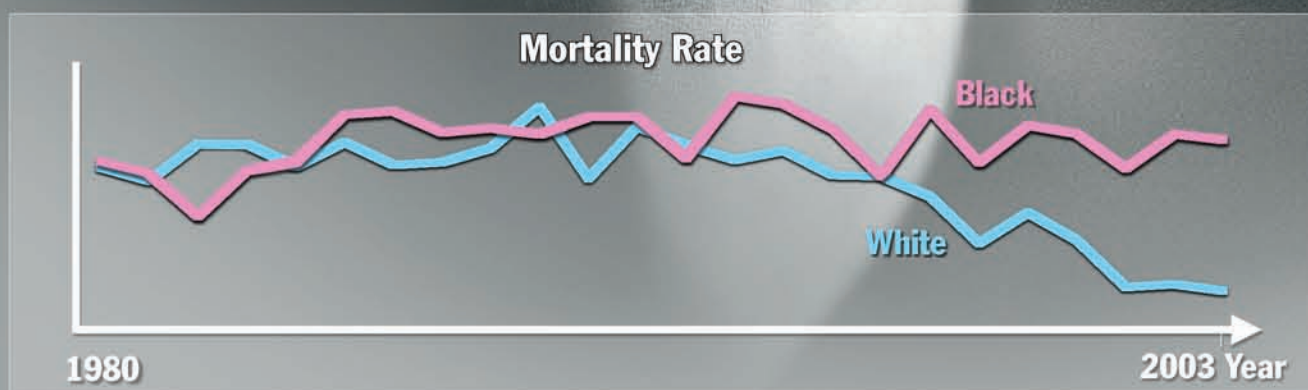


Improving Quality and Reducing Disparities in Breast Cancer Mortality in Metropolitan Chicago



A Report Prepared by the Metropolitan Chicago Breast Cancer Task Force

October 2007

***This report is dedicated to all the women and their families
in Metropolitan Chicago who have been impacted by breast cancer.***

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Improving Quality and Reducing Disparities in Breast Cancer Mortality in Metropolitan Chicago

Prepared by

Metropolitan Chicago Breast Cancer Task Force

October 2007

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Letter from the Metropolitan Chicago Breast Cancer Task Force Co-Chairs

As you know we have accepted being co-chairs of the Chicago Breast Cancer Task Force. In addition we presided over the first “call to action” and set up various groups to examine data and the issues confronting the disparity in breast cancer mortality in Chicago for Black and White women. In 1980 breast cancer mortality rates for White and Black women were equal. Since then, however, the rate for White women has declined substantially while the rates for Black women have not declined at all. Therefore, we must organize our care delivery system properly so that we can achieve the same improvements in Black women as the improvements in cancer mortality achieved by White women.

This would be so important. But even more is possible. If we as a city can achieve the highest quality of breast health, we will not only reduce the Black mortality rates but also improve outcomes for all women in the city. This must be our ultimate goal. All three of us agree that this goal is obtainable. And we need to do it now.

The work of the Task Force has been a process of steady progress. At the October 2006 press conference that announced these shocking disparities, the concept of the Task Force was introduced and the three of us were announced as co-chairs. We also stated then that we would soon hold a Summit to initiate the work of the Task Force. This Summit took place in March of 2007, and was an enormous success as over 200 people spent the entire day deciding on next steps. Three Action Groups were formed that day, met for the first time, and sketched out their future work. It was also agreed that we would present a report on our work to the public in October 2007. This is the document that you are now reading.

During the past six months the Task Force has worked with incredible dedication, energy and intelligence. Although no one was paid for doing this work, the three Action Groups met regularly, often long after “regular working hours” had expired, wrote many thousands of words, prepared presentations for each other, did an enormous amount of research, and came up with a plan. It is a plan devised by breast cancer survivors, radiologists, advocates, CEOs and many more Chicago residents who believe in equity in health and that the highest quality of health care should be available to every person in the city.

As proud as we are to have chaired such a process, and as pleased as we are with this report, it is sobering and crucial to understand that the real work is just beginning. This Report delineates those steps which much be pursued for us to accomplish our goals of excellence and equity in breast health for the women of Chicago. Both are mandatory – excellence without equity is unfair and equity without excellence is nothing.

We invite you to join us in this process. Only if we all participate can this plan become a reality. The women of our city deserve no less.

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Executive Summary

INTRODUCTION

The Metropolitan Chicago Breast Cancer Task Force was formed in response to a report from the Sinai Urban Health Institute describing the growing Black:White breast cancer mortality gap and from other published research regarding breast cancer in Chicago. The Task Force held a founding Summit on March 23, 2007, which was attended by more than 200 concerned advocates and professionals and received wide media coverage, including spots on more than a dozen radio and television stations and prominent newspaper articles.

The morning of the Summit featured speakers discussing issues related to three key hypotheses (Box 1) proposed to explain the growing breast cancer disparity in Chicago. In the afternoon, the participants divided into three Action Groups focusing on the three hypotheses. These Action Groups, comprised of over 100 people in all, met regularly from March until mid September to explore these hypotheses and prepare this report.

Background: Disparities in Breast Cancer Mortality in Chicago

The main findings stimulating this work are presented in Figure 1. As can be seen, breast cancer mortality rates were the same for Black and White women in Chicago in 1980 (at about 38 per 100,000 women, age adjusted). Rates stayed more or less equivalent until the early 1990s when they began to diverge. By 2003 a large disparity is evident, with the Black mortality rate (40.4), 68% higher than the White rate (24.0). Thus, since the period of equality in 1980, a huge disparity opened up by 2003. This means that in those 23 years in Chicago, Black women experienced no improvement whatsoever in breast cancer mortality.

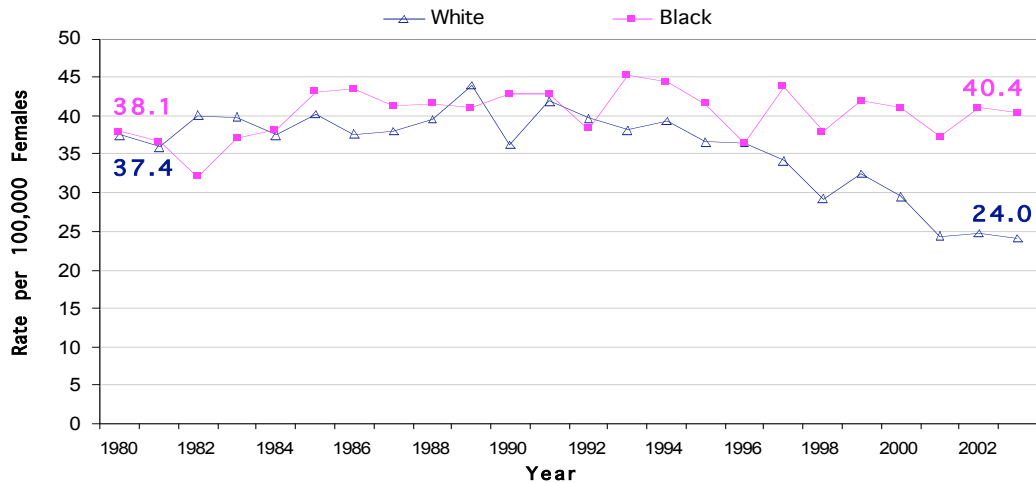
A table presented in the Introduction to this Report shows the dramatic increase in these disparities in recent years. The accompanying bar chart shows that the most recent difference between Black and White women in Chicago was 68%; whereas it was only 11% in New York City and 37% for the entire country. Furthermore, the figures for New York City and the U.S. have been rather constant since 2000, compared to Chicago's rapidly widening disparity.

It is important to note that the disparities seen in Chicago are not the result of biological differences in breast cancer between Black and White women, although recent studies have noted that there is biological variability in the presentation of breast cancer. The comparisons with New York City and the entire U.S. make it clear that biology cannot be blamed for the disparity in mortality rates in Chicago. We suggest the answer lies in the system – a system of care in Metropolitan Chicago that has failed in the most basic of ways to preserve the health of Black women. The system must be repaired, and this may best be accomplished by focusing on the recommendations in this Report offered by the Task Force.

Box 1. Three Hypotheses Explaining Breast Cancer Disparities

1. Black women receive fewer mammograms;
2. Black women receive mammograms of inferior quality; and
3. Black women have inadequate access to quality treatment once a cancer is diagnosed.

Figure 1. Black and White Breast Cancer Mortality Rates in Chicago, 1980-2003



Based on many years of work in this field, on the data presented in the publication, and on an extensive review of the literature, the Task Force posits three main hypotheses that could explain the racial disparities in breast cancer mortality in Chicago (Box 1).

This Report is organized according to these three hypotheses. Decisive action must be taken now. This is the view of our Task Force and the purpose of this Report.

CHAPTER 1. Access to Mammography

After correcting for bias in self-reported data, it is estimated that 70% of White women in Chicago over the age of 40 have received a mammogram in the last 2 years, as compared to 55% of Black women. Because early detection is essential to reduce breast cancer mortality, the Task Force strongly supports the elimination of barriers to equal access to mammography and other diagnostic services for all women. These barriers are identified in this Report, along with associated recommendations to remedy the problems.

Barriers to Access to Mammography

Based on a comprehensive literature review, landmark studies conducted at both the University of Illinois at Chicago and the University of Chicago, and feedback from our Town Hall meetings, we identified the following barriers to obtaining breast cancer screening. Each is described further in the Report:

- Cost of screening and diagnosis, including lack of insurance, rejection of Medicaid because it pays too little, and out of pocket expenses
- Inability to navigate the medical system, particularly the complex web providing breast health care to women without insurance
- Lack of knowledge about where to obtain a no-cost or low-cost mammogram
- Distance to providers of no-cost or low-cost mammography
- Lack of trust in health care providers and institutions
- Fear and anxiety
- Cultural beliefs and misconceptions about breast cancer

- Language and health literacy issues
- Work and family responsibilities

Interventions to Overcome These Barriers

In an effort to overcome these barriers, advocates, researchers, and health care providers have tested a wide variety of interventions. Many have proven to be successful. After listening to the experiences of women who attended the Town Hall meetings and studying more than 100 articles in the field, we have identified the following interventions that have demonstrated effectiveness in overcoming the barriers cited above:

- Mitigating the costs associated with mammography through safety net programs, improvement in insurance coverage, the elimination of co-pays, etc.;
- Assuring that mammography sites are geographically distributed and not just concentrated in affluent sections of the city and suburbs;
- Helping providers to be more welcoming to women seeking breast screening as many women report racist behaviors towards them as well as other forms of disrespect;
- Encouraging physicians to recommend mammography screening to their patients by using computer reminders, post cards, notes placed in charts, etc., to substantially increase mammography use;
- Using patient advocates and navigators to help overcome barriers such as language, health literacy, logistics, and fear. They should come from the community, be culturally sensitive, and have personal experience with breast cancer, for example breast cancer survivors;
- Addressing entire communities through education and awareness programs to improve and enhance the understandings of breast cancer and screening mammography.

The most critical need is to remove the financial barriers to screening and diagnosis. The cost of a mammogram must be eliminated as a barrier to breast health. This, in concert with the additional recommendations, will allow us to narrow and even eliminate the racial and ethnic disparities in access to breast cancer screening. All that is needed is for us to marshal the will and the resources to implement what has already been demonstrated to be effective.

The Capacity of Mammography Availability

We posed the following question: If all the age-eligible women decided to get mammograms as recommended by the guidelines, would the Chicago metropolitan area have adequate capacity to provide them? Although we could find the names of the mammography providers, we found little additional information to allow us to answer this question. We thus contacted the institutions that provide mammograms to women living in Metropolitan Chicago and asked them to complete a comprehensive survey. We were able to locate 87 such institutions and obtained responses from 82% of them. Based upon these data, and for the first time in Chicago as far as we know, we have an estimate of current capacity for screening mammography of 207,000 women, with a maximum potential of 384,000. Both of these are far smaller than the number of mammography age-eligible women in Chicago - 588,000 women according to the Census.

We also found that there are differences in access to mammography and diagnostic follow-up services that favor White women in Chicago. The largest difference by far appeared to be with respect to access to a breast imaging specialist when having mammograms interpreted. Prior research has shown that breast imaging specialists tend to do a better job interpreting mammograms. We also found large differences in access to factors related to better image quality (digital mammography) and timeliness of follow-up (same day mammogram readings). Overall, these results suggest that differences in image

quality, interpretation quality, and timeliness of follow-up of a suspicious mammogram finding may be contributing to the greater breast cancer mortality for Black women as opposed to White women in Chicago.

CHAPTER 2. Quality of Mammography

The second of our three hypothesized causes for the racial disparity in breast cancer mortality involves the quality of mammography. Specifically, it is known that the quality of mammography varies considerably and we suspect that it is often inferior for Black women. This would result in, among other things, missing small tumors and thus losing the opportunity to successfully treat them. This hypothesis is supported by a growing number of anecdotes and data collected here in Metropolitan Chicago. The issue then becomes: How can we improve the quality of mammography for all women and thus help eliminate the disparity in breast cancer mortality? We were able to delineate four main aspects of this issue.

The Need to Report and Evaluate Measures of the Quality of Mammography

Although the American College of Radiology recommends that measures of the quality of mammography process be collected and reported, very few mammography centers in Metropolitan Chicago do this. We think that it is imperative for such data to be gathered, examined, and then used for continuous quality improvement. Although there are about a dozen such measures, we suggest that four of these are most essential: (1) the number of cancers detected for every 1,000 screening mammograms, with a benchmark of 6 or a rate of 0.006; (2) the proportion of detected cancers that are less than 1 cm in size, with a benchmark of 30% or more; (3) the proportion of cancers detected at an early stage of 0 or 1, with a benchmark of 50% or more; and (4) the proportion of women with an abnormal mammogram who are lost to follow-up, with a benchmark of 10% or less.

Workforce Issues

It is well established that radiologists who specialize in mammography and read primarily mammograms in their practice are significantly better at identifying small, early stage cancers. As is the case in the rest of the country, Chicago has too few of these expert mammographers. Not surprisingly, these experts tend to work at large university facilities rather than the safety net institutions that serve poor women and women of color.

Diagnosis and Follow-Up Communication

After a woman's mammogram is judged to be abnormal, she must return for diagnostic procedures as soon as possible to determine whether she has cancer. If she does have cancer, then treatment must be started in a timely manner. These issues of timeliness are crucial, because delays of several months can mean the difference between saving the breast with lumpectomy or removing the breast with mastectomy, as well as the potential for cancer to spread. Ideally, there should be no more than three months between the time of the abnormal mammogram and the start of treatment. Yet, data collected in Chicago showed that delays are frequently much greater than they should be for poor women. One technique that has been found to be effective in minimizing these delays and the loss of women to follow-up is the use of patient navigators. For example, at two Chicago institutions in which the loss to follow-up rates were over 25%, navigators have been able to reduce the loss to almost zero.

The Safety Net and Stroger Hospital

For good breast health care to be provided to disadvantaged women, it is essential that safety net institutions function well. There are several safety net institutions in Chicago and they function remarkably well considering the inadequate resources they are provided by our health care system. In Chicago, the center of the safety net is John H. Stroger Jr. Hospital of Cook County (a.k.a. Cook County). At the current level of funding, this hospital cannot possibly provide mammography for all the women who need it.

Nor is it reasonable to expect that one institution will ever be able to adequately serve all the health care needs for the financially disadvantaged in Cook County. In contrast, New York City has eleven safety net hospitals distributed throughout the metropolitan area to serve the health care needs of the disadvantaged.

CHAPTER 3. Quality of Treatment

In recent years, significant advances have been made in breast cancer treatment, so that it now is considered a curable disease. Nevertheless, studies have shown that higher percentages of Black women die from breast cancer than White women, even when their cancer is diagnosed at the same stage. The National Cancer Institute's Black:White Survival Study showed that 21% of Black patients failed to receive the minimum expected standard of care, as compared to 15% of White patients. Thus, our third hypothesized cause of the racial disparity in breast cancer mortality in Chicago is that Black women have reduced access to high quality treatment.

As this Action Group proceeded with its task, it became clear that the etiology for differences in treatment were complex and multi-factorial, resulting from variations in the treatment that a patient is offered, accepts, and receives. The group explored many issues that can contribute to decreasing the survival disparity in Metropolitan Chicago and focused on those that are amenable to change. Importantly, several themes emerged such as issues of access to care, socioeconomic factors, environmental factors, comorbid conditions, health literacy, cultural beliefs, and lack of trust in the health care system. All of these may play a role in affecting what treatment is actually received.

We were encouraged to find that there are many effective interventions that can overcome almost all of these barriers. Among these are:

- Expanding insurance coverage
- Improving proximity to treatment sources and increasing proximate access to specialists
- Providing and expanding availability of disability coverage
- Minimizing logistical barriers (transportation, childcare, etc.)
- Decreasing fragmentation in care and improving coordination of services
- Addressing issues of cultural beliefs, health literacy, and trust in the medical system
- Educating the public regarding breast cancer
- Educating providers regarding cultural barriers to care
- Decreasing the impact of comorbid conditions on breast cancer treatment/outcome

In addition, we need to create systems to measure and evaluate the quality of treatment provided across Metropolitan Chicago, in order to use this information for continuous improvement. Finally, we thought it would be essential to improve Cancer Registry Data by coordinating communication among registrars to improve treatment and follow-up measures, and we recommend working with the Illinois State Cancer Registry to streamline this effort.

The Appendices

One of the unique features of this Task Force has been a great deal of original work that we were able to accomplish even beyond our meetings and the written Report. Much of

that is presented in appendices of the Report. We would like to call your attention to these. They may be found at the end of our Report and on the website: www.chicagobreastcancer.org.

- Appendix A presents a detailed report of the capacity survey of Metropolitan Chicago mammography facilities, the first of its kind, as far as we know;
- Appendix B presents a summary of the four Town Hall meetings that were held in vulnerable communities across Metropolitan Chicago. Over 150 women came out to inform us, often passionately and in great detail, about their experiences in seeking breast health care;
- Appendix C presents details on creating a Metropolitan Chicago Breast Cancer Consortium, one of our most important recommendations;
- Appendix D presents the findings from a series of Focus Groups conducted with health care providers about the quality of mammography, detailing what is wrong and how to fix it;
- Appendix E presents an overview of how a Regional Health Information Organization (RHIO) works. Developing a RHIO in Chicago is a long-term goal but an important one;
- Appendix F provides a summary of research findings from Focus Groups with women conducted by the Center for Interdisciplinary Health Disparities Research at the University of Chicago;
- Appendix G provides a summary of interviews conducted with various health care providers on barriers women face in accessing treatment.

Our Recommendations

All of the work summarized above will only have meaning if we can use the information to improve the system of breast health care in Metropolitan Chicago and minimize disparities in breast cancer

mortality. Toward this end, we have formulated 37 actionable recommendations which, if implemented, will move us in this direction. The Recommendations follow in summarized form. Some are ready to be implemented today; others require further study and definition. For purposes of brevity, some of the individual recommendations in the Report have been blended into a combined recommendation here that fall into eight categories. Complete details are contained in the full Report. We also support the rigorous evaluation of the effectiveness of all the recommendations.

1) Access and Cost

Mammography and treatment for breast cancer must be available for all women in Illinois. Thus, cost must be removed as a barrier for screening and treatment. The Illinois Breast and Cervical Cancer Screening Program and the Stand Against Cancer Program need to be fully funded. The Cook County Bureau of Health Services needs to adequately fund breast cancer screening for its patients. State insurance laws need to be modified to eliminate co-pays and deductibles for breast cancer screening and treatment. Providers in Metropolitan Chicago will be asked to provide screenings and treatment in a coordinated manner to women in need.

2) Education and Outreach

There needs to be a combination of culturally relevant community education and outreach as well as targeted media campaigns to increase awareness about the importance of early detection and treatment of breast cancer. Culturally relevant educational materials need to be collected and distributed widely. Providers need to receive training in cultural awareness. Providers will be encouraged to establish systems to remind patients of the need for mammography. There needs to be one Metropolitan Chicago number where women can call to access screening and treatment services.

3) *Capacity*

A unique survey conducted by the Task Force revealed that there is not enough capacity (only about 65%) in Metropolitan Chicago to screen all the eligible women. Screening and treatment facilities for underserved women are limited and poorly distributed across the area. A blue ribbon committee will be assembled to address capacity issues for breast screening, diagnosis and treatment in Metropolitan Chicago and will report back by October 2008.

4) *The Quality of the Mammography Process and Quality of Treatment*

In order to improve the quality of mammography screening and breast cancer treatment across Metropolitan Chicago, a number of Chicago area health care organizations have agreed to create a Metropolitan Chicago Breast Cancer Consortium to identify, measure and share quality measures that have been shown to be important in breast cancer screening and treatment. A quality initiative will provide free consultations to institutions to improve breast cancer outcomes. All Metropolitan Chicago hospitals providing screening and treatment will be asked to voluntarily participate.

5) *Diagnostic Follow-up and Communication*

The mammography follow-up process is complicated and fraught with multiple breakdowns. Women need to be able to self-refer for breast cancer diagnostic tests and there needs to be a state law to allow this. There also needs to be a systematic manner in which diagnostic breast testing results are communicated especially because Black women are less likely to attend facilities where results are directly communicated. An expert panel will be assembled to make recommendations on diagnostic follow-up that can be adopted across Metropolitan Chicago. Timely access to breast diagnostic services must be made available by coordinating access to services at all institutions.

6) *The Healthcare Safety Net*

Vast gaps in the safety net have likely contributed to the breast cancer mortality disparity in Chicago. There is not enough capacity in Metropolitan Chicago to screen all the eligible women. Screening and treatment facilities for underserved women are limited and poorly distributed. The Cook County Health System cannot manage the volume of patients in need of diagnosis and treatment. The Task Force suggests that a public-private collaboration including strategic placement of digital screening facilities across the area, linked with a centrally located accessible state-of-the-art diagnostic and consultation center (staffed by experts) be established. This would provide a level of care currently not available to underserved women and could serve as a model to the nation. A blue ribbon committee will be assembled to address the feasibility of creating such a facility in Metropolitan Chicago and will report back by October 2008.

We also recommend that proven programs such as the use of navigators who help women get timely care should be implemented more widely.

7) *Mammography Specialist Workforce*

There is a limited workforce of trained mammography specialists in Metropolitan Chicago. We recommend expanding mammography specialty training within physician training programs. We also propose creating a “mini” fellowship to train general radiologists at safety net hospitals to improve the quality of their mammography readings.

8) *Illinois State Cancer Registry*

The Illinois State Cancer Registry needs to be enhanced to include breast cancer treatment data. It is currently under-funded and thus cannot provide adequate data on disparities in care in Illinois. This is an important deficit which needs to be remedied.

Introduction

In March of 2007, the Metropolitan Chicago Breast Cancer Task Force was formed in response to a report from the Sinai Urban Health Institute describing the growing Black:White breast cancer mortality gap, and much other published research regarding breast cancer in Chicago. The Task Force is chaired by three of Chicago's leading health care executives, Sr. Sheila Lyne, CEO, Mercy Hospital, Ms. Ruth Rothstein, former CEO of the Cook County Bureau of Health Services, and Donna Thompson, CEO of Access Community Health Network.

This group held a Summit on March 23, 2007, which was attended by more than 200 people including breast cancer survivors, advocates and activists, several medical center CEOs, radiologists, oncologists, surgeons, epidemiologists, and foundations including the Michael Reese Health Trust, the Avon Foundation, and the Susan G. Komen for the Cure organization. The Summit also received extraordinary media coverage, which included spots on more than a dozen radio and television stations and prominent newspaper articles.

The morning of the Summit featured speakers discussing issues related to three key hypotheses (Box 1) that could explain the growing breast cancer disparity in Chicago.

Box 1. Three Hypotheses Explaining Breast Cancer Disparities
<ol style="list-style-type: none">1. Black women receive fewer mammograms;2. Black women receive mammograms of inferior quality; and3. Black women have inadequate access to quality treatment once a cancer is diagnosed.

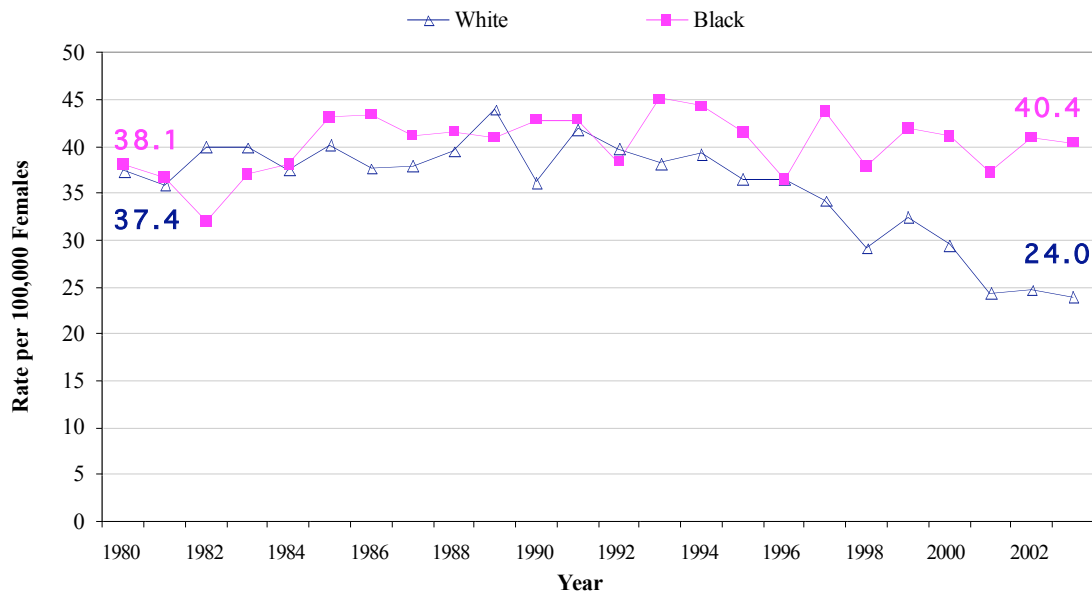
After lunch, the participants divided up into three Action Groups consistent with these hypotheses. The Action Groups, comprising over 100 people in all, met frequently from March until mid-September, often hearing formal presentations from experts in the field and other times engaging in energetic discussions. We held many subcommittee meetings, engaged with leading researchers, and assembled a great deal of epidemiological data. We also initiated several unique activities. Some examples of these are given here:

- We interviewed providers, lay people and advocates, cancer organizations, health system CEOs, and national groups concerned with breast cancer;
- We established a website for sharing relevant articles and posting schedules of meetings and minutes, etc. (www.chicagobreastcancer.org);
- We convened Focus Groups with general practitioners, radiologists, and mammographers;
- We held four Town Hall meetings around Chicago and in the suburbs;
- We conducted the first-ever survey of mammography capacity in any city in the U.S.

The list of all participants in the three Action Groups is included on pages iii-viii. As you can see, every sector of Metropolitan Chicago concerned with breast cancer is represented here. An unlimited amount of gratitude is due to these people who participated with only one thought in mind – to improve breast health in Metropolitan Chicago.

A composite report from these three Action Groups is presented here with specific recommendations for remedying the racial

Figure 1. Black and White Breast Cancer Mortality Rates in Chicago, 1980-2003



disparity in breast cancer mortality in Metropolitan Chicago. This report contains a series of recommendations with achievable goals that, if applied, can reduce the mortality gap in breast cancer. Supporting evidence for these recommendations is presented in three chapters, consistent with the proposed hypotheses (Box 1). Also included are detailed appendices summarizing research findings and highlights from the many activities of the Task Force.

This is an action report. The proposals contained in the following pages must be implemented soon. If implemented, they will improve breast health care for all women in Metropolitan Chicago and begin to eliminate the racial disparities in breast cancer mortality. If we fail to implement these recommendations, more women will die. It is now time for all of us in Metropolitan Chicago to work together and take action. We can and must do no less.

Background: Disparities in Breast Cancer Mortality in Chicago

In January of 2004, epidemiologists from Mount Sinai's Urban Health Institute (SUHI) published an article in the *American Journal*

of Public Health examining Black-White differences in health outcomes in Chicago as indicated by 14 measures of prominent health conditions.¹ They found that most of the disparities in these measures had grown worse between 1990 and 1998, a period during which disparities should have been shrinking, according to the Healthy People Initiative as summarized in *Healthy People 2000*.² One of the racial disparities that had increased the most during this interval was breast cancer mortality.

SUHI researchers, along with Dr. David Ansell, continued to pursue this issue of breast cancer mortality and in 2007 they published a paper concerned solely with breast cancer.³ The main findings of this paper are presented in Figure 1. As can be seen, breast cancer mortality rates for Black and White women were the same in Chicago in 1980 (at approximately 38 deaths per 100,000 women, age adjusted). Rates stayed more or less equivalent until the early 1990's when they began to diverge. By 2003, the Black mortality rate (40.4) was 68% higher than the White rate (24.0). Thus, from equality in 1980, a huge disparity opened up by 2003. This happened because during this

Table 1. Breast Cancer Mortality Disparities in Chicago, Recent Years

Year	Black Mortality Rate/100,000	White Mortality Rate/100,000	Disparity (Ratio)
1996	36.5	36.5	1.00
1999	42.0	32.5	1.29
2000	41.1	29.5	1.39
2001	37.3	24.4	1.53
2002	41.0	24.7	1.66
2003	40.4	24.0	1.68

interval the White rate declined (by 36%) but the Black rate actually increased slightly (by 6%). Thus, in those 23 years in Chicago, Black women experienced no improvement whatsoever in breast cancer mortality, despite the improvements in early detection and treatment experienced by White women in Chicago and throughout the U.S.

Table 1 presents mortality rates from recent years and one can see, in sobering detail, the steady growth of the racial disparity in breast cancer mortality.

Another glimpse into this racial disparity in breast cancer mortality can be seen in Figure 2, created for this Task Force Report. We have shaded in the 22 community areas (out of Chicago's total of 77) with greatly elevated breast cancer mortality rates. Note that 20 of these 22 areas are predominately Black, and most of them are almost entirely Black. This is indeed a stark example of inequality.

Because of this rapid rise in the ratio of rates, we also explored whether such a disparity was common in other parts of the country. Figure 3, also newly generated for this Task Force report and never before presented, provides the answer to this question. As can be seen, in recent years (between 2000 and 2004), the average Black:White disparity in breast cancer mortality was 9% in New York City and 35% for the U.S. as a whole. These data may be compared to 68% in Chicago for 2003, the last year for which data are available here. Thus, the disparity in

Chicago was more than seven times worse than in New York and two times as bad as for the entire country. Another startling observation is that while the disparities have been relatively flat in both the U.S. as a whole and for New York City, the disparity in Chicago has been growing. Taken together this information presents terrible news, but also suggests at the same time that it is possible to improve the situation in Chicago.

Based on many years of work in this field, on the data presented in the publication, and on an extensive review of the literature, the authors posited three main hypotheses that could explain the racial disparities in breast cancer mortality in Chicago.

Figure 2. Chicago Community Areas with the Highest 2001-2003 Average Annual Breast Cancer Mortality Rates

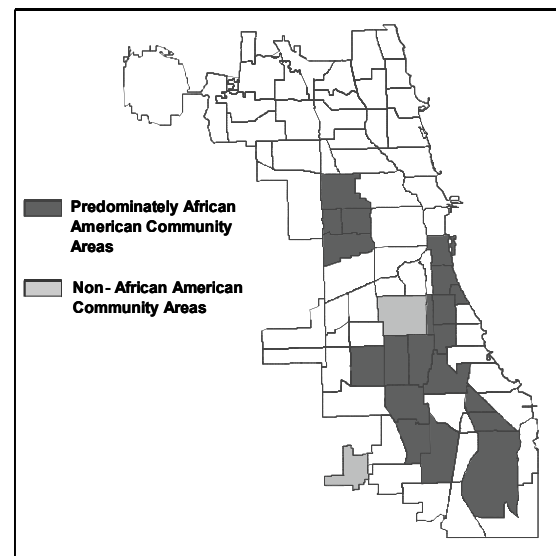
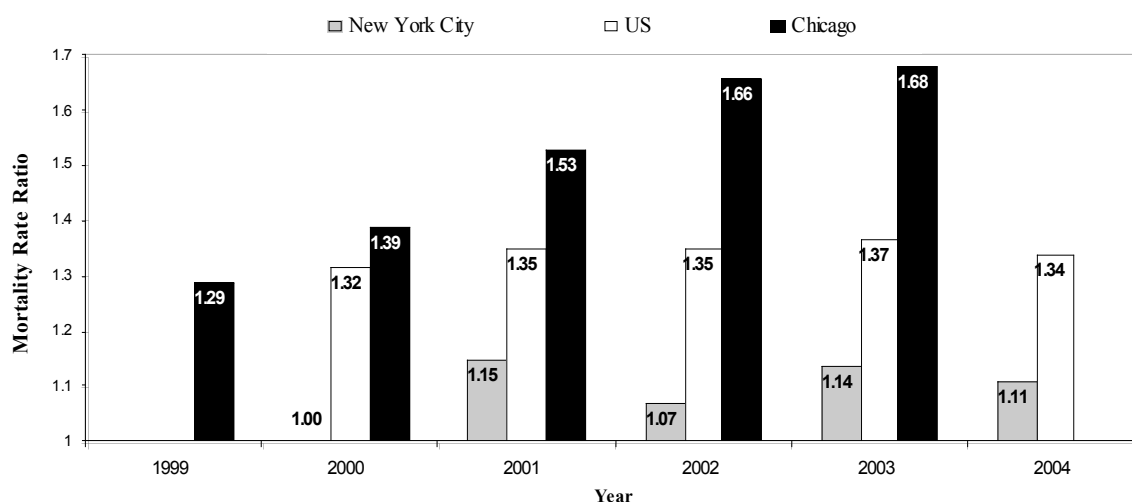


Figure 3. Black and White Disparities in Breast Cancer Mortality Rates in Chicago, New York City, and the United States, 1999-2004



It must be noted here that these data speak dramatically to the question of the role of genetics in generating the disparities in Chicago. Either there is no role or genetics plays a very minor role at most. How else could we explain the recent growth in disparities over the past 10 years and the huge difference in disparities among Chicago, New York City and the entire U.S.?

Clearly the answer lies in the system – a system of care in Metropolitan Chicago that has failed in the most basic of ways to preserve the health of Black women. The system must be repaired, and this may best be

accomplished by focusing on the recommendations of the Task Force in this Report. We urge you to read the Report, pay close attention to the unique appendices, and then get involved with us to help implement the recommendations.

Decisive action must be taken now. To paraphrase an old activist, “Analysts have only studied the world. The point, however, is to change it.”

David Ansell, MD, MPH
Steve Whitman, PhD

References

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- ²US Department of Health and Human Services. Healthy people 2000: National health promotion and disease prevention objectives. US Government Printing Office, Washington, (DC); 2001.
- ³Hirschman J, Whitman S, Ansell D. The Black:White disparity in breast cancer mortality: The example of Chicago. *Cancer Causes Control* 2007; 18:323-333.

Recommendations

The recommendations that follow, written by the three Action Groups of the Task Force, contain both specific Recommendations that we can start to implement today and some areas in which further study and investigation are necessary. This Recommendation section is divided into four parts. The first part is an overarching recommendation from the Task Force. The following three sections contain the specific recommendations of the three Action Groups.

SECTION 1. Establish the Office of the Metropolitan Chicago Breast Cancer Task Force

Since March 2007, this Task Force has been staffed by members of the Sinai Urban Health Institute as a contribution from the Sinai Health System, and by the volunteer work of hundreds of individuals from institutions across Metropolitan Chicago. The Task Force has also received major support from the Avon Foundation. All contributed support will end on October 17, 2007, the date of our Media Conference and the official release of this initial Report.

Action: To pursue the recommendations contained in this report will require that the Metropolitan Chicago Breast Cancer Task Force office be established and funded over the next three years. This includes hiring an Executive Director, an administrator, and providing office space and other administrative support.

The responsibilities of the Executive Director will include the following:

- To oversee the implementation of the Recommendations;
- To coordinate the work of the Study Groups that is proposed in some of the following Recommendations;

- To educate Metropolitan Chicago about the issues described in this report;
- To interact with state and local agencies involved in breast health work;
- To assure that all work done under the aegis of the Task Force is fully evaluated, widely disseminated and made transparent to all;
- To produce an annual progress report to the Metropolitan Chicago Breast Cancer Task Force;
- To assure that the grants that pass through the Task Force to other organizations (e.g., the Sisters Network or the Black Nurses Association) are administered appropriately and rigorously evaluated; and
- To pursue new grants and assure that they are administered appropriately.

The executive director will report to the Steering Committee of the Task Force. The Steering Committee will consist of three community representatives, the co-chairs of each of the Action Groups, and David Ansell, MD, MPH and Steve Whitman, PhD.

SECTION 2. Improve Access to Mammography

The following are recommendations to improve access to mammography in the Metropolitan Chicago area. Frequently the information we use in this section is pertinent to the city of Chicago only, since that was what was available to us. When we use data we note whether they are for the City of Chicago or the Metropolitan Chicago area. Some caveats are in order before setting out the recommendations:

- All aspects of breast health are linked to each other. For example, we gain nothing by providing access to mammography unless the quality of mammography is excellent. We also gain nothing if we provide access to excellent mammography but follow-up for abnormal mammograms and treatment are not available.
- We arrange the following recommendations into three categories: **Cost, Education and Outreach**, and **Capacity**. We realize that these matters are not entirely unrelated but such a presentation allows for clarity.
- We realize that there is a substantial array of techniques for breast cancer screening like clinical breast exams, breast self-exams, MRIs, etc. However, for simplicity all of the following recommendations are about screening for breast cancer with mammography. Of course, all techniques should be included when and where appropriate;
- This Report cannot serve as an operational or administrative document. Thus, when recommendations appear we are aware that details about such matters are omitted. These will be supplied as we pursue funding opportunities.

A. Cost

The cost of a mammogram must be eliminated as a barrier to breast health. As long as cost is a barrier, that will keep the women of Metropolitan Chicago from having the best possible breast health and will contribute to sickness and death. We therefore propose the following:

1. Mammography must be made available at no cost to all women who do not have health insurance. We understand that there must be a long-term solution for this coverage recommendation. There are several options for ensuring the success of this recommendation such as a federal or state plan for universal coverage for all residents and/or approval of a Medicaid waiver for Illinois that extends eligibility for

coverage based on higher income levels. In the short-term, both governmental and private funds must be provided to ensure that at point-of-service no woman will be denied service because of a lack of on-site, out-of-pocket payment.

Action: Advocate with the state legislature for both short and long term solutions with elected officials and departments of public health. In addition, ask hospitals, voluntary agencies, and medical societies to make this recommendation their major charitable, fund-raising and legislative priority; and, keep the media well-informed.

2. The process by which mammography becomes realistically affordable to all women must be initiated immediately. We understand that a phase-in of the determined policy may be necessary. This phase-in should require no more than three years before it is fully operational. The Illinois Department of Public Health Office of Women's Health must take responsibility for spearheading the long-term solution through seeking expanded coverage of the services through governmental programs and ensuring immediate, adequate funding of breast health programs.

Action: Advocate with the state legislature and executive branch to fully fund the IDPH office and breast health programs; and mandate IDPH to participate actively in seeking a long-term funding solution.

3. Medicaid does not reimburse at a reasonable level to cover provider costs (facility and physician) for mammogram services. This contributes to a reluctance to provide mammograms to Medicaid patients and causes providers to evaluate the number of such exams they provide. This is not

only an unacceptable practice in general but once again disproportionately impacts poor women of color.

Action: Advocate with the state legislature for an increased Medicaid reimbursement rate for mammography for 2008.

4. Safety net providers (such as Stroger Hospital of Cook County) should be provided with sufficient funding to continue to provide both screening and diagnostic mammography. For example, Stroger Hospital currently has funding for only two radiologists to read mammograms. This is grossly inadequate. In addition, the salaries for those positions are far below the going rate in Chicago, making it difficult to hire and retain radiologists.

Action: Work with the Cook County Commissioners and other safety net providers to step up the commitment to ensure that women are able to obtain affordable mammography services. It must be made a priority that public money be used to provide screening services in a timely manner, as well as to ensure coverage of other diagnostic and treatment services.

5. We acknowledge the recent expansion of the Illinois Breast and Cervical Cancer Program (IBCCP), and we recognize both the IBCCP and the Stand Against Cancer (SAC) Program to be viable methods for addressing the recommendations listed above. However, these programs would require additional funding to ensure that we are able to provide mammograms to all in need. To thus enhance access to screening and diagnostic services, along with the additional funding we recommend increasing the number of hospitals and other providers, to give wider access to quality mammography services, focusing on those who serve the most clinically and economically at-

risk populations throughout the Metropolitan Chicago area.

Action: Advocate with the state legislature to increase funding for IBCCP and SAC and solicit additional hospitals and providers to become contracted under the program in 2008. Hospitals and providers in communities with large populations of African-American women should be given priority.

6. For insured women the additional expense associated with mammography, such as co-payments and deductibles, present significant barriers to participation in breast cancer screening, particularly for women with lower incomes. These women do not qualify for the programs available to uninsured women in Illinois, and the additional expense causes them to forego breast cancer screening because they cannot afford it.

Action: Advocate with the state legislature to require insurance companies to cover the entire cost of annual mammograms and other tests necessary for cancer detection and abolish co-payments and deductibles for these tests.

B. Education and Outreach

We understand that even if there were no financial barriers many women would not obtain a mammogram. This is because of the numerous reasons delineated in this chapter's section on barriers (Section 3) – lack of knowledge about where to obtain a mammogram, lack of an understanding about why it is important, fear, lack of transportation, child care, and other problems. Thus, two broad types of interventions are needed to help women access available mammography – education and outreach.

1. There must be updated information available about where (and how) to

obtain a mammogram, particularly low cost or no cost mammograms. The information should be made available by telephone “hotline” and website in as many languages as possible, but absolutely in Spanish since such a large and growing proportion of Chicago is Hispanic. There are a number of such telephone hotlines currently available in Metropolitan Chicago, but the information provided is not always current. For example, a hospital’s quota may have been filled earlier that week and women are then turned away. Most importantly, all such provided information must be user friendly.

Actions: We recommend that a single telephone hotline and website be developed that will provide up-to-date user-friendly information about mammography availability so that a woman can determine in real time where she can obtain a mammogram. We recommend that the various providers of these hotlines join forces to create a single source of information that they can all tap into, to provide current accurate information to women seeking mammograms. These services should be designed and publicized to ensure that there is a resource to find out about the availability of no-cost and affordable services on a real-time basis. We recommend that the American Cancer Society take the lead in this effort by calling together the groups who currently provide telephone hotlines in the Chicago Metropolitan area, to work collaboratively to develop such a website and hotline.

2. There needs to be a central repository of culturally relevant information that explains the importance of breast health and mammography, which can be made available to outreach workers in Metropolitan Chicago. This information should be available in a variety of formats (for example, paper, electronically, radio, etc.) and in as

many languages as possible. Such information exists (e.g., from the National Cancer Institute at http://cancercontrolplanet.cancer.gov/breast_cancer.html) but we must advertise it and take advantage of it.

Action: A subcommittee will be assembled by the Breast Cancer Task Force to gather all such printed and electronic materials currently available, to evaluate them and make specific recommendations for needed improvements, both in content and modes of delivery. These recommendations will include time tables and budgetary needs for completing this activity. Advertising firms with experience in reaching communities of color and African-American communities in particular will be consulted, as well as community partners. The subcommittee will report its findings no later than October 2008.

3. We recommend the development of a website that will provide a comprehensive listing and description of outreach programs in Metropolitan Chicago, to facilitate identification of resources, networking, and communication. To begin this effort, an inventory of existing outreach programs will be formulated, and subsequently a network of such programs will be created for coordination and evaluation.

Action: Assign a staff person for this activity with the goal of preparing and disseminating a definitive report in one year. Assign a staff person for development of the website and updating the information provided on the website.

4. We further recommend that a collaboration of volunteer organizations, such as the Chicago chapter of the Sisters Network (African-American breast cancer survivors), Sisters Embracing Life

(African-American cancer survivors) and the Black Nurses Association (BNA), be funded to lead breast health education programs throughout the area, especially in African-American communities in which breast cancer mortality is high. To effectively penetrate these communities, we envision 50 such programs a year for three years be provided by these organizations, with the final number of programs to be determined through the planning process. In addition, we recommend that a media-based public relations campaign to increase awareness of the importance of mammography be developed for minority media outlets.

Action: Determine the mechanism for such funding, develop a contract, and initiate the funding. The collaboration would develop an annual work plan with a schedule to ensure coordination.

5. We furthermore recommend that evidence-based outreach programs for breast cancer screening be carried out with a sample of community institutions such as churches, beauty shops, and others that penetrate the community and serve the very poor. We envision nine such programs per week for three years, with the final number of programs to be determined through the planning process. This process should be continued for three years and these efforts should be carefully evaluated to determine whether they increase mammography utilization.

Action: Hire three breast cancer survivors for three years to implement this activity. Carefully monitor and evaluate these activities. Organize a group of culturally appropriate volunteers to assist with such activities.

6. Finally, we recommend that some combination of the city, state, and

insurance company coverage provide funds for regular breast health education and outreach. Since the proposals discussed above are for at most three years, there must be a mechanism that sustains these efforts. Here is what we propose. If a fund (e.g., Medicare, Medicaid or other insurance plans) pays an extra \$10 for each screening mammogram, then for every 3,000 mammograms, that fund will pay \$30,000, which is the approximate cost to hire a community outreach worker. We recommend that this become a regular part of the mammography process. Thus, if a hospital does 12,000 mammograms a year that hospital would receive \$120,000 to hire four community outreach workers. The job for these workers would be to do outreach and education for mammography in vulnerable populations.

Action: Assemble a committee to precisely define details of this process. The subcommittee will report its findings no later than October 2008. While this is happening, we recommend that one safety net hospital be funded for this activity on a pilot basis (at a level of one outreach worker for each 3,000 mammograms). As soon as the funding is secured, a hospital will be selected by the Breast Cancer Task Force Steering Committee. It will serve as a model for what is possible and thus this effort will be carefully evaluated.

7. In each of the four Town Hall meetings, our Task Force has been told repeatedly that much of what goes wrong with access to mammography in Metropolitan Chicago is related to rudeness and inappropriate behavior, including perceived or overt racism, on the part of staff at mammography sites. Women are emotionally vulnerable when facing the threat of breast cancer, and discourteous treatment by staff is a significant barrier that must be remedied.

Action: Fund training in sensitivity and cultural competency for staff members of institutions providing mammography. The training will be offered by organizations that have a history of success in providing training in cultural competency and will be provided on-site to maximize participation.

8. There is extensive literature that demonstrates that reminder notices from physicians are effective in motivating women to obtain mammograms. (Of course, this can only occur if the woman has a medical home.) We thus recommend that the Task Force hire a person to identify and evaluate appropriate existing reminder systems (i.e., web based, Windows based). Task Force staff would provide consultation with providers to educate them about current packages and suggest integration into provider-based systems.

Action: Hire this person for three years. Monitor the number of providers using reminder notice packages pre and post contact with the Task Force staff person.

C. Capacity

Our capacity survey yielded dramatic, never-before documented findings of vastly inadequate mammography capacity (less than two-thirds of what would be needed if all age-eligible women sought a mammogram) and inferior quality due to inadequate resources at those institutions that serve Black women.

Action: Fund one individual under the direction of the Task Force Director to lead a blue ribbon committee to address breast cancer screening and diagnostic capacity in Metropolitan Chicago and to produce a definitive report by October 2008 on how to remedy this situation.

SECTION 3. Improve the Quality of the Mammography Process

The following are the recommendations to improve the quality of the mammography process in Metropolitan Chicago. This is not simply about the technical quality of the mammograms that Black women receive, but includes the communication process and the timeliness of diagnosis and referral to treatment for women with abnormalities. All of these processes need improvement in Metropolitan Chicago for all women. Our suggestions fall into four areas of concern: **Quality of the Mammography Process; Diagnostic Follow-up and Communication; Solutions for the Safety Net; and, Physician and other Workforce Issues in Breast Imaging.**

A. The Quality of the Mammography Process

1. Creating a consortium of health care organizations to establish, measure and share quality data regarding the breast cancer diagnostic process will help improve quality for all and thus reduce disparities. There are a number of well-established quality measures for the mammography process. If all breast centers measured and shared these with each other and the public, this could lead to improvement in the quality of breast care for all women in Metropolitan Chicago. Since we know that the simple measurement of quality is likely not enough, it is important that specialists in mammography quality help those institutions having problems in achieving the established quality benchmarks. Finally, we need better cooperation among institutions to help coordinate the diagnosis of breast cancer and reduce delays for underserved women.

Action: We recommend five years of funding and the establishment of a Breast Cancer Consortium of Metropolitan

Chicago healthcare organizations who would agree to:

- *Select, define and publish quality standards for the mammography screening and breast cancer diagnostic process for all healthcare institutions in Metropolitan Chicago;*
 - *Share data through a common regional database, for example the National Consortium of Breast Centers (NCBC);*
 - *Create a free consultation service comprised of local experts to help institutions improve their quality and provide consultations as requested;*
 - *Coordinate the care of women in need of breast diagnostic services in Metropolitan Chicago.*
2. Currently, there are no mandatory reporting requirements for breast cancer as there are for other disease entities. In addition there is no statewide tracking of the elapsed time from a mammogram abnormality until the time of treatment. These measures could be readily collected and would provide insight into these important quality measures, thereby addressing racial disparities.

Action: Hire an advocate to persuade the State legislature, Illinois Department of Public Health and the Center for Medicare Services to include breast cancer quality measures as part of mandatory hospital reporting.

Action: Require the Illinois State Cancer Registry to collect data on time from diagnosis to treatment.

B. Diagnostic Follow-up and Communication

There are multiple breakdowns in the mammography diagnostic process that can lead to delays in the diagnosis of breast cancer. These breakdowns include the lack of availability of old films, the inability of women to self-refer for diagnostic tests, poor communication regarding test results and lack

of access to timely diagnostic services. We propose the following:

1. Allow self-referral for mammography screening and diagnosis. Currently women cannot self-refer for either screening or diagnostic mammography because breast centers do not want to assume the liability of follow-up of abnormal results and would prefer this be done by primary care physicians. This is different from other disease entities for which individuals can self-refer. Since many Black and poor women have no medical home this creates an unnecessary barrier to breast cancer diagnosis.

Action: Hire an advocate to develop consensus for a state law to allow for women to self-refer for mammography follow-up and diagnostic tests.

2. Create a centralized referral service to get women in need of diagnostic mammography or biopsies into institutions around Chicago. Women, especially those attending safety net clinics, do not have timely access to breast diagnostic services. There are unacceptable delays in accessing Stroger Hospital services and current community-based services are inadequate and poorly coordinated.

Action: Convene a committee to identify barriers and limitations in current services and recommend to the Task Force ways to expand navigation to reduce diagnostic delays. Report back with recommendations by October 2008.

3. Women face difficulties in obtaining their prior mammograms, thus adding to delays in the breast cancer screening and diagnostic process. Creating a Metropolitan Chicago digital film library would allow for the sharing of digital mammography films among breast centers, reducing duplication and improving the speed of the diagnostic process.

Action: Create a committee to explore the benefits and challenges of designing and creating an interconnected digital mammography film library as part of a Regional Health Information Organization (RHIO). Hire a consultant to assist. Report back in October 2008.

4. The communication of mammography screening results to patients by primary care physicians is highly variable and must be improved. In Chicago, Black women are only half as likely as White women to attend locations where diagnostic results are given in person.

Action: Bring breast imaging experts from Chicago organizations together to develop a consensus on a best practice for abnormal mammogram reporting and offer recommendations for Metropolitan Chicago breast imaging services. Report back to the Task Force by October 2008.

C. Solutions for the Health Care Safety Net

1. The regional health care safety net is broken in regard to the quality and capacity of breast screening and diagnostic services. Stroger Hospital does not have the resources to provide adequate care to all who need it in Metropolitan Chicago. There needs to be a regional solution to this problem that addresses capacity and quality. We recommend that there be a public/private partnership to develop a comprehensive breast screening and diagnostic facility that will work with affiliated community-based screening centers. This might combine the current physical locations of the Chicago Department of Public Health mammography sites linked with other strategically located screening sites in under-resourced communities which would then be linked digitally to a central diagnostic and consultation facility. Navigation and other support resources would be included in this model of care. While there are not easy

technological solutions to the problem of breast cancer disparity in Metropolitan Chicago, the emergence of digital mammography creates the possibility for institutions to share digital images and to develop regional strategies for the more efficient reading of mammograms and more rapid diagnosis of breast cancer. Since digital images can be read at a distance, it would add creative, new solutions to the access and quality issues in Metropolitan Chicago.

Action: Develop a Task Force to study the feasibility of a public/private partnership to create a comprehensive breast screening and diagnostic center with community based geographically dispersed screening centers to address the current deficiencies in the public safety net. Hire a consultant to assist with this process. Report back by October 2008. In the interim, pilot digital mammography and computer aided diagnosis in Chicago Department of Public Health sites in Chicago over the next two years. Carefully evaluate this by linking the acquisition of digital technology to participation in the Consortium and the measuring and sharing of quality data.

2. There are immediate needs for breast cancer diagnostic services in Metropolitan Chicago for women who cannot get timely appointments. All Chicago area hospitals are being asked to provide timely and free care (as necessary) to women facing delays getting diagnosed and treated for breast cancer by safety net providers.

Action: Ask all institutions that offer diagnostic services to agree to take on additional patients by January 2008. Coordinate with the American Cancer Society and Y-Me. This could be an activity of the Consortium and be coordinated by the staff of the Consortium.

D. Physician and Other Workforce Issues

1. The Focus Groups and interviews we conducted all pointed to the fact that there is a shortage of specialty trained radiologists to read mammograms in Metropolitan Chicago. Minority women are more likely to have their mammograms performed at institutions staffed by general radiologists than White women who are more likely to have their mammograms performed at institutions staffed by specialists. This specialty disparity can affect the quality of care women receive. If the skills of the general radiologists could be improved, disparities will lessen.

Action: Create a mini-fellowship, staffed by local area experts in breast imaging, to improve the skills of current practicing general radiologists reading mammograms in underserved settings in Metropolitan Chicago.

2. There are not enough incentives to get specialty trained mammographers to work in urban, safety net settings. The shortage of trained mammographers in Metropolitan Chicago is exacerbated by the fact that there are only three training sites in Chicago and only five or six individuals receiving training annually.

Action: Create a state medical student loan repayment program to assist mammography specialists who choose to practice in Metropolitan Chicago and downstate settings that serve a significant proportion of Medicaid covered women. Fund one additional fellow training spot in the mammography fellowship programs at Northwestern University, the University of Chicago and Rush University Medical Center to increase the pipeline of trainees in the mammography field in Metropolitan Chicago.

SECTION 4. Improve Quality of Treatment

Breast cancer patients in Metropolitan Chicago, and specifically African-American patients, face a multitude of barriers when trying to secure access to quality treatment, as evidenced by the testimonials of individual patients, insights from providers, and information derived from groundbreaking new studies. Addressing these barriers will require a coordinated effort not only by provider organizations, but also in the policy arena to help remove structural barriers and mitigate patients' cultural and environmental barriers. The Metropolitan Chicago Breast Cancer Task Force's Quality of Treatment Action Group believes that implementing the following policy prescriptions will significantly help patients better navigate care systems and access potentially life-saving treatment options. The recommendations fall into three areas of concern: **Access and Cost of Care, Education and Outreach, and Quality Measurement.**

A. Access and Cost of Care

Accessing affordable breast cancer treatment must be an option for all women with breast cancer. As long as barriers to treatment exist, the women of Metropolitan Chicago will continue to experience undue sickness and death. We thus propose the following:

1. Treatment for breast cancer must be available for and accessible to all women. Uninsured, underinsured and undocumented women face major barriers to receiving timely and complete breast cancer treatment and palliative care. Under the current Medicaid Treatment Act, uninsured women who have legally resided in the U.S. for at least five years can access complete coverage for breast cancer treatment at Medicaid rates. But this leaves out undocumented women and women who have legally resided in the U.S. less than five years. It also

challenges women to find providers who accept Medicaid rates. Many insured women also face costly co-pays due to the high costs of treatment. Comprehensive coverage for all aspects of treatment, including the health maintenance / primary care needs of breast cancer is lacking. In addition, limited disability coverage, along with the lack of job security often prevents working women from receiving necessary treatment for breast cancer.

Action: Advocate with the Governor's office and the Illinois State Legislatures to identify statutorily protected funding and coverage mechanisms to provide universal breast cancer diagnosis and treatment coverage for all women in Illinois and as a longer term goal, support universal healthcare coverage in Illinois. To ensure such action, we recommend the following actions:

- *Pursue state legislation to mandate disability protection for employees with cancer;*
- *Provide advocacy for continued support of the Treatment Act, and fully fund and expand the IBCCP;*
- *Increase reimbursement to providers who treat Medicaid patients to cover the cost of treatment;*
- *Expand eligibility of the Treatment Act to include all residents regardless of the duration of their residency;*
- *Advocate for all insurance policies to guarantee coverage of breast cancer treatment, medication and all related treatment costs;*
- *Prepare legislation to remove co-payments for treatment services and medicines in order to increase affordability of services;*
- *Support universal health care coverage for all uninsured Illinois residents.*

2. The capacity of specialized breast cancer treatment services in Metropolitan Chicago must be expanded and made available to all women. Studies suggest that women treated by breast cancer specialists have better overall health outcomes than women treated by non-specialists. Currently there is a dearth of American College of Surgeons Commission on Cancer approved cancer treatment facilities and breast cancer specialists in vast areas of Metropolitan Chicago particularly in the south and south suburban areas. In addition, very few institutions participate in the IBCCP which can make it challenging to have Treatment Act documentation completed in a timely fashion. It is imperative for all providers to be educated about the Treatment Act and have the ability to facilitate the process immediately at the point of diagnosis.

Action: We recommend that the Metropolitan Breast Cancer Consortium provide a thorough and scientific assessment of each treatment facility's capabilities. This assessment should be completed by October 2008. Findings from this report should be presented to provider and hospital associations and state legislators with the goal of improving geographical accessibility for all women to the highest quality breast cancer treatment specialists and facilities.

3. Encourage and provide incentives to providers throughout the Metropolitan Chicago area to participate in the IBCCP program and accept Medicaid patients.

Action: Advocate for increased Medicaid reimbursement rates for breast cancer care providers. Encourage Metropolitan Chicago hospitals to become providers of IBCCP and begin discussions about lack of breast cancer specialty care capacity in

underserved areas. Advocate with the State to provide stipends to hospitals who are providers of IBCCP.

4. Provide case management, navigation and other social support to underserved women needing breast cancer treatment.

Action: To achieve this goal, we recommend the following steps be taken:

- *Assemble a committee of the Task Force to precisely define details of this process. Partner with the American Cancer Society and other providers of navigation and case management services. The subcommittee will report its findings no later than October 2008;*
 - *While this is happening, we recommend that one safety net hospital be funded for this activity on a pilot basis (with one support/outreach worker for each 75 breast cancer patients). As soon as the funding is secured, the hospital will be selected by the Breast Cancer Task Force Steering Committee. It will serve as a model for what is possible and thus this effort will be carefully evaluated;*
 - *Advocate with the State legislature for increased funding and support of Patient Navigators who can assist women as they access treatment for their breast cancer;*
 - *Complete a comprehensive examination of breast cancer centers nationally and identify best practices that can be adapted to and implemented for the breast cancer patients in Metropolitan Chicago. This report should be completed and presented to the Breast Cancer Task Force by October 2008.*
5. Expand and improve the availability and quality of transportation options to and from diagnosis and treatment options for low-resource patients.

Action: Assemble a committee to explore how to implement a subsidized public transportation program for travel to and from cancer care similar to PACE services for the elderly. Identify one safety net hospital to pilot and evaluate this program and report back to the Breast Cancer Task Force Steering Committee no later than October 2008.

B. Education and Outreach

The Task Force believes that extensive community and provider education is needed regarding the benefits of breast cancer treatment. This should include community outreach and extensive use of the media. We also believe that providers of breast cancer treatment should receive training in cultural awareness and sensitivity as this might be a barrier for some women to pursue treatment. Specifically we recommend:

1. To fund coordinated outreach and media education programs through grassroots and other well-established community organizations such as the Black Nurses Association, Sisters Network or The Rose emphasizing the importance and efficacy of breast cancer treatment.
2. To develop, support and encourage provider education campaigns to improve providers' cultural awareness and competencies and promote team-based care.

Action: This effort can be coordinated with the similar recommendation of the Access to Mammography Action Group. Funding is needed to support outreach and create public service announcements.

Action: Assemble a committee of community organizations such as the Black Nurses Association, Sisters Network and members of the Breast Cancer Task Force to identify the components of such a campaign. Report back to the Task Force Steering

Committee by October 2008. Begin cultural awareness campaign in 2009.

3. To provide resources and institutional support for the implementation of cultural competency and awareness trainings for all staff working at health care facilities in the Metropolitan Chicago area and ultimately lobby for change in state law requiring cultural competency certification (similar to laws passed in California and New Jersey).

Action: Under the auspices of the Task Force, assemble a committee to develop effective cultural competency and awareness trainings throughout the Metropolitan Chicago area. Enlist the support of institutions, community members and those working on the above- mentioned cultural awareness campaign to evaluate the trainings and develop a plan on how to offer training to all health care providers. Report back to the Task Force Steering Committee by October 2008. In the long term, support advocacy efforts requiring cultural competency and awareness training for all health care employees and continue to get institutional support from professional organizations, clinics and hospital administration to make sure providers have time available for training and to offer continuing education credits, when applicable.

C. Measuring the Quality of Treatment.

1. There is no established program for the collection of treatment quality indicators across institutions in Metropolitan Chicago to help elucidate differences and/or disparities in treatment that may be experienced by breast cancer patients at their treating institutions. While there are established data collections systems targeting all cancers in Illinois, our review of them suggests that none are adequate to help explain or address

the widening mortality in breast cancer disparity documented in Chicago.

Action: We recommend the funding and establishment of a consortium of Metropolitan Chicago health care organizations who would agree to:

- *Establish and publish quality standards for the breast cancer treatment process for all healthcare institutions in Metropolitan Chicago;*
- *Share data through a common regional database, for example the National Consortium of Breast Centers (NCBC);*
- *Perform a pilot study to examine 5-10 clinical performance measures across at least five treatment facilities in the Metropolitan Chicago area, including safety net hospitals in 2008.*

2. Enhance the Illinois State Cancer Registry to include breast cancer treatment data. It is currently underfunded and thus cannot provide adequate data on disparities in care in Illinois. This is an important deficit and needs to be remedied.

Action: Advocate with the Illinois State Legislature to adequately fund the Illinois State Cancer Registry and to include breast cancer treatment data. A staff person with a background in health administration and policy should be hired to assess how to enhance ISCR and meet the data needs for overall improved breast cancer care. Report back to the Task Force examining the key issues and offer a concrete proposal with budget and timeline on how to enhance the ISCR no later than October 2008.

3. Require that all healthcare institutions collect race and ethnicity data at each visit. Unless accurate racial and ethnic

origin data is collected, it is impossible to begin to adequately identify disparities and target solutions to address these inequalities. Current methods of collection, i.e., assignment of race/ethnicity based on a clerical “guess”, are inadequate. Data should be collected on income, insurance status and area of residence as well so links between these factors and race/ethnicity can be examined. There is also no consistent requirement for the measurement of race and ethnicity at

Illinois health care institutions, making health disparities analyses difficult. Since health disparities are a national health issue, there needs to be uniform data collection at the point of care. Other states have such requirements.

Action: Work with an identified Illinois State Legislator to draft legislation for mandatory collection of race and ethnicity at all health care encounters and then work to get this legislation enacted.

CHAPTER 1.

ACCESS TO MAMMOGRAPHY

SECTION 1. Introduction

Early detection of breast cancer provides the best chance for disease-free survival, and mammography can identify cancer in the earliest stages, long before it can be felt as a palpable lump. According to several major randomized controlled trials, mammography screening every 1-2 years can reduce the risk of mortality from breast cancer by about 30%.^{1,2,3} Thus, reduced access to mammography would be expected to contribute to the excess breast cancer mortality seen in Black women in the Metropolitan Chicago area.

Rates of Mammography Use

To examine this issue, the Access to Mammography Action Group reviewed local and national data about mammography use among women of different races. On the surface, it appears that Black and White women in Chicago are similar in terms of mammogram use. Examination of the Chicago portion of the Behavioral Risk Factor Surveillance System (BRFSS)⁴ suggests that a similar proportion (about 80%) of Black and White women over the age of 40 have received a mammogram in the last 2 years. These findings are consistent with more recent local data obtained from the *Improving Community Health Survey* conducted by the Sinai Urban Health Institute.^{5,6} But it is important to note that both of these reports are based on information provided by women from memory, rather than actual medical records. Studies have shown that women tend to over-estimate how frequently they obtain mammography, regardless of whether they provide the data in person (Sinai Survey) or by phone (BRFSS).^{7,8} Even more importantly, studies have shown that different groups vary in their over-reporting, with higher rates of over-reporting among poor women. Because

this over-reporting may be as high as 25-30% among poor women,^{9,10} it would be expected to contribute to racial differences in measurement of mammography use, given Black women's greater likelihood of living in poverty¹¹. Although it is difficult to estimate the true proportions, if we apply this information to the self-reported data for Chicago, the figures are likely to be closer to 70% for White women and perhaps as low as 55% for Black women, rather than the reported 80%.

Frequency of Mammography Use

An additional important issue, which is less well studied, is the frequency of mammography use. The benefit of mammography is limited if a woman has just one isolated mammogram. An appropriate sequence of mammography, such as 2 mammograms in 3 years, or 3 in 5 years, is much more likely to detect cancer early and save lives. This is particularly important since changes are identified through comparison with previous mammograms. Unfortunately, data are rarely collected on rates of participation in sequential mammography screening,¹² thus making this issue difficult to examine. However, if Black women are less likely than White women to receive mammograms at appropriate intervals, this also would contribute to disparities in mortality.

Conclusion

Despite the fact that utilization of mammography screening has increased over the past 30 years, it is likely that there is still a gap in screening rates between Black and White women, which would contribute to disparities in breast cancer mortality in the Metropolitan Chicago area. Studies adjusting for over-reporting in survey data suggest considerably lower screening rates for Black women. In addition, in order to more

accurately measure appropriate use of mammography, future data must examine the proportion of women who receive mammograms at optimal intervals. Because early detection of breast cancer reduces mortality, assuring regular access to mammography for ALL women in Metropolitan Chicago is essential. The purpose of this chapter of the Report is to provide both an examination of barriers to mammography in the Metropolitan Chicago area and recommendations that will allow us to provide for adequate screening in a manner that will minimize morbidity and mortality from breast cancer.

SECTION 2. Barriers to Mammography Screening

Introduction

Many of the barriers to mammography and breast cancer screening are common to women in general, but there also is a growing body of literature that seeks to identify issues for specific cultural groups. Because mortality rates are highest in Chicago in African-American women, studies that focus on these women are of particular interest to this Report. These studies have been conducted in cities throughout the U.S, and so inform us generally.

We are fortunate, however, in that two of the four Centers for Population Health and Health Disparities funded by the National Cancer Institute are located here in Chicago: one at the University of Chicago (Director: Dr. Sarah Gehlert) and the other at the University of Illinois at Chicago (UIC) (Director: Dr. Richard Warnecke). For the past four years, these two centers have been collecting data specifically identifying the barriers to mammography and timely diagnosis of breast cancer here in the Metropolitan Chicago area. Findings from these two centers are highlighted in this section of the report, providing the specificity needed to target the current issues contributing to excess mortality for women of color in Chicago.

Health System-Level Barriers

Cost of screening and diagnosis. Not surprisingly, studies have shown that out-of-pocket cost is a significant barrier for women with lower incomes in the U.S. For example, in Boston women who lack private health insurance have their first mammogram at age 46 on average, six years later than women with insurance.¹³ In interviews and Focus Groups conducted in Chicago by the two NCI-funded Disparities Centers, lack of health insurance, as well as the out-of-pocket costs for women with insurance, has been cited repeatedly as the single most important barrier preventing participation in mammography screening.^{14,15,16,17}

Persistence required to navigate the medical system. Information collected from 260 low income women undergoing diagnostic evaluation for suspicious breast symptoms in Chicago has demonstrated that a high level of persistence is required to navigate the health care system network, adding weeks and months to the time needed to reach diagnosis.¹⁴ If a woman has cancer, delaying evaluation of a breast problem for several months can allow the cancer to spread and sometimes mean the difference between saving the breast (lumpectomy) and removing the breast (mastectomy).

Lack of information about where to obtain a mammogram. In Chicago, Focus Groups and Town Hall meetings made clear that many women do not know where to go for no-cost or low cost mammography.¹⁴ Women knew about Stroger Hospital but not about other options that may be closer to where they live. Although there are multiple telephone hotlines serving the Chicago area, hotline providers reported difficulty in accessing up-to-date information from mammography providers regarding changes in the availability of no-cost or low cost mammograms. As a result, patients reported being sent to facilities, only to find that the allocated number of no-cost mammograms had already been expended.

Distance to mammography providers. Long travel times to get to the mammography

facility, often requiring multiple bus transfers, were cited as a problem for women in Chicago. Women reported that they needed to take the entire day off from work to get a mammogram because of the travel time and clinic wait time.¹⁴

Provider-Level Barriers

Trust in health care providers and the health care system. Lack of trust in physicians, stemming from negative personal experiences, was found to be a significant barrier to mammography by both of the NIH-funded Disparities Centers in Chicago.^{14,15} The historical record of mistreatment of African-Americans in the U.S., particularly for medical experimentation, has been cited as a primary reason for mistrust in the health care system.¹⁸ Likewise, the persistence of racial bias in the provision of health care has been documented in recent studies.^{19,20} Mistrust also has been found to be a barrier to cervical cancer screening for African-American women, particularly those with low education levels.²¹

Patient-Level Barriers

Fear and anxiety. Although lower levels of anxiety may stimulate women to contact their health care provider, higher levels of anxiety and fear cause immobilization. In Focus Groups and interviews with women in Chicago, fear was named as one of the primary reasons that women delay in contacting a health care provider after they find a suspicious breast symptom, such as a breast lump.^{14,16,17} At least six additional studies of African-American women have also found that fear inhibits action and increases delay time for women with a suspicious breast symptom.^{22,23,24,25,26,27}

Cultural beliefs and knowledge about breast cancer. A variety of cultural beliefs, such as fatalism, have been found to contribute to a reluctance to participate in breast cancer screening. In rural North Carolina, Lannin et al. found that later-stage breast cancer was associated with the belief that exposure of the tumor to air (through surgery) would cause cancer to spread.²⁸ They found that women

who held any of the culturally-derived folk beliefs, fundamentalist religious beliefs, fatalism, or believed that they would be less attractive to men were all more likely to present with advanced disease.

In two recent studies conducted in Chicago, African-American and Latina women endorsed beliefs likely to contribute to later-stage presentation of breast cancer.^{16,17} Four categories of cultural beliefs were identified that would contribute to later-stage diagnosis: (a) faith-based beliefs; (b) futility of treatment; (c) incorrect ideas about breast symptoms; (d) use of self-help techniques. For example, the idea that faith in God would protect a woman from breast cancer was more common among African-Americans (39%) and Latinas (38%) than Caucasians (5%). All three groups believed that prayer could make breast lumps disappear, although this was twice as common among African-Americans (48%) as Latinas (25%) and Caucasians (22%). Similarly, more African-Americans (19%) and Latinas (23%) than Caucasians (3%) believed that if a woman had enough faith in God, she would not need treatment for breast cancer.

Regarding the futility of treatment, the belief that “it doesn’t really matter if you get treated for breast cancer, because if you get cancer, it will kill you sooner or later”, was more widely endorsed by Latinas (36%) than African-Americans (8%) or Caucasians (2%). Participants stated that this belief led to the decision to refuse treatment to make death come as quickly as possible, and thus make it easier on the family emotionally and financially. This belief also made women reluctant to go for screening, because it was felt to be futile. Regarding breast symptoms, more African-Americans (14%) and Latinas (18%) believed that breast lumps had to be painful to be cancer, which was less common among Caucasians (5%).

Language. In a study of 72,417 women in Boston, women who did not speak English began screening with mammograms nine

years later (at age 49) than women who spoke English. For non-English speaking women who also did not have private health insurance, screening with mammography was started 15 years later (at age 55) than their counterparts.¹³

Work and family responsibilities. Because women are generally the caretakers of their families, as well as work outside the home, they report that there is little time to take care of their own health needs. Childcare and work responsibilities were cited specifically by women in Chicago as interfering with the ability to get a mammogram. The fact that many mammogram providers do not have weekend and evening hours contributes to the difficulty.¹⁴

Conclusion

Studies conducted in the Chicago metropolitan area have confirmed that significant barriers to mammography exist and are widespread. This likely contributes to higher mortality rates among African-American women. The most powerful barriers operate at the health system level, affecting both insured and uninsured women. However, provider and patient-level issues also need to be addressed. The identification of these barriers provides insight into potential strategies for increasing mammography use among women of color, specifically for Metropolitan Chicago.

SECTION 3. Interventions to Improve Access to Mammography

Introduction

As noted throughout this report, mammography has been demonstrated to be an effective screening process for breast cancer. Studies show that when mammography screening is operating effectively it can prevent about one-third of the deaths from breast cancer.^{1,2} This is the case since the early detection of breast tumors makes most of them treatable and thus prolongs life.³

The key words in the preceding paragraph are “operating effectively.” A lot of events must occur for the mammography process to operate effectively. To begin with, women must be able to obtain mammograms regularly (yearly or bi-yearly, depending upon current recommendations). But this is not so easy to do. In the preceding section of this chapter, we describe the barriers to regularly obtaining mammograms. They include: a) lack of knowledge that a mammogram is needed; b) lack of knowledge about where one can obtain a mammogram; c) insurance (cost or affordability); d) transportation difficulties, etc. And, as noted in the previous section, each of these general categories has subcategories. For example, knowledge that a mammogram is needed depends upon whether a physician has recommended it, attitudes towards the health care system, issues of communication (e.g., matters of language and literacy), etc.

In a perfect society there would be no barriers. Mammograms would free, there would be no waiting time, and education about the importance of mammography would be widespread. Because we don’t live in a perfect society, many advocates, caregivers and researchers have utilized and evaluated interventions designed to overcome barriers such as those noted above. Interestingly, many interventions have been shown to be effective though none of course work for all people all of the time.

After extensive reading of the literature (well over a 100 articles in peer-reviewed journals on this topic), we have come to the conclusion that what works best is putting into place multiple interventions to address various barriers simultaneously.^{29,30} Such interventions have been shown to increase mammography use by 15% - 30%.^{31,32} It is widely agreed that the most authoritative reviews of the literature (or meta-analyses) come from the Cochrane Database. One such recent review analyzed all interventions for increased mammography that utilized randomized controlled trials. Its conclusion was: “Most active recruitment strategies for breast cancer screening

programs examined in this review were more effective than no intervention. Combinations of effective interventions can have an important effect.”³³

The U.S. Preventive Services Task Force routinely recommends best-practices in preventive medicine and its recommendations are generally followed throughout the country.³⁴ One of the areas of concentration is cancer screening in general and breast cancer screening in particular.³⁵ All of the interventions discussed below are consistent with the Task Force recommendations. What follows is a discussion of these interventions, emphasizing those that will most likely be helpful in an area like Metropolitan Chicago. We are guided in this effort by the schema developed by Blackman and Masi³⁶ and by Peek and Han.¹¹ These Chicago-based authors suggest that there are three broad levels of factors involved in breast cancer screening: health system-level, provider-level, and patient-level.

Health System-Level Interventions

Cost is the leading barrier for not obtaining a mammogram. This includes lack of insurance, out of pocket expenses, and lack of a medical home or regular physician. Of course the corresponding interventions for such barriers would be to make mammograms either available at no-cost or at least fully affordable to women with insurance. One story that we have heard frequently from women in Metropolitan Chicago describes how some mammography sites will not provide services to women who are funded by Medicaid because Medicaid pays too little. Of course poor women and women of color are much more likely to be insured by Medicaid and thus denied mammograms for this reason. This, in turn, would increase disparities in breast cancer mortality.

Overcoming the cost barrier is essential. As Peek and Han note:¹¹ “Providing free or low-cost mammography is a particularly effective strategy and has been shown to increase mammography use by 45% in low income populations.”^{37,38} In a comprehensive review

of the literature (consisting of 42 carefully selected publications), Masi, Blackman and Peek cite several studies that demonstrate the effectiveness of interventions that addressed financial concerns among low-income women. They conclude that “... an important first step toward reducing breast cancer mortality among low-income and minority women is to identify financial and logistical barriers to screening and follow-up testing and provide services which overcome these barriers.”²⁹

Other system-level barriers include proximity to a mammography site, readily available appointments, and hours that the clinic is open, among others.

One of the most frequent complaints we heard from women who related their experiences to us concerned the racism and other hostile attitudes on the part of the staff at mammography sites who gave them incorrect and/or unhelpful information about where, when, and how a mammogram could be obtained at the given site. We have not been able to find even one article that described an intervention to fix such an issue, but certainly work in this area is desperately needed.

Provider-Level Interventions

As noted above, it has been shown repeatedly that women who do not receive a physician recommendation for a mammogram obtain fewer mammograms. Further, Black and other poor women receive fewer such referrals.³⁹ For example, the main reason women give for not obtaining a mammogram is that a physician did not recommend one. It therefore follows that an essential intervention would be encouraging physicians to provide such referrals. This has been facilitated by providing physicians with computerized reminders for their patients, by reminders placed in charts, etc. In short, helping the physician help the patient obtain a mammogram has been demonstrated to be an effective intervention.²⁹

The literature about the impact of provider-level interventions on mammography use was

reviewed by Mandelblatt and Yarbrough. They located 35 well-documented interventions in this area. Such interventions increased mammography use by about 17%.³² The authors furthermore found that when multiple interventions were employed mammography use increased by 21%. In all cases, these interventions demonstrated significantly greater improvements than the control groups.

Patient-Level Interventions

Barriers that may be mitigated at the patient level include knowledge that a mammogram is recommended, attitudes toward breast cancer, attitudes toward a historically biased health care system, awareness about where to go for a mammogram, language, literacy and other communication issues, and information on how to pay for a mammogram. All of these may fall under the inter-related categories of outreach and education. Interventions for all of these barriers have been shown to be quite effective.

The central theme that runs through such outreach and education programs is that they must be culturally sensitive, are best implemented by people from the community we are seeking to reach, and that effectiveness is enhanced when these outreach workers are breast cancer survivors themselves.^{40,41} Sometimes these projects are referred to as Navigation Programs. As Blackman and Masi note: "Integral to the success of patient-focused interventions is sensitivity to the culture and language of the population receiving assistance."³⁶ Many others have echoed this observation: "Effective breast cancer prevention and control programs must address and develop culturally competent models that promote behavioral change in [African-American] women."⁴²

Among successful models of this work are the Forsyth County Cancer Screening Project⁴³ and the Witness Project ("A culturally competent, community-based breast and cervical cancer education program developed with and for African-American women").^{44,45} In the former, for example, the regular use of mammography increased from 31% to 56%.

Other interventions that have relied on social networks have been found to increase mammography rates by as much as 22%.^{30,31} One such program was implemented in 30 African-American churches in the Nashville area. Participants were interviewed, the intervention about breast cancer and breast screening was implemented and then the participants were interviewed again. In the end, 256 women went through the full program. Those who received the intervention were significantly more likely to have had a mammogram after the intervention when compared with the control group.⁴⁶

Another program of this sort involving African-American women recruited from urban Atlanta showed similarly significant increases in mammography use compared to a control group. The intervention involved "a culturally sensitive educational program that emphasized the need for screening that was delivered by lay health educators from the community."⁴⁷ Still another program, with the educational component implemented by health professionals, was implemented in high rise housing in the Minneapolis area. The authors conclude: "These findings suggest that a multidimensional intervention which reaches women within their social environment and uses community volunteers can increase mammography utilization among women in public housing."⁴⁸ It is interesting to note that the vast majority of women in this study were White.

The literature about the impact of patient-level interventions in general on mammography use, consisting of 63 well-documented interventions culled from an initial list of 600, was reviewed and summarized by two prominent researchers in this field. They found that such interventions increased mammography use by about 15%.³¹ In all cases these interventions demonstrated significantly greater improvements than the control groups.

Other studies have found that providing targeted (tailored) messages directly to the patient, in the form of reminder letters, phone

calls, etc. was also effective.^{30,49} Similarly, Rauscher and his colleagues concluded about their study among North Carolina women: “In this cohort, of rural African-American women, positive change in mammography attitudes was associated with greater mammography use.”⁵⁰

Still others have shown that community education has increased mammography use significantly. Legler and her colleagues reviewed 38 previous studies describing interventions for use with women who had historically low mammography screening rates. They concluded that: “The strongest interventions addressed structural, economic, and geographic barriers to mammography, as well as intrapersonal and interpersonal factors.”⁴⁹

Multiple Level Interventions

As noted above, many researchers have found that multiple interventions will work better than any single one. When considering a huge urban population, like that contained in Metropolitan Chicago, this would appear to be an even more compelling formulation.

Peek and Han have summarized this situation well: “Because underserved communities frequently have numerous barriers to breast screening, the most effective programs have incorporated multiple strategies, such as those that combine access-enhancing interventions with individual-directed interventions [a 27% increase in mammography rates] or programs that combine access-enhancing interventions with system-directed interventions [a 19% increase].⁴⁹ Caution should be used in interpreting these results, however, because the number of available studies was small.”¹¹

Similarly, Legler and her colleagues note: “As has been found for other health behaviors, we found that multiple strategies were generally more effective than single strategies for increasing mammography use.” They also note, with great relevance for this Report: “People who do not follow recommended

health advice are often referred to as the hard to reach. As our results show, in the case of mammography, they may not be so much hard to reach as not reached with the appropriate interventions.”⁴⁹

SECTION 4. Mammography Capacity in Chicago

We posed the following question to ourselves: If our efforts are successful and most age-eligible women in Chicago try to get a mammogram, will Chicago have adequate capacity? After searching long and hard we discovered that there was no information available that would allow us to answer this question. We thus initiated a major survey of all institutions that provide mammograms to women living in Chicago and asked them to complete a comprehensive questionnaire. We were able to locate 87 such institutions, 50 in the city and 37 in surrounding suburbs. Seventy-one of these 87 (82%) responded to our survey (including 43 of the 50 in Chicago, or 86%) and we were able to estimate capacity from the non-respondents.

Based upon these data, and for the first time ever in Chicago (or, we imagine, for any other city), we estimate that the number of screening mammograms (we emphasize that this does not include diagnostic mammograms) provided to women who live in the city of Chicago in 2007 will be 207,000. Employing projection techniques developed by the Government Accounting Office, we estimate the maximum capacity (if they were at full staff) of these institutions for Chicago women to be 384,000. Two major observations emerge immediately. First, according to the U.S. Census there were 588,000 women ages 40 – 70 in Chicago in 2000. Thus, if every age-eligible woman came in to get a mammogram every year, then Metropolitan Chicago would not have enough actual (207,000) or maximal (384,000) capacity to meet the need (588,000) for Chicago women. In fact, we would have only 65% of the needed capacity.

A second crucial issue emerged from the survey. We asked the radiology centers to describe 18 features of their mammography services that were related to quality. Examples were whether mammograms were double read, whether they had dedicated mammographers, whether there was same day reporting for diagnostic mammograms, etc. We then compared those centers that served predominately Black women with those that served predominately White women.

We found that there are differences in access to mammography and diagnostic follow-up services that favor White women in Chicago. The largest difference by far appeared to be with respect to access to a breast imaging specialist when having mammograms interpreted. Prior research has shown that breast imaging specialists tend to do a better job interpreting mammograms. We also found large differences in access to factors related to better image quality (digital mammography) and timeliness of follow-up (same day mammogram readings). Overall, these results suggest that differences in image quality, interpretation quality, and timeliness of follow-up of a suspicious mammogram finding may be contributing to the greater breast cancer mortality for Black women compared to White women in Chicago. (All details of this survey are presented in Appendix A.)

SECTION 5. The Town Hall Meetings

As noted above and discussed in detail in Appendix B, the Task Force held four Town Hall meetings, usually from 5 pm – 8 pm, in underserved communities throughout the city. The meetings were held on August 21 and 23 and September 6 and 13. The purpose of these meetings was to gain input from the community about what was effective and what was not effective in dealing with the issue of breast cancer in their communities. Much of the discussion was about difficulties in obtaining mammograms. As these conversations took

place, it was difficult not to notice how the comments from the attendees were very much consistent with what we had been reading in the literature. Some of the quotes we transcribed are shown below.

"It is just too hard to find a location that offers mammography. I used to go to Cook County Hospital but now they don't offer mammograms any more. I don't know where to go."

"We need more information out here and it needs to be what we can understand and relate to. It has to be more friendly. None of that mumbo-jumbo. Sometimes when see that literature I just pass it right by."

"We have so many responsibilities that we just don't have time to read literature that's too hard."

"Only one doctor in my life has told me to get a mammogram. They just don't think it's a priority for us (Black women)."

"Outreach seems to take place in strange places at strange times. If you want to reach us, then get us where we're at – at child care, beauty shops and places like that."

"You all need to hire people from the community. It will not only work better but it will help us build capacity here. It's not even enough if they're Black, they have to be from HERE."

"I don't go to doctors. I just don't trust them. My uncle still talks about that Tuskegee mess."

"We have to improve our attitudes toward ourselves and taking care if ourselves."

"It's just too hard to keep watching all this suffering and dying from breast cancer. You all should do something about that."

"There is no way to find a place to get a mammogram. Doctors won't even accept Medicaid any more. Where do we get mammograms? I ask my friends. No one knows."

"I am an advocate. I became involved because I am tired of us dying so much. There are no programs to help us. We have to sound the alarm among our Sisters."

"We have to let our families and our Sisters know about it. We have to deal with our bodies. We can't be ashamed. We have to train our mothers and daughters."

"We are too afraid. A lot of us just don't want to hear about this."

"We need to learn how to work this system. What do these things mean? We need education and knowledge about this."

Conclusion

As the great deal of information compiled above indicates, there are a large number of effective interventions that would allow us to narrow and even eliminate the racial and ethnic disparities in access to screening for breast cancer. Some would work well by themselves and almost all would work well in consort. All that is left is for us to marshal the will and the resources to implement what has already been demonstrated to be effective.

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CHAPTER 2.

QUALITY OF MAMMOGRAPHY

SECTION 1. Introduction

It is well established that regular mammography screening can reduce the risk of mortality from breast cancer.^{1,2,3} But this is only the case if the mammography screening is of the highest quality. Inefficiencies and errors in the screening process decrease the likelihood of detecting breast cancer at an early stage, when the disease is most curable and chances of survival are highest.⁴

One possible explanation for the disparity in breast cancer mortality for Black and White women in the Metropolitan Chicago area is a difference in the *quality of the mammogram process*. Several studies suggest there are racial differences in mammography quality. For example, Black women experience longer delays from initial abnormal screening to diagnosis of breast cancer compared to White women.^{5,6,7}

The Quality of Mammography Action Group worked with a number of local institutions to assess mammography disparities in the Metropolitan Chicago area. In addition to reviewing cancer detection rates from these institutions, we also examined the distribution of highly trained radiologists, support staff, and advanced equipment throughout Chicago. We analyzed data from the mammography capacity survey and consulted with physicians, technologists, community members, and many others. These sources suggest there are more missed cancers, fewer highly trained radiologists, inferior equipment, and greater communication gaps in those institutions that predominately serve minority populations in the Chicago area. For example, our capacity survey showed that Black women in Chicago were much

less likely than White women to attend facilities where abnormal results were directly communicated to women while they were waiting.

All women in Chicago deserve the best cancer screening and diagnostic services. The purpose of this chapter is to review aspects of mammography that should be improved. The chapter is divided into five sections. Section Two of this chapter introduces the mammography process, quality criteria, and four key measures of mammogram quality. In this section, we also stress the importance of making mammogram quality data publicly available. Section Three addresses the problem of mammography follow-up. Section Four addresses physician workforce issues in Chicago related to mammography. Finally, Section Five addresses specific problems with the safety net in Chicago. Each section has one or more major findings representing the key ideas generated by the group.

SECTION 2. Measuring the Quality of Mammography

Introduction to the Mammography Process

The process of finding an early breast cancer requires many aspects of the health care system to work well. First, the woman or patient must have a medical home because self-referral for mammography is not common practice (unlike other public health measures such as flu shots, for example). Once in the medical home, the doctor needs

"For as long as I've been going to the doctor, maybe one doctor has told me to get a mammogram so I think a lot of times the doctor's office don't tell you."

- Westside Town Hall

Box 1. Criteria for High Quality Mammography⁹

- First, high quality breast screening programs are those that maintain meticulous quality control and closely monitor the equipment, film, and processing of the mammograms.
- Second, it is critical to employ highly skilled technologists who are experienced in appropriately positioning patients and applying the necessary compression.
- Third, a successful program will detect minimal cancers. This is dependent on the experience of the radiologists who interpret the mammograms. Research has demonstrated that radiologists who specialize in mammography and those who read many mammograms as part of their practice are more likely to be able to find small cancers than those who do not fit these characteristics.
- Fourth, a high quality program will not lose patients to follow-up. If it does, then these patients may have breast cancer and not even be aware of it. It is thus important to maintain tracking programs which ensure that patients are not lost to follow-up and which facilitate more rapid diagnosis and treatment.
- Fifth, patients presenting for annual mammography allow for the detection of smaller, incident (new) cancers as opposed to the larger cancers often found when patients delay screening.

to make the referral for annual screening mammograms, and mammography services must be available and convenient. Next the patient and the physician must be made aware of the results and the recommendations. When additional referral(s) for follow-up or diagnostic services are required, they must be done in a timely manner. Finally, once the patient is diagnosed with breast cancer, she must immediately begin planning for treatment with her specialists. The pathway from mammography screening to breast cancer detection and treatment must be prompt and effective in order for early detection and thus better survival from breast cancer to occur.

Provider-patient communication is essential to the screening process. The woman and her doctors must form a partnership which is built on trust, quick turn-around times, and effective communication. Provider-patient communication may depend on the process in place to communicate findings to the patient. If findings are communicated only

to the patient's regular provider this could cause a delay in diagnosis; alternatively, if the patient lacks a regular provider she may not get the initial mammogram results unless she initiates contact with the mammogram facility. Also, women may be less likely to follow through with diagnosis if they cannot get time off from work, lack health insurance or otherwise are unable to pay for

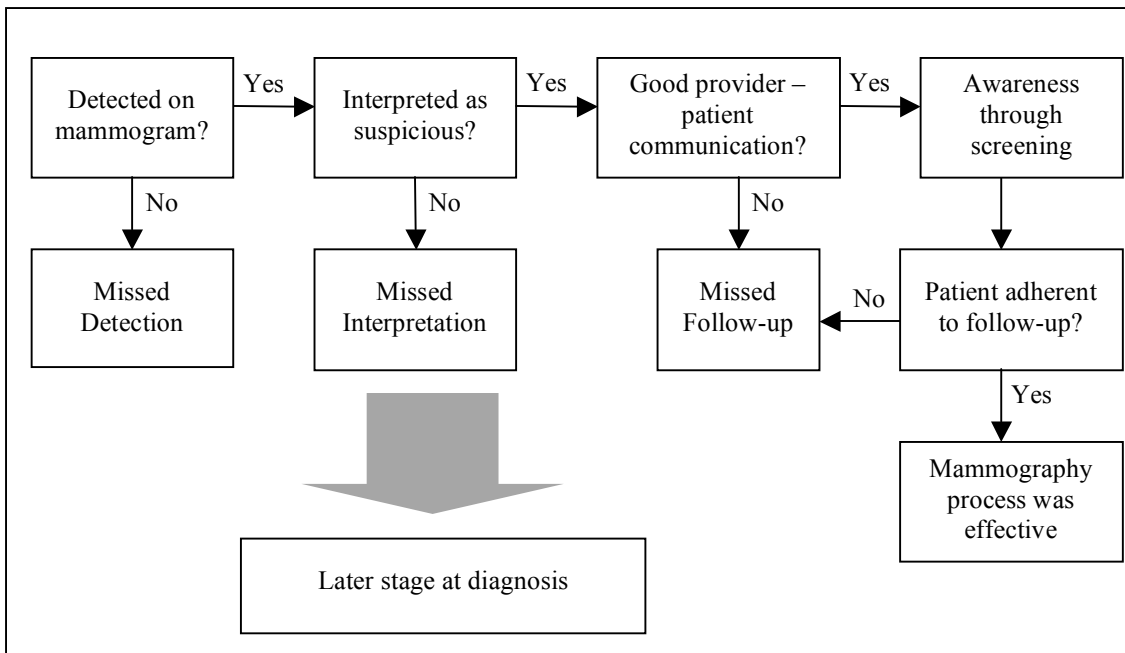
"After she was diagnosed with breast cancer, the problem came when they pushed the papers in her face and said go here. Since the doctor treated it so lightly, the patient won't follow-up with her care, she thinks it's a little thing and the cancer might go away."

- Southside Town Hall

"If you have to worry about trying to get to an appointment...trying to get to the hospital...trying to get to the doctor...if you don't have bus fare...if you can't get a PACE bus...you don't have a job...it makes the experience far worse than it has to be...it doesn't have to be that way...you don't have to die..."

- South Suburban Town Hall

Figure 1: Mammography Process and Effectiveness



care. Other barriers such as transportation and lack of childcare can also limit follow-up.

As if the system were not complex enough, there are elements to a mammogram that must be attained in order to consider it of high quality. Radiologists are mandated to ensure that a mammogram is of the utmost highest possible standard so that if a breast cancer is present on the film it can be found.⁸ In fact, the American College of Radiology, the lead radiology accreditation body, suggests the specific elements needed in order for a mammography program to be considered high quality (Box 1, page 30).⁹

The ability of a program to detect minimal cancer (the third bullet point in Box 1) and not lose women to follow-up (the fourth bullet point in Box 1) are the most crucial aspects in determining the success of the screening process and can make the difference between life and death for the woman. Unfortunately, if small cancers are not found or the woman is lost to follow-up later stage cancer may ensue. Delays in quality control or follow-up will reduce the benefit of mammography.⁴

Figure 1 illustrates all the processes required to detect breast cancer early, beginning with the interpretation of the mammogram film

through communication of results and follow-up.

Key Measures of Mammogram Quality

While there are a number of different measures of mammography quality, we have identified four key measures for assessing the efficacy of the screening process. The first is the rate of detection. For every 1,000 screening mammograms that are done it is expected to find about 6 breast cancers. This rate, 0.006, is an average that is based on millions of mammogram exams worldwide.^{4,10-20} The detection rate will be lower for women who are screened regularly (as low as 2 breast cancers per 1000) and higher for women who are rarely screened (as high as 10 breast cancers per 1000).⁹ For example, the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which provides mammogram to poor women who are not regularly screened, found a breast cancer detection rate of 0.0094 or 9.4 per 1000 based upon the experiences of about 1.2 million women between 1991 and 2002.²⁰ Table 1 reviews some of the studies that have been published in this field. Note that the rates shown gather rather narrowly around 0.006 and that these rates are based upon over 6,000,000 mammograms. This suggests that breast cancer screening programs

that find cancer detection rates far from 0.006 may have significant problems with the quality of their cancer detection processes.

A number of Chicago area institutions have voluntarily shared their cancer detection rates with this Task Force. In Chicago, institutions serving similar populations have markedly different cancer detection rates per 1000.

Some are as much as 50% lower than other institutions serving like populations. The implication of this is that there are some Chicago institutions that are likely missing up to half the cancers that are expected. Of special note is the fact that these institutions tend to serve predominately minority populations.

mammography process is the proportion of minimal cancers that are detected. The American College of Radiology recommends that 30% or more of the breast cancers detected by mammography be less than one centimeter in size.⁹ Our examination of detection rates in Chicago revealed large disparities in the percentage of minimal cancers found across institutions. For example, women regularly attending Institution X (an unnamed Chicago institution) will have a 17% chance of having a minimal cancer detected, compared to a greater than 60% chance at Institution Y. It should be of no surprise that women with minimal breast cancers are more likely to survive the disease. Institution X serves a predominately minority population and Institution Y a predominately White population.

The second measure of the quality of the

Table 1. Breast Cancers Diagnosed Per 1,000 Screening Mammograms

First Author	Year	N	Sample Description	Age	Cancer Type	Rate/1,000 Mammograms
NHS Breast Program ⁴	2003	1,495,000	United Kingdom	>50	DCIS	1.4
					Invasive	5.2
May ¹⁰	2000	46,000	U.S. – Black	>40	Invasive only	5.0
		308,000	U.S. – White	>40		6.0
		109,000	U.S. – Hisp	>40		3.9
Wang ¹¹	2001	127,000	Norway	60-69	Invasive only	5.4
Carney ¹²	2003	464,000	7 U.S. states	>40	Including DCIS	4.8
Adcock ¹³	2004	40,000	Colorado	NA	NA	7.5
Smith-Bindman ¹⁴	2006	790,000	Mam registries – White	>40	Including DCIS	7.0
		62,000	Mam registries – Black	>40		7.3
		91,000	Mam registries – Hisp	>40		5.3
Yankaskas ¹⁵	2005	1,200,000	U.S. Consortium	>40	NA	6.1 first mam
				>40		3.8 subsequent mam
Sickles ¹⁶	2002	48,000	UCSF-specialists -generalists	ave=59	NA	6.0
						3.4
Poplack ¹⁷	2000	48,000	New Hampshire	NA	Including DCIS	3.3
Yankaskas ¹⁸	2004	>1,000,000	25 European Countries	50-64	Including DCIS	3.7-10.6 first mam
						1.7-5.4 subsequent mam
Rosenberg ¹⁹	2006	2,580,151	6 U.S. cities and states, community-based centers	NA	Including DCIS	4.6
NBCCEDP ²⁰	1991- 2002	2,038,118	U.S.	>40	Including DCIS, LCIS, invasive	9.4

* DCIS=Ductal Carcinoma In Situ; mam=mammogram; NA = Not available; LCIS=Lobular Carcinoma In Situ

The third measure is the proportion of “early” (stage 0 or stage 1) breast cancers detected by the screening. Early cancers should make up 50% or more of the cancers detected.⁹ Again, we found large differences in the percentage of early cancer detected in Chicago. In some programs as many as 80% to 90% of the screened cancers are early. In others, the proportion of early (and thus more treatable) breast cancers is less than 50%.²¹

The fourth measure is the proportion of women with abnormal mammograms who are lost to follow-up (Section 3, page 34). Loss to follow-up means the rate at which the institution ‘loses’ the patient as indicated by no record of additional recommended services at that institution or others within some amount of time. While there is no national standard for the proportion of women lost to follow-up, most experts believe that this should be no more than 10% of the women screened. In some programs in Chicago, as many as 30% of women with abnormal mammograms are lost to follow-up.²¹

Additional details regarding measuring the quality of mammography can be found in Online Appendix O-A.

The Collection and Reporting of Quality Measures

The above measures, evaluated together, speak to the quality of the mammography process and the systems in place for follow-up care. While these are among many quality measures recommended by the American College of Radiology, they are not required for certification and virtually no medical centers in Chicago routinely collect them.

Moreover, in Chicago, in 2007, women are unable to find out if their mammography center is doing quality work. This is because even if quality data were collected, there is no requirement for centers to disseminate information on the percentage of breast cancers that are detected as minimal cancer, the proportion of patients lost to follow-up or other indicators of quality. In addition, safety net mammography programs, such as the

Illinois Breast and Cervical Cancer Programs (IBCCP) and Stand Against Cancer (SAC), do not require quality standards when selecting its participating institutional partners. The transparent public reporting of healthcare quality information has become commonplace and mandatory for many conditions. For example the Centers for Medicare and Medicaid Services (CMS) has a tool which allows the public to view selected quality measures for any institution in the U.S.²² In fact, many have argued that measuring quality and openly sharing quality data will ultimately lead to not only improved performance but also reduce mortality.^{23,24,25} If mammography providers collected measures of quality and made the results transparent for the public of Chicago, mammography quality would improve.

The Value of a Breast Cancer Consortium

Nationally, there have been consortia of mammography facilities that have grouped together to share outcome data, largely for research purposes. For example, in New Hampshire over 85% of the facilities that provide mammography participate^{17,26} while in Metropolitan Denver over half the facilities participate. A national not for profit group, the National Consortium of Breast Centers has initiated a web-based mammography quality reporting system that provides feedback to participating institutions on the quality of their work.²⁷ See details at Online Appendix O-B.

This past summer, under the auspices of this Action Group, leaders from Access Community Health Network, Advocate Healthcare, the Chicago Department of Public Health, Mercy Hospital and Medical Center, Rush University Medical Center, Sinai Health System, and the Metropolitan Chicago Healthcare Council met to discuss the feasibility of creating a Metropolitan Chicago Breast Cancer Consortium that would do three things: 1) identify and measure a series of quality markers pertinent to the breast cancer diagnostic and treatment process, 2) develop strategies to coordinate care among institutions to improve breast cancer outcomes for all women, and 3) create a team to help

institutions improve their quality processes. This group of health care leaders agreed to convene a larger group of healthcare institutions after the release of this report to pursue the formal creation of a consortium (Appendix C). A meeting was also conducted with the director of the National Consortium of Breast Centers to discuss having a Metropolitan Chicago Breast Center group to share data.

The following are the conclusions of the Task Force with regard to the mammography process:

- *The quality of the breast cancer screening process in Metropolitan Chicago varies greatly by institution. Black women are more likely to attend institutions that either do not measure mammography quality, or if they do, provide inferior quality than do top Chicago healthcare institutions, contributing to the higher Black mortality rates from breast cancer.*
- *There are national standards for measuring the quality of the mammography process that all Metropolitan Chicago health care institutions should be required to collect and share.*
- *The IBCCP, the statewide breast cancer screening program, does not use quality measures to choose participating institutional partners. It must begin to do so.*
- *A group of Metropolitan Chicago health care institutions have expressed an interest in collaborating for the sake of setting standards for measuring and improving breast care for all women.*

SECTION 3. Diagnostic Follow-up and Communication

The value of screening mammography is only as good as the communication and receipt of needed follow-up after an abnormal mammogram. Delays in diagnosis and treatment both contribute to mortality and have been shown to decrease survival by up to twelve percent.²⁸ Numerous causes contribute to delays in diagnosis and treatment. Patient factors such as not having time to obtain services, fear of breast cancer, home responsibilities, lack of transportation, inadequate insurance, and loss of pay as well as several system factors such as busy clinics, misunderstanding the diagnostic and follow-up guidelines, and inadequate results communication may all lead to delays in the mammography process.^{5,29} In fact, studies have shown that only a fraction of patients who need follow-up are receiving it (for various reasons).^{29,30}

“We would send patients to (unnamed hospital); it would be a black hole. Six months later, you’d get batches of them... then you’d have to go through and see that nobody had been notified.”

- Primary Care Physician Focus Group

“I have good insurance...you would not believe that I had to keep calling my nurse to get my results...the nurse wouldn’t call me back...I had to call my primary care doctor to get him to put the order through...I was frustrated...here I have good insurance...how are those people who don’t have insurance...how are they managing...this should not have happened.”

- South Suburban Town Hall

“A Navigator who can find these patients, and then to follow-up with these patients to find out where they live, that is what we need. ...It’s not that women don’t want to go in, it’s just that getting them in is harder. The systems that have worked in those clinics are the people that have a dedicated person, who help patients get over their barriers.”

- Primary Care Physician Focus Group

Box 2. Loss To Follow-up and Timeliness Measures

- Loss to follow-up (not returned within 2 months) after abnormal mammogram
- Number of days from abnormal screening to initial diagnostic work-up
- Number of days from screening to final diagnosis (all diagnostic tests complete)
- Number of days from initial diagnostic work-up to final diagnosis
- Number of days from diagnosis to treatment should be no more than 30 days
- Number of days from screening to breast cancer treatment

Research suggests that Black women have longer delays from initial abnormal screening to diagnosis of breast cancer compared to White women,^{5,6,7} even after controlling for income, comorbid conditions, cancer detection method, tumor biology and other factors.^{6,31} Provider communication is one factor contributing to delay, especially in public clinics.^{5,29,32,33} For example, a recent study found that compared to White women, Black women were twice as likely to not be notified about an abnormal result or to misinterpret the information she received.³³ Based on feedback from primary care physicians, technologists and the from the community Town Hall meetings, we believe that this is also true in Metropolitan Chicago. Moreover, our capacity survey showed that Black women in Chicago were less likely than White women to attend facilities where abnormal screening results were directly communicated to women while they were waiting.

Timeliness and Loss to Follow-Up

Health care institutions should make every effort to follow-up with patients who have abnormal findings in a timely manner. Ideally, a breast cancer diagnosis should occur within 30 days of an abnormal screening mammogram.⁷ Once a breast cancer is diagnosed the patient should enter treatment within 30 days of the diagnosis,⁶ or no more than three months from the time of the abnormal mammogram.^{28,32} The time from recommendation for screening until ultimate treatment of breast cancer is referred to as

cycling time, which was adapted from the Oncology Roundtable, a group concerned with measuring cancer quality.³⁴ Cycling time is measurable (though rarely measured) and might be the ultimate quality measurement to understand the breast cancer mortality disparity in Chicago.

Timeliness is a measure of time between two events, for example, the number of days between an abnormal screening mammogram and a final diagnosis of breast cancer. Unfortunately, most timeliness measures do not have national benchmarks associated with them yet. (See Box 2 for suggested timeliness and loss to follow-up measures.)

Preliminary data from selected institutions in Chicago show that the abnormal mammogram follow-up rates vary, similar to the other quality measures.²¹ At two Chicago institutions the lost to follow-up rates were over 25% respectively. These rates were reduced to almost zero when on-site patient navigator programs were created. Patient navigators are lay health workers or professionals who work with women to get them back for follow-up testing. Pioneered in Harlem, NYC, they have been used around the country to improve adherence with the breast cancer diagnostic process.³⁵

Comments from all three Focus Groups (Appendix D) conducted by this Action Group reinforce the need for improved navigation services for women and suggest that in Chicago many aspects of the follow-up

process are flawed. Poor women face difficulties getting mammograms in this first place and they face barriers to follow-up. Women may not receive contact about the abnormality, they may not understand the need for follow-up, and they often have trouble obtaining old mammogram films which are frequently done at other institutions. One other difficulty women face is obtaining the referral for the diagnostic work up needed after an abnormal mammogram. Unlike other diagnostic tests, women are generally not allowed to self-refer to breast cancer screening or for diagnostic testing without a medical home. This barrier is more burdensome for low income minority women and those without insurance.

Finally, a subgroup of this Action Group met to discuss technological means of improving the mammography process. One problem voiced by community members, technologists, radiologists and primary care physicians alike was the problem of obtaining the women's prior mammogram for comparison. This single step in the mammography process can cause huge delays in care because it requires the woman to physically return to the prior institution to request the old films and then bring those films to the second institution to be read. New federal law allows the creation of Regional Health Information Organizations (RHIOs) to allow the flow of confidential health information among institutions (Appendix E). The Action Group subgroup recommended exploring the creation of a digital mammography image library to allow for the cross institutional sharing of digital mammography images as a component of a larger breast cancer quality consortium. This would eliminate the difficulties women and institutions face when trying to obtain the old breast images for comparison, as well as speed up a component of the diagnostic process.

The following are the conclusions of the Task Force with regard to mammography follow-up issues:

- *Black women in Chicago face excessive delays in getting timely follow-up for abnormal mammograms. This is a likely contributor to breast cancer mortality differentials in Chicago.*
- *Women across Metropolitan Chicago often have trouble getting their old mammograms for review when these are done at other institutions. This can delay diagnosis.*
- *Local navigators at safety net providers have been shown to increase show rates for follow-up mammograms.*
- *The difficulty many Black woman face securing a medical home linked to a provider of mammography creates unacceptable delays in screening, diagnosis and treatment.*
- *Women have to make too many visits to get breast cancer diagnosed. This places an unusually difficult burden on women and creates delays.*
- *It may be possible to create a Chicago metropolitan mammography digital image library to allow for the easy comparison of old mammography films.*

SECTION 4. Physician and Other Workforce Issues in Breast Imaging

Research suggests that specialists detect more cancers and more early-stage (0 and 1) cancers than general radiologists.¹⁶ As shown in Table 2, specialists are almost twice as likely to identify a cancer on a screening mammogram as a general radiologist (6.0/1000 vs. 3.4/1000) and more likely to detect early, curable cancers. A woman going

Table 2. Cancer Detection Rates: Breast Imaging Specialist vs. General Radiologists Who Interpret Mammograms¹⁶

	Specialists	Generalists
Cancer detection rate at screening	6.0/1000	3.4/1000
Cancer detection rate at diagnostic mammography	59.0/1000	36.6/1000
Stage 0 and 1 cancer detection rate at screening	5.3/1000	3.0/1000

to an institution where specialists read all the mammograms will have twice the chance of having an early breast cancer detected if it is on her mammogram than if she goes to an institution without a breast specialist.

In general, institutions in Chicago with specialized trained radiologists reading the mammogram have better breast cancer outcomes than those hospitals and clinics where non-specialized radiologists read the mammograms. These institutions have more support staff and tend to have more advanced equipment. They also tend to serve a different racial and ethnic mix of patients. In our capacity survey of mammography facilities in Metropolitan Chicago, White women were 2.5 times more likely than Black women to have their mammograms at facilities staffed by mammography specialists. This differential quality is thought to be one significant contributor to the Black- White breast cancer mortality disparity in Chicago.²¹ During Focus Groups with primary care providers, those providers could readily tell from the quality of the mammography reports which institutions were providing high quality mammograms for their patients and which ones were not. One physician compared the mammogram quality at one community hospital compared to an academic institution as the difference between a “Chevy and a Cadillac.”

Do we get a sense about differences in quality of mammograms? “Sadly yes...we can. General radiologists read the mammograms, therein lies the answer. It should be a dedicated mammographer.”

- Primary Care Physician Focus Group

Based on these findings, one question arises: Why don’t we allow only mammography specialists to read and interpret mammograms? The answer is not simple. Generally, the availability of highly qualified radiologists is critical in guaranteeing access to high quality breast imaging. A number of articles over the past decade have focused on manpower issues in radiology, and several authors have predicted a significant shortage of radiologists overall in the U.S. in the near future. The American College of Radiology performed a large scientific survey of radiologists in 2003, with a special focus on breast imaging specialists and on mammography interpretation. The survey included trainees and retirees, as well as active, practicing radiologists. The results related to breast imaging are detailed in the following paragraphs.³⁶

There are approximately 28,000 radiologists in the U.S., 61% of whom read and interpret mammograms. However, in city centers of large metropolitan areas, a smaller percentage of radiologists (43%) interpret mammograms, compared to the suburbs or smaller cities where 77% of radiologists interpret mammograms.³⁶ Moreover, while only a small percentage (19%) of radiologists who read mammograms are located in the city centers of large metropolitan areas they interpret nearly one third of all U.S. mammograms.³⁶ Between 5 and 10% of all radiologists are specialists in breast imaging.³⁶ A breast imaging specialist is defined as someone who devotes at least 30% of their clinical time interpreting mammograms, has completed a breast imaging fellowship, or self-reports breast imaging as a primary or secondary specialty. Thirty percent of U.S. mammograms are interpreted by specialists.³⁶

Unfortunately, with at most 10% of all radiologists specializing in breast imaging, the workload is shared by too few physicians. Although there are general radiologists interpreting mammograms, about 21% stated that they would prefer to spend less time interpreting mammograms.³⁷

The dearth of specialists in mammography is reflected in the number of vacant positions across the U.S. A scientific survey of 575 breast imaging practices in the U.S. conducted between October, 2003 and April, 2004 demonstrated that 29% of practices had job vacancies for radiologists who read mammograms. Ten percent had two or more openings; many had open positions for more than two years.³⁷ In academic practices, 48% had position openings for breast imaging specialists compared to 35% of urban-community based practices, 25% of suburban practices and private practices, and 11% of rural practices. Other studies have shown similar results and have noted that more non-profit institutions have shortages than for-profit institutions. These workforce issues contribute to longer wait times to have a mammogram appointment in these practices.^{37,38} Staffing shortages are also prevalent for the technologists who perform mammograms.³⁸

If we assume that all of the statistics and information provided above can be applied to the physician workforce in the Metropolitan Chicago area, there are a number of significant problems to address. The demand for breast imaging specialists is increasing, due to both increasing patient volumes and new technologies. The shortage of well-qualified personnel is probably due to several factors, including fewer residents entering the field, malpractice concerns, and financial strains. In Chicago, there are at least ten vacancies for breast imaging specialists, not including most of the safety net providers who use general radiologists to read mammograms and are unlikely to be able to attract specialists.

In sum, there is a shortage of radiologists who specialize in mammography; and, non-specialists tend to detect fewer cancers. Are there ways to improve the cancer detection rates of non-specialty trained mammographers? One methodology is second readings, common in Europe but not feasible in the U.S. and rarely practiced in Chicago. Technology is available to read mammograms. One such technology is computer-aided diagnosis (CAD), a process where a computer independently reviews a mammogram from the radiologists. CAD has not been proven, however, to improve cancer detection rates. The other technology is digital mammography, which is superior to conventional film mammography in women under 40, especially those with dense breasts.³⁹ While not thought to be superior to film technology in expert hands⁴⁰, digital mammography lends itself to better storage of the film image and easier transport of the image to other diagnostic centers, a factor important for women who sometimes have to go to different centers for screening and diagnostic mammograms.

The Task Force believes that a free consultation service could improve the quality of the mammography readings by non-specialists in Chicago by working with them over a period of time in a “mini fellowship”. By going to the community sites and working with the community based radiologists over time in a structured program, it is believed that the quality of the readings could be improved. A handful of Chicago breast specialists have expressed an interest in providing this service.

Finally, it might be possible to attract more doctors to choose breast imaging as a specialty by reducing the financial barriers to becoming a specialist and creating more training spots in Chicago. Additionally, digital mammography screening services could be located in communities where the poor women live and the mammograms could be read at institutions where specialists are more likely to work. This is the methodology applied in most European countries and may be the most economical plan in Metropolitan Chicago.

The following are the conclusions of the Task Force with regard to mammography workforce issues:

- *Black women in Chicago are less likely to be screened in institutions where mammography specialists read the films, probably resulting in lower cancer detection rates.*
- *There is a shortage of trained specialized radiologists and technologists in Chicago. This shortage needs to be addressed.*
- *There are technologies that might be advantageous to use in safety net and underserved populations to improve cancer detection rates by allowing for remote readings by specialists.*
- *There may be ways to improve the skills of non-specialists who read mammograms at Chicago institutions by offering them focused training by specialty physicians.*
- *There may need to be innovative infrastructure solutions to address the workforce needs.*

SECTION 5. Failure of the Health Care Safety Net in Metropolitan Chicago and the Quality of Breast Health Services

A discussion of the quality of the mammography process would be deficient if the gaps in the public safety net were not addressed. Since many of the quality measures in the mammography process depend on timely testing and follow-up, the long delays for both mammography and breast diagnostic services in the public health safety net were identified by the Task Force as a notable quality issue. The rising gap in Breast Cancer mortality disparity in Chicago compared to New York despite similar poverty levels among the Black populations in each city has been attributed by Task Force members in part to the inability of the public sector health infrastructure to provide the

most basic quality standards of breast health care to women in Metropolitan Chicago compared to NYC.⁴¹

At one point in time, the County Bureau of Health Services had received national recognition for its groundbreaking breast cancer screening and diagnostic services.⁴² Mobile vans screened women in remote areas of Cook County, mammograms were readily available at Stroger and Provident hospitals and timely diagnostic follow-up was available. Referral linkages with other safety net providers were well established, allowing for the referral of women for diagnosis and treatment. However, presently screening mammograms are not routinely available and diagnostic work-ups are delayed beyond the most basic community standards of quality care.

While the Illinois Breast and Cervical Cancer Screening Program (IBCCP) and the Access Community Health Network's Stand Against Cancer Program coordinate breast cancer screenings, diagnosis, and treatment for uninsured women, the enrollment process is demanding and the available Chicago sites are limited. Poor women often have to travel long distances outside their communities to access these services. None of the major teaching hospitals in Chicago actively participate in providing these mammogram examinations.

"I can't go to you, doctor, or any other hospital because I don't have health insurance and County sends you a bill now...the reason why a lot of women don't go, we don't have income and don't have no insurance."

- West Humboldt Park Town Hall

There are some short term and longer term solutions to the problem with the public health safety net. There is agreement within the Task Force that the burden of breast health care for underserved women in Metropolitan Chicago cannot be carried by just a few institutions. In the short term, there should be collaboration between the Cook County

Bureau of Health and other major healthcare institutions to coordinate timely follow-up to women in need of breast health care. A recent program linking patients in need of diagnostic colonoscopies within the County System with availability of these services at Rush University Medical Center is an example of such a partnership.

Longer term, the infrastructure deficiencies in the public healthcare sector, must be addressed if the quality differential is to be adequately addressed. Certainly adequate funding of the public sector, including the Cook County Bureau of Health Services is required. However, the County Health System cannot be the sole solution to the quality of breast care issues that underserved women face. As part of the Task Force deliberations, a multidisciplinary group of breast cancer experts from the public and private sector health care sectors in Chicago met to discuss the feasibility of redesigning the public sector infrastructure to better serve all women in need of breast health services in Metropolitan Chicago. To create this infrastructure would require an unprecedented public private partnership including the State of Illinois, the City of Chicago, Cook County and private sector institutions. It is believed that such a systematic approach is ultimately required in Metropolitan Chicago, if high quality breast care for all women is going to be achieved.

The following are the conclusions of the Task Force with regard to the current safety net:

- *The regional health care safety net in general and the Cook County Health System in particular cannot reliably deliver timely screening or diagnostic mammography follow-up to the patient populations at risk. This is a major quality issue and affects breast cancer outcomes.*
- *Short-term there needs to be better coordination between the County Bureau of Health Services and private sector institutions to provide timely breast cancer diagnosis and treatment services. The breast cancer screening and diagnostic services that are offered in Metropolitan Chicago to underserved women are poorly coordinated leading to unacceptable delays.*
- *Long-term solutions to the screening, diagnosis, and treatment gap must be found including adequate funding for public sector services and greater region wide public-private partnerships to address the infrastructural deficiencies in the system.*

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CHAPTER 3.

QUALITY OF TREATMENT

SECTION 1. Introduction

Despite a lower incidence of breast cancer at every stage of the disease, Black women are more likely to die from it than White women. Even when Black women present at the same stage, they still experience worse outcomes in terms of survival. In the past decade, several studies have attempted to explain why this is the case and many have attempted to close the gap, yet this disparity continues to persist.

In Chicago, a recent epidemiological study by Hirschman and colleagues confirms this finding. They report that White women (148 per 100,000 women) get breast cancer far more often than Black women (126 per 100,000), and yet Black women are 68% more likely to die from it.¹ To our knowledge, the magnitude of this Black-White disparity is far greater than what has ever been documented nationally or in other urban settings.

In early stage breast cancer, it is well established that treatment, including surgery, chemotherapy, hormonal therapy, biological therapy and radiation therapy, can prevent distant spread of cancer and can cure patients. One possible, and likely probable, explanation of the increased disparity in breast cancer survival between Black and White women in Chicago is a difference in the quality of breast cancer treatment received. This may be due to differences in treatments offered to, accepted or received by patients, or a combination of these.

To explore this issue, the Metropolitan Chicago Breast Cancer Task Force established the Quality of Treatment Action Group. The tasks of this Action Group were to elucidate possible reasons for potential disparities in breast cancer treatment experienced by different racial and ethnic groups, to recommend potential solutions to reduce these disparities, and to improve overall breast cancer outcomes. As the group proceeded with these

tasks, it became clear that the etiology of differences in treatment was complex and multifactorial.

Issues of access to care, socioeconomic factors, environmental factors, comorbid conditions, lack of patient education, provider-patient miscommunication, overall mistrust in the health care system, and fragmentation of the health care system may all play a role in affecting what treatment is actually received, offered and delivered.

Biology and genetics were two of the first explanations we considered. The literature suggests that Black women tend to have more aggressive tumors that are often less responsive to treatments. For example, they have higher rates of estrogen receptor negative tumors and are therefore not able to take advantage of the strides in treatment made by new anti-estrogen therapies.² However, if differences in survival can be explained only by differences in biology, the disparity between Black and White women should not differ in magnitude between the nation and New York City versus Chicago. Therefore, we examined other explanations for the significant disparity in survival experienced by Black women in Chicago.

Because so many factors affect the quality of treatment that a patient is offered, accepts, and receives, multidimensional solutions must be developed to deliver equal quality of care that will improve breast cancer outcomes. To do this, in the following chapter we present:

- (1) Challenges facing providers delivering and patients obtaining quality treatment;
- (2) Possible solutions to improve breast cancer survival for all women; and
- (3) Recommendations on interventions that can make a substantial impact on decreasing disparities and improving overall breast cancer outcomes.

SECTION 2. The Problem

During the course of our discussions and research over the last six months, several themes emerged. These include barriers to accessing treatment, fragmented care, low health literacy and mistrust of the medical system, and why measuring quality matters.

A. Barriers to Accessing Treatment

Insurance Coverage

Forty-seven million Americans currently are without health insurance. That number is actually higher depending on the definition of “uninsured” that is used. It is well accepted that insurance status (i.e., the ability to pay for health care) is the most important predictor of the quality of health care received. Illinois has progressive legislation that has improved access to coverage (i.e., Medicaid) for uninsured women diagnosed with breast cancer. The Medicaid Treatment Act (September 2006) ensures Medicaid coverage of medical treatment to all women diagnosed with breast cancer who are documented residents for a minimum of five years and meet certain income requirements. Recent expansion of this Act (October 2007) ensures coverage to women, irrespective of income. Women who meet these criteria receive complete treatment coverage with a breast cancer diagnosis. While this measure is certainly a step in the right direction, it is not adequate to fully address the disparities in treatment coverage experienced by women who are documented residents for less than five years or women who are undocumented.

In addition, many of the working poor, among whom African-Americans are overrepresented, may be employed at jobs that do not provide full health coverage or have high co-payments, placing them at a disadvantage in receiving full coverage of breast cancer treatment. Merely having insurance does not guarantee adequate coverage or the ability to pay for all services or medications. Treatments are extremely expensive, with surgical costs up to \$20,000, chemotherapy costs up to \$35,000

and radiation costs up to \$80,000. Women who are underinsured may not have adequate funds to cover the entire cost of breast cancer treatment. In fact, it was reported by Focus Groups conducted in Chicago that some women never return for treatment after receiving a diagnosis of cancer because of the prohibitive cost. Women consciously choose to forego treatment because they have no “extra” money for health care.³

For women without coverage or with inadequate coverage, their choices are to obtain care through the public health care system in Cook County, to pay for their medical care out of pocket (a prohibitive cost for most) or to choose to forego treatment until it can no longer be avoided. The current public health care system in Cook County is financially strapped and in the process of eliminating resources and services, which were already deficient in meeting the health care needs of breast cancer patients without adequate insurance coverage. Even without budget cuts, the needs of the uninsured and underinsured are far greater than the resources available through the public hospital system (Stroger Hospital and the Bureau of Health Services of Cook County). The County system does not have enough resources to provide timely care to all of the ever-increasing number of uninsured and underinsured needing screening, diagnostics and treatment for breast cancer.

“I was diagnosed with breast cancer last year August... I am under the care of Cook County Hospital and I have to say that Cook County takes excellent care of you. I did a self exam and found a knot up under my arm. I went to the emergency room. Through the emergency room they did all the necessary tests. I had a mastectomy of the right breast and right now I’m in chemotherapy... They provided me with the medical card and they provided me with transportation. ... The only problem that I can see is financially...I go to the hospital at least 3-4 times a week and I really can’t work right now because of my health... If I wasn’t living here I would be on the street... homeless with breast cancer and no money.”

- West Humboldt Park Town Hall

An additional issue for many patients is inadequate or lack of coverage for prescription medications, often leading to high, unaffordable co-pays. This forces many patients to forego purchasing medications that would improve their breast cancer outcomes. In particular, women may be unable to afford anti-hormonal medications such as tamoxifen or aromatase inhibitors (which can cost up to \$300 per month), despite the fact that these medications decrease the risk of recurrence by up to 50%.

Alternately, some may “stretch out the prescription” by taking only half of the recommended dose which may ease the cost burden but decreases the efficacy of the drug.

Lastly, the problem with the current coverage situation is that not all providers will accept Medicaid reimbursements. It has been well documented in the literature that breast cancer outcomes are better when care is provided by specialists who treat high volumes of breast cancer patients and at hospitals that perform a high volume of breast cancer operations.^{4,5} However, not all patients have equal access to surgical specialists or other oncology specialists, which may contribute to disparate outcomes.

Limited Disability Coverage

Currently, social security disability is only available to patients with breast cancer who can demonstrate that the disability is likely to persist beyond 12 months.⁶ While the treatment time for early stage breast cancer is prolonged, most patients complete active treatment within nine months. It may be possible to obtain disability for women who have more advanced disease and often need treatment for the rest of their lives, yet those with earlier stage disease are unlikely to qualify. Patients have the option to take leave through the Family Medical Leave Act but this does not guarantee income during the time they are off treatment. Some employers may offer medical leave benefits to ensure health care coverage but this does not always guarantee job security. Others may offer

short term or long term benefits but these are based on eligibility and are employer specific. Without any financial assistance, these women must continue to work, often at jobs that do not easily allow time off of work for treatments. For those who can not adhere to their work schedules, many face the prospect of losing their job and their source of income. For some, this is the only or predominant source of income for their families. This means some patients are forced to choose between paying the rent or feeding their kids and adhering to a treatment schedule, and most often, treatment is thus not delivered as intended. It is easy to see how this can result in worse outcomes for these patients.

Proximity to Treatment

Women who undergo breast cancer treatment by medical specialists at comprehensive care centers experience higher rates of survival.^{7,8,9} The assumption here is that a specialized breast surgeon may have more experience performing the appropriate breast cancer operations. In addition to the surgical specialist, there are two types of specialists who are involved with treatment *after* surgery: medical oncologists (who offer chemotherapy, hormonal therapy and biological therapy) and radiation oncologists (who offer radiation therapy). Visits to these specialists and adherence to the treatments they administer require frequent and regular appointments. Such treatments, often referred to as adjuvant therapies for patients with early stage breast cancer, have been shown in multiple studies to improve survival rates when administered appropriately and on schedule.

Unfortunately, many patients in the Metropolitan Chicago area have to travel great distances to access such specialty care. There are areas of Cook County, notably the south suburban communities, which are underserved by breast cancer specialists. In our County’s public health care system, it may take patients up to two to three hours each way with public transportation to access the only public hospital providing specialty care. This results in many other problems for

patients as the long day needed to access specialty care means more time off from work, difficulties in arranging for child or elder care, and increased transportation costs. Thus, distance may prove prohibitive to a patient's receipt of quality treatment.

"Transportation is a barrier to safety net hospitals... location is inconvenient. If the sites were in the community, women would go."

– Southside Town Hall

Furthermore, Stroger Hospital is the only public hospital available for care of breast cancer patients who are uninsured or underinsured. For a while, there had been some diagnostic testing available at other County-owned facilities (i.e. Provident). However, the availability of such services were limited (no availability of image guided biopsy, no MRI available, etc) and have recently decreased further. While attempts had been made in the past to decentralize these services, i.e., having chemotherapy services available in other locations, most breast cancer care is still provided at Stroger Hospital. The existence of one public facility, as opposed to multiple ones throughout Cook County, contributes to the problem of accessibility facing many women merely on a geographic basis, forcing them to have to travel substantial distances to reach services at the central public facility. In comparison, the public facility in New York City, which is geographically smaller than Chicago, is served by the Health and Hospitals Corporation (a public benefit corporation). It operates 11 hospitals throughout the city increasing the likelihood that an individual can access care closer to home. Thus, when treatment facilities are closer to home, there is a greater likelihood that women will access care in a timely fashion, with greater ease and with fewer obstacles.

Even if patients were not dependent on the public health system and all had adequate insurance coverage, there are still areas of the city and county that are significantly

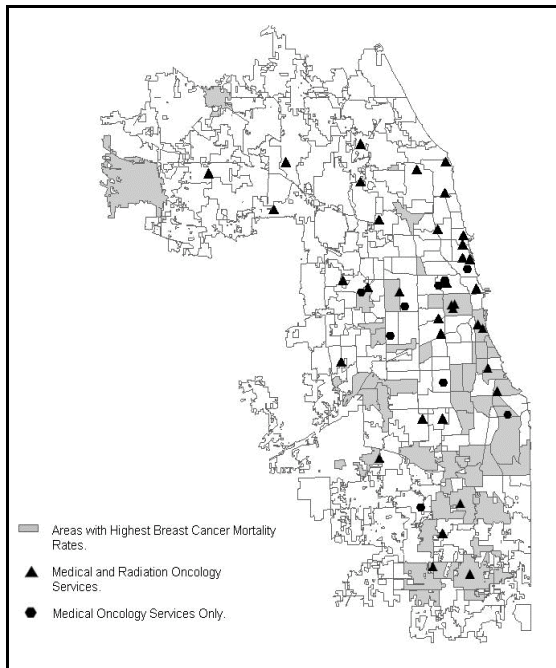
underserved in terms of access to cancer care. To better understand where women are able to access these services, we surveyed general hospitals in Cook County and inquired about available adjuvant therapies. Figure 1 maps the location of medical and radiation oncology facilities in Cook County and illustrates areas of high mortality rates. As evidenced by the figure, there are certain areas without nearby therapy treatment centers. It is also interesting to note that those areas with the highest mortality rates are least likely to have medical and radiation oncology services that are in close proximity. These areas are also less likely to have cancer programs approved by the American College of Surgeons Commission on Cancer (ACoS CoC). Sixteen institutions have ACoS CoC approval in Cook County (www.facs.org/cancer/). Though such approval is not required to provide cancer care, overall it demonstrates a health care institution's level of commitment to ensuring quality treatment.

Logistical Barriers

Even a patient with adequate insurance may face other financial difficulties due to the costs associated with cancer care. These can include the costs of transportation and child or elder care, or the ability to pay rent or bills if required to take off work for treatments, particularly if the employer does not provide for adequate disability coverage. Focus Groups conducted in Chicago identified consistent themes in which there is a lack of attention to breast cancer by some members of the community, because individual concern "pales in comparison to competing risks of daily survival, particularly in light of multiple responsibilities related to caring and supporting their families."¹⁰ (To learn more about these Focus Groups, see also Appendix F).

While some of these logistic and financial barriers have been touched upon earlier and in other chapters of this report, it can not be emphasized enough that without a basic accessibility to transportation, the means to provide care to children and elders, the ability to take time from work for evaluation

Figure 1. Map of Hospitals Offering Medical and Surgical Oncology Services in Cook County, Illinois



and care, the means to pay for treatment and easy access to specialists, the ability to effectively communicate with providers (i.e., language barriers), and the ability to understand what is being communicated (i.e., if all information is written and the patient has a low literacy level) disparities in outcomes are certain. And yet, even if all these things were readily available to all patients, it bears remembering that the current health care system, even in its best form, is a difficult one for many to navigate. It can be confusing to navigate the complex systems that are involved with breast cancer care, requiring visits to multiple practitioners and a variety of testing and treatment sites.

The difficulty in navigating the system is hard enough for those with familiarity with the medical system and resources; it is so much harder for those without these things and without the social support networks to aid in the navigation. These logistical barriers can lead to delays in care, which contribute to worse outcomes.

B. Fragmented Services

Quality breast cancer treatment requires the coordination of services offered by multiple specialists from different departments. Screening and diagnosis alone can involve radiology and pathology while treatment may further involve, but is not limited to, surgery, medical oncology, radiation oncology, plastic surgery, physical therapy, social services and nursing.

Though many of these services exist within a health system, not all health care facilities offer the spectrum of care necessary for comprehensive care. The problem of not having several different specialty services offered under the same roof, or nearby, can lead to delays in treatment, poorly coordinated care and unnecessary duplication of testing.

While most insured patients have their cancer treatment facilitated through their primary care provider, many patients, particularly those who are uninsured or underinsured, may not. They are faced with obtaining care from other available sources. For some this is an emergency room, for others it may be a practitioner based in the community who can provide some aspect of necessary care but not all due to financial constraints. It is possible for women to obtain free mammograms at one facility, but then they may have to seek care elsewhere for further diagnostic evaluation of an abnormality and then go to yet another facility for definitive treatment, all the while without any coordination of care. This fragmentation of care leads to variety of problems in ensuring optimal treatment including delays in diagnosis and treatment, repetition of testing procedures when accurate reports are unable to be obtained (which also increases the cost of care), and the performance of procedures that may ultimately limit a patient's treatment options (i.e., an inappropriately performed excisional biopsy may commit a patient to a mastectomy who might otherwise have been a conservation candidate). While a degree of fragmentation of care is evident throughout our health care system, that which is experienced by the uninsured and

underinsured is greater and certainly contributes to disparities in outcome.

"A patient had insurance (HMO) - and was diagnosed with breast cancer. The doctor told her she could not go anywhere else (for care). Six months later she got a referral. By the time she was in treatment she had stage 4 cancer. She reached out and the doctor didn't help."

– Southside Town Hall

C. Misperceptions, Low Health Literacy, and Mistrust of the Medical System Affect Treatment Received

Misperceptions

Many misconceptions around cancer and its care are prevalent in a variety of cultures. Some of these misconceptions are found in certain cultures while others seem to be prevalent among many in the lower socioeconomic strata where lack of education may be the root cause. An individual's notions about cancer, its behavior and its response to treatment may affect the time of presentation resulting in later stages of diagnosis, delays in starting treatment and the lack of adherence to the recommended treatment. Beliefs about the nature of cancer ("all cancers are fatal"), the lack of need for early treatment ("it doesn't have to be treated until it bothers me"), the behavior of cancer once a biopsy is performed ("biopsy causes cancer to spread"), the lack of efficacy of breast cancer treatments and exaggerated notions concerning toxicity may all affect an individual's acceptance of treatment options. In Chicago, recent studies have documented that such notions are pervasive among African-Americans and found that they contribute to delay in seeking evaluation of suspicious breast symptoms.^{3,11} These notions may be the result of lack of education or the result of strong beliefs held in the patient's community. Unless the beliefs are understood, it can affect the ability of practitioners to provide care to patients, which can translate into worse outcomes for patients contributing to the survival disparities observed in Chicago.

Low Health Literacy

Another challenge to receiving quality treatment is low health literacy. Health literacy is the ability of patients to obtain and understand the basic health information needed to make appropriate decisions regarding their health care and to adhere to treatment recommendations. A recent study shows that approximately 90 million adults in the U.S. have fair to poor health literacy.¹² Race, language and age have all been shown to be associated with inadequate or lack of health literacy.¹³ Lack of health literacy has been linked to inferior outcomes, and therefore likely also plays a part in breast cancer disparities.

Mistrust of the Medical System

Thirdly, while lack of trust in the medical establishment is not unique to any one ethnic or racial group, historical discrimination and abuses have created mistrust in the system by some racial and ethnic groups, notably the African-American community. The history of discrimination and unethical experimentation on African-Americans dates far back and includes incidents such as the Tuskegee syphilis experiment.^{14,15} As a result, there continues to be a lingering distrust by many in the African-American community that affects the acceptance and receipt of health care. Real or perceived discrimination is still cited by patients in their descriptions of their experiences of encounters with the medical system.^{16,17} This discrimination may be on the basis of race or ethnicity, socioeconomic status, or insurance status. This may lead patients to either seek care in facilities without as many available resources, change providers multiple times producing delays in diagnosis and treatment, or forego care entirely if faced with the prospect of receiving care in a setting where discrimination is perceived. Thus, misconceptions around cancer care, low education and health literacy, and mistrust of the medical system may negatively impact the quality of treatment that is ultimately offered, accepted and received, contributing to poor cancer outcomes and the disparity in breast cancer survival experienced in certain communities.

D. Role of Comorbid Conditions

One potential explanation for a portion of the increased mortality experienced by African-American patients is the presence of comorbid conditions and their contribution to overall mortality. One article showed a significant survival disadvantage for Black women with breast cancer in terms of all-cause, breast cancer-specific and competing causes-specific mortality.¹⁸ This may have significant implications as we seek to address the Black-White disparity in mortality in Chicago.

The presence of comorbidities can significantly affect the treatment options that are offered to patients.^{19,20} Particular drugs which have been associated with improved survival rates of patients with breast cancer, such as adriamycin and herceptin, have a known side effect of cardiac dysfunction. Patients with hypertension, diabetes, and known cardiac disease may be limited in their ability to receive these drugs. If these comorbidities are poorly controlled, leading to pre-existing cardiac dysfunction, these patients may not be able to receive optimal therapy, which can contribute to inferior outcomes.

Control of these comorbid conditions may be an important way of improving the survival of African-American breast cancer patients and reducing racial disparities in survival. In fact, control of just two comorbidities, diabetes and hypertension, could have a major beneficial impact. This requires that patients have established primary care physicians to care for these competing illnesses. Without the ability to provide good primary care, we cannot hope to close the mortality gap. This is becoming increasingly difficult as primary care has become a target of cost saving measures in a time of fiscal crisis in our public health care system.

E. Measuring Quality of Treatment

More and more attention is being paid to the clinical quality of breast cancer care in the U.S.^{21,22,23} Evidence shows that examination

of quality measures can lead to improvements in clinical performance.^{24,25} The following section presents the challenge of measuring breast cancer treatment quality in Chicago and why measuring quality matters.

Inconsistent Adherence to Clinical Guidelines

Studies have documented persistent shortcomings in adherence to clinical guidelines since the early 1980s²⁶ with moderate improvements in the 1990s.^{22,27} Specifically, findings indicate substantial variation in breast cancer care by age^{28,29}, geographic region,^{30,31} adjuvant therapies¹⁷ and breast conserving treatment options.^{30,32} In addition, there is evidence of disparities in breast cancer management whereby 21% of Black patients failed to receive the minimum expected standard of care (as defined by National Cancer Institute consensus statements) compared to 15% of White patients.¹⁷ The consequences of such differences have suggested that despite our nation's great scientific and financial resources, only 33% of Americans receive optimal breast cancer treatment.³³

Limited Quality Measures

The lack of system-wide accountability of breast cancer care makes it difficult to measure its quality. Studies suggest that when quality indicators are collected, examined and made transparent across institutions, clinical performance improves.^{24,25} By measuring quality, particular targets for interventions aimed at improving the quality of care can be identified and implemented, subsequently improving survival for all patients.

Currently, there is no established program to routinely collect quality indicators in Chicago and programs that do exist are often incomplete. For instance, the National Consortium of Breast Centers (NCBC) is a members-only consortium of hospitals that gather a core set of measures to improve and sustain quality standards in comprehensive breast programs. There are 22 sites in Illinois and 4 in Chicago that are part of this

Consortium with limited data available for review online. However, this program is voluntary and associated with a nominal fee. Unfortunately, fees may limit the participation of some institutions, notably those that deal with the uninsured and underinsured populations, and yet these are the very institutions that should be examined for underlying disparities in treatment.

Poor Data Collection Systems for Treatment

Furthermore, there are established data systems that target all cancers (i.e., institutional tumor registries, National Cancer Data Base, Illinois State Cancer Registry, etc), but no system to specifically target breast cancer treatment in Chicago. For instance, the Illinois State Cancer Registry offers statewide cancer surveillance but does not capture process or performance measures associated with cancer care (e.g., it includes first course of treatment, but no follow-up treatment measures), which can be most relevant to making changes and timely improvements in quality of care. Another source of data on breast cancer patients is the Illinois Breast and Cervical Cancer Program. This program which ensures access to breast cancer screening and diagnostics but collects detailed information only on women enrolled in the program and also has limited information on the quality of treatment. Each established data system collects different measures and few have the ability to interface easily with others, making it difficult to get a clear picture of what is going on with individual patients or groups of patients.

Lastly, another issue that further impacts the ability to analyze quality of care by racial disparities is the poor collection of racial and ethnic information. Without accurate collection of racial and ethnic information, along with other factors that affect access to health care, it is impossible to understand why some segments of the population do not receive appropriate care and what steps are necessary to overcome these barriers.^{34,35}

SECTION 3. The Solution

A. Improve Access to Care

Ensure Comprehensive Insurance Coverage

No improvement in outcome is possible until equal access to treatment is achieved. Without the ability to receive affordable breast health care, many patients will continue to avoid appropriate treatment, present at later stages of disease, avoid timely interventions and cut corners on their treatment to lower their costs. Either public medicine must be expanded and improved in Metropolitan Chicago or some form of universal health coverage must be enacted.

“Financial barriers go beyond being un- or underinsured. Many African-American patients hesitate to seek screening and treatment for breast cancer because the patient and the family’s daily routines and schedules are so drastically altered. It’s tougher to withstand the financial and logistical pressures of breast cancer without a lot of resources.”

– Provider Interviews

Ensure Disability Coverage

Unless patients are able to take the time from work required to deal with the morbidities of treatment with the assurance of some financial support and job security following treatment, they will continue to be forced to choose between work or managing their daily lives and necessary treatments for survival. One possible solution to this is to offer automatic and immediate enrollment in disability coverage for all upon diagnosis of breast cancer.

Improve Access to Specialty Treatment Services

Unless patients can easily access specialty care, they will continue to face disparities in health care arising from either receiving services from less specialized sources or from facing innumerable logistic obstacles to receiving care in appropriate time frames. Either of these situations will have a significant negative impact on outcome and

contribute to perpetuating the disparity in mortality. One potential solution is to expand the network of public hospitals such that there is an improved likelihood of being able to access public specialty care in one's own neighborhood. In this time of contracting public medicine services in Chicago and Cook County, this is unlikely to occur. Another solution is to facilitate more adequate reimbursement schedules to specialty providers, thereby increasing the likelihood that these providers are willing to accept Medicaid reimbursements and Medicare patients.

Eliminate Logistical Barriers

There are already established programs that work to lower logistic barriers to care.³⁶ The American Cancer Society offers patient navigation, and operates seven Comprehensive Resource Centers in healthcare facilities throughout the state (five in Cook County) with a special emphasis on reaching underserved populations and improving health disparities. Among other services, they are able to help patients access financial resources to help pay for expenses related to cancer care. This can include transportation costs, as well as referrals to other social service agencies. The goal of patient navigation is to prevent patients from falling through the cracks of our very complicated healthcare system and to make quality cancer treatment available and accessible to all patients. However, these programs do require support and expansion to fully meet the needs faced by patients with breast (and other) cancers. These services need to be expanded.

There are many other programs nationwide making inroads to improve the quality of breast cancer care (see Online Appendix O-C). Implementing such programs to improve the navigation of care is necessary, but often requires institutional, legislative and financial support. We recommend a comprehensive study of best practices from these programs that can be adapted to and implemented for the needs of breast cancer patients in Metropolitan Chicago.

B. Improve Coordination of Care

The coordination and integration of services from multiple disciplines is essential to offering high quality breast cancer care. First, it is important to improve coordination of care between institutions and breast cancer care providers. There should be a decrease in time to diagnosis and treatment, a decrease in the number of duplicated tests and procedures, and a decrease in the likelihood of inappropriate care.

Second, coordinating enrollment into the Medicaid Treatment Act is essential to avoid delays in treatment. All institutions should establish a referral process to a lead IBCCP agency to facilitate this process. A solution might be for the proposed Consortium to work with the Office of Women's Health in educating and establishing a system whereby health care institutions can process documents to enroll women into the Treatment Act within their organizations and avoid delays in obtaining Medicaid coverage.

"The oncology department had some of the best people both in medical expertise and bedside manner... my concern is that many good people...may miss the mark because the process to get the great care is so arduous... The best cure is of no value if the delivery system fails."

– Patient Story, Letter to Dr. Sarah Gehlert

C. Expand Outreach Efforts and Social Networks

Public Education Campaign

The disparity in breast cancer survival between Black and White women needs to be more broadly publicized so that target communities are aware of the existing situation. Education concerning breast cancer must be delivered in culturally sensitive ways, seeking to address the specific concerns of these communities. The educational materials must be interesting and understandable – both in content and in

language. Target communities need to be counseled regarding their misconceptions about breast cancer screening and treatment. As well, education needs to be provided to address attitudes and beliefs that may stand in the way of community members seeking appropriate care, including distrust of the medical system and choice of nontraditional medical practices. Interventions employing health workers from the community have been shown to be effective with case finding, outreach and culturally sensitive education particularly among underserved populations.^{37,38,39} These programs should be considered for Metropolitan Chicago.

Communities and patients should receive information to accurately address misconceptions about cancer and health beliefs that may be detrimental to seeking care. For instance, important messages regarding the curability of early stage breast cancer, especially when treated in a timely and appropriate manner need to be provided. Education regarding the types and benefits of treatment needs to be available to dispel myths such as “surgery may cause the cancer to spread” and the side effects of chemotherapy and hormonal therapy make them impossible to tolerate. Communities should also be educated regarding existing payment options for those without insurance, such as IBCCP and the Medicaid Treatment Act. Then, delays due to lack of insurance may be avoided.

In addition, communities and patients should be made aware of the many existing support groups that can help them understand their disease, figure out what questions to ask of their care providers, and aid in helping patients figure out how to ask the questions. Linking breast cancer patients to survivors from their own communities with personal stories may increase their comfort with, knowledge of and ultimately timely use of the health care system.

Provider Education Campaign

Health care providers need to acknowledge that cultural competency is not innate and

furthermore, that it is not adequately taught in the current medical, nursing, and allied health curricula. Many well meaning providers may act in ways that may be perceived as discriminatory even though their actions may not be intended that way. This may negatively impact the patient’s willingness to access care and result in poor outcomes.¹⁶ Providers need to be educated that these misperceptions exist and may contribute to disparities in outcomes. Greater emphasis needs to be placed on evaluating all health care providers’ cultural awareness and sensitivity starting at the beginning of their training and throughout their professional careers.

D. Treat and Control Competing Comorbidities

Unless comorbid conditions are also addressed, many communities, notably the African-American community, will always have a disparity in outcome. It is not enough to provide adequate breast cancer care if diabetes or hypertension may compromise the breast cancer treatment options available or lead to earlier deaths.

E. Measure Quality of Treatment

Create a System to Measure Quality

There is no established program for collection of quality indicators across institutions in Metropolitan Chicago in a transparent way that can help elucidate disparities in health care offered by treatment facilities. If a city or county wide cancer care data system could be developed to collect and analyze quality indicators, it may be possible to truly identify sources of disparity and drive change. All relevant institutions will need to be involved in this process to ensure their buy-in and compliance in order to achieve the ultimate goal of performance improvement based on quality measures. There must be a process to measure these quality indicators. An independent data management agency must train and provide support to institutions to collect the established clinical quality measures. There must be a process to review

the quality indicator data. This review process can identify disparities as well as generate the development of solutions, eventually leading to improvement in the delivery of care. Furthermore, to establish a comprehensive and coordinated city- or county- data system, we recommend cooperation among groups providing and collecting cancer data, integration with national efforts to further quality of care and application of new information technologies.²¹

Collect Racial and Ethnic Information

Unless accurate self-reported racial and ethnic origin data is collected, it is impossible to begin to adequately identify disparities and target solutions to address these inequalities. Data should also be collected on other socioeconomic factors including income, insurance status and place of residence so links between these factors, race/ethnicity and outcomes can be more closely examined.

Enhance Breast Cancer Surveillance Systems

If more accurate and complete data on breast cancer patients can be obtained, it will become easier to identify disparities in presentation, treatment and outcome. As mentioned earlier, the Illinois State Cancer Registry (ISCR) is an incidence only database that primarily collects data on newly diagnosed cases of cancer. It lacks adequate resources for follow-up and quality control, resulting in poor and incomplete data. There are other databases that measure quality of treatment and studies have documented how to enhance existing data surveillance systems to improve the overall quality of cancer care.^{34,35} We recommend a comprehensive review of these data sources and lessons learned from them be completed and a proposal of possible solutions to enhance breast cancer surveillance, measure quality of treatment, and improve clinical performance.

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Appendix A.

Capacity Survey of Metropolitan Chicago Mammography Facilities

Introduction

There is a widening Black:White breast cancer mortality disparity in Chicago. Black women are 68% more likely to die from breast cancer than White women. This disparity has been increasing since the early 1990's. In fact the breast cancer mortality rates for Black women in Chicago have increased in recent years while the rates for Whites have decreased.¹ This means that Black women are not benefiting from the technological advancements we have made in mammography over the last two decades.

To respond to this unacceptable and growing breast cancer mortality disparity, we formed the Metropolitan Chicago Breast Cancer Task Force (MCBCTF). The MCBCTF consists of advocates, physicians, administrators, researchers and epidemiologists who are concerned with improving breast health. The purpose of this Task Force is to generate a list of evidence-based recommendations which will improve the access to and quality of breast cancer detection and treatment.

One goal of the Task Force is to implement interventions to increase the number of age-eligible women in Chicago who obtain annual screening mammograms. Another goal is to work toward improving the quality of the process of obtaining mammography. To inform these goals we undertook a survey of mammography facilities in the Metropolitan Chicago region, with two goals in mind. The first was to determine if there is the capacity to screen all age-eligible women. There are about 588,000 women aged 40 – 70 living in Chicago.² In order for every age-eligible woman in Chicago to obtain a mammogram annually, Chicago would need 588,000 screening mammography appointments each year. Because data are not systematically collected regarding the total number of mammography slots available in Metropolitan Chicago, we sought information to

understand how available capacity compared with this need.

A second goal was to understand the variability in the types of services offered at different facilities (i.e., services potentially related to the quality of the mammography process) and to determine if women of different racial and ethnic backgrounds had equal access to these services.

Methods

The Survey

Researchers from the Sinai Urban Health Institute and University of Illinois at Chicago School of Public Health partnered to develop a survey to estimate the current mammography capacity in Metropolitan Chicago. The survey, which contains 35 questions, takes about 10 minutes to complete. We asked facilities to provide information related to capacity including the number of screening and diagnostic mammograms performed per month, hours of operation, number of machines, number of imaging technologists and radiologists interpreting mammograms, and level of difficulty maintaining staffing. Regarding factors potentially related to the quality of imaging, we asked about the availability of digital mammography, breast ultrasound, and other more advanced imaging methods. Information potentially related to the quality of interpretation included whether screening and/or diagnostic mammograms were routinely double read, or read with computer-assisted diagnosis. Regarding factors potentially related to the timeliness and relative ease of diagnostic follow-up we asked whether mammograms were read on site, on the same day of the exam, how abnormal results were usually communicated to patients, and whether diagnostic imaging and biopsy services were available at that facility.

Recruitment of Mammography Centers

In order to determine what mammography facilities existed in the metropolitan area that served Chicago residents, we compiled a list of Food and Drug

Administration certified mammography facilities from the following website: www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfMQSA/mqsa.cfm. We recruited our partners in the MCBCTF to distribute the survey to their contacts in the radiology departments on the list. Once that method was exhausted, we asked the co-chairs of our Task Force to contact the CEOs of the medical centers for which we did not have any other access. We identified and attempted to survey 50 mammography centers located in Chicago and an additional 37 suburban centers. The overall response rate was 82%, 86% (43 out of 50) for the Chicago sites and 76% (28 out of 37) for the suburban sites.

Estimating Mammography Utilization and Capacity ***Mammography utilization***

We asked each site how many screening and diagnostic mammograms were done in an average month. In order to estimate the annual number of screening and diagnostic mammograms provided by each facility we multiplied the monthly reported mammograms by 12, separately for screening and diagnostic mammograms.

We asked each suburban site to estimate its proportion of patients who were residents of Chicago; we then multiplied the estimated number of screening (and diagnostic) mammograms by this proportion in order to estimate the number of screening (and diagnostic) mammograms performed specifically on Chicago residents.

Mammography maximum capacity

We estimated each facility's maximum capacity in two ways. First, we used a 2002 Government Accounting Office (GAO) definition of maximum capacity³ that assumes that two mammograms can be performed per machine per hour in each clinic performing mammograms. This definition does not account for the possibility of staffing shortages and other factors and therefore may not represent maximum capacity. Second, as part of the survey, we asked each site: "Roughly what percentage capacity is your facility at now?" Each site could select one of the following responses: <25%, 25-49%, 50-74%, 75-89%, 90-99%, 100%. We defined each facility's "maximum perceived capacity" as the total

number of mammograms performed divided by the midpoint of the selected response category.

Estimating non-response for both utilization and capacity

There were 16 sites (7 Chicago and 9 suburban) that did not respond to our survey. Since the remaining 7 non-responding Chicago sites were smaller institutions, we estimated the numbers of screening and diagnostic mammograms based on the mean values for participating facilities obtained after excluding the larger academic centers. For suburban sites we used the mean number of screening exams for participating facilities that were performed on Chicago residents. In a similar manner we estimated the number of machines, number of hours open, and maximum perceived capacity based on information available on participating non-academic facilities.

Facilities also reported an approximate percentage of their patients who were Black and Hispanic in categories of <25%, 25-49%, 50-74% and 75% and above. We used the midpoint of the category selected by each facility (12.5%, 37.5%, 62.5% and 87.5%) as an estimate of the percentage of patients who were either Black or Hispanic, and we assumed that the remaining proportion of patients were predominately White. The total number of annual screening mammograms at each facility was then multiplied by the approximate proportion of their White, Black, and Hispanic patients to arrive at an approximate number of screening mammograms performed in each racial/ethnic group at each facility.

In order to examine differences in the availability of high quality services to White, Black and Hispanic women, we tabulated the proportion of facilities that provided various services (e.g., digital mammography). We performed separate calculations for White, Black, and Hispanic women, giving more weight to facilities that provided a greater percentage of the total number of screening mammograms in each racial/ethnic group.

We used data from the U.S. Census (<http://factfinder.census.gov>) to estimate the number of age-eligible women in Chicago, defined as ages 40 - 70. Data were collected between July and

September of 2007, entered into an MS Access database and then analyzed in SAS (v. 9.0).

Results

Mammography Utilization and Capacity

Table 1 presents the estimated mammography utilization for Chicago residents for City and Suburban sites. In 2007, approximately 207,000 screening mammograms will be provided to Chicago residents. The estimated Maximum Perceived Capacity is about 40% greater than the current number of screening mammograms actually obtained (N=287,000); capacity according to the GAO definition is almost double (85% greater) the current number of screening mammograms actually obtained (N=384,000). Both Maximum Perceived Capacity (48% of need) and GAO Capacity (65% of need) fall well short of the number of mammogram appointments needed (N=588,000) to screen all Chicago women annually.

Distribution of Screening and Diagnostic Services

As Table 2 indicates, White women were considerably more likely than Black or Hispanic women to have mammograms at facilities (1) where digital mammography was available; (2)

where only breast imaging specialists read mammograms; and (3) where mammograms were always read on the same day so that patients could be informed of their mammogram results immediately. On the other hand, Black and Hispanic women were considerably more likely than White women to have mammograms at facilities where all mammograms were either read by more than one radiologist or were interpreted with the help of computer aided detection (CAD).

Discussion

We found that if every woman between 40 and 70 years of age who lives in Chicago tried to obtain a mammogram every year, consistent with most recommendations, we would not be able to provide these services without increasing the number of mammography machines and staff. In contrast to our findings for Chicago, the Government Accounting Office (GAO) evaluated capacity for the nation as a whole following enactment of the Mammography Quality Standards Act (MQSA) and found that capacity was adequate.³

Table 1. Mammography Utilization and Estimated Screening Mammography Capacity for 2007, Including Mammographic Need Based on 2000 U.S. Census

	Chicago Sites	Suburban Sites (Chicago Residents)*	TOTAL For Chicago Residents
Number of centers	50	37	87
Number of screening mammograms	178,978	27,696	206,674
Number of diagnostic mammograms	83,790	8966	92,756
Total number of mammograms	262,767	36,662	299,429
Maximum capacity for screening mammograms based on GAO	326,963	57,036	383,999
Maximum capacity for screening mammograms based on perceived capacity	240,421	46,148	286,569
Annual mammographic need	---	---	587,531

*Adjusted for proportion of Chicago residents who receive mammograms in the suburbs

Table 2. Distribution of Mammography Services by Race/Ethnicity

	<i>Percentage of Mammograms</i>		
	White (%)	Black (%)	Hispanic (%)
Factors Affecting Image Quality			
Breast ultrasound available	67	69	77
All technologists are mammography-dedicated	35	33	39
Digital mammography available	56	21	31
Factors Affecting Interpretation Quality			
Computer-Aided Detection (CAD) or double reads on all mammograms	44	61	44
All mammograms read by breast specialists	57	23	32
Timeliness in Communicating Results			
Face-to-face on same day as exam	67	50	42
Diagnostic Services Available on Site			
Diagnostic mammography	67	69	77
Breast magnetic resonance imaging	41	38	51
Breast nuclear medicine scanning	27	25	42
Biopsy available on site	60	65	75
Same-day biopsy available	22	25	23

In Chicago, mammography capacity is only at about 65% of what would be needed to enable all age-eligible women to get screening mammograms each year. The National Breast and Cervical Cancer Early Detection Program, state-wide programs such as Illinois Breast and Cervical Cancer Programs and local programs such as Stand Against Cancer all provide and encourage uninsured women to have annual screenings, and these programs will continue to increase the need for services (as will recommendations from this Task Force). All of this suggests that it is crucial now to begin to build mammography capacity in the Metropolitan Chicago area.

A recent study by the office of U.S. Representative Anthony D. Weiner of New York documented that between 2000 and 2007 the percentage of mammographic facilities that closed was nearly twice as great in New York City as in the nation as a whole.⁴ Two other studies conducted since 2000 have documented the presence of staffing shortages of radiologists who

read mammograms as well as shortages of certified mammography technologists.^{5,6} None of these studies examined the situation in Metropolitan Chicago. In addition, a review from the Institute of Medicine (IOM) found that mammography services are not growing proportionally with the population growth in the U.S..⁷ This survey discussed in this Report does not contain data that would allow us to compare Chicago capacity over time. It does, however, make clear that capacity here is inadequate.

In Chicago, based on the current Census (2000), it appears that approximately 50% of all age-eligible women residing in Chicago obtain a mammogram in a given year. Consistent with this, according to the most recent data available from the Illinois Behavioral Risk Factor Surveillance System, approximately 60% of women aged 40 years and older report having had a mammogram within the past year.⁸ The American Cancer Society (ACS) currently recommends annual mammograms to detect breast cancer beginning at age 40,⁹ while the

U.S. Preventive Services Task Force recommends mammograms every one to two years.¹⁰

In addition, we found that there are differences in access to mammography and diagnostic follow-up services that favor White women in Chicago. The largest differences by far appeared to be with respect to access to digital mammography and access to a breast imaging specialist when having mammograms interpreted. Prior research has shown that breast imaging specialists tend to do a better job interpreting mammograms, and that digital mammography does a better job of detecting tumors in women with dense breasts. We also found that White women were the most likely racial/ethnic group to have mammograms at facilities where suspicious mammogram findings were communicated on the same day as the exam. This is important because this reduces diagnostic delays, the likelihood of miscommunication and women being lost to follow-up after an abnormal mammogram.

To our knowledge, ours is the first survey of mammography facilities ever conducted for any city in the U.S. An important limitation to these results is that they refer to the percentage of women who obtained mammograms at facilities with certain attributes related to improved imaging, interpretation, and timeliness of follow-up. These results do not refer to the percentage of women who actually obtained these services. For example, we do not know what percentage of White, Black, and Hispanic women received a digital mammogram; we can only approximate the percentage who obtained a mammogram at a facility with digital mammography services. Nonetheless, overall, these results suggest that differences in image quality, interpretation quality, and timeliness of follow-up of a suspicious mammogram finding may be contributing to the greater breast cancer mortality for Black women as opposed to White women in Chicago.

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Appendix B.

Town Hall Synopses

Over the past six months, the Metropolitan Chicago Breast Cancer Task Force has worked to establish a set of recommendations to address the Black:White disparity in breast cancer mortality and to improve breast health services for all women in the Metropolitan Chicago area. Fueled with prevailing statistics documenting the problem, the Task Force also recognized that any recommendations put forth void of contributions from the community would be incomplete. Documenting the experiences of women utilizing the current system of care is essential to this process. Through the generous financial support of the Avon Foundation, the Task Force sponsored a series of four public Town Hall meetings in communities with high breast cancer mortality rates to allow the voices of the community to be heard with respect to their experienced barriers and their recommendations for change. The following report summarizes the planning, coordination and outcomes of each meeting.

Planning and Coordination

Considerable time and effort went into the preparation of each Town Hall meeting. Members of the Task Force began by reaching out to organizations based in the target communities to co-sponsor the events and to obtain community participation. Over 2,000 flyers were distributed for each Town Hall with hopes of having at least 50 participants for each event. Members of the Task Force went out into the community several days before the meetings to personally hand out flyers to individuals in key places such as laundromats, stores, coffee shops, medical clinics, health fairs, etc. These efforts were in addition to the canvassing efforts put forth by the co-sponsoring organizations. For each respective Town Hall discussion, many hours were spent in meetings, making phone calls, sending emails to secure a panel of medical professionals, and to invite representatives

from resource organizations that provide educational, social and/or medical services related to breast cancer. Overall, each Town Hall was scheduled for two hours and maintained a consistent agenda which included welcoming remarks, an introduction to the Task Force and its purpose, a brief presentation of data and an explanation of the disparity in breast cancer mortality. At least an hour and a half was reserved for community discussion questions and answers. The Task Force provided food and beverages for the attendees.

Meeting Outcomes

“...I look at the mortality maps and graphs of the Southland ... I don’t only see numbers... I actually see a face... I see my mother... I see my mother dead at 46... (In tears)... So I’m hoping that the recommendations will force the issue that Cook County has a hospital that is actually very nice...that we can’t even use...I’m hoping that the recommendations will force the existing breast health programs (at) St. James, Ingalls, and Advocate to the table...”

- South Suburban Town Hall Participant

Southside Town Hall

Tuesday, August 21, 2007, the Metropolitan Chicago Breast Cancer Task Force held its first Town Hall meeting on the Southside of Chicago at the Carter G. Woodson Library in a predominately African-American community. Fifty-seven community members attended the meeting. The panel of medical professionals for this meeting included Dr. Anngell Jones, a general surgeon at Mount Sinai Hospital, Dr. Pam Ganschow, Director of the Illinois Breast and Cervical Cancer Screening Program at Stroger Hospital, Dr. Elizabeth Marcus, Chair of Breast Oncology at Stroger Hospital,

and Sharon Brown-Elms, Chief Technologist, Rush Breast Imaging Center at Rush University Medical Center. The following organizations were on hand to provide clinical and educational resource information regarding breast cancer: Susan G. Komen Foundation, Gilda's Club, the American Cancer Society, Y-Me, Access Community Health Network, Sinai's Woman to Woman Program, and The Sisters Network. Dr. Janice Phillips, a Nurse Researcher from the University of Chicago facilitated the passionate discussion at this meeting. Dr. Steven Whitman, Director of the Sinai Urban Health Institute, led a discussion of the data that stimulated the creation of the Task Force.

Three overarching themes were highlighted in the meeting as contributing factors to the Black:White disparity: inadequate access to care; lack of knowledge, and poor provider/patient communication. The following comments were made with respect to each of the stated barriers:

Access to Care

- "...the larger cancer resource organizations do not serve the Black community enough. For women who do not have insurance, expenses are a huge barrier... the Black community doesn't receive funds from these organizations."
- "Can't get tests in a timely fashion. By the time they do, we find out we have cancer."
- "Mount Sinai Hospital is good to work with for free mammograms, but the private and academic centers do not provide enough free or charity care."
- "Transportation is a barrier to safety net hospitals...location is inconvenient. If the sites were in the community, women would go."
- "Poor reimbursements is no incentive for doctors to take Medicaid patients."
- "In order for women to get a mammogram, they need to be able to get a

clinical breast exam; that's a problem for women in the southland area... for women who are uninsured. There's no referral service in place to help women navigate the system."

Lack of Knowledge

- "We met a lady that was 70 years old. Not only had she not had a mammogram, she didn't even know what a mammogram was. That's very scary."
- "Black women are not aware of what is available and where to go."
- There is "no marketing to these communities" for the IBCCP program.

Poor Provider-Patient Communication

- "Primary care physicians are important in the process (*from screening to treatment*) and their attitude can be a barrier."
- "After she was diagnosed with breast cancer, the problem came when they pushed the papers in her face and said go here. Since the doctor treated it so lightly, the patient won't follow-up with her care; she thinks it's a little thing and the cancer might go away."
- "A patient had insurance (HMO) - and was diagnosed with breast cancer. The doctor told her she could not go anywhere else (*for care*). Six months later she got a referral. By the time she was in treatment she had stage 4 cancer. She reached out and the doctor didn't help."
- Patients mistrust the care and the system. Women turn down free services; they don't think the service is good.

The Town Hall participants were specific in their recommendations for improvements to the current system of care.

- "They (*Black women*) need, from beginning to end, quality care that is not delayed. It should be timely and followed

through if they got cancer, through treatment and beyond.”

To improve the gaps in the safety net care, the Town Hall participants suggested that the number of facilities that provide charity services for people in the south side communities needs to be increased. This would also address the barriers related to transportation. The current safety net system is inadequate and needs to be expanded to include [south suburban] sites such as St. James and Ingalls hospitals. Women currently do not know where to go for free or low cost services. Increased marketing is needed to connect programs like the Illinois Breast and Cervical Cancer Prevention (IBCCP) program to communities that would most benefit from their services. Navigation services are needed throughout the city to help women access medical service. Lastly, improved, culturally competent education is needed for Black women to address their fears and “take control of their breast health.” We need to “teach women at the grass roots level how to navigate the system, give patients guidance, teach them how to get biopsies, follow-up and how to seek treatment.”

Westside Town Hall

The second Town Hall was held on Thursday, August 23, 2007, at the Westside Health Authority located in Chicago’s Austin community. Nearly 30 community members braved extreme weather to attend the meeting. Unlike the first Town Hall, the majority of participants were not survivors of breast cancer, but rather were women interested in and eager for more information, not only for themselves but also for the community at large. Many of the attendees were leaders for the “Every Block a Village” organizing effort taking place in the community of Austin. The panelists were internist Dr. David Ansell of Rush University Medical Center and surgeon Dr. Anngell Jones, from Mount Sinai, who also participated in the first Town Hall. Susan G. Komen Foundation, American Cancer Society, Access Community Health Network

and Y-Me Illinois provided resource information at this event. The facilitator for this meeting was Jacqueline Reed, Founder and Executive Director of the Westside Health Authority. Once again, Dr. Whitman started the program by presenting the underlying data on breast cancer mortality.

The following comments from Westside community members were divided into the three overarching thematic barriers evidenced in the first Town Hall discussion: access to care, lack of knowledge, and poor provider/patient communication:

Access to Care

- “A lot of people don’t have insurance in a lot of lower paying jobs and large companies employ high numbers of people but there’s no health insurance and so you don’t go if you have to pay.”
- “Everything is so hard for us (*Black women*). I have to go and wait at Cook County Hospital. It’s a struggle. Then they also told me, you could go to Mount Sinai. Well, Mount Sinai is further for me than Cook County Hospital. Even when it’s free, it’s hard for you to get there. You don’t have a car, gotta get on a bus, everything that’s free for us is a struggle to get to, if you’re poor.”
- “... If you’re in that seven year period (*referring to drug patent length*) and you don’t have the income to pay it, you’re not taking medication so you may die from it anyway.”
- “...let’s say I get detected with breast cancer so now I need a different level of mammography. I’m uninsured and if I go to County, I’m going to wait a year for that to happen and that’s outside of the 6 months we were just talking about (*referring to difference in outcome with diagnosis/treatment delay*) so, we really need to think about how the Task Force is going to think about it, that body. Let’s say we did get mammography vans, I think it’s unethical to get vans,

get all these people to be screened for breast cancer and we find it which is great, but we can't do nothing about it. Then what do we have people do? We have people go home and worry and wait and it's a horrible experience. So we need to think about that."

Lack of Knowledge

- "I'm not really sure how often you would get a mammogram."
- "I'm hearing from Dr. Ansell, that you put it on the back burner for 6 months it could drastically change the outcome and she probably doesn't know that. She's probably thinking she still has time and the second thing is that even if she goes for a mammogram she doesn't know what to know whether this a quality mammogram or not a quality mammogram. How do we educate the women to be good advocates for themselves?"
- "That's where we come in with giving out information and teaching people. That should be or could be a huge job, campaign type of thing 'cause people need more information."
- "We just don't get all the information we need as African-Americans. Some people say it's out there, they get it. But you know, we need an extra push. You're a 65 year old woman, you taking care of 5-6 kids, you need a push. You know, even if you are a 32 year old woman, your taking care of a bunch of kids, you still need a little push. You need more information, you need to know the seriousness, and that's one thing we don't get 'cause we just don't hear it enough."
- "I look at the women in our community and we have a lot of responsibilities on our plate. With work and kids and other responsibilities, we may not be in avenues where that information is so readily available."

- "All of the people in the community probably know they are pre-disposed to an illness that they don't want to find out about. We have to find a way to get people past that, I don't want to know. It's better to know and start getting things figured out and work well before they get worse than to know that you're at risk and not know."

Poor Provider-Patient Communication

- "For as long as I've been going to the doctor, maybe one doctor has told me to get a mammogram, so I think a lot of times the doctor's office don't tell you."
- "If you do not have insurance, you do not go the doctor as frequently so the lack of education, you don't know how to get that so often. Most Black women do not have insurance, do not get it done unless they go to the doctor for something else and then it's recommended that they do have the mammogram done. And sometimes by the time they do, it's sometime too late."
- "Part of the responsibility for educating the patient is on the doctor and if the doctor doesn't know when a woman should have a mammogram or doesn't care if a woman has a mammogram or doesn't think a woman can afford a mammogram, then he isn't properly incentivized if he really doesn't refer that woman for that test."

Community members provided these specific recommendations for action:

- "Some of the information distributed in the community can be put in a creative way to really capture people's attention...and really give them the basic information to either be aware or some simple quick educational information on there so people know this is the next step as far as if I have any questions, this is what I can probably call to get more information."

- "...being in areas where we know they (*Black women*) are going to be at to give them that information and have someone who could possibly look like them who could break it down on their level. Sometimes when you see certain stuff, it may go over your head and this is like, 'oh, okay, I don't really understand this.' Someone who can make it so simple in just the way you explain the different levels of the exam. It's like, 'Oh, now I understand there are different levels of the exams or the results you can look at.' Something like that would really cause awareness to get people to say, 'Oh, I have to ask for it.' "
- "Get people where they are at. If you see they are overwhelmed with children and family life, offer them something to help them where they are then. That's your buy-in. If you see they need help with child care, help them find child care for their children. You're going to build rapport with that person. We can't do it always individually, with each individual community person but it's a start even in a group setting, you find out what that group needs. What is the overlapping thing that group needs and you find that thing and address it and you get those people's buy-in and they are going to listen to you. They trust somebody who's going to go to what they're in to."
- "Another way to bring awareness is having more Focus Groups. You have a lot of caregivers with children in school without immunizations. So what kind of ways can we reach those parents or caregivers in the same way? Mobile clinics that some schools are doing to try to reach women in more creative ways especially in those communities where you know there's a low turn out rate of women having breast exams like they should. What ways can we get to those particular communities, outreach to them to get them more involved and engaged."
- "It's one thing for the American Cancer Society to hire Black people to come out to Black neighborhoods to do some of this outreach, to speak the language, to get in front of the nail shop to do it, but I think more importantly, it's important to have people from the community as advocates for themselves and build capacity on our blocks, and work with an organization in the community...we need a way of debriefing and discussing what they said, rehashing what each other say and that way, we build up more interest for ourselves. If we leave home after hearing a presentation and go back to our individual houses and we think about the children having to start school in two weeks and I don't have this for that child and you're thinking about all this other stuff and you put this on the back burner. But if you know in two weeks you have to come back here for another briefing about breast cancer then it'll be in the back of your mind that you have another meeting that you have to go to, it'll be another reminder for us to think about some of the things that we learned so back to how do we begin to build awareness? And not just a one shot Johnny kind of thing, to be a capacity in the community to support each other and to think about things and to share experiences. I just want us to understand the value of relationships in the community because these relationships help us change our behavior. It's not just a matter of having a van come in on Sunday morning at the church but you have to have something there when that van leaves."
- "Mothers are the first teachings of the child. We have to educate women that they set an example like that. They don't go to the doctor. They say if they got something, they don't want to know about it. If the women ain't going, they figure if she ain't going, why should I?"

South Suburban Town Hall

On Thursday, September 6, 2007, the third Town Hall meeting was held at St. James Hospital and health Centers in the South Suburb of Chicago Heights, Illinois, a predominately African-American lower income community. Thirty concerned members of the community, advocates and breast cancer survivors attended this meeting. Those South Suburbs that were represented included individuals from Chicago Heights, Markham, Robbins, Richton Park, Matteson, Country Club Hills, Sauk Village, and Hazel Crest. A panel of medical professionals in the field of breast cancer was available to answer any questions and address concerns of the attendees. This panel included Dr. Janice Phillips, a Nurse Researcher from the University of Chicago and Dr. Ruta Rao, a Medical Oncologist from Rush University Medical Center.

In addition, several organizations provided resource materials and/or were on hand to provide information regarding breast cancer including: Susan G. Komen Foundation, Gilda's Club, the American Cancer Society, Y-Me, Access Community Health Network, Jennifer S. Fallick Cancer Support Center, Illinois Department of Health: Office of Women's Health (IBCCP), Sisters Embracing Life, The Sisters Network and the Southland Coalition to Conquer Breast Cancer. Margaret Davis of the Healthcare Consortium of Illinois moderated the discussion and encouraged attendees to share testimony and/or experiences that would highlight the need for resources and education in the South Suburbs. Dr. Whitman initiated the Town Hall with a discussion of the breast cancer mortality data.

A few participants provided very powerful and emotional testimonies and some community advocates discussed some of the services they provide and activities that are currently taking place in the South Suburban communities. A few of the overarching themes highlighted at this Town Hall were: inadequate access to resources in the South Suburbs, lack of education about breast cancer in the community, difficulty navigating the system, and poor provider/patient

communication. Below are some excerpts of statements made by those who were in attendance:

Access to Resources

- “As Hispanics, we tend not to go to the doctor...we tend to let it sit...I know that we have high rates also...there is nothing here (*information relevant to Hispanic population about breast cancer*)... what about me?”
- “We are having issues here in the South Suburban area...there are major issues in the Suburban area ...a lot of women (*African-American*) have moved to the South Suburban area from Chicago without resources...also the Hispanic community is growing especially in Chicago Heights and Ford Heights and other (*surrounding*) areas and the services are not available for them as well...”
- “We do know that we don’t get our fair share of dollars in the South Suburbs...and we need these dollars in order to put a comprehensive system of care around Women’s Health in the South Suburbs...this system of care can be predicated on our existing facilities...because some of them (*referring to existing healthcare systems*) charge co-pays which make it hard for women to get services...and many of them are kind of far... and the PACE bus is not (*available*)... you can’t get there and transportation is a major issue...”
- “I live in Markham... and as a Markham resident I can identify with this study that labeled many Chicago neighborhoods void of supermarkets and fresh fruits and vegetables as ‘*Food Deserts*’...substitute the supermarkets with hospitals and healthcare services and you can label Markham and many other Southern Suburbs as ‘*Healthcare Deserts*’...many of the women in these areas are low-income and are either uninsured and underinsured...making the surrounding hospitals and services out of reach...”

- “I found a lump in December but my insurance didn’t kick in until January...so I actually had to wait in order to make my appointment to see my gynecologist...so luckily (*for me*) it was that short lapse of time from December to January (*before diagnosed*)...thank God I had insurance...I was in an industry (*Food Service*) that was void of healthcare...had I been at a restaurant (*that didn’t provide insurance*) I would have been lost...”
- “It’s difficult to get screenings...there is no more Mammo-Van...we need improvement in services...whether it’s Cook County...whether it is hospitals...I commend those hospitals who are able to provide ‘Charity’ care for services...”
- “They (*Cook County*) don’t have staff...we found 200 women in the Southern Suburbs who were in that delayed group of the 9,000 who had not found out about the outcome of their mammography (*referring to the cuts at Cook County*)...”
- “We tried the hotline (*Illinois Breast & Cervical Cancer 800 number*)...there is sometimes limited space in various geographic areas and we need to improve them...and one of the (*other*) problems is the reimbursement rate (*for doctors and radiologists*)...if you are on Medicaid that’s a problem...”
- “Another problem is this issue of co-pay...it seems like if you don’t have any money you shouldn’t have to do a co-pay...”

Lack of Education about Breast Cancer

- “Younger and younger women are dying of breast cancer...being diagnosed with breast cancer...I’m 35 and I know that education and outreach needs to start sooner...I was diagnosed three months after my 34th birthday.”
- “One of the big things was lack of knowledge (*in the South Suburb Communities*)...a lot of beliefs in the community...such as ‘I won’t claim it’...a lot of beliefs about what may or may not cause it such as the type of bra you wear...if you use deodorant then that too will cause you to get breast cancer...if you have surgery then that causes the breast cancer to spread...they also have the belief that Black women are not getting the same treatment as White women...there are a lot of things like that (*myths*)...such and such had surgery and then they died a month after they had the surgery...if that person did then I won’t get it (*referring to surgery*)...knowledge is one of the key points that we need to get out...”
- “The women in my community (*Robbins*) are silent...they keep it to themselves...they respond to education or information that makes them more knowledgeable than they were...what I’ve found is that since we don’t have a newspaper or local TV...we have ‘Run-and-Tell-It’ communication (*they gonna run and tell another and another*)...word gets around real fast about what’s going on (*this way*)...”
- “If you are learning about breast cancer...information technology hasn’t been given to everyone...in some communities the network is not there...”
- “A lot of it has to do with communication and education...in our culture (*Hispanics*)...the unfortunate part about our culture is we still have that macho partner and if our gynecologist is a male, our macho partner says it’s not nice for him to touch our breasts because that

means he is touching the female body ... 'I (*the macho male*) don't like anybody touching your body' (*because of the jealousy thing...*)... a lot of Hispanic women do not go to the doctor because their husbands do not allow them to go...they have to sneak out the house ...they have to lie to get out the house...that is a barrier for them...and when they go to the doctor they are not going to the doctor...they are going to the hospital because now they have pain in their breasts...they have liquid...but it's a little too late...it's still in the culture... we're still trying to educate them..."

- "Healthcare and religion (*faith-based organizations*) got to work together (*to educate the community*)...we need you to teach us (*faith-based organizations*) to break more traditions...some of the older pastors aren't there yet...we need to bring some of them to the table...to hear about what our wives and women are going through...we need to get the Hispanic pastors to come in with us (*too*)..."

Difficulty Navigating the System and Poor Provider-Patient Communication

- "It seemed like time stood still (*after finding the lump and insurance kicked in*) because it took two weeks for me to make an appointment to see my gynecologist...then to see the breast surgeon...then to get the bone scan...to get the CT Scan...then another test and another test... I was like 'When do I get treated!'...from the time I found my lump to the end of my surgery was 7 months...and then 9 complete months to the end of my radiation...it's more than about having insurance and access...the whole experience is just unbelievable...to not have insurance and to not have access it just escalates everything...In the Southern Suburbs if you have to worry about trying to get to an appointment ...trying to get to the hospital...trying to get to the doctor...if you don't have bus fare...if you can't get a PACE bus... you don't have a job...it makes the experience

far worse than it has to be...it doesn't have to be that way...you don't have to die..."

- "I get my mammograms...just August 8th I had my mammogram...I left feeling good... got a letter saying that I needed to come back for another mammogram...I went back on the 21st (*August*) ...we went out of town...came back I got another letter saying I needed an MRI...went Tuesday (*September 4th*) for an MRI and today (*September 6th*) I got results saying they saw something in my right breast...the whole process was just draining...I have insurance...I have good insurance...you would not believe that I had to keep calling my nurse to get my results...the order was made by my gynecologist... the nurse wouldn't call me back...I had to call my primary care doctor to get him to put the order through to get my MRI...I was frustrated...here I have good insurance...how are those people who don't have insurance...how are they managing...this should not have happened..."

West Humboldt Park Town Hall

The fourth and final Town Hall meeting was held on September 13, 2007, in the predominately African-American community of West Humboldt Park at Sanctuary Place, a residential facility for low income women at risk for homelessness.

The Women's Club of the West Humboldt Park Development Council (WHPDC) co-sponsored the Town Hall and opened the meeting with an inspirational reading about the importance of loving and taking care of oneself. In addition, the sponsors raffled off passes for the Chicago Transit Authority and gift certificates to Wal-Mart, Target, and Jewel/Osco. Following the raffle, the participants heard brief presentations regarding the Breast Cancer Task Force and the data by Dr. Whitman illustrating the disparity in breast cancer mortality. Next,

Janece Simmons of the WHPDC facilitated the discussion part of the meeting. Dr. Anngell Jones of Mount Sinai Hospital, Dr. Pam Ganschow of Stroger Hospital, Sharon Brown Elms of Rush University Breast Imaging Center, and Nicole Calhoun of the American Cancer Society and Northwestern Memorial Hospital participated as panelists to answer audience questions. Following the discussion, there was another raffle drawing, and an interpretive dance performance by Jessica Runnels of the Najwa Dance Corps. As with the previous Town Halls, organizations provided resource materials and/or were on hand to provide information regarding breast cancer. The West Humboldt Park Town Hall included: The Avon Foundation, Susan G. Komen Foundation, Gilda's Club, the American Cancer Society, Y-Me, Access Community Health Network, Mount Sinai Hospital's patient navigation program and woman to woman program, Louise Landau Health Center and the Illinois Breast and Cervical Cancer Program.

Attendees at each Town Hall have been unique. There were forty-seven participants at this meeting consisting of community members, Sanctuary Place residents and employees. The majority of the participants were women in their forties who had had at least one mammogram in their lifetime and were affected by breast cancer in some way. At least nine participants were breast cancer survivors themselves. Despite the uniqueness of the group, the participants spoke of barriers that were quite consistent with the previous Town Hall meetings. Unemployment, lack of insurance, lack of knowledge, personal behaviors, and poor provider/patient communication were named as the factors prohibiting women from getting annual mammograms.

The following comments illustrate the overall sentiment of the participants:

- "I can't go to a doctor or any other hospital because I don't have health insurance and County sends you a bill now...the reason why a lot of women

don't go, we don't have income and don't have no insurance."

- "I'm forty-three. I just had my first mammogram. I was on drugs and I wasn't thinking about that."
- "By not having the knowledge, that stops you from doing some things (*like getting a mammogram*). It's having the knowledge and having the people available to help you."
- "Back in the day they didn't have this info...I had 4 aunties, my sister, and 3 cousins died from breast cancer. About two months ago... I noticed that I was discharging from my breast. I went to Mount Sinai to have a free mammogram. I had to let go of potato chips. I had to let go of pop. I did the necessary things to find out what's going on with me. If you have to let some stuff go, you need to let it go. It's about you. They found out that nothing was wrong. So the moral of the story is you've got to ... take care of you... if there is a will there is a way."
- "I was diagnosed with breast cancer last year August. I am under the care of Cook County Hospital and I have to say they take excellent care of you. I did a self exam and found a knot up under my arm. I went to the emergency room. Through the ER they did all the necessary tests. They did a mastectomy of the right breast and now I'm in chemo. They provided me with the medical card and they provided me with transportation. ... The only problem I see is financial. But, I really can't work right now because of my health. ... I go to the hospital 3 to 4 times a week. ... If I wasn't living here, I would be on the street homeless with breast cancer and no money."

Conclusion

In summary, the findings from the Town Hall meetings were consistent with the other findings of the Task Force including the provider Focus Groups and interviews. Inadequate access to care and resources, lack of knowledge, and poor provider/patient communication were consistently named as contributing factors to the disparity in breast cancer mortality. In addition, unemployment, difficulty navigating the system, and fear were also discussed as barriers to appropriate screening and treatment for African-American, low-income and uninsured women across the Metropolitan Chicago area.

The Town Hall attendees provided targeted recommendations to improve the problem which included expansion of safety net care in the city and south suburbs, use of culturally appropriate educational materials and culturally sensitive health educators. Most importantly, the participants saw themselves (*Black women*) as key partners in reducing the disparity.

“Until we sound the alarm, nobody else is going to take this situation seriously. We are the ones that are dying.”

- Southside Town Hall Participant

Appendix C.

Creating a Metropolitan Chicago Breast Cancer Consortium

The progress of the Metropolitan Chicago Breast Cancer Task Force has created the opportunity to create a Metropolitan Chicago Breast Cancer Consortium. This initiative would allow the sharing of clinical quality data in a confidential manner among institutional stakeholders, allow for coordination of care for women in need of timely diagnosis and treatment, and holds the potential to improve health outcomes and push breast cancer mortality improvement initiatives metropolitan wide. If successful, it also has the potential for becoming the basis of an ongoing effort to share quality and safety data for other issues of common concern. It is consistent with national movements to create Regional Health Information Organizations and Patient Safety Organizations.

Several community stakeholders including leaders from Rush University Medical Center, Mercy Hospital, Sinai Health System, the Chicago Department of Public Health, Advocate Health System, Access Community Health Network, and the Metropolitan Chicago Healthcare Council have already agreed to participate in this Consortium. The goal would be to address issues of access to and quality of breast cancer screening, diagnosis and treatment. These stakeholders will reconvene in the late fall of 2007 to discuss next steps; they hope to be joined by other Metropolitan Chicago health care institutions and other stakeholders.

The Consortium would be considered a “Medical Study” of the Illinois Department of Public Health, which would afford the quality data sharing an additional degree of protection under the Illinois Medical Studies

Act. In addition, advice of health care legal counsel has been sought to identify the legal issues associated with this type of effort.

Some of this shared data collection could be facilitated by a number of precedents in the U.S. The National Consortium of Breast Centers, a not-for-profit, national organization of breast centers, has created a database that allows providers to confidentially and voluntarily submit clinical data and receive access to abstracted comparative data and national and Chicago-area benchmarks. The data collection can be expanded to facilitate the needs of Chicago institutions. The cost is minimal and there are already developed methodologies for collecting data that could be easily replicated in Chicago. There have also been some longstanding breast cancer consortiums around the U.S., formed in the 1990s as research efforts; they have mastered the data collection and management for large numbers of breast centers. Contact has been made with them and their experience will be helpful in guiding the Chicago Consortium.

One particular benefit of the Consortium will be to create a quality improvement team consisting of a radiologist, a lead technologist, an administrator, and a data expert to review the processes of care delivery and data measurement at the participating organizations as a quality improvement methodology. Another benefit will be to allow organizations to participate in coordinated metropolitan efforts to facilitate care for women in need. Finally, it is expected that the quality measures agreed upon by the Consortium would be shared annually with the public when it is felt that the data quality is adequate.

Appendix D.

Findings from Health Care Provider Focus Groups

As stated in the Report, the disparity in breast cancer mortality is due in part to the inconsistencies and inefficiencies of the breast cancer detection process which also includes the technical quality of the mammography services provided. To ensure that the recommendations put forth by the Quality of Mammography Action Group (QoM) will be reflective of and responsive to these existing barriers, a series of Focus Groups and interviews were conducted with medical providers throughout the city of Chicago to better understand the gaps in the current process to detect breast cancer and where intervention is needed to improve the quality of care. The following is a summary of these meetings and the recommendations for change that came out of them.

Radiology Technologists

On Tuesday, July 10, 2007, the QoM Action Group hosted the first Focus Group at Rush University Medical Center. The purpose of this meeting was to talk to radiology technologists regarding their experiences in providing mammography services. The meeting was facilitated by one of the QoM Task Force members, while several other members were present to record the participants' comments. The facilitator used a pre-scripted question guide to lead the Focus Group which consisted of topics related to patient communication, adequacy of equipment, training and staffing, logistics and barriers to patient follow-up as well as differential mammography quality between imaging centers.

Eight female mammography technologists representing various mammography centers throughout the Chicago metropolitan area participated in the Focus Group. The institutions represented included: Advocate Health Care, Mercy Hospital, Northwestern

Memorial Hospital and Rush University Medical Center. Sixty-three percent (5 out of the 8) attendees were dedicated technologists with 100% of their time devoted to performing mammograms. The remaining three participants dedicated 60-95% of their time to performing mammograms. The women had 34 years of combined experience performing mammograms.

Several factors that negatively impact the quality of the breast cancer detection process were noted:

- Primary Care Physicians' (PCPs) knowledge and practice of the proper mammography referral process is inadequate. PCPs do not routinely perform clinical breast exams.
- Inability to accept age-appropriate self-referred patients for mammograms due to legal liabilities and restrictions.
- Low insurance payments for mammography services.
- Patient barriers such as mis-information, transportation, child care, language, and fear of the mammogram itself and/or fear of a diagnosis of breast cancer.
- Political and financial burdens of mammography departments because this service does not generate revenue. These departments are the last to be upgraded.
- Educational materials are not all culturally competent.
- In some facilities, the mammography technologist is of a different race than the patients. The technologists suggested that greater diversity in the staffing of mammography centers may improve patient comfort level.

- Insufficient staffing to complete administrative tasks and mammography procedures.

To address the barriers impacting the quality of the mammography services provided, the technologists provided the following recommendations for improvement:

- Universal referral to reduce the number of referrals required for additional services related to an abnormal mammogram result. The radiologist could then perform the service without the patients needing to see their PCP for a referral. This would decrease the time to diagnosis, improve patient follow-up time, and decrease losses to follow-up.
- Increase public education that is culturally competent.
- Increase PCP education.
- Increase recruitment of ethnic/minorities into the professional field.
- Increase availability of digital mammography units for facilities without one.
- Increase the number of stand alone mammography facilities as well as extend their hours of operation to evenings and weekends.
- Increase staffing for facilities with large patient volumes and few technical staff to improve work flow. This could be accomplished by hiring clerks to handle the administrative tasks which prevent technologists from spending more time doing exams.
- Increase availability of cross training and continuing education for technologists.
- Improve communication between the technologist and the radiologist.

Primary Care Physicians (PCPs)

The second Focus Group meeting was conducted with PCPs on July 17, 2007. The meeting location and logistics were consistent with that of the Radiology Technologist Focus Group. Six physicians and one physicians' assistant attended the meeting. They represented community-based medical facilities rather than academic centers. Their patient population consisted largely of racial/ethnic minorities and uninsured or underinsured clients.

Overall the issues raised in this meeting revolved around patient referrals and follow-up care, which was consistent with some of the comments put forth by the radiology technologists. In particular, the PCPs revealed that there are a limited number of mammography facilities where they can refer their uninsured patients for mammograms. They utilize the resources available; however, these facilities are unreliable and do not meet the demand. In addition, follow-up for patients with abnormal findings is inadequate. The PCPs do not consistently receive the results of patients' exams which can delay follow-up care for those patients with abnormal findings.

The PCPs listed several barriers to quality care including the following:

- Patients do not receive regular reminders or referrals for mammograms.
- Lack of insurance or underinsured payer status is a barrier to having a routine source of medical care as well as obtaining routine mammograms.
- Patients who do not have a medical home or routine care often present for care with more acute medical issues that overwhelm physicians' time and resources. This presents a barrier to receiving routine screenings.
- When patients are referred for mammograms, central scheduling systems or scheduling for free mammograms is inconsistent and

uncoordinated. Stroger-Cook County Hospital is the safety net for all other programs and there is much inconsistency and lack of coordination. Uninsured, underinsured, and Medicaid patients are left with no facilities to rely upon to obtain mammograms and follow-up care.

- Overall patient follow-up care for abnormal mammograms is inadequate.
- Navigation services are non-existent or sparsely available to assist patients with finding facilities that provide mammograms or follow-up for abnormal exams.
- Many mammography facilities will not see patients without the prior mammogram films. Obtaining films is not always an easy process for patients.
- Finally, patients have fears and personal priorities that are often barriers to seeking and obtaining routine mammograms.

Despite the complexity of the barriers explained above, the physicians gave several specific recommendations to improve the issues surrounding patient referrals and follow-up which are listed below.

- Primary care physicians need automated reminder systems to help improve referral for mammograms.
- Navigation services should be instituted to address barriers related to patient follow-up and compliance to medical appointments.
- Outreach and advertising to target communities should be increased as tools to increase patients' knowledge and understanding of breast cancer and to address related barriers to screening utilization.
- The city needs a hotline to improve coordination of available appointments and scheduling of those slots.

General Radiologists

Lastly, the Quality of Mammography Action Group interviewed 9 general radiologists regarding their perceived barriers to the technical quality of mammography and the quality of the cancer detection process, as well as suggestions for improvement. Seven of the questionnaires were completed as self-administered surveys by radiologists from Advocate Health System. Radiologists from St. Anthony and St. Bernard Hospitals were interviewed to provide information for the two remaining questionnaires.

On average, the radiologists spent 42% (range of 10-80%) of their practice interpreting mammograms compared to other radiological procedures such as chest x-rays. They each read 1,000-6,000 mammograms annually, with a mean of 4,000. The average number of years of experience reading mammograms for the general radiologists was 17 years, with a range of 1 - 47 years.

The doctors were asked to rank their level of enjoyment of reading mammograms from 1 (like getting a root canal) to 10 (it is my passion). The responses ranged from 3 to 10 with an average score of 7. In addition, the radiologists were asked to rank their level of comfort reading mammograms with 1 being the lowest and 10 the highest with an average response of 9.

The quality barriers indicated by the general radiologists included the following:

- Lack of understanding of mammography and breast cancer statistics by primary care physicians, patients, and the media. There is a misconception of when patients should receive mammograms and how often a cancer is diagnosed;
- Lack of utilization of mammography;
- Lack of insurance;
- Genetic and social factors;
- Overall poor primary care.

The recommendations for improvement:

- Universal referrals are needed.
- Digital mammography units for those clinics which do not have one.
- Improved and increased audits of quality indicators.
- Patients need yearly mammograms at the same site.
- Mammograms should be read by an experienced radiologist.
- Technologist Extenders, under the direct supervision of experienced radiologists, can be used to read mammograms to improve the shortage of readers.
- Increase hospital and provider reimbursement for mammograms and reduce medical liability.
- Improve the BIRAD system by reducing
- the number of categories.

Summary

Across the Focus Groups and interviews the providers consistently indicated four key factors that inhibit the early detection of breast cancer and thereby contributing to the disparate mortality rates for Black and White women in Metropolitan Chicago. Although not directly a part of the detection process, lack of insurance and insufficient coverage are barriers to patients maintaining a medical home as well as seeking routine medical care, including screening. All participants reported inconsistent mammography referral patterns. Primary care physicians are not routinely referring their patients to receive mammograms and without a doctor's referral patients can not receive the exam; self-referral for mammography is not available. This barrier is most apparent for PCPs who care for mostly uninsured or underinsured patients. In addition to the delay in entering the detection process, the follow-up for women who have obtained mammograms is inadequate from the letters used to notify patients of their exam results to scheduling for diagnostic procedures to obtaining a final diagnosis.

Given the complexities of the current process and the existing barriers, the medical providers gave specific suggestions to address these issues. First, there is a need for increased capacity to provide free or low cost mammography services to uninsured or underinsured women in Metropolitan Chicago. Second, patient navigators are needed to improve patient education and access to medical care and to overcome the fears and stigma of obtaining mammograms. Patient navigators could work in the communities to accomplish these tasks or within health care facilities. They could also assist patients who require follow-up for abnormal screenings navigate the system until a final diagnosis is obtained, and beyond if the patient was diagnosed with cancer.

To address the non-patient related barriers, the providers stated universal referrals would greatly reduce the problem of patient loss to follow-up and inappropriate diagnostic prescriptions. A universal or global referral form would allow the radiologist to perform necessary procedures at the initial diagnostic visit rather than sending the patient back to a primary care doctor to obtain another referral for another diagnostic procedure. This procedural change is potentially cost effective and time efficient for the medical facility, the provider, and the patient. Lastly, variations in the technical quality of the mammography service were also indicated as a barrier. The providers recommended that all mammography facilities have digital mammography units to improve the quality of the mammogram study which may also improve interpretation of exams and improve cancer detection.

In summary, the Quality of Mammography Action Group was given specific suggestions from medical providers across the metropolitan area on methods to address the flaws in the current breast cancer detection process. Provider and patient level barriers were highlighted along the spectrum of care. The Task Force will utilize these findings to establish specific recommendations to improve the quality of the services provided and to facilitate early detection of breast cancer for all women in Metropolitan Chicago.

Appendix E.

A High Tech Mammography Film Sharing System

Research suggests that one barrier to mammography screening is obtaining prior films. In fact some institutions in Metropolitan Chicago require that previous films be made available before a mammogram will be done. Unfortunately, obtaining prior mammogram films is a difficult task for most people, let alone poor women who rely on the public health safety net. In addition, many women have mammographic services at multiple institutions in the area making finding the prior film very difficult. There are also additional costs associated with obtaining and/or shipping the films to the new facility. Regardless, the burden is placed solely on the woman, who likely without any guidance from the providers, may not even know how to ask for the prior film.

With the current technology and the increasing switchover from analog (physical x-ray images) to digital images (viewable by computer), we are in a position to begin converting the x-ray images to digital images. The conceptual design will be similar to that of a Regional Health Information Organization (RHIO) for the city. A RHIO is an organization of public and private sector

stakeholders which promotes the use and secure exchange of digital images (mammograms) and reports. This system would provide a solution that delivers a focused and unique opportunity to capture and share mammography data metropolitan area-wide, leveraging current technology while fostering between facility “sharing” to reduce the repetition of unnecessary procedures.

This type of technology would free up physical space designed for storing analog films and replace it with a secure computer terminal which would have the needed virtual memory storage as well as the ability to send the report, any needed data, and the films to other providers who have a similar system. A RHIO system would be able to link these prior films regardless of where the films were taken and would be available to those institutions who participate in the Consortium. It would also eliminate the risk of damage or loss of films.

The details of the RHIO concept can be found in our online appendix at the following website: www.ChicagoBreastCancer.org.

Appendix F.

University of Chicago Focus Groups

Summary Research Findings from:

A Community-Based Approach to Understanding Community Attitudes, Beliefs, and Concerns about Breast Cancer and Its Treatment

Sarah Gehlert, PhD, Christopher Masi, MD, PhD, Courtenay Savage, AM, Maria Ferrera, AM, Annie Pope, MSW, Alice Furumoto-Dawson, PhD, Jewell Brazelton, MSW, Robert Coleman, MSW

The Center for Interdisciplinary Health Disparities Research at the University of Chicago (CIHDR) was funded by the National Institutes of Health in 2003 to investigate the determinants of Black and White differences in breast cancer mortality in two locations: the South Side of Chicago and Ibadan, Nigeria. CIHDR's unique interdisciplinary approach partnered social, behavioral, and biological scientists with community residents. Its first year of operation in Chicago was devoted to conducting 49 community-based participatory Focus Groups for residents of fifteen South Side neighborhood areas, in order to ensure that local knowledge was used to understand Black and White differences in breast cancer. Because no single community agency was well enough positioned to represent South Side concerns about breast cancer and related health issues, we decided to gain insight into community concerns, beliefs and attitudes toward breast cancer and its treatment through the use of a grass-roots recruiting approach. A five-member advisory committee made up of community residents from various backgrounds was convened to help devise plans for these Focus Groups as well as the research design and measures for the investigations to be conducted during subsequent years of operation. The group met semi-monthly.

First, we reviewed Chicago Department of Public Health data on each of the fifteen neighborhood areas to ensure that the composition of Focus Groups would

appropriately reflect their demographics. Once a demographic profile had been established (age, gender, median family income, education, religious affiliation), CIHDR staff went into the neighborhoods and passed out flyers on the streets, at bus stops and in parking lots. We sent letters of introduction and flyers to community agencies, aldermen's offices, health clinics, churches, etc., inviting adults over eighteen years of age to take part in groups. Project staff spoke at these sites when invited. After an interview with Dr. Gehlert, the editors of the *Chicago Defender*, the oldest continuously published African-American newspaper in the U.S., published an article on the project, which urged residents to "take part in this valuable project."

Over 1,300 people called the number provided to volunteer. We selected 503 to form two to three groups per neighborhood area that: 1) represented the demographics of the area; and 2) would result in groups heterogeneous in terms of age, gender and socioeconomic status, while avoiding situations in which some person(s) in the group would be dominant over others (e.g., including a participant's work supervisor or having a mother on TANF [public assistance] in a group otherwise made up of professional men).

Each group had 10-12 participants and was facilitated by two staff members. The staff consisted of two community research

assistants, four doctoral and five master's students from the School of Social Service Administration, a doctoral student from Chicago State University, a summer extern from the University of Missouri-Columbia, a high school apprentice from CIHDR's Summer Research Apprenticeship Program and Drs. Gehlert and Masi. Staff took part in an all-day training led by Dr. Gehlert. The group interviews followed the approach outlined in Martha Balschem's Cancer in the Community, in which participants were asked broad questions to stimulate discussion, without biasing its nature and direction, (e.g., "What comes to mind when you think of breast cancer, the disease itself?"). The two-hour interviews were recorded, professionally transcribed, and analyzed using NVivo software. At the end of the Community Based Participatory Research (CBPR) Focus Group interview, participants were asked to review instruments to be used in scientific investigations and to provide feedback on their suitability and relevance to their concerns.

Several themes emerged from the Focus Groups. These themes include a lack of attention to breast cancer by some members of the community, because individual concern "pales in comparison to the competing risks of daily survival, particularly in light of multiple responsibilities related to caring for and supporting their families."¹

*(Emphasis added): And where you kids are. Can they make it home too? That's all. **You're not worried about breast cancer.** And it's something that should be addressed but it's not. And like Sam said, you're talking now, racial but also economics. Lincoln Park, Bellwood, Lincolnshire, they can talk about breast cancer, okay.* (Salant & Gehlert, 2007, p.19)

References

¹Salant T, Gehlert ST. Collective memory, candidacy, and victimization: Community epidemiology of breast cancer risk. *Sociology of Health and Illness* 2007. (In Press)

²Masi CM, Gehlert SJ, Ferrera MJ, Savage CE, Walker WJ, Winitzer RF. Perceptions of breast cancer and its treatment among African-American women and men: A qualitative study. *Social Science and Medicine* 2007. (Manuscript submitted for publication.)

In addition, Focus Group members expressed a concern with the type and level of care provided at public health care facilities.

The quality of care you get from a public health clinic is not going to be the same quality of care you get from a private physician. You can walk in the Board of Health and it's a completely different atmosphere than the Lynn Sage Breast Cancer Center, where you got nice lights, you got TV going and soft jazz playing and you got coffee and snacks, and "can I help you" as soon as you walk in the door. They are going to take care of you - and if you go to the Board of Health Center, there are 30 people all at the same time, and you got to sit there and wait (Masi et al., 2007, p. 7).²

Another common theme was the lack of available information on breast cancer and wellness on the South Side.

I also think that information and education is very important in the South Side community or any Black community because a lot of us, we don't go to the hospital. We will medicate our self before we see what's wrong. I know I've done it many times myself. They need to really come out here with pamphlets and things of that nature to show the community (Masi, et al., 2007, p.12).

For more in-depth reading of themes that emerged from these Focus Groups and to learn more about this work, please visit the Center website: <http://cihdr.uchicago.edu>.

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Appendix G.

Health Care Provider Interviews on Access to Treatment

A diverse group of health care providers in the Metropolitan Chicago area were contacted to learn about their perspectives on access to treatment barriers impacting breast cancer patients and how these might be affecting Chicago's Black:White disparity in breast cancer mortality. Providers' insights were simultaneously unique and mutually reinforcing, affording new understandings of patients' experiences while supporting many commonly held views. A few key topics emerged that provide an important framework for understanding and addressing access to treatment barriers. While this section of the report focuses on patient barriers after their initial access to screening and diagnostic services, many barriers encountered by patients span the continuum of care and are not exclusive to pre- or post-screening periods.

The findings of the Task Force's outreach to providers should not be construed as statistically significant findings. The goal in contacting providers was to understand the micro-level, front-line experiences and stories of those intimately involved with treating breast cancer patients and helping them and their families. Viewed in this light, and considering the corroborating evidence from the *Breast Cancer in Chicago: Eliminating Disparities and Improving Mammography Quality*¹ report, provider perspectives provide a unique and personal look into what kinds of barriers impede breast cancer patients after they have been diagnosed. It is important to note that many providers explicitly noted that many patient barriers disproportionately impact all patients of lower socioeconomic status, and that these barriers are not experienced solely by the African-American community. However, providers also recognized socioeconomic status barriers tend to affect a higher proportion of African-Americans, and that some barriers exist that are unique to the African-American community.

One of the most common issues cited by caregivers was patients' difficulty in securing reliable and timely transportation for chemotherapy, radiation and the myriad post-chemotherapy appointments needed to fight and monitor the disease. Possible barriers mentioned include families owning one or no vehicles; the length of trips to reach treatment facilities (which are not evenly dispersed throughout Metropolitan Chicago area) combined with the frequency of treatment sessions; the unreliability of contracted Medicaid transporters; and the lack of financial or logistical resources required to transport a cancer patient as needed.

Erin Kessler, an ACS Patient Navigator at Rush University Medical Center, said:

Financial barriers go beyond being un- or underinsured. Many African-American patients hesitate to seek screening and treatment for breast cancer because the patient and the family's daily routines and schedules are so drastically altered. It's tougher to withstand the financial and logistical pressures of breast cancer without a lot of resources.

Access to quality provider networks, and the ability to navigate provider networks, is another major barrier for many patients. Shalise Roberts, RN, a Public Health Nurse with the CCDPH, pointed out that many patients with coverage through the IBCCP program have difficulty receiving initial screening and treatment following a diagnosis because of the uneven distribution of provider organizations that accept Public Aid breast cancer patients.

The Cook County Department of Public Health has made a renewed effort to identify providers who are willing to provide mammograms to women eligible for IBCCP coverage. While some providers offer these lower-cost mammograms to ensure all women have access, some women face barriers because not enough providers are accepting IBCCP-eligible patients.

Providers also indicated that deficient patient education processes—and patients' subsequent lack of understanding about breast cancer and the importance of the treatment process—often hamper efforts to provide treatment to African - Americans. The need for improved patient liaison services—possibly through the extension of Patient Navigation programs—was cited as an important component of improving patient awareness about all steps of the screening and treatment process. Dr. Ruta Rao, MD, a medical oncologist at Rush, cited patient education as a critical factor:

Patient education is key, either through a Patient Navigator with the time and resources to help the patient navigate all steps of the care process, or through a nurse who is able to coordinate care and serve a similar role.

This lack of access is deeply connected to the problems faced by many uninsured and under-insured patients in Metropolitan Chicago. While the barriers to the uninsured are clearer, under-insurance and its corresponding high out-of-pocket costs also deter patients from seeking critical breast cancer care. One example cited by multiple providers is the prohibitively high price of co-pays for hormone medications confronting many low- and middle-income patients. Dr. Rita Nanda, MD, of the University of Chicago Medical Center, reported:

Many Medicaid and other low-income patients have high co-pays or lack prescription drug insurance, so they are effectively forced to forego purchasing necessary hormone therapy medication.

A separate issue related to access is the need for providers to coordinate to optimize the breast cancer treatment capacity in Metropolitan Chicago. Eileen Knightly, RN, Breast Center Director at Mercy Hospital and Medical Center, believes that for breast cancer services

infrastructure to treat as many patients as possible, programs have to collaborate:

Outreach through the IBCCP has been successful, although we need to collaborate with all the IBCCP centers to assure we are doing effective outreach and not all reaching the same population in a competitive approach.

Finally, providers cited culturally specific barriers that play a role, albeit one difficult to isolate or define. Mistrust of the medical community was cited as a possible reason for lower utilization of breast cancer services, as were communication barriers between patient and providers and between institutions and communities. Another African-American community-specific factor was one that is equally understandable and sad. Providers cited a lack of understanding from patients about the efficacy of medical treatment. This may be something akin to a sense of fatalism, possibly stemming from frayed lines of communication and patients' communal experiences with breast cancer—which for other community members are more likely to have ended in death, given the disparate mortality rates between Whites and African-Americans. Irene Pierce, RN, of the Lake County Health Department, said:

To reach the African-American and lower socioeconomic status communities, we need to focus on communication to stress early detection as a life saving measure. We need more Public Service Announcements on high-volume stations and other like-minded strategies to ensure that we actually reach the people we are trying to educate.

These provider perspectives on access to treatment barriers contributed to the preparation of the Quality of Treatment Chapter herein. For more details about these interviews conducted by the Quality of Treatment Action Group, see the Online Appendix O-D.

References

¹Hirschman J, Whitman S, Ansell D, Grabler P, Allgood K. Breast cancer in Chicago: Eliminating disparities and improving mammography quality. Sinai Urban Health Institute, Chicago (IL); October 2006.

***For more information about the Metropolitan Chicago Breast Cancer Task Force and
a pdf of this report, visit:***

www.chicagobreastcancer.org.

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The Metropolitan Chicago Breast Cancer Task Force was created after the Chicago Breast Cancer Summit of March 23, 2007, with the goals of improving the quality of breast health and of reducing the increasing Black:White disparity in breast cancer mortality in the Metropolitan Chicago area. For more information on the Task Force, please see our website: www.chicagobreastcancer.org