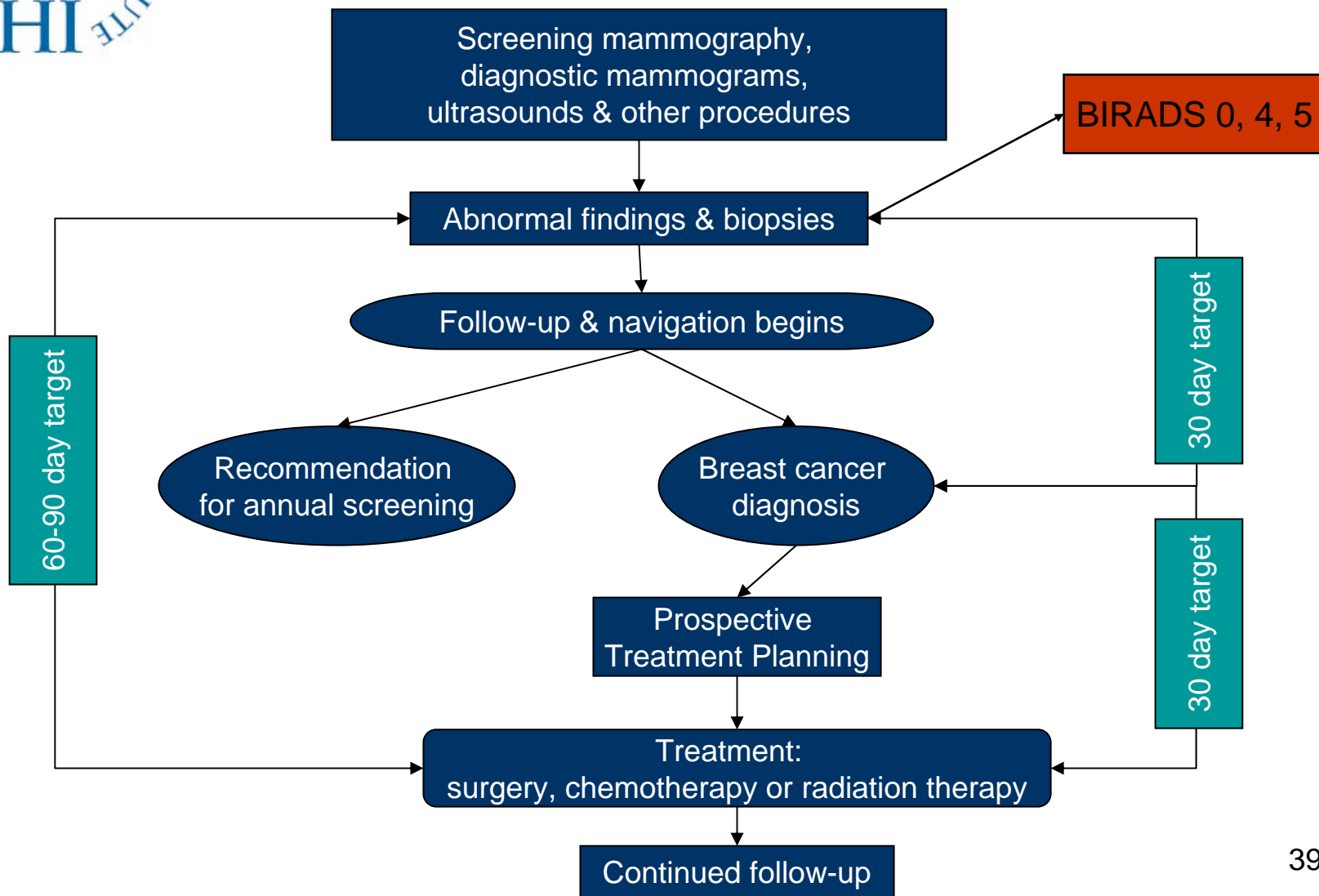


# Navigation Project Goals:

- Decrease loss to follow-up.
- Expedite follow-up for diagnosis & treatment
  - Communicate results to PCP, facilitate the referral process for additional services.
  - Ensure an appointment is scheduled and it is communicated to the patient.
  - Contact patients for missed follow-up appointments.
  - Acquire comparison films upon request.
  - Reduce patient barriers to making appointments.
- Navigate patient through diagnosis and treatment.



# Navigation Program Project Flow





# Evaluating our Navigators

- Hospital level data/tumor registry.
  - Lost to follow-up
  - Timeliness
  - Treatment recommendations and completion
- Hand collected data
  - Time spent doing navigation activities
  - Follow-up at other facilities



# Loss to Follow-Up (LFU): Screening Mammograms

Measure	Goal	2005	2006	2007	2008
LFU for BIRADS 0 • Recommended Immediate Follow-up	<10%	33%	18%	8%	8%
LFU for BIRADS 4 & 5 • Suspicious for & likely cancer	<10%	7%	4%	0%	10%

The goal is of course 0%, but a reasonable loss to follow-up rate should be <10%.



# Timeliness of diagnosis & treatment

Measure	Goal	2005	2006	2007	2008
Median # of days between abnormal screening and initiation of treatment	<b>60 days</b>	40 days (0-266)	45 days (11-356)	64 days (13-364)	73 days (39-353)
Median # of days between diagnosis and initiation of treatment	<b>30 days</b>	28 days (3-283)	17 days (4-365)	20 days (0-105)	40 days (26-67)

**Even navigators face barriers when working within the system!!!**



# Breast Cancer Follow-Up

	2005	2006	2007	2008
• Treated at Sinai	60%	83%	81%	82%
• Deaths	4%	2%	0%	0%
• Treated at other facilities (Lost to Sinai)	12%	6%	19%	9%
• Refused treatment	6%	0%	0%	9%
• <b>Loss to follow-up after diagnosis: Unable to contact</b>	<b>22%</b>	<b>8%</b>	<b>0%</b>	<b>0%</b>



# Top 5 Lessons Learned



# Lesson 1: Listen to the Women

- Townhall meetings & community forums have been essential to tailoring our programs in Chicago.
  - Women spoke to us at Townhall meetings about their experiences navigating the health care system for breast health.
  - Women and men come to community forums pleading for help.
    - Both types of meetings revealed that the system was not working for all women.



# Lesson 2: Outreach = Time + Energy

- Have to connect to the community.
  - Find CBO's and make partnerships.
  - Be honest about what you can offer the organization/client.
  - Do what you say you will do.
- Be persistent and patient.
  - Sometimes the organization needs to get to know you, once they do they will open up to your service.
- The word will get out.



## Lesson 3: Navigators also have Barriers

- Since navigators bridge gaps between PCP, radiologists, oncologists, technicians....and patients, often navigators receive push back along the diagnostic pathway.
  - This adds time to the diagnosis.
- Our navigators have been removed from department by security and been written up in Human Resources because they are persistent and strong advocates for the patients needs.



# Lesson 4: Programs Need to be Focused

- Navigators cannot do everything.
  - Facilities have staff to file records, find on-site films, send reminders for appointments, process films...
  - Navigators should not be responsible for tasks that already have a designated staff member.
    - In a resource poor environment this is very important to prevent.
- Most importantly, the navigators must know when their job begins and ends.
  - From the community to the medical center/screening.
  - From an abnormal mammogram to recommendation of annual screenings or breast cancer diagnosis.
  - From the start to the end of treatment.



## Lesson 5: Evaluation is Essential - 1

- All too often programs do great things, but the evaluation is weak, or the results are never published.
  - When designing HHL an our in-house navigation project, we found very little in the literature about outcomes, data collection or evaluation and tracking clients.
- So we had to make our best guess.



## Evaluation is Essential - 2

- HHL tracks every aspect of what they do.
  - # of workshops and/or community events.
  - # of clients who want services.
  - # of clients who actually get services.
  - # of contacts needed to get women in to each service.
- The Navigation Program in house tracks activities, and we request clinical data from the hospital.



## Evaluation is Essential - 3

- Programs need to understand the data.
  - Everyone who does any type of navigation should know the epidemiology of breast cancer in the communities they serve.
    - Breast cancer incidence and mortality.
    - Breast cancer disparities-do they exist?
  - Finally, how are the program outcomes related to eliminating the disparity.



# Thank you for listening!

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