

FACTORS THAT INFLUENCE FOLLOW-UP AFTER AN ABNORMAL  
MAMMOGRAM

A Dissertation

by

VALERIE ANNE COPELAND

Submitted to the Office of Graduate Studies of  
Texas A&M University  
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

December 2006

Major Subject: Health Education

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## ABSTRACT

Factors That Influence Follow-up After an Abnormal Mammogram. (December 2006)

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Chair of Advisory Committee: Dr. Jeffrey J. Guidry

The focus of this study was to explore women's experiences with follow-up after an abnormal mammogram, and factors that influence follow-up. Factors, including health status, found in the cancer screening and treatment literature, are necessary in identifying variables which have the potential to affect a person's perception, and promote or deter follow-up. Protection Motivation Theory constructs utilized in this study are found in the literature to improve diagnostic health behaviors such as performing breast self-examination and complying with diagnostic tests.

A non-experimental, descriptive, cross-sectional design was used to identify the barriers to follow-up after an abnormal mammogram by: 1) determining the noncompliance rate of follow-up mammograms among women screened at an urban hospital's mammography mobile unit in North Texas (October 1, 2004, to September 31, 2005) who were found to need further evaluation for suspected abnormal findings; and 2) identifying factors associated with noncompliance and perceived barriers to noncompliance.

The sample consisted of 262 participants, 136 (52%) women whom the hospital reported had not returned for follow-up and 126 (48%) women who were reported to

have returned. A logistic regression model was performed using follow-up as the dependent variable. The variables most related to follow-up were (1) number of mammograms in the last 5 years; (2) having health insurance; (3) having problems receiving abnormal mammogram results; (4) having problems receiving or making a follow-up appointment; (5) taking off from work for the follow-up appointment; (6) not having transportation to follow-up appointment; and (7) waiting a long time to receive the follow-up appointment.

Non-compliance to recommended follow-up after an abnormal mammogram is a serious public health concern, since breast cancer screening can improve breast cancer outcomes only if prompt diagnostic resolution and access to state-of-the-art care is available to all screening participants. This study adds to the literature on predictors of follow-up after an abnormal mammogram, as well as the to the health disparities literature.

## DEDICATION

This dissertation is dedicated with love to my parents, Stanley Copeland and Geraldine T Copeland, whose faithful love and support throughout the years has allowed me to grow, learn and succeed. Thank you with all my heart.

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This study would not be possible without the support of numerous individuals.

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A very special thanks is due to my other angels, Dr. Evaon Wong-Kim and Dr. Hee-Soon Juon who provided invaluable support and patience. They both explained statistics in practical and applicable terms and assisted me with data analysis.

I cannot forget my friends and family, who commiserated with me, and supported me. Thanks Mom, Dad, Vanessa, Helen, Becky, Bonnie, Vickie, Mary Jo, and Mary Jean just to name a few.

Finally, I would like to thank GOD. I can do all things through Christ who strengthens me –Phillipians 4:13.

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## CHAPTER I

### INTRODUCTION

#### Overview

Despite the recent statistics indicating a decrease in breast cancer mortality, breast cancer continues to be one of the leading causes of morbidity and mortality among women in the United States. Breast cancer screening aims to detect cancers when they are as small as possible and before there is evidence of lymph node dissemination. Few women in a regularly screened population should be diagnosed with late-stage cancer because, in theory, screening should identify cancers before they progress to later stages.

Mammography screening is an effective tool for the prevention of breast cancer mortality. Many women have abnormal findings on screening mammograms that require follow-up to eliminate the possibility of breast cancer. A recent review of studies on follow-up of abnormal screening examinations reported that, in the majority of studies, 75% of patients did not receive adequate follow-up care (Bastani et al., 2004). When an abnormality is detected on screening mammography, clinical evaluation and a thorough radiological work-up are needed to determine the significance of the abnormality. Delays in follow-up for abnormal mammograms potentially can lead to more severe outcomes associated with breast cancer, including later stages of diagnosis and subsequent increased mortality.

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This dissertation follows the style of *Evaluation & The Health Professions*.

Waiting for a definitive diagnosis following an abnormal mammogram is a critical element in the breast cancer care process. Despite the potential seriousness of women receiving inadequate or no follow-up after an abnormal mammogram, there has been little research on the determinants of follow-up of abnormal mammograms (Arnsberger Webber, Fox, Zhang, & Pond, 1996; Barton et al., 2004; Boudreau, McNally, Rensing, & Campbell, 2004; Juarbe et al., 2005; Kaplan, Crane, Stewart, & Juarez-Reyes, 2004; Kerlikowske, Smith-Bindman, Ljung, & Grady, 2003; Kerlikowske, 1996; Lipkus, Halabi, Strigo, & Rimer, 2000; McCarthy, Ulcickas Yood, Boohaker, et al., 1996; McCarthy, Ulcickas Yood, Janz, et al., 1996; Olivotto et al., 2002; Strzelczyk & Dignan, 2002; Taplin, et al., 2004; Thorne, Harris, Hislop, & Vestrup, 1999; Yabroff et al., 2004). This study seeks to identify factors that influence a woman obtaining follow-up after an abnormal mammogram.

### Breast Cancer Statistics

Breast cancer is a leading cause of death among women in the United States and is the most common type of cancer in women worldwide. About 200,000 women are diagnosed, and approximately 40,000 deaths are attributed to breast cancer each year. It is the most frequently diagnosed cancer in women. Breast cancer incidence rates have risen in the United States for the past two decades due to increased use of mammography; however, in some populations, particularly among racial minorities and the poor or medically underserved, the percentage of women with advanced disease at diagnosis remains high (American Cancer Society [ACS], 2005a; Jacobellis & Cutter, 2002; Jones et al., 2005; Juarbe et al., 2005; Kaplan et al., 2004; Kerlikowske et al.,

2003; Kerner et al., 2003; Olivotto et al., 2002; Strzelczyk & Dignan, 2002; Yabroff et al., 2004).

Although the lifetime chance of developing breast cancer is higher for White women than for Black and Hispanic women, Black women and subgroups of Hispanic women have a lower breast cancer survival rate. According to the American Cancer Society (ACS), approximately 19,240 African-American women in the United States were expected to be diagnosed with breast cancer during 2005, and approximately 5,640 of these women were expected to die from it; an estimated 11,000 Hispanic women were diagnosed with breast cancer during 2003, and roughly 1,600 of these women died from it. A potential explanation is that follow-up after an abnormal mammogram is delayed or incomplete, and thus, the benefits of screening are not being realized (ACS, 2003; ACS, 2005b; Jacobellis & Cutter, 2002; Yabroff et al., 2004).

#### *Screening Mammography*

Numerous studies have shown that early detection saves lives and increases treatment options. Mammography is the single most effective method of early detection because it can identify cancer several years before physical symptoms develop. Screening mammography typically includes two views of each breast. Mammography is highly accurate, but like most medical tests, it is not perfect. Generally, mammography will detect about 80%-90% of breast cancers in women without symptoms. Recent estimates indicate that over a 10-year period of annual mammogram screenings, women confront a 50% cumulative risk of obtaining at least one false-positive mammogram (ACS, 2005a; Heckman et al., 2004; Kerlikowske et al., 2003).

Mammogram results are classified according to the American College of Radiology Breast Imaging Reporting and Data System (BIRADS) classifications (Table 1): (0) indeterminate reading, more information needed; (1) normal; (2) benign or stable abnormality, standard screening follow-up recommended; (3) benign or stable abnormality, six month screening follow-up recommended; (4) suspicious abnormality, consider biopsy; and (5) highly suggestive of malignancy (Juarbe et al., 2005; American College of Radiology, 2004).

**Table 1.**  
**Radiology Breast Imaging Reporting and Data System (BIRADS)**

<b>BIRADS Category</b>	<b>What It Means</b>
0	More information is needed to give a final mammogram report.
1	Your mammogram is normal.
2	Your mammogram shows only minor abnormalities that are not suspicious for cancer. No additional testing is needed.



### *Abnormal Mammogram Results*

Although the overwhelming majority of women who undergo screening each year do not have breast cancer, a number of women have their mammograms interpreted as abnormal or inconclusive until further tests are performed. Part of breast cancer screening is the assessment of abnormal screening results. The assessment may involve physical examination, imaging with magnified or other special mammography studies, ultrasonography, imaging-directed biopsy, or surgical biopsy. Fletcher (2000) states in a national study of mammography centers, 11% of mammograms require follow-up; others find approximately 6% to 7% of screening mammograms have abnormal findings. Elmore et al. (1998) reports if a woman 50 years old or older has ten mammograms, then the chance that she will have at least one false positive is approximately 56% and may be as high as 75%. Lerman and Rimer (1995) project if 38% of the 48 million American women aged 40 and over have mammograms, then more than three million will have an indeterminate or positive test result every year. About 5-20% of mammograms are in abnormal categories; of these, 6-18% will require some type of further examination. Yabroff et al. (2004) find prior studies report between 32% and 98% of women with abnormal mammograms receive at least some follow-up. In addition, Yabroff et al. (2003) report approximately 9% of their sample, almost 1million women, do not complete any diagnostic follow-up after abnormal mammograms (ACS, 2005a; Olivotto et al., 2001).

The most common and most worrisome mammographic abnormalities found on screening examinations that require further evaluation are masses and calcifications.

Each of these mammographic abnormalities can lead to several diagnoses including cyst, benign nonproliferative lesions, benign proliferative lesions with or without atypia, fibroadenoma radial scar intramammary lymph node, lipoma, galactoceles, ductal carcinoma in situ and invasive cancer for masses and benign nonproliferative lesions, benign proliferative lesions with or without atypia, fat necrosis, atherosclerosis, dermal lesion, ductal carcinoma in situ, and invasive cancer for calcifications (ACS, 2005a; Yabroff et al., 2004).

### Follow-up

A screening mammogram does not diagnose cancer; rather, it identifies women with abnormalities who require follow-up. Additional diagnostic procedures must be recommended, ordered, performed, and received to accomplish the goal of determining the presence or absence of disease. Follow-up or additional testing (a) might rule out the presence of breast cancer; or (b) might confirm that cancer may indeed be present, thereby necessitating serious and invasive medical interventions. Waiting for a definitive diagnosis after an abnormal screening mammogram can cause anxiety and distress for women, which may last for months. Hislop et al. (2002) suggest that for women who are subsequently diagnosed with cancer, this initial period of distress may create difficulty with trust and confidence in the healthcare system, and may, for the remainder of women, deter further screening compliance. Although identified as a significant concern, few studies have assessed the anxiety associated with the process from screening to definitive diagnosis (ACS, 2005a; Bastani et al., 2004; Heckman et al., 2004; Olivotto et al., 2001).

### *Compliance*

The appropriate time span for follow-up after abnormal screening mammography, from notification of test results to diagnostic evaluation, has not been established. Most studies that determine the timeliness of follow-up after abnormal screening mammography mark the beginning of the follow-up period as the index date of the abnormal screening examination. The endpoint of the period is variously defined as the time it takes until the first diagnostic test; the time it takes to biopsy; the time spent completing the work-up; and the time spent on the final disposition. Appropriate follow-up of abnormal test results requires multiple steps and can take several weeks.

Several studies in the literature document follow-up rates for abnormal breast cancer screenings. These rates range from 50% to 93%, with the best follow-up being among women whose exam requires immediate follow-up (62%-93%). Taplin et al. (2004) find that follow-up of abnormal mammograms is a quality-of-care issue that appears to account for a small proportion of the late-stage cancer issues among women. Although most abnormal studies turn out to be false positives, a significant proportion are associated with carcinoma, and all abnormalities require prompt follow-up care (Fillmore, Beekman, Johnson Farmer, & Gold, 2003; Karliner, Kaplan, Juarbe, Pasick, & Perez-Stable, 2005; Kerlikowske, 1996; Kerner et al., 2003; Poon et al., 2004).

### *Mammography Results Notification*

Due to concerns regarding timely and appropriate notification of women about the results of their mammograms, the Mammography Quality Standards Act (MQSA) reauthorization (HR 4382) passed by Congress and effective since April 28, 1999,

include mandatory reporting of mammogram results directly to all patients, not only self-referred patients. This requirement states that the results should be provided as a “summary of the written report sent directly to the patient in terms easily understood by a lay person” (Federal Department of Agriculture, 2004, p. 12). This summary does not need to contain the detailed information that is sent to referring physicians or to self-referred patients, but it must include specific information notifying the woman of how she should proceed. The regulation requires that notification be sent in a timely manner (less than 30 days). The American College of Radiologists (ACR) recommends that all centers have written procedures for transmission of the written summary report to the patient and requires a log or radiology information system (RIS) be used to track reporting. In addition, MQSA and ACR specify that results with lesions that are suspicious or highly suggestive of malignancy should prompt the facility to make reasonable attempts to communicate with the patient as soon as possible.

Mammography centers are required to be MQSA-certified in order to operate (ACS, 2005a; Boudreau et al., 2004).

### *Barriers to Follow-up*

The patient, the provider, and the system all contribute, in part, to inadequate follow-up. Patients, for example, may decide that they want a second opinion, may be worried about the cost, may be fatalistic, or may fear a painful procedure. Additionally, the patient may delay follow-up because she thinks the mammogram is normal and no further follow-up is necessary, because she does not have access to reliable transportation, because she does not have a usual source of care, because she worries

about cancer and is afraid of losing her breast, because she has difficulty arranging childcare, or worries about lost wages during the time that she has to take off work to receive follow-up. Providers may delay follow-up when their work-up causes a delay, when they do not recommend appropriate follow-up, and when they misdiagnose the results. System barriers to follow-up include delayed notification of results, scheduling delays, cancellations, difficulty in obtaining an appointment, long waits in the doctor's office, and inconvenient facility hours (Bedell et al., 1995; Jones et al., 2005; Juarbe et al., 2005; Kaplan et al., 2004; Karliner et al., 2005; Kerner et al., 2003; McCarthy, Ulcickas Yood, Boohaker, et al., 1996; McCarthy, Ulcickas Yood, Janz, et al., 1996; Poon et al., 2004; Rojas & Mandelblatt, 1996; Strzelczyk & Dignan, 2002; Taplin et al., 2004; Yabroff et al., 2004).

### *Conceptual Framework*

Theory-based research over the past 20 years demonstrates how people use healthcare and how patients make decisions about whether or not to follow medical advice are influenced by individuals' beliefs and perceptions in combination with environmental resources or barriers. A summary of the literature on follow-up and Protection Motivation Theory suggests the health action a woman takes after being told her mammogram indicates a need for further testing or treatment has been strongly influenced by the following: 1) her understanding of the meaning of the abnormal results; 2) whether she believes she is at risk for breast cancer; 3) whether she believes that the medical recommendations will make a difference in her health; 4) whether she can follow the recommendation; and 5) what problems, barriers, and costs she will face

if she follows the recommendation (Ell et al., 2002; Floyd, Prentice-Dunn, & Rogers, 2000; Maddux & Rogers, 1983; Milne, Sheeran, & Orbell, 2000; Rippetoe & Rogers, 1987; Shelton & Rogers, 1981; Sturges & Rogers, 1996).

### Study Aims

This research explores women's experiences with follow-up after an abnormal mammogram and factors that influence follow-up through the use of a telephone interview. Health status and possible barriers to follow-up variables, found in the barriers to cancer screening and treatment literature, are necessary in identifying variables which have the potential to affect a person's perception, and promote or deter follow-up. Protection Motivation Theory constructs utilized in this study are found in the literature to improve diagnostic health behaviors such as performing breast self-examination and compliance with diagnostic test to identify a fictitious disease.

The measures of outcome in this study are follow-up and no follow-up after an abnormal mammogram, and the predictors of each of these dependent variables. In this study, the definition of an abnormal mammogram is similar to that used by Kerlikowske (1996): quite simply, an abnormal mammogram necessitates further diagnostic testing.

Independent variables, or variables that are associated with the outcome, include mammogram utilization, health insurance coverage, regular source of health care, cost, fear of getting breast cancer, expectations of the follow-up procedure, difficulty getting appointments, difficulty getting time off from work for medical appointments, difficulty finding transportation, and waiting a long time for medical appointments.

### Theoretical Definition of Terms

In this study, the definition of **abnormal mammogram** is similar to that used by Kerlikowske (1996): one that necessitates further diagnostic testing.

**Follow-up** is defined as “diagnostic procedures recommended, ordered, performed or received to accomplish the goal of determining the presence or absence of disease” (Bastani et al., 2004, p. 1191).

### Significance of Research to Practice

When interpretation of a screening mammogram indicates that additional diagnostic studies are needed, there should be no barriers or delay that would prevent the performance of further diagnostic tests. Understanding the association between follow-up and factors that influence follow-up may help identify strategies to improve follow-up. The progress to reduce breast cancer mortality remains a challenge and depends on the ability to institute the most effective approaches in prevention, early detection, follow-up, and treatment. The challenge is to provide the best-quality care for women undergoing mammography screening by maximizing the benefits associated with a timely diagnosis of cancer (Committee on Gynecologic Practice, 2002; Barton et al., 2004; Juarbe et al., 2005, Kaplan et al., 2004; Yabroff et al., 2004).

## CHAPTER II

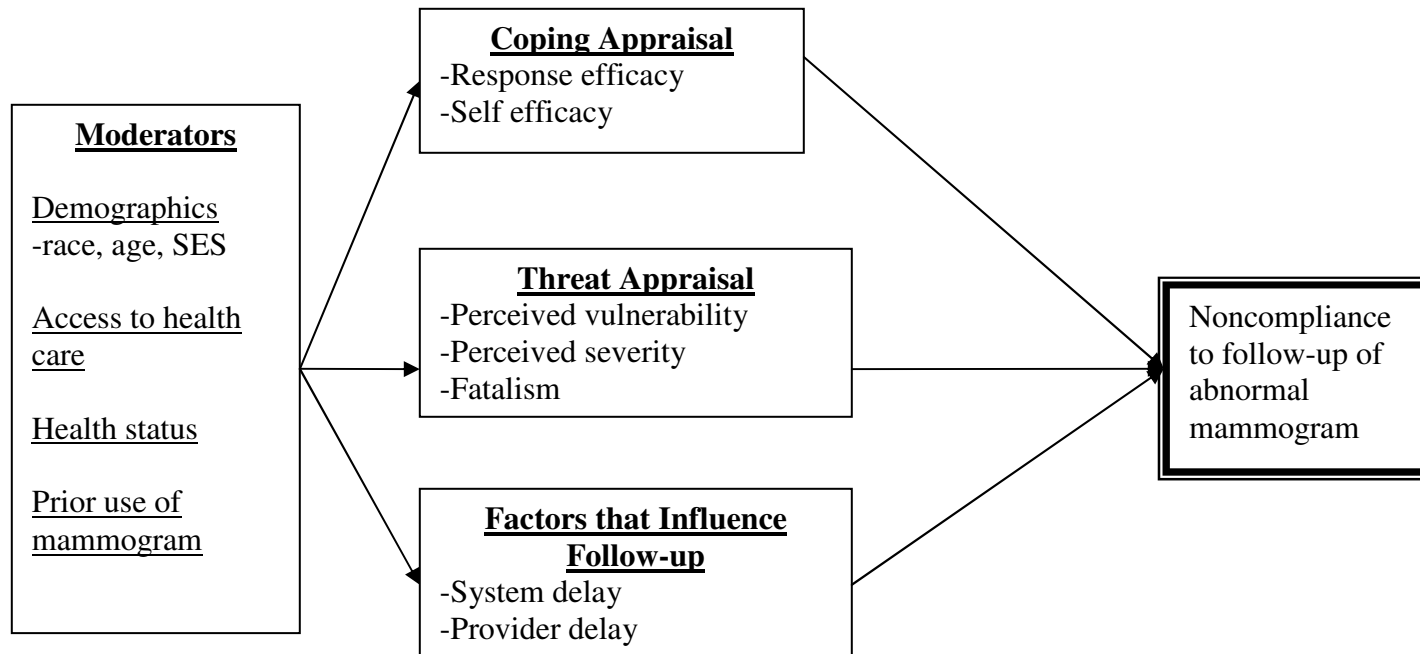
### REVIEW OF RESEARCH

#### Conceptual Framework

Coping and threat appraisal constructs of Protection Motivation Theory, along with moderators (demographic and health information) and questions found in the literature regarding barriers to follow-up (system, provider and patient delays), were chosen for this study to identify factors that influence follow-up and to serve as a guide in explaining the relationship of predictor variables to the outcome variable follow-up (see Figure 1). Formulated research questions are based on a review of the literature on barriers to follow-up and the Protection Motivation Theory.

The conceptual framework for this study was based on Protection Motivation Theory. Prentice-Dunn et al. (2001) demonstrated that threatening health information prompts one to act in a variety of ways to minimize the perceived danger. Prentice-Dunn et al. (2001) corroborate the findings of others that emphasize personal vulnerability to breast cancer can be an effective means of motivating women to act to protect their health. The addition of coping information moves the individual away from a maladaptive reaction to the threat. Additionally, Floyd et al. (2000) and Milne et al. (2000) found that PMT constructs were useful in predicting the intention to change behavior. Coping appraisal constructs had a stronger association with intention to change behavior than threat appraisal constructs. In addition Milne et al. (2000) found that intentions are satisfactory predictors of health behaviors as PMT suggests.





**Figure 1.**  
**Conceptual Framework for the Proposed Study: Measurements**

### *Overview of Protection Motivation Theory*

The original version of Protection Motivation Theory (PMT) grew out of research on fear appeals. “A fear appeal is an informative communication about a threat to an individual’s well-being” (Milne, Sheeran, & Orbell, 2000, p. 107). Additionally, PMT was introduced to operationally define the components of a fear appeal in order to determine the common variables that produce attitude change (Milne et al., 2000). It was assumed that each component of a fear appeal would initiate a corresponding cognitive mediating process. These processes, in turn, would influence protection motivation in the form of intention to adopt the recommended behavior contained within the fear appeal (Boer & Seydel, 1996; Floyd, Prentice-Dunn & Rogers, 2000; Helmes, 2002; Maddux & Rogers, 1983; Milne, Orbell & Sheeran, 2002; Milne et al., 2000; Milne & Orbell, 2000; Prentice-Dunn, Floyd & Flournoy, 2001; Rippetoe & Rogers, 1987; Rogers, 1975; Shelton & Rogers, 1981; Sturges & Rogers, 1996; Tanner, Day & Crask, 1989).

PMT describes the processes involved in determining whether an individual will respond to a threat, such as a threat to health, by adopting a recommended coping response (Rogers 1975; Maddux & Rogers, 1983). For example, PMT can help to determine whether an individual will be motivated to comply with the recommendation for a follow-up appointment after an abnormal mammogram. PMT’s primary focus is aimed at two cognitive processes—threat appraisal and coping appraisal—that result in protection motivation (the motivation to perform or not perform a health behavior), which, in this study is operationally defined as the interest in and intention to comply

with follow-up recommendations after receiving abnormal results from a screening mammogram (Boer & Seydel, 1996; Floyd et al., 2000; Helmes, 2002; Maddux & Rogers, 1983; Milne et al., 2002; Milne et al., 2000; Milne & Orbell, 2000, Prentice-Dunn et al., 2001; Rippetoe & Rogers, 1987; Rogers, 1975; Shelton & Rogers, 1981; Sturges & Rogers, 1996; Tanner et al., 1989).

Threat appraisal is derived from the perceptions that one is personally vulnerable to a disease, combined with the beliefs that the disease in question would have severe consequences. Perceived vulnerability assesses how personally susceptible an individual feels to the communicated threat. Perceived severity assesses how serious the individual believes that the threat would be to his or her own life. Where perceived vulnerability and perceived severity are high, an individual is presumed to experience a significant degree of personal threat. The way in which a person responds to appraise threat is determined by coping appraisal (Boer & Seydel, 1996; Floyd et al., 2000; Helmes, 2002; Maddux & Rogers, 1983; Milne et al., 2002; Milne et al., 2000; Milne & Orbell, 2000; Prentice-Dunn et al., 2001; Rippetoe & Rogers, 1987; Rogers, 1975; Shelton & Rogers, 1981; Sturges & Rogers, 1996; Tanner et al., 1989).

In the original development of the theory, Rogers (1975) identified response efficacy as the main determinant of coping appraisal. Response efficacy concerns beliefs that adopting a particular behavioral response will be effective in reducing disease threat. Maddux and Rogers (1983) expanded the components of coping appraisal to include self-efficacy and response costs in the coping appraisal component of the model. Self-efficacy concerns an individual's belief about whether or not he or she is

able to perform the recommended coping response. Response costs consists of beliefs about how costly performing the recommended response would be to an individual (Boer & Seydel, 1996; Floyd et al., 2000; Helmes, 2002; Maddux & Rogers, 1983; Milne et al., 2002; Milne et al., 2000; Milne & Orbell, 2000; Prentice-Dunn et al., 2001; Rippetoe & Rogers, 1987; Rogers, 1975; Shelton & Rogers, 1981; Sturges & Rogers, 1996).

In summary, PMT proposes that an individual will adopt a protective behavior if he or she believes that the disease is severe and likely to occur and perceives the protective behavior to be effective in reducing the threat of the disease, carries a low cost, and is something they feel capable of doing. PMT can explain and predict the motivation to change health behavior (Boer & Seydel, 1996; Floyd et al., 2000; Helmes, 2002; Maddux & Rogers, 1983; Milne et al., 2002; Milne et al., 2000; Milne & Orbell, 2000; Prentice-Dunn et al., 2001; Rippetoe & Rogers, 1987; Rogers, 1975; Shelton & Rogers, 1981; Sturges & Rogers, 1996).

### *Summary of Research*

An extensive review of the literature and research on PMT indicates that it has been applied to a diverse array of topics, including areas of interest beyond health-related issues. PMT has been applied to injury prevention, environmental concerns, and protecting others. It also has been widely applied to health-related behaviors. In most of these studies, PMT has frequently been used as a framework for health education interventions designed to influence health behavior. According to PMT, for example, pamphlet content can mediate adaptive protective health behavior. The main fields of

application to date are reducing alcohol use, enhancing healthy lifestyles (e.g., promoting or increasing exercise, increasing the amount of calcium intake in the diet to prevent osteoporosis, and enhancing dental brushing and flossing), enhancing diagnostic health behaviors (e.g., the intention to perform breast self-examination and the use of diagnostic test to identify a fictitious disease), and preventing disease (e.g., enhancing the intention to use condoms to prevent getting infected with HIV and sexually transmitted diseases). The four central factors of PMT are well researched, and most studies found significant effects of the constructs of PMT on intention to adopt behavior(Boer & Seydel, 1996; Floyd et al., 2000; Helmes, 2002; Maddux & Rogers, 1983; Milne et al., 2002; Milne et al., 2000; Milne & Orbell, 2000, Prentice-Dunn et al., 2001; Rippetoe & Rogers, 1987; Rogers, 1975; Shelton & Rogers, 1981; Sturges & Rogers, 1996; Tanner et al., 1989).

### CHAPTER III

#### LITERATURE REVIEW

##### Barriers to Follow-up

Although barriers have been identified systematically as obstacles to obtaining screening mammograms and cancer treatment, few studies have examined barriers to follow-up of abnormal mammograms in the same manner, despite high rates of noncompliance. Most studies have either looked at the barriers to cancer screenings and cancer treatment or have measured the follow-up rates for women with abnormal cancer screening results. Some studies assume that inadequate follow-up or noncompliance with follow-up for abnormal mammograms have occurred infrequently or that the barriers to follow-up of abnormal mammograms have been identical to the barriers to cancer screenings and treatment (Barton et al., 2004; Bastani, Yabroff, Myers, & Glenn, 2004; Bedell, Wood, Lezotte, Sedlacek, & Orleans, 1995; Boohaker, Ward, Uman, & McCarthy, 1996; Burack, Simon, Stano, George, & Coombs 2000; Fillmore, Beekman, Johnson Farmer, & Gold, 2003; Heckman et al., 2004; Hislop et al., 2002; Jones et al., 2005; Juarbe et al., 2005; Kaplan, Crane, Stewart, & Juarez-Reyes, 2004; Karliner, Kaplan, Juarbe, Pasick, & Perez-Stable, 2005; Kerlikowske, 1996; Kerlikowske, Smith-Bindman, Ljung, & Grady, 2003; Kerner et al., 2003; McCarthy, Ulcickas Yood, Boohaker, et al., 1996; McCarthy, Ulcickas Yood, Janz, et al., 1996; Myers, Balshem, Wolf, Ross, & Millner, 1993; Myers et al., 1999; Poon et al., 2004; Rojas & Mandelblatt, 1996; Strzelczyk & Dignan, 2002; Thorne, Harris, Hislop, & Vestrup (1999); Yabroff et al., 2004; Yabroff, Washington, Leader, Neilson, & Mandelblatt,

2003).

The time involved in completing follow-up tests will be affected by a variety of conditions. Causes of untimely follow-up after abnormal mammography are largely unknown. There are three main types of delay that may contribute to untimely follow-up after an abnormal mammography: patient delay, provider delay, and system delay (Bastani et al., 2004; Bedell et al., 1995; Boohaker et al., 1996; Burack et al., 2000; Fillmore et al., 2003; Jones et al., 2005; Juarbe et al., 2005; Kaplan et al., 2004; Karliner et al., 2005; Kerlikowske, 1996; Kerlikowske et al., 2003; Kerner et al., 2003; McCarthy, Ulcickas Yood, Boohaker, et al., 1996; McCarthy, Ulcickas Yood, Janz, et al., 1996; Myers et al., 1993; Myers et al., 1999; Poon et al., 2004; Rojas & Mandelblatt, 1996; Strzelczyk & Dignan, 2002; Thorne et al., 1999; Yabroff et al., 2004; Yabroff et al., 2003).

#### *Patient Delay*

Patient delay occurs when patients' behaviors slow the follow-up process and include a prolonged decision-making period or refusal of further medical evaluation. Patient-induced delays may result from a fear of painful, invasive procedures (such as a biopsy), fear of losing a breast, fatalism, costs, inconvenient appointment hours, lack of knowledge of sources of care, history of infrequent or non-existent mammogram utilization, and worries about cancer. Other factors cited less often include long waits in the clinic, transportation or child-care problems, and loss of pay. Women also fail to complete follow-up after an abnormal mammogram because they feel too old for treatment, they feel that nothing is bothering them, they believe their physician has told

them that it is unnecessary, they have a low perceived risk of breast cancer, or they do not want to know if something is wrong (Bastani et al., 2004; Bedell et al., 1995; Boohaker et al., 1996; Burack et al., 2000; Fillmore et al., 2003; Guidry, Matthews-Juarez, & Copeland, 2002; Kaplan et al., 2004; Karliner et al., 2005; Kerlikowske, 1996; Kerner et al., 2003; McCarthy, Ulcickas Yood, Boohaker, et al., 1996; McCarthy, Ulcickas Yood, Janz, et al., 1996; Rojas & Mandelblatt, 1996; Yabroff et al., 2004; Yabroff et al., 2003).

McCarthy, Ulcickas Yood, Boohaker, et al. (1996) and McCarthy, Ulcickas Yood, Janz, et al. (1996) found that factors associated with inadequate follow-up included no history of a mammogram prior to the initial screening mammogram and low socioeconomic status (SES). These results are consistent with those of previous studies, which found low income to be associated with not keeping scheduled appointments even when cost was removed as a barrier. However, Kerner et al. (2003) found no association between SES variables and timely resolutions of an abnormal breast finding. In addition, McCarthy, Ulcickas Yood, Boohaker et al (1996) found that although most women apparently were notified of their results, many women with inadequate follow-up may not understand that they need further evaluation and the importance of this evaluation. Karliner et al. (2005) found that while 70% of their sample reported full understanding of their physician's explanation of their mammogram, 30 % reported less than full understanding, and there were some differences by ethnicity and language. Women interviewed in a language other than English were less likely to report full understanding of their physicians' explanation of their mammogram, with Asian women



being least likely to report full understanding. Among the women with the most suspicious results, nearly half of these women did not understand that their mammogram was abnormal. Kaplan et al. (2004) reported that women who are not clear about where to go to receive follow-up care may feel discouraged and may not invest the additional time needed to find out where to receive the appropriate care. This problem may be compounded in larger facilities, where communication may falter because of a larger patient population. Additionally, follow-up instructions can be confusing if care must take place at different sites within the hospital that are unfamiliar to the patients. This is especially a concern for low-income and ethnic minorities, who may be at greater risk of getting lost in the system.

A number of studies have found that women who receive abnormal screening results, including false-positive mammograms, experience a variety of emotions, including distress and anxiety. In theory, the resolution of abnormal results should relieve these emotional states. Many studies have documented an increase in anxiety among women with false-positive mammograms, with this anxiety lasting from less than one month to as long as three years after the screening mammogram. Barton et al. (2004) found that three weeks after their mammograms, nearly 50% of the women who had false-positive mammograms reported having symptoms of anxiety about their mammograms, compared with 28% of women with normal mammograms. Even three months after the mammogram, 28% of women with false-positive mammograms reported anxiety related to their mammogram. Hass, Cook, Puopolo, Burstin, and Brennan (2000) found that substantial anxiety remains over an eight-month period for

many women who receive an abnormal mammogram result. Heckman et al. (2004) found that women who were recalled for additional testing after receiving a suspicious mammogram reported significantly more breast pain, reduced sexual sensitivity, and elevated levels of anxiety, and women who received an abnormal screening mammogram but were later identified as being cancer-free engaged in significantly more breast and non-breast related medical visits than did women whose initial breast screening results were normal. The consistency of this finding across many settings indicates the need for strategies to reduce the anxiety associated with abnormal mammogram results (Bastani et al., 2004; Burack et al., 2000; Hislop et al., 2002; Kaplan et al., 2004; Karliner et al., 2005; Kerner et al., 2003; Thorne et al., 1999; Yabroff et al., 2004; Yabroff et al., 2003).

Although follow-up after an abnormal mammogram has not been extensively examined, most of these studies have looked at patient delays. Few studies, however, have examined delays associated with health care provider and system-level health care delivery.

#### *Provider Delay*

Provider delays or delays that were attributed to the physician or other health care providers include misdiagnosis when cancer symptoms are ignored or when a suspect finding is not followed-up. Boohaker et al. (1996) asserted that physician forgetfulness, belief that the abnormal findings were trivial, and the anticipation that the patient was expected in the clinic anyway have also been cited as being related to the lack of appropriate follow-up by physicians. Additionally, Myers et al. (1999) found

that provider-related factors, such as years of experience, the belief that complete diagnostic evaluation is efficacious, and the perception that complete diagnostic evaluation is part of standard practice were associated with intention to complete diagnostic evaluation for abnormal colorectal findings (Bastani et al., 2004; Bedell et al., 1995; Jones et al., 2005).

### *System Delay*

Bedell et al. (1995) found that system delays or delays resulting from routine system practices at a facility, included general scheduling delays or time spent waiting for a physician and follow-up (diagnostic and/or surgery) appointments, postponement or cancellation of procedures, tests or appointments, delay in the reporting of test results or examination results to the provider, and unavailable or lost records that extended the follow-up time for the patient. McCarthy, Ulcickas Yood, Janz et al. (1996) reported that females who reported getting medical appointments was very or moderately difficult were four times more likely to have inadequate follow-up (Bastani et al., 2004; Jones et al., 2005; McCarthy, Ulcickas Yood, Boohaker, et al., 1996).

It is interesting that the few studies that look at system- and provider-related delays in conjunction with patient delays have cited provider and system delays to be the most common delays. Bedell et al. (1995) found that nearly half of the delay in follow-up resulted from system factors, such as general scheduling delays or times spent waiting for appointments and follow-up procedures to be scheduled and completed, waiting for reports of results, and waiting for retrieval of lost or missing records. Misdiagnosis was the most common reason for provider delay in follow-up.

Several studies have suggested that nonwhite women may experience delayed resolution of an abnormal mammogram result. Chang et al. (1996) and McCarthy, Ulcickas Yood, Boohaker, et al. (1996) both reported possible differences in receipt of follow-up between racial/ethnic groups. In a study conducted by Jones et al. (2005), over 28% of women who received abnormal or inconclusive results following a screening mammogram did not receive the recommended follow-up. Several factors influenced whether or not a woman received adequate follow-up of an abnormal mammogram, including race/ethnicity. Forty percent of African American women and 18% of White women did not receive the recommended follow-up. Kaplan et al. (2004) found that almost 9% of Latinas attending public health facilities did not receive any type of follow-up care. Haas et al. (2000) did not demonstrate a difference in timeliness of care by race. However, African American women in the Haas study were less satisfied with their care. These results suggest that this dissatisfaction may create barriers for future care. Ethnic disparities in survival that may be attributed to late-stage diagnosis suggest that management recommendations and social and cultural factors during screening follow-up procedures may affect outcomes (Juarbe et al., 2005; Karliner et al., 2005; Kerlikowske, 1996; Kerlikowske et al., 2003; Kerner et al., 2003; Rojas & Mandelblatt, 1996; Strzelczyk & Dignan, 2002; Yabroff et al., 2004; Yabroff et al., 2003).

### *Cancer Fatalism*

A dearth of research exists in the area of cancer fatalism. The difficulty experienced while investigating this area is that similarly related concepts such as

pessimism, powerlessness and helplessness have been used interchangeably with fatalism. Although these perceptions are inherent in fatalism, cancer fatalism is “the belief that death is inevitable when cancer is present”, (Powe, Daniels, & Finnie 2005, p. 318) and has been identified as a barrier to cancer screening, detection, and treatment, and can be viewed as a situational manifestation of fatalism in which the individual becomes entrapped in a cycle of late cancer diagnosis, limited treatment options and ultimately death. Powe & Finnie (2003) state that cancer fatalism is most prevalent among African Americans, females, older people and people with low incomes and low educational levels (Powe, 1996; Powe & Weinrich, 1999; Powe & Finnie, 2003; Powe, Daniels, & Finnie, 2005).

#### Factors that Influence Compliance

Patients who have reported being told that they need follow-up for their abnormal mammogram results and who understand the follow-up plan were more likely to complete appropriate follow-up in a timely manner. Patients who have reported asking questions during the initial screening examination and patients who reported being told by staff what would happen next if they had an abnormal result were more likely to complete follow-up in a timely manner. Type of follow-up procedure recommended was significantly associated with receipt and adequacy of care. For example, women who were referred for a follow-up clinical breast exam had lower odds of returning for care, and women referred for a six-month follow-up mammogram had lower odds of returning for follow-up care. These women may have perceived such recommendations as indicative of a less serious abnormality and may have

underestimated the importance of returning for and completing their follow-up. Hass et al. (2000) found that women received a more timely evaluation for their breast problems if they were older, belonged to a managed care plan, or had a more significant radiographic abnormality. Kaplan et al. (2004) found that a small patient population, a patient's comfort with staff, a patient's familiarity with the facility, and greater proximity of the different departments involved in follow-up care may all contribute to improved patient follow-up (Bastani et al., 2004; Bedell et al., 1995; Boohaker et al., 1996; Burack et al., 2000; Fillmore et al., 2003; Hislop et al., 2002; Jones et al., 2005; Juarbe et al., 2005; Karliner et al., 2005; Kerlikowske, 1996; Kerlikowske et al., 2003; Kerner et al., 2003; McCarthy, Ulcickas Yood, Boohaker, et al., 1996; McCarthy, Ulcickas Yood, Janz, et al., 1996; Poon et al., 2004; Rojas & Mandelblatt, 1996; Yabroff et al., 2004; Yabroff et al., 2003).

## CHAPTER IV

### METHODOLOGY

The purpose of this chapter is to describe how the research was conducted, including the study design and methods, setting and sample selection, protection of human subjects, procedures, operational definitions of concepts, measurements, and data analysis methods.

#### Design

A non-experimental, descriptive, cross-sectional design was used to identify the barriers to follow-up after an abnormal mammogram by 1) estimating the noncompliance rate of follow-up mammograms among women screened at an urban hospital's mammography mobile unit in North Texas (October 1, 2004, to September 31, 2005) who were found to need further evaluation for suspected abnormal findings; and 2) identifying factors associated with noncompliance and perceived barriers to noncompliance (see Figure 1).

#### Setting

The urban hospital and six satellite clinics offer preventive medical services that include adult medicine, pediatrics, family planning, basic x-rays, lab work, dental services for children, and psychosocial services. Moreover, the hospital provides screening mammograms to women aged 40 years and older at the six clinics.

The mammography mobile unit has a regular schedule to visit five of the clinics. The frequency of the mobile unit visits to the clinics depends on the size of the clinic, the percentage of female patients aged 40 years and older, and the number of women

referred for a mammogram. The sixth clinic has a stationary mammography unit, which is used for patients at that clinic and patients from the five other clinics who cannot climb the stairs of the mobile unit. At each of the clinics, women are referred for a mammogram by their health care provider. They are given an appointment and are called the day before the appointment as a reminder. During fiscal year 2004/2005, the mammography mobile unit provided over 3,300 screening mammograms to clinic patients. Care is provided regardless of the ability to pay. Although other patients are treated in the hospital, clinics, and research programs, the poor and near poor are the target populations for the institution. The outpatient population is an ethnically diverse group.

At the screening mammogram, each patient completes a breast cancer assessment, which consists of demographics, family history of breast cancer, and history of breast cancer screenings (Appendix A). Mammography Mobile Unit staff also teach mammogram patients individually or in a group how to perform breast self-exam by showing an American Cancer Society breast self-exam video. They also discuss with patients when and how they will receive their results, what to do if their mammogram is abnormal, and what additional tests would need to be performed to determine whether it is breast cancer.

### Sample

Because prior research was conducted on primarily Caucasian populations, this study was directed at indigent populations that are primarily minority. The population



from which the sample was drawn consists of all women screened at a mammography mobile unit at five clinics during fiscal year 2004/2005 (October 1, 2004, to September 31, 2005) who were found to need further evaluation for suspected abnormal findings. During fiscal year 2004/2005, the mammography mobile unit performed 3,336 mammograms; 524 of the mammograms were found to be abnormal. Of the 3,336 women who received a mammogram 49% were African American, 35% were Hispanic, 10% were White, 5% were Asian, and less than 1% were Native American (see Table 2). Of the 524 women who had mammograms found to be abnormal, 47% were African American, 32% were Hispanic, 15% were White, 2% were Asian, and 1% was Native American (see Table 3). All female patients who had a screening mammogram during fiscal year 2004/2005 that produced abnormal results and who were referred for further diagnostic follow-up procedures or treatment were recruited for the proposed study.

**Table 2.**  
**Screening Mammograms by Race**  
**2004/2005 Mammography Mobile Unit**

Race	Number	Percent
African American	1635	49%
Hispanic	1178	35%
White	346	10%
Asian	171	5%
Unknown	5	<1%
Native American	1	<1%
Total	3336	100%

**Table 3.**  
**Abnormal Mammograms by Race**  
**2004/2005 Mammography Mobile Unit**

Race	Number	Percent
African American	246	47%
Hispanic	169	32%
White	77	15%
Asian	23	4%
Native American	7	1%
Unknown	2	<1%
Total	524	100%

### Sample Exclusions

Women were excluded from the study if there was evidence of a previous diagnosis of breast cancer, previous surgical procedure, or previous follow-up procedure, such as a fine-needle aspiration, from an abnormal mammogram. Asian and Native American races were excluded from the study because of the small numbers of abnormal mammograms during the specified time (Asian—23 abnormal mammograms; Native Americans—seven abnormal mammograms).

### Protection of Human Subjects

The study was approved by the Institutional Review Boards at Parkland Health and Hospital System, University of Texas Southwestern Medical School, and Texas A&M University (Appendix B). The initial contact with the study subjects was through a study introduction letter from a health care provider. The study subject was given a brief description of the study (general purpose, subject criteria, subject payment, and assurance of confidentiality) and was asked to return a signed Health Insurance Portability and Accountability Act (HIPAA) form in an enclosed stamped envelope. After a signed HIPAA was obtained, trained interviewers telephoned and attained verbal consent to interview subjects. In the telephone script that interviewers read, subjects were told that their participation in the study was voluntary and were given again a brief description of the study. Subjects were informed that they could withdraw from the study at any time, and were assigned a code before the interviewer began the telephone interview. Subjects were informed that their name and other identifying information would not remain on the questionnaire and that results would remain with the researcher

in a secure location. Subjects were also informed that only the investigator and research coordinator would have access to the subjects' identification codes, which would be destroyed upon completion of the study.

### Procedure

A medical provider practicing at the clinics initiated recruitment. He sent 393 letters to women screened at the mammogram mobile unit at the clinics during fiscal year 2004/2005 (October 1, 2004, to September 31, 2005). The letter provided information about the study and asked the women to return a signed HIPAA authorization. Trained interviewers called women who returned the signed HIPAA form and read the telephone script that asked if the women would consent to a telephone interview. If the women consented to the telephone interview, the interviewer proceeded with the study questions (Appendix C). Participants were informed that the general nature of the study was to investigate "things women can do to stay healthy". All participants were told that their participation was completely voluntary and that any information gathered would remain strictly confidential. They were also made aware of their freedom to withdraw from the study at any time. All participants were sent a \$10.00 phone card upon completion of the questionnaire.

The urban hospital required that members of their staff serve as interviewers and provided some recommendations. Eight African American and Hispanic clinic staff members were selected. Seven interviewers were bilingual. They were paid a stipend. Interviewers attended two four-hour trainings prior to conducting the interviews. During the first training, the principle investigator and research coordinator presented the nature

and purpose of the study, discussed the total survey process and the role of the interviewer, and reviewed the questionnaire. The principal investigator read each question, identifying the type of question, how to record the answer, and how and when to probe for answers, stressing the importance of following the survey process (Aday, 1996; Fowler, 1995). Interviewers practiced reading the telephone script and administering the questionnaire to each other. Interviewers were encouraged to read and study the telephone script and questionnaire and were asked to practice with a friend or family member during the week. During the second training, interviewers posed problems and questions they had encountered while practicing. Also, interviewers practiced while the principle investigator and research coordinator listened. Although many of the interviewers had prior experience conducting telephone interviews, they were pleased that this study provided extensive training for them.

#### Operational Definition of Concepts

The data on **abnormal mammograms** during fiscal year 2004/2005 was provided by the hospital. The hospital provided demographic information of women who received an abnormal mammogram.

The data on **follow-up** of abnormal mammograms for fiscal year 2004/2005 was provided by the hospital. The hospital provided the names of women who received follow-up and the names of women who did not receive follow-up.

#### Measurement

A 54-question questionnaire in both English and Spanish was used in this study (Appendix D).

### *Demographic Questions*

Five questions were asked to gather demographic data about age, level of education, marital status, work status, and income. All questions except for one regarding income were adapted from the Behavioral Risk Factor Surveillance Survey 2005 (CDC, 2005). The Center for Disease Control, Behavioral Risk Factor Surveillance System (BRFSS) is the primary source of information on major health risk behaviors among Americans. States use standard procedures to collect data through a series of monthly telephone interviews with U.S. adults. Nationwide, the BRFSS collects data on risk behaviors in 24 categories, including demographics, health care access, health care utilization and women's health. After panel review the question about income was adapted from Bloom, Hayes, Saunders and Hodge, 1989 because that question was clearer (Table 4).

### *Factors that Influence Follow-up Questions*

Several questions in the survey were developed by the investigator from factors identified in the literature as barriers to follow-up after an abnormal mammogram. Factors include, but are not limited to, the participant's belief that the mammogram was normal and so no further follow-up was necessary, financial concerns/cost, inconvenient clinic hours, cancellation of follow-up appointments, long waits at the clinic, transportation difficulties, childcare issues, and loss of wages. The purpose was to determine whether those factors would also be considered barriers in this population (Table 4).

**Table 4.**  
**Instrument Variables by Question Numbers**

Variable	Questions
Demographics	Question # 50, 51, 52, 53, 54
Health Status	Question # 1
Regular source of care	Question # 2, 3
Insurance	Question # 4
Barriers to f/u	
Costs	Question # 5, 6, 12, 13
Transportation	Question # 7
Other Barriers	Question # 23a, b, c, d, e, f, g, h, I, j, k, l, m
Prior mammogram	Question # 8, 9, 10
Mammogram recommended	Question # 11
Reason for mammogram	Question # 14
Mammogram results	Question # 15, 16, 18, 18a
Received f/u appointment	Question # 17
Understand results	Question # 19
Further evaluation f/u	Question # 20, 21
Diagnosed w/ cancer	Question # 22
Noncancerous surgery	Question # 24, 25
Family history	Question # 26
Clinical breast exam	Question # 27, 28
Breast Self Exam	Question # 29, 30
Protection Motivation Theory concepts	
Severity	Question # 31, 34, 47
Vulnerability	Question # 32, 33, 35, 38,
Response Efficacy	Question # 36, 41, 43, 45
Self-Efficacy	Question # 40, 44, 48, 49
Rational Problem-Solving	Question # 39,
Fatalism	Question # 37, 42, 46

*Protection Motivation Questions*

A 20-question section adapted from Rippetoe's (1985) research was used to test the participant's perceived vulnerability to breast cancer, perceived severity of breast cancer, perceived response efficacy of mammography and follow-up exams to make a difference in her health, and perceived self-efficacy to determine if she can do what is

necessary to complete the recommendation. The items were measured on a Likert scale with responses ranging from strongly disagree (1) to strongly agree (5) (Table 4).

The questionnaire was translated into Spanish and back-translated into English by the hospital translators.

The instrument was examined by a panel of experts - a researcher, statistician, health educator, social worker and nurse, all university faculty members. Two focus groups – one English and one Spanish – with seven women in each group examined the questionnaire for content validity and to evaluate the vocabulary of the questionnaire. It was then revised based on feedback from the experts and focus group participants (Aday, 1996; Fowler, 1995). Focus group participants were either members of a breast cancer survivor group or had been screened at the hospital's mammogram mobile unit. Additionally, the instrument was pretested as a telephone survey with 20 women who had been screened at the mammogram mobile unit to identify the time needed to complete an eight-page questionnaire and to identify possible problems associated with questions asked by telephone.

The results from the focus groups indicated a need for participants to provide answers to sociodemographic data (i.e., age) rather than having to choose an answer from one of the prepared options. Questions were also reworded for easier comprehension. The results of the pretest indicated that the questions need to be asked slowly and clearly for participants to be able to understand and answer. In addition, when reading statements that were measured on a Likert scale, interviewers needed to repeat possible Likert scale answers after each statement. The time needed to complete



the questionnaire ranged from 15-20 minutes. The women included in the pretest and focus groups were homogenous in age range, income, and educational level.

### Data Analysis

The measures of outcome in this study are follow-up and no follow-up after an abnormal mammogram, and the predictors of each of these dependent variables. The data on follow-up was provided by the hospital.

Independent variables, or variables that are associated with the outcome, include demographic variables such as age and race, mammogram utilization, health insurance coverage, regular source of health care, and coping appraisal (response efficacy, self efficacy) and threat appraisal constructs (perceived vulnerability, perceived severity, fear arousal/fatalism). Additional independent variables include factors found in the literature to influence follow-up such as difficulty getting appointments, difficulty getting time off from work for medical appointments, difficulty finding transportation, and waiting a long time for medical appointments.

## CHAPTER IV

### RESULTS

#### Data Analysis

Each completed questionnaire was coded with an identification number, and a log of the questionnaires was kept. Data entry began as questionnaires were completed. All data was entered by the investigator using SPSS version 13. All data were checked and cleaned by the investigator. Exploratory analyses were conducted to determine the frequency of missing data. With the exception of the variable income which had about 14% missing data other variables had only 2% missing data.

#### Description of Sample

As planned, subjects were recruited from the population of women screened at an urban hospital's mammogram mobile unit at five satellite clinics during fiscal year 2004/2005 (October 1, 2004, to September 31, 2005) who were found to need further evaluation for suspected abnormal findings. On May 15, 2006, a medical provider practicing at the clinics, sent 393 letters to the subjects. The letter provided information about the study and asked the women to return a signed Health Insurance Portability and Accountability Act (HIPAA) authorization, giving permission for contact, in an enclosed addressed and stamped envelope. Twenty-one letters were returned due to wrong address and unable to forward. One hundred and fifty-six women returned their signed HIPAA forms. On June 13, 2006 a second letter with HIPAA form was sent to the remaining 216 women. One hundred and fifteen women returned their signed HIPAA forms. Data collection began on July 10, 2006, and was completed on August 11, 2006.

Four subjects declined to participate in the survey. Reasons given included: (1) “did not want to take the time to complete the interview”; (2) “too tired to complete the interview”; (3) “under too much stress, and did not want to talk now”; and (4) “did not want the hospital to review her medical records”. Two subjects began the interview and subsequently refused to complete the survey. One subject said that she was tired of the questionnaire and wanted to stop, and the other said that the interviewer asked too many questions. Three study subjects were not interviewed because interviewers could not contact them. Full data analysis is reported for a final sample size of 262.

#### Demographic Characteristics of Sample

Table 5 displays the frequency and percentage distribution of the demographic characteristics of the women in the sample. The sample consisted of 262 participants, 136 (52%) women who the hospital reported had not returned for follow-up and 126 (48%) women who were reported to have returned. The ages of the women in the sample ranged from 36 to 83 years, with a mean age of 55 and a median age of 54 (SD=9.949). Fifty percent of participants were African American, while 38% were Hispanic, and 12% were White. Thirty percent of the participants preferred to be interviewed in Spanish. Thirty percent of the participants were married, while 22% were divorced, 20% were widowed, 12% were separated, 13% reported being single, and 2% stated that they were a member of an unmarried couple and 1% refused to answer the question. Forty-seven percent of participants stated that their household income was less than \$10,000.00, and 82% of respondents stated that their income was less than \$30,000.00. Sixteen women stated that their husbands or family members handled all

**Table 5.**  
**Demographic Characteristics of Sample**

Characteristic	Frequency	Percentage	Cumulative Percentage
<u>Follow –up</u>			
Received follow-up	126	48.1	48.1
Did not receive follow-up	136	51.9	100.0
<u>Race</u>			
White	31	11.8	11.8
African American	132	50.4	62.2
Hispanic	99	37.8	100.0
<u>Language</u>			
English	184	70.2	70.2
Spanish	78	29.8	100.0
<u>Marital Status</u>			
Married	79	30.2	30.2
Divorced	57	21.8	51.9
Widowed	52	19.8	71.8
Separated	32	12.2	84.0
Never been married (Single)	33	12.6	96.6
A member of an unmarried couple	5	1.9	98.5
Refused to answer	4	1.5	100.0
<u>Income</u>			
Less than \$5,000	57	21.8	21.8
\$5,000 to \$9,999	65	24.8	46.6
\$10,000 to \$19,999	65	24.8	71.4
\$20,000 to \$29,999	27	10.3	81.7
\$30,000 to \$39,999	10	3.8	85.5
\$50,000 and over	1	.4	85.9
Don't know	16	6.1	92
Refused to answer	21	8.0	100.0
<u>Employment</u>			
Employed for wages	73	27.9	27.9
Self-employed	14	5.3	33.2
Out of work for more than 1 year	59	22.5	55.7
Out of work for less than 1 year	11	4.2	59.9
Homemaker	51	19.5	79.4
Student	2	.8	80.2
Retired	47	17.9	98.1
Refused to answer	5	1.9	100.0

**Table 5.**  
**Continued**

Characteristic	Frequency	Percentage	Cumulative Percentage
<u>Education</u>			
Never attended school or kindergarten only	7	2.7	2.7
Grades 1 through 8 (Elementary)	62	23.7	26.3
Grades 9 through 11 (Some high school)	54	20.6	46.9
Grades 12 or GED (High school graduate)	82	31.3	78.2
College 1 year to 3 years (Some college or Technical school)	36	13.7	92.0
College 4 years or more (College graduate)	15	5.7	97.7
Refused to answer	6	2.3	100.0
<u>Age</u>	Mean age 55 Median age 54 Standard deviation 9.949 Minimum age 36 Maximum age 83		

financial matters and that they were unaware of their total household income. Thirty-three percent of respondents were employed, while 27% were unemployed, 20% were homemakers, and 18% were retired. Only 6% of respondents graduated from college, 14% had some college, 31% graduated from high school or obtained a GED, and 21% had some high school education. Twenty-six percent of respondents had less than an eighth-grade education.

### Collinearity

Twenty statements adapted from Rippetoe's (1985) research and used to test the participants' protection motivation were determined to be part of either the coping appraisal or threat appraisal constructs (Table 6). "Collinearity involves the relationship of the independent variables (predictors) to one another" (Kleinbaum, Kupper, Muller, & Nizam 1998, p.237). The statements were then examined for collinearity (Table 7), and variables with high collinearity (Questions 36, 40, 44, and 45) were deleted (Table 8). The remaining variables were used in further analysis. There were no variables with very high collinearity in the Threat Appraisal variables; therefore, no variables were deleted (Table 9).

**Table 6.**  
**Protection Motivation Statements by Construct**

**Coping Appraisal**

*Response Efficacy*

36. Having regular mammograms is the best, most effective method of detecting breast cancer early.

41. Having a yearly mammogram will not drastically improve my chances of surviving breast cancer.

43. If I get regular mammograms, my chances of detecting breast cancer are extremely high.

45. If I have an abnormal mammogram, I believe that the cancer will be detected early and I will survive.

*Self-efficacy*

40. If I have an abnormal mammogram, I can go to the follow-up exams.

44. If I have an abnormal mammogram, I believe I can get all the follow-up exams.

48. Other women are more capable of going to follow-up appointments than I am.

49. Going to follow-up exams are easy to do.

**Threat Appraisal**

*Perceived vulnerability*

32. There is a good probability that cancer may now be developing in my breast.

33. I am more vulnerable to breast cancer than anyone else.

35. My chances of developing breast cancer are small.

38. I am currently at risk for developing breast cancer.

*Perceived severity*

31. In spite of advances in modern medicine, breast cancer is as serious and dangerous a disease as it was several years ago.

34. The majority of women who develop breast cancer have serious emotional as well as physical side-effects.

47. Even with advanced medical procedures, the best treatment for cancer involves radical surgical techniques.

*Fatalism*

37. There are so many ways to get cancer today, it's just a matter of time; I might as well just try and accept it.

42. Only time will tell if I develop breast cancer; nothing can be done anyway but wait.

46. If you are destined to die of breast cancer, you will; there is really little you can do about it.

**Table 7.**  
**Correlation of Coping Appraisal Variables**

Coping Appraisal Statements	Q 36 Mammogram most effective method (RE)	Q 40 I can go to f/u exams (SE)	Q41 Mammogram will not improve survival (RE)	Q43 Chances of detecting BrCa is high (RE)	Q44 I believe I can get f/u exams (SE)	Q 45 Cancer will be detected early (RE)	Q48 Others more capable of getting f/u (SE)	Q49 F/u is easy (SE)
Q 36 Mammogram most effective method (RE)	1							
Q 40 I can go to f/u exams (SE)	.759(**)	1						
Q41 Mammogram will not improve survival (RE)	.197(**)	.401(**)	1					
Q43 Chances of detecting BrCa is high (RE)	.574(**)	.382(**)	.075	1				
Q44 I believe I can get f/u exams (SE)	.706(**)	.901(**)	.320(**)	.411(**)	1			
Q 45 Cancer will be detected early (RE)	.708(**)	.585(**)	.158(*)	.646(**)	.605(**)	1		
Q48 Others more capable of getting f/u (SE)	-.358(**)	-.177(**)	.009	-.233(**)	-.270(**)	-.354(**)	1	
Q49 F/u is easy (SE)	.752(**)	.956(**)	.380(**)	.422(**)	.917(**)	.622(**)	-.171(**)	1

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).



**Table 8.**  
**Correlation of Coping Appraisal after Reduction**

Coping Appraisal Statements	Q41 Mammogram will not improve survival (RE)	Q43 Chances of detecting BrCa is high (RE)	Q48 Others more capable of getting f/u (SE)	Q49 F/u is easy (SE)
Q 36 Mammogram most effective method (RE)				
Q 40 I can go to f/u exams (SE)				
Q41 Mammogram will not improve survival (RE)	1			
Q43 Chances of detecting BrCa is high (RE)	.382(**)	1		
Q44 I believe I can get f/u exams (SE)	.320(**)	.411(**)		
Q 45 Cancer will be detected early (RE)	.158(**)	.646(**)		
Q48 Others more capable of getting f/u (SE)	.009	-.233(**)	1	
Q49 F/u is easy (SE)	.380(**)	.422(**)	-.171(**)	1

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

**Table 9.**  
**Correlation of Threat Appraisal**

Threat Appraisal Statements	Q 31 BrCa serious disease (S)	Q32 Ca now developing in breast (V)	Q 33 Vulnerable to BrCa (V)	Q34 Serious emotional side effects (S)	Q35 Chances of getting BrCa small (V)
Q 31 BrCa serious disease (S)	1				
Q32 Ca now developing in breast (V)	.404(**)	1			
Q 33 Vulnerable to BrCa (V)	.451(**)	.585(**)	1		
Q34 Serious emotional side effects (S)	.615(**)	.433(**)	.465(**)	1	
Q35 Chances of getting BrCa small (V)	-.425(**)	-.474(**)	-.611(**)	-.440(**)	1

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

**Table 9.**  
**Continued**

Threat Appraisal Statements	Q37 Accept breast cancer (F)	Q38 At risk for developing BrCa (V)	Q42 Time will tell if I get BrCa (F)	Q46 Little you can do about BrCa (F)	Q 47 Best treatment – radical surgery (S)
Q37 Accept breast cancer (F)	1				
Q38 At risk for developing BrCa (V)	.486(**)	1			
Q42 Time will tell if I get BrCa (F)	.855(**)	.500(**)	1		
Q46 Little you can do about BrCa (F)	.862(**)	.534(**)	.892(**)	1	
Q 47 Best treatment – radical surgery (S)	.414(**)	.472(**)	.519(**)	.514(**)	1

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

### Instrumentation

Internal consistency reliability “measures the extent to which performance of any one item on an instrument is a good indicator of performance on any other item in the same instrument” (Waltz, Strickland, & Lenz, 1991, p. 166). Cronbach’s coefficient

alpha was computed to determine the internal consistency of the 20-question section adapted from Rippetoe's (1985) research that was used to test a participant's protection motivation. The resulting alpha coefficients were: Coping Appraisal = .76 and Threat Appraisal = .70 (Tables 10 and 11). The resulting alpha coefficients for each construct were: Severity = .84, Vulnerability = .31, Response Efficacy = .57, Self-Efficacy = .68, and Fatalism = .95 (Table 12). These results were somewhat consistent with Rippetoe's (1985) results that determine the alpha coefficients: "Severity = .78, Vulnerability = .67, Response Efficacy = .86, Self-Efficacy = .78, and Fatalism = .66" (Rippetoe, 1985, p. 50). In addition, these results indicate that the measures were satisfactory.

**Table 10.**  
**Reliability Statistics for Coping Appraisal**

Cronbach's Alpha	N of Items
.762	11

**Table 11.**  
**Reliability Statistics for Threat Appraisal**

Cronbach's Alpha	N of Items
.703	8

**Table 12.**  
**Reliability Statistics for Severity, Vulnerability, Response Efficacy, Self-Efficacy**  
**and Fatalism**

Construct	Cronbach's Alpha	N of Items
Severity	.844	3
Vulnerability	.305	4
Response Efficacy	.567	4
Self-Efficacy	.678	4
Fatalism	.952	3

#### T-test and ANOVA Comparisons

Women who obtained follow-up were compared to those who did not obtain follow-up. Analysis using *t*-tests were performed on the following variables: age, education, income, health status, time since last mammogram, and number of mammograms in last five years (Table 13). Subjects were similar in their report of these variables. Analyses using ANOVA were conducted on the following variables: marital status, obtaining clinical breast exam, and race (Table 14). There were no significant differences between women who obtained follow-up and those who did not obtain follow-up.

**Table 13.**  
**T-tests to Determine Differences between the Two Groups of Women (Follow-Up**  
**and No Follow-Up)**

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	T	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Age	Follow-Up	1.649	.200	-.318	260	.750	-.393	1.232	-2.819	2.034
	No Follow-Up			-.317	253.314	.751	-.393	1.236	-2.828	2.043
Education	Follow-Up	.653	.420	.393	254	.695	.061	.155	-.245	.367
	No Follow-Up			.393	253.054	.694	.061	.155	-.245	.367
Income	Follow-Up	.804	.371	-.2421	223	.016	-.373	.154	-.676	-.069
	No Follow-Up			-.2441	222.610	.015	-.373	.153	-.673	-.072
Health status	Follow-Up	.024	.877	-.272	260	.786	-.027	.100	-.223	.169
	No Follow-Up			-.272	259.217	.786	-.027	.100	-.223	.169
Time since last mamm	Follow-Up	.006	.938	-.095	260	.925	-.089	.941	-1.941	1.763
	No Follow-Up			-.095	256.589	.925	-.089	.942	-1.944	1.766
How many mamm in 5 yrs	Follow-Up	.062	.803	-.1379	260	.169	-.266	.193	-.645	.114
	No Follow-up			-.1380	259.265	.169	-.266	.192	-.645	.113

**Table 14.**  
**ANOVA Tests to Determine Differences between the Two Groups of Women**  
**(Follow-Up and No Follow-Up)**

		Sum of Squares	Df	Mean Square	F	Sig.
Race	Between Groups	.606	1	.606	1.411	.236
	Within Groups	111.745	260	.430		
	Total	112.351	261			
Marital Status	Between Groups	.000	1	.000	.000	.998
	Within Groups	541.674	256	2.116		
	Total	541.674	257			
CBE	Between Groups	.038	1	.038	.302	.583
	Within Groups	32.527	260	.125		
	Total	32.565	261			

#### Logistic Regression Model

A logistic regression model was performed using follow-up as the dependent variable. Independent variables used in the model included demographic variables such as, race, age, education, marital status, employment, income, health status, mammogram utilization, health insurance coverage, and regular source of health care. Other variables found in the literature that influence follow-up were included in the model, such as difficulty getting appointments, difficulty getting time off of work for medical appointments, difficulty finding transportation, and waiting a long time for medical appointments. Constructs for Protection Motivation Theory were utilized to determine if perceived vulnerability, perceived severity, fatalism, response efficacy, and self-efficacy were associated with the outcome variable follow-up.

Table 15 summarizes the outcome of the model. The variables most related to

follow-up were (1) number of mammogram in the last 5 years (OR=8.795); (2) having health insurance (OR=5.941); (3) having problems receiving abnormal mammogram results (OR=3.852); (4) having problems receiving or making a follow-up appointment (OR=7.739); (5) taking off from work for the follow-up appointment (OR=4.105); (6) not having transportation to follow-up appointment (OR=4.171); and (7) waiting a long time to receive the follow-up appointment (OR=6.454).

Protection Motivation Theory constructs listed in Table 6 had no statistically significant association with the outcome variable follow-up.



**Table 15.**  
**Logistic Regression**

Independent Variables	B	S.E	Odds Ratio	Sig.	95.0% C.I. for EXP(B)	
					Lower	Upper
Race	.339	.349	.943	.332	.708	2.782
Age	-.005	.022	.045	.831	.953	1.040
Education	-.138	.161	.731	.392	.635	1.195
Marital Status	.144	.130	1.211	.271	.894	1.491
Employment	-.188	.101	3.501	.061	.680	1.009
Income	.146	.182	.644	.422	.810	1.654
Health Status	.076	.225	.112	.737	.693	1.677
# of mammograms in last 5 years	.388	.131	8.795	.003	1.140	1.903
When last mammogram	.501	.258	3.784	.052	.996	2.735
Insurance	3.221	1.321	5.941	.015	1.880	334.020
Regular source of care	21.517	20658.580	.000	.999	.000	.
Problem receiving results	-1.619	.825	3.852	.050	.039	.998
Problem making/receiving f/u appointment	1.455	.523	7.739	.005	1.537	11.934
Hospital canceling f/u appt.	-42.138	35102.842	.000	.999	.000	.
Mammogram results lost	-.075	.904	.007	.934	.158	5.453
Hospital rescheduling f/u appt.	19.700	28405.932	.000	.999	.000	.
F/U appt. inconvenient	.155	1.025	.023	.880	.157	8.697
Take off work for f/u appt.	1.586	.783	4.105	.043	1.053	22.662
No transportation to f/u appt.	-1.478	.724	4.171	.041	.055	.942
Problem paying for exam	-.486	.585	.692	.406	.195	1.934
Receiving unexpected bill for f/u	-.303	1.877	.026	.872	.019	29.242
Insurance covering f/u	2.496	1.530	2.661	.103	.605	243.515
Waiting to receive the f/u appt.	-2.017	.794	6.454	.011	.028	.631
Waiting to be seen by dr. at f/u	1.363	.758	3.239	.072	.886	17.260
BrCa is a serious disease	.115	.279	.171	.680	.649	1.940
Cancer may be developing in Br	-.187	.361	.270	.604	.409	1.682
More vulnerable to BrCa	-.697	.519	1.800	.180	.180	1.379
Women BrCa serious side-effects	-.281	.368	.582	.446	.367	1.554
My chances of getting BrCa are small	.805	.444	3.283	.070	.936	5.339
Mamm. best way to detect BrCa	-.110	1.043	.011	.916	.116	6.919
Just a matter of time to get BrCa	.313	.578	.293	.588	.441	4.241
I am at risk for developing BrCa	.917	.584	2.460	.117	.795	7.864
Prospect of BrCa makes me get mamm.	2.081	1.590	1.712	.191	.355	180.849
I can go to the f/u exam	-2.764	2.571	1.156	.282	.000	9.732
Yearly mamm will not improve chances	.236	.330	.513	.474	.663	2.419
Time will tell if I develop BrCa	.307	.539	.324	.569	.472	3.910
Mamm detect BrCa high	.057	.758	.006	.940	.240	4.683
I can get all f/u exams	-.498	1.389	.129	.720	.040	9.236
Cancer will be detected early	.408	1.179	.120	.729	.149	15.156
Destined to die of BrCa	-.421	.513	.675	.411	.240	1.793
Best trmt. is radical surgical tech.	.051	.383	.018	.894	.496	2.231
Other women more capable of f/u	-1.298	.724	3.211	.073	.066	1.129
Going to f/u is easy to do	.804	2.016	.159	.690	.043	116.181
Constant	15.540	46130.535	.000	1.000		

## CHAPTER VI

### DISCUSSION, IMPLICATIONS, RECOMMENDATIONS, AND CONCLUSIONS

In this final chapter, a discussion about the process of conducting the research will precede an overview of the study's significant findings. These findings will be discussed in relation to existing research studies, variable relationships, and applicability of the theoretical model. Limitations of the study that may affect the validity or the generalizability of results will also be reviewed. Implications for health education practice will be addressed, followed by recommendations for future research and conclusions.

#### Conducting the Research

The implementation of this telephone survey was feasible and did not place undue burden on subjects. Two hundred seventy-one women returned their Health Insurance Portability and Accountability Act (HIPAA) forms. There was no excess burden on interviewers conducting the telephone interviews. Staff indicated that the length of the interview was short enough for them to conduct interviews many times throughout the day. Interviewers also stated that several subjects, at the end of the interview, expressed appreciation for the opportunity to participate in the study. Subjects said that participation in the study increased their awareness and compelled them to reflect on their health and other issues in their lives. Several study participants who did not obtain follow-up asked the interviewers for assistance in obtaining their results and appointments for follow-up exams. In addition, several Spanish-speaking participants

asked interviewers to explain their results in Spanish and to assist them in obtaining follow-up appointments.

### Relationships of Variables to Outcome

#### *Number of Mammograms in the Last Five Years*

There was a significant positive relationship between the independent variable “number of mammograms in the last five years” and the outcome variable follow-up. Women who had a higher number of mammograms in the last five years were more likely to obtain follow-up for their abnormal mammogram. This relationship is supported by the literature. McCarthy, Ulcickas Yood, Janz, et al. (1996) stated that females who reported during the interview that they had one or two mammograms in the past five years were four times more likely to receive inadequate follow-up compared to women who had had three to four mammograms (McCarthy, Ulcickas Yood, Boohaker, et al., 1996; McCarthy, Ulcickas Yood, Janz, et al., 1996).

#### *Insurance*

Whether or not the study respondent reported having insurance also had a significant positive relationship with the dependent variable follow-up. Forty-eight percent of participants in this study reported having health care coverage, including private insurance or government plans such as Medicare and Medicaid, and an additional 47% of study subjects stated that they were enrolled in the hospital’s health plan. Similarly, Juarbe et al. (2005) found that 95% of the women in their study were insured. One study reported that women received a more timely evaluation for abnormal mammogram results if they belonged to a managed health care plan, while another study

stated that women who had no health insurance had a lower compliance with follow-up. Because most of our study participants had insurance, this study may not accurately reflect the challenges of having no insurance in the evaluation of abnormal mammograms (Haas et al., 2000; Juarbe et al., 2005; Strzelczyk & Dignan, 2002).

*Did You Have Problems with Receiving Mammogram Results?*

Several studies (Bedell et al., 1995, Chang et al., 1996, and McCarthy, Ulcickas Yood, Janz, et al., 1996) identified problems receiving mammogram results as a barrier to completing follow-up. Chang et al. (1996) surmised that these problems might be the result of incorrect contact information and effectiveness of communication between provider and patient. In this study, the variable of a problem receiving mammogram results had a surprisingly negative relationship with follow-up. Women who reported receiving their mammogram results still did not go for follow-up. This finding is important because it points out that there is another factor here influencing participants' decisions not to complete follow-up. Perhaps even though respondents received their results, they did not understand them or the importance of obtaining follow-up (Bedell et al., 1995; Chang et al., 1996; McCarthy, Ulcickas Yood, Janz, et al., 1996).

*Did you Have Problems with Receiving/Making Follow-up Appointment?*

Respondents who reported having difficulty making or receiving their follow-up appointments were more likely not to obtain follow-up. Several studies in the literature concurred with this finding. Hislop et al. (2002) reported this as the most frequently reported delay among women in their study (Bedell et al., 1995; Chang et al., 1996; Hislop et al., 2002; McCarthy, Ulcickas Yood, Janz, et al., 1996).

*Did You Have Problems with Having to Take Off Work?*

Women in this study who reported having a problem taking time off from work for their follow-up appointment were more likely not to obtain their follow-up exams. Only one other study in the literature looked at this variable. Rojas and Mandelblatt (1996) stated that non-compliers to follow-up frequently reported barriers that included loss of pay due to having to take time off from work (Rojas & Mandelblatt, 1996).

*Did You Have Problems with Not Having Transportation to the Follow-up Appointment?*

Women in this study who reported having problems with transportation to their follow-up appointments were more likely not to obtain follow-up care. The study conducted by Kaplan et al. (2004) agreed with our findings that women are less likely to return for follow-up if they have problems with transportation. This positive relationship between the outcome variable of follow-up and the variable of transportation has been discussed in the literature several times (McCarthy, Ulcickas Yood, Boohaker, et al., 1996; McCarthy, Ulcickas Yood, Janz, et al., 1996).

*Did you Have Problems with Waiting a Long Time to Receive the Follow-up Appointment?*

Study participants who reported having to wait a long time before receiving a follow-up appointment were more likely not to get follow-up care. Bedell et al. (1995) concurred with this finding. In Bedell et al.'s (1995) study, nearly half of the diagnostic-interval delay in the public hospital resulted from system factors, such as time spent waiting for appointments and diagnostic procedures to be scheduled. In Bedell et al.'s (1995) study, this finding was one of the most striking differences observed between the

public and private sites of care. This is especially of concern since the women acquiring health care services at public hospitals are more likely to be indigent and ethnic minorities and may be at a greater risk of getting lost in the system.

#### Overview of Other Significant Findings

The most prominent finding in this study is the disturbingly high percentage (52%) of women who did not obtain follow-up care after notification of their abnormal mammogram. Several studies in the literature also found high percentages of women not complying with recommended follow-up. Yabroff et al. (2004) found that prior studies have reported that between 32% and 98% of women with abnormal mammograms receive at least some follow-up. In addition, Yabroff et al. (2003) reported that approximately 9% of their sample, almost one million women, did not complete any diagnostic follow-up after abnormal mammograms. Kerner et al. (2003) found that 39% of women in their study were found not to have completed diagnostic examinations, while Kaplan et al. (2004) found that over 90% of the women in their study returned for some follow-up care. Given the impressive increase in proportion of women receiving screening mammograms, it is critical that we ensure that women who have made the effort to obtain screening mammograms receive the maximum benefit from the screening tests. In addition, even though lack of follow-up for a specific abnormal mammogram may not be associated with a diagnosis of advanced breast cancer, women without cancer who do not complete any diagnostic follow-up may also fail to return for breast cancer screening and/or may delay seeking care should they have breast cancer symptoms in the future.

Subjects in this study were likely to have a regular source of care (99%) at the clinics where they received their mammograms. Studies in the literature suggest that women who have poorer access to care because they are likely to have no regular source of care are less likely to obtain follow-up care. Cost was not considered a barrier in this study because 48% of respondents reported having health care coverage, including private insurance or government plans such as Medicare and Medicaid. Additionally 47% of study subjects stated that they were enrolled in the hospital's health plan. Moreover, only 3% of women stated that within the last year, they had needed to see a doctor but could not do so because of the cost, and only 4% stated that within the last year, they had needed prescribed medication but could not buy it because of costs. Kaplan et al (2004) found that women were less likely to return for follow-up care if they reported inability to pay for the care. Several other studies report similar findings (McCarthy, Ulcickas Yood, Boohaker, et al., 1996; McCarthy, Ulcickas Yood, Janz, et al., 1996; Rojas & Mandelblatt, 1996).

Overall, in regards to mammogram utilization, 78% of subjects in this study reported having a mammogram within the past year, and 30% reported having five mammograms in the last five years. This is comparable with the Centers for Disease Control and Prevention's national and Texas data on mammography utilization. In 2004, 74.9% of women nationally and 67.8 % of women in Texas stated that they had had a mammogram in the last two years (CDC, 2004). Ninety percent of study participants reported having a clinical breast exam by a doctor or other health professional, and 45% of respondents stated that they had had a clinical breast exam within the last year.

Eighty-five percent of respondents said that they knew how to examine their breast for lumps, and 39% said that they performed breast self-exam once a month.

According to McCarthy, Ulcickas Yood, Boohaker, et al. (1996), although most women were notified of their results, many women with inadequate follow-up may not understand that they need further evaluation and the importance of this evaluation. Women in this study who did not obtain follow-up were more likely not to understand the results (33%) than women who did get follow-up (2%). These results are similar to those in Karliner et al. (2005), who found that 30% of their sample reported not understanding their physician's explanation of their mammogram. Furthermore, 77% of women who did not obtain follow-up reported that they were not told they needed further evaluation, while 71% stated that they never received a follow-up appointment after receiving their mammogram results.

### Limitations

There were several limitations to this study. First of all, patients were not randomly selected; only women who returned their HIPAA forms were interviewed. Secondly, only women who were screened at the hospital's mammogram mobile unit at five clinics and were found to need further evaluation were included in the study. Our findings may not be generalizable to other settings. Thirdly, we only used records from one hospital to assess patients' compliance with follow-up. Although most patients receive all of their care at this indigent-care hospital, it is possible that some chose to follow-up elsewhere. Fourth, since staff from the hospital were interviewers and respondents were aware of this, participants may have responded to questions in an effort



to please interviewers. Finally, the associations reported here should be interpreted with caution, as many of the measures were taken retrospectively, and there is a possibility of recall bias. Additionally, we cannot determine whether responses were a justification for actions. For example, women who did not comply with follow-up may have justified their actions by stating that they thought their mammogram results were normal.

### Implications

This study adds to the literature on predictors of follow-up after an abnormal mammogram. Although rates of mammography screening have improved among women, there may still be barriers of timely performance of subsequent evaluation of abnormal mammography. This is a serious public health concern since breast cancer screening can improve breast cancer outcomes only if prompt diagnostic resolution and access to state-of-the-art care is available to all screening participants. For women ultimately diagnosed with breast cancer, even short delays in diagnostic resolution may be important.

The study also contributes to the health disparities literature. Although previous studies regarding factors that influence follow-up are diverse racially and economically, this study's population is primarily low-income minority populations.

### Recommendations

It is imperative that medical personnel make a concerted effort to insure that patients fully understand mammography results and follow-up instructions. Improving communication of mammogram results and ensuring that the woman with abnormal findings fully understands the results and the timing of follow-up may improve

compliance with follow-up. Improving communication during the mammogram process and ensuring that the patient is told of next steps may also improve compliance with follow-up. Strategies advocated by health literacy experts, which include asking patients to describe their understanding after information is delivered to them, may be helpful. Entrance and navigation through the system could be facilitated by a dedicated, multidisciplinary staff to evaluate breast disease. Primary care providers, working more closely with surgeons and radiologists, could more effectively communicate concerns, discuss results of tests, and establish plans for care. Urgency must be conveyed to the hospital staff about scheduling appointments, diagnostic tests, and procedures so that there are minimal wait times.

Further research is needed to delineate the relationships between poverty, limited health care resources, and provider-patient communications to follow-up care. Exploration of the association between incomplete follow-up and future screening behaviors, as well as the roles of health literacy and risk perceptions, are important areas for in-depth research. In addition, further qualitative inquiry in this area will not only deepen our knowledge about determinants of compliance, but it may also suggest avenues of intervention aimed at providing patient-centered quality care and decreasing or eliminating disparities in compliance rates. Ultimately, the benefit of early detection will depend on the translation of abnormal screening results into prompt diagnostic and treatment services.

### Conclusions

This study identified several factors affecting return for follow-up care after an abnormal mammogram. Because the acceptance and use of mammography is the single most effective method of early detection, it is particularly important to understand the reasons for delay, as well as inadequate and non-compliance to follow-up care after an abnormal mammogram. We must continue our efforts to educate women to follow routine screening recommendations, to recognize breast cancer symptoms earlier, and to recognize the benefits of early detection; furthermore, providers must strive to diagnose breast cancer as early as possible and target efforts to improve timeliness of care and minimize avoidable delays.

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APPENDIX A  
BREAST CANCER ASSESSMENT

# PARKLAND SCREENING MAMMOGRAPHY

Clinic: (BFHC) (DSHC) (EDHC) (GHC) (SEHHC) (VHC) Provider/Doctor \_\_\_\_\_  
(Homes) (MLK) (OR)

**Please Print!!!**

Date / Fecha \_\_\_\_\_

Name / Nombre \_\_\_\_\_ , \_\_\_\_\_ , \_\_\_\_\_  
(Last Name/Apellido) (First Name/Primer Nombre) (Middle Initial/Inicial)

Address / Direccion \_\_\_\_\_  
(Street/Calle) (City/Cuidad) (Zip Code/Zona Postal)

Home Phone # / Telefono ( ) \_\_\_\_\_

Parkland Medical Record # Or Social Security Number  
Numero de Expediente O Seguro Social \_\_\_\_\_

Date of Birth / Fecha de Nacimiento \_\_\_\_\_ Age / Edad \_\_\_\_\_

Ethnicity-Circle One: (African American/Black) (American Indian) (Asian/Pacific Islander) (Hispanic/Hispano)  
Grupo Etnico : Marque Uno: (White) (Other \_\_\_\_\_)

What language do you speak at home?  
Que idioma(s) se hable en su casa ? \_\_\_\_\_

In case of an emergency, who should we call?  
En case de emergency, con quien nos podemos comunicar? \_\_\_\_\_

\_\_\_\_\_  
(Name / Nombre) (Phone # / Telefono) (Relationship / Parentesco)

1. Have you ever been diagnosed with cancer?  
Ha usted tenido cancer? ☐ No ☐ Yes/Si

If yes / Responde si : What type of cancer? / Que tipo? \_\_\_\_\_  
Did you have radiation therapy? / Recibio radiacion? ☐ No ☐ Yes/Si

2. If any of your relatives listed below had breast cancer, please check the box below.  
Write the age they were when they were told they had breast cancer.  
Si alguno de los siguientes parientes a tenido cancer de los senos, marque la caja apropiada.  
Escriba que edad tenian cuando se le notifico que tenia cancer de los senos.

☐ Grandmother / Abuela ☐ Mother / Madre ☐ Sister / Hermana ☐ Daughter / Hija  
Age / Edad \_\_\_\_\_ Age / Edad \_\_\_\_\_ Age / Edad \_\_\_\_\_ Age/Edad \_\_\_\_\_

3. How many times have you been pregnant? Are you pregnant? Yes No Maybe  
Numeros de embarazos? \_\_\_\_\_ (esta Embarazada?) (si) (no) (Quizas)

How many babies were born live? Beginning of last Mentrual Period \_\_\_\_\_  
Cuantos bebes nacieron vivos? \_\_\_\_\_ (Quando Empazo su Ultimo Periodo?) Month (Mas) Day (Dia) Year (Año)  
Your age at first pregnancy  
Edad de primer embarazo \_\_\_\_\_

4. Have you had a hysterectomy? / Le han extraido la matriz? ☐ No ☐ Yes/Si When? \_\_\_\_\_  
Were your ovaries removed? / Incluye ovarios? ☐ No ☐ Yes/Si Cuando

5. At this time, are you taking female hormones? ☐ No ☐ Yes/Si  
Toma hormonas?  
If yes, what are they called? / Que tipo? \_\_\_\_\_  
How long have you taken them? / Por cuanto tiempo los a tomado? \_\_\_\_\_

☐ Prior Film Request  
on File

Label

**6. Have you had a mammogram before?**

*Ha tenido mamograma?*

☐ No

☐ Yes/Si

**If yes, where / Donde:**

**When / Que fecha:**

**7. What is your bra size? / Talla de brassiere?**

**8. When did a doctor or nurse last check your breasts?**

*Cuando fue la ultima vez que un doctor o enfermera le examino los senos?* \_\_\_\_\_ MONTH/YEAR (MES/ANO)

**9. At this time, do you have any or the following breast problems?**

*Tiene hoy alguno de los siguiente problema en los senos?*

	No	Yes/Si	For how long <i>Por cuanto tiempo</i>	R	L
<b>Breast lump / Masa/Bolita</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>
<b>Nipple change or discharge</b> <i>Tiene cambio o desecho de su pezon</i>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>
<b>Breast pain or Other Problems (please describe)</b> <i>Dolor del seno o otro problema (Describe)</i>			_____		

**10. Have you ever had any of the following breast procedures? / Ha tenido cirugia del seno?**

	No	Yes/Si	When? Cuando	R	L
<b>Needle biopsy / Biopsia con aguja</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>
<b>Surgical biopsy / Biopsia cirugia</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>
<b>Cyst drainage / Desague de quiste</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>
<b>Breast implants / Implantes de senos</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>
<b>Implant removal / Le han sacado implante</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>
<b>Cancer lumpectomy / Lumpectomia para cancer</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>
<b>Mastectomy / Mastectomia</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>
<b>Breast radiation / Radiacion de senos</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>
<b>Breast reduction / Reduccion de senos</b>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>

X \_\_\_\_\_

**Patient Signature** (Firma del Paciente)

**DO NOT WRITE BELOW THIS LINE**

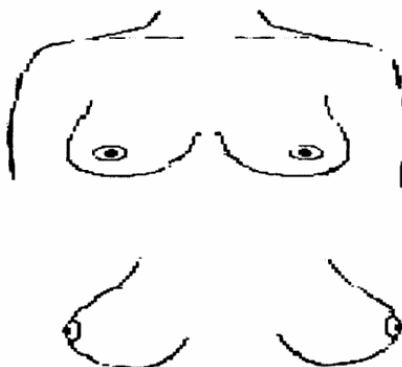
OLD FILMS AVAIL. AT  
TIME OF EXAM? Y / N

RT'S INITIALS \_\_\_\_\_

COMMENTS

**RT.**

**LT.**





APPENDIX B

IRB

PARKLAND HEALTH & HOSPITAL SYSTEM

UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL SCHOOL

TEXAS A&M UNIVERSITY

<b>Date:</b>	Tue, 14 Feb 2006 17:25:16 -0600
<b>From:</b>	"VALERIA HART" <VHART@parknet.pmh.org>
<b>To:</b>	valerie.copeland@sbcglobal.net
<b>Subject:</b>	Re: IRB

RE: IRB pending      Barriers to followup

This proposal had been approved by the PHHS Institutional Research Committee. This approval is contingent upon IRB approval and completion of a research account for service billing (SAR) if applicable. Please fax a copy of the IRB approval letter to 214-590-4595 when obtained if you have not already included it in your packet. Send by mail, to my attention, a copy of the IRB final date-stamped consent and HIPAA authorization forms: address to Clin Research, PHHS, mc 7750. A formal letter of approval will be forwarded after administrative signatures are completed and the SAR is complete if applicable.

#### PENDING ITEMS

1. IRB approval - please fax letter when obtained; sent stamped consent to address above

Do not start recruitment until IRB approval is completed

No SAR needed; fees waived

Good luck with your research!

vh

**SOUTHWESTERN**  
 THE UNIVERSITY OF TEXAS  
 SOUTHWESTERN MEDICAL CENTER  
 AT DALLAS

**Institutional Review Board**

TO: Valerie Copeland, MPH  
 c/o Vickie Henry, BS  
 PH-BHFWr

FROM: *Jan Harrell for*  
 Robert Bash, MD  
 Institutional Review Board 2 Chairperson  
 IRB - 8843

DATE: April 12, 2006

RE: **Expedited Approval of Protocol and HIPAA Waiver  
 Acknowledgment of HIPAA Authorization**  
 IRB Number: 012006-056  
 Title: Quantitative Analysis of Barriers to Follow-Up After an Abnormal  
 Mammogram

The Institutional Review Board (IRB) at the University of Texas Southwestern Medical Center has determined that this research is eligible for expedited review in accordance with 45 CFR 46.110(a)-(b)(1), 63 FR 60364, and 63 FR 60353. The IRB Chairman approved the protocol on March 31, 2006. IRB approval of this research lasts until March 30, 2007. If the research continues beyond twelve months, you must apply for updated approval of the protocol one month before the date of expiration noted above. **The Board waived the use of consent form in accordance with 45 CFR 46.116(d). Your approved subject sample size is 393 subjects.**

The IRB requires that you report to the Board any unexpected adverse events that occur during the study. In the future, if you require a modification to the protocol, obtain review and approval by the Board prior to implementing any changes except when prompt changes are necessary to eliminate apparent immediate hazards to a subject.

The IRB requires that all personnel who interact with research subjects or who have access to research data identified with the names of subjects receive a copy of the Federal Wide Assurance on file with the Department of Health and Human Services. Document their agreement to comply with the statements therein. Such documentation should be kept with other records of the research, which are subject to review by the IRB. Copies of the Federal Wide Assurance and the Federal regulations governing the participation of human subjects in research (45 CFR 46) are available on the IRB website:  
 (<http://www8.utsouthwestern.edu/utsw/cda/dept31018/files/41623.html>)  
 or from Jan Harrell at [irb@utsouthwestern.edu](mailto:irb@utsouthwestern.edu).

If applicable, approval by the appropriate authority at a collaborating facility is required before subjects may be enrolled on this study.

If you have any questions related to this approval or the IRB, you may telephone Jan Harrell at 214.648.9453.

Enc: HIPAA Waiver  
 Project Summary  
 NR1-EXP copy  
 HIPAA Authorization

RB/iw

## TEXAS A&amp;M UNIVERSITY

## VICE PRESIDENT FOR RESEARCH - OFFICE OF RESEARCH COMPLIANCE

1186 TAMU  
College Station, TX 77843-1186  
1500 Research Parkway, Suite B-150

979.458.1467  
FAX 979.862.3176  
<http://researchcompliance.tamu.edu>

Institutional Biosafety Committee

Institutional Animal Care and Use Committee

Institutional Review Board

DATE: May 9, 2006

## MEMORANDUM

TO: Valerie Copeland  
Health & Kinesiology MS

FROM: Dr. Steven Moore, Chair  
Institutional Review Board



SUBJECT: Initial Review

Protocol Number: 2006-0264

Title: Quantitative Analysis of Barriers to Follow-up after an Abnormal Mammogram

Review Category: Expedited

Approval Period: May 9, 2006 to May 8, 2007

## Approval determination was based on the following Code of Federal Regulations:

45 CFR 46.110(b)(1) - Some or all of the research appearing on the list and found by the reviewer(s) to involve no more than minimal risk.

**Category 7:** Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation or quality assurance methodologies.

## Provisions:

This research project has been approved for one (1) year. As principal investigator, you assume the following responsibilities:

- 1) **Continuing Review:** The protocol must be renewed each year in order to continue with the research project. A Continuing Review along with required documents must be submitted 30 days before the end of the approval period. Failure to do so may result in processing delays and/or non-renewal.
- 2) **Completion Report:** Upon completion of the research project (including data analysis and final written papers), a Completion Report must be submitted to the IRB Office.
- 3) **Adverse Events:** Adverse events must be reported to the IRB Office immediately.
- 4) **Amendments:** Changes to the protocol must be requested by submitting an Amendment to the IRB Office for review. The Amendment must be approved by the IRB before being implemented.
- 5) **Informed Consent:** Information must be presented to enable persons to voluntarily decide whether or not to participate in the research project.

APPENDIX C

STUDY INTRODUCTION LETTER

HIPAA AUTHORIZATION

INTERVIEW TELEPHONE SCRIPT

**Study Introduction Letter (English)**

Date

Name

Address

City, State, Zip Code

You had a mammogram (breast X-rays) done a little while ago. We are doing a research study to try to find out about some things women could do to stay healthy. We hope that you will agree to help us and be a part of our study. If you agree, please read and sign the form, which you will find in the envelope along with this letter. Then mail it back to us in the stamped envelope we sent you. Once we get your filled-out form someone from Parkland will call to ask you a few questions about how things went when you had your mammogram and other tests, if you had any. The call will take about 10 to 15 minutes. Any personal information about you will be kept private. Your name will not be used – we will use an ID (identification number) instead. After we have talked with you we will send you a \$10 phone card.

If you have any questions, please call Vickie Henry, Project Coordinator at (214) 266-1240. Thank you in advance for your help.

Sincerely,

## **Carta de Presentación del Estudio**

Fecha

Nombre

Dirección

Ciudad, Estado, Código Postal

Hace apenas un tiempo a usted se le hizo un mamograma (rayos X de los senos). Nosotros estamos llevando a cabo un estudio de investigación para llegar a saber de aquéllas cosas que la mujer pudiera hacer para mantenerse saludable. Esperamos que usted esté de acuerdo en ayudarnos y en participar en nuestro estudio. Si usted está de acuerdo, favor de leer y firmar el formulario, el cual encontrará en el sobre junto con esta carta. Devuelva por correo ésta en el sobre con sello que le enviamos. Ya cuando hayamos recibido su formulario contestado, alguien de Parkland la llamará para hacerle unas cuantas preguntas sobre como le fue cuando a usted se le hizo un mamograma y otras pruebas, de haberle hecho alguna otra. La llamada se tomará de unos 10 a 15 minutos. Cualquier información personal de usted permanecerá privada. No se usará su nombre — en su lugar usaremos un ID (número de identificación). Después de haber hablado con usted le mandaremos una tarjeta para llamadas telefónicas con un valor de \$10.00.

Si usted tiene cualquier pregunta, favor de llamar a Vickie Henry, Coordinadora del Proyecto al (214) 266-1240. Le damos por anticipado las gracias por su ayuda.

Sinceramente,

**The University of Texas Southwestern Medical Center at Dallas  
Children's Medical Center, Parkland Health & Hospital System  
Retina Foundation of the Southwest, Texas Scottish Rite Hospital for Children  
Zale Lipshy University Hospital, St. Paul University Hospital  
The University of Texas Southwestern Moncrief Cancer Center**

**Authorization for Use and Disclosure of  
Health Information for Research Purposes**

NAME OF RESEARCH PARTICIPANT:

---

1. You agree to let Parkland Health & Hospital System share your health information with Valerie Copeland and her staff ("Researchers") for the purpose of the following research study: Barriers to Follow-up after an Abnormal Mammogram, a study looking at the barriers women encounter when they get a mammogram on the Parkland Mammography mobile unit, receive abnormal results and have to go to Parkland Health & Hospital System for more exams. IRB# 012006-56 ("Research Project").

2. You agree to let the Researchers use your health information for this Research Project. You also agree to let the Researchers share your health information with others who may be working with the Researchers on the Research Project ("Recipients") as follows.

- Jeffrey J. Guidry, PhD, Texas A&M University
- The UT Southwestern Institutional Review Board (IRB). This is a group of people who are responsible for assuring that the rights of participants in research are respected. Members and staff of the IRB at UT Southwestern may review the records of your participation in this research. A representative of the IRB may contact you for information about your experience with this research. If you do not want to answer their questions, you may refuse to do so.
- Representatives of the Office of Human Research Protections (OHRP). The OHRP may oversee the Research Project to confirm compliance with laws, regulations and ethical standards.

3. Whenever possible your health information will be kept confidential. Federal privacy laws may not apply to some institutions outside of UT Southwestern. There is a risk that the Recipients could share your information with others without your permission. UT Southwestern cannot guarantee the confidentiality of your health information after it has been shared with the Recipients.



4. You agree to permit the Researchers to use and share your health information as listed below:

Results of mammogram obtained between October 1, 2004 and September 31, 2005; demographic information(race, age); home telephone contact information; survey information obtained during telephone interview.

5. The Researchers may use your health information to create research data that does not identify you. Research data that does not identify you may be used and shared by the Researchers (for example, in a publication about the results of the Research Project); it may also be used and shared by the Researchers and Recipients for other research purposes not related to the Research Project.

6. This authorization is voluntary. Your health care providers must continue to provide you with health care services even if you choose not to sign this authorization. However, if you choose not to sign this authorization, you cannot take part in this Research Project.

7. This Authorization has no expiration date.

8. If you change your mind and do not want us to collect or share your health information, you may cancel this authorization at any time. If you decide to cancel this authorization, you will no longer be able to take part in the Research Project. The Researchers may still use and share the health information that they have already collected before you canceled the authorization. To cancel this authorization, you must make this request in writing to: Vickie Henry, 3310 Live Oak, Dallas, TX 75235, (214) 266-1240.

9. A copy of this authorization form will be provided to you.

\_\_\_\_\_  
Signature of Research Participant

\_\_\_\_\_  
Date

**For Legal Representatives of Research Participants (if applicable):**

Printed Name of Legal Representative: \_\_\_\_\_

Relationship to Research Participant: \_\_\_\_\_

*I certify that I have the legal authority under applicable law to make this Authorization on behalf of the Research Participant identified above. The basis for this legal authority is:*

\_\_\_\_\_.

(e.g. parent, legal guardian, person with legal power of attorney, etc.)

---

Signature of Legal Representative

---

Date

**The University of Texas Southwestern Medical Center at Dallas  
Children's Medical Center, Parkland Health & Hospital System  
Retina Foundation of the Southwest, Texas Scottish Rite Hospital for Children  
Zale Lipshy University Hospital, St. Paul University Hospital  
The University of Texas Southwestern Moncrief Cancer Center**

**Autorización para Usar y Revelar Información sobre Información de Salud  
con Propósitos de Investigación**

NOMBRE DEL PARTICIPANTE EN INVESTIGACIÓN:

---

1. Usted está de acuerdo en permitir que el sistema conocido en inglés como Parkland Health & Hospital System comparta información sobre su salud con Valerie Copeland y su personal (Investigadores) en la Universidad de Texas Southwestern Medical Center en Dallas con el propósito de realizar el siguiente estudio de investigación: Obstáculos al Seguimiento luego de un Mamograma Anormal, un estudio que examina los obstáculos con los cuales las mujeres se enfrentan cuando obtienen un mamograma en la unidad móvil de Mamografías de Parkland (conocido en inglés como Parkland Mammography mobile unit), con resultados anormales y tienen que ir a Parkland Health & Hospital System para más exámenes. Número del Consejo de Revisión Institucional 012006-56 ("Proyecto de Investigación")

2. Usted está de acuerdo en permitir que los investigadores usen información sobre la salud de usted en este Proyecto de Investigación. Usted también está de acuerdo en permitir que los investigadores compartan la información de su salud con otras personas que pueden estar trabajando con los investigadores en el Proyecto de Investigación ("Receptores") como sigue:

- Jeffrey J. Guidry, PhD, Texas A&M University.
- El Consejo de Revisión Institucional (IRB, por sus siglas en inglés) de UT Southwestern. Este es un grupo de personas responsables de asegurar que se respetan los derechos de los participantes en investigación. Los miembros o personal del IRB en este centro médico pueden revisar los archivos de su participación en esta investigación. Un representante del Consejo se podrá comunicarse con usted para pedirle información sobre sus experiencias en esta investigación. Si usted así lo desea, puede rehusar a contestar sus preguntas.
- Representantes de la Oficina de Protección de Investigación Humana (OHRP, por sus siglas en inglés). El OHRP podrá supervisar el Proyecto de Investigación para confirmar cumplimiento con las leyes, reglamentos y estándares éticos.

3. Siempre que sea posible se mantendrá confidencial la información de su salud. Las leyes Federales de Privacidad pueden ser no aplicables a algunas instituciones fuera de UT Southwestern. Hay un riesgo de que, sin su permiso, los Receptores puedan

compartir información sobre usted con otros. La UT Southwestern no puede garantizar la confidencialidad de su información de salud después de que se ha compartido con los Receptores.

4. Usted esta de acuerdo en permitir que los Investigadores usen y compartan información sobre su salud como se indica a continuación: Los resultados del mamograma que se obtuvieron entre el 1 de octubre del 2004 y el 31 de septiembre del 2005; información demográfica (raza, edad); información para comunicarse con usted, teléfono de la casa; información de la encuesta que se obtuvo por medio de entrevista telefónica.

5. Los Investigadores podrán usar la información sobre su salud para crear datos de investigación que no lo identifican a usted. Los datos de Investigación que no le identifica a usted podrán ser usados y compartidos por los Investigadores (por ejemplo, en una publicación sobre el los resultados de este Proyecto de Investigación); podría también ser usado y compartido entre los Investigadores y los Receptores para otros propósitos de investigación no relacionados con el Proyecto de Investigación.

6. Esta autorización es voluntaria. Su proveedor de servicios de salud debe continuar proporcionándole los servicios de salud aún cuando usted decida no firmar esta autorización. Sin embargo, si usted decide no firmar esta autorización, usted no podrá participar en el Proyecto de Investigación.

7. Esta autorización no tiene fecha de caducidad.

8. Si usted cambia de opinión y no quiere que nosotros recopilemos y compartamos información de su salud, en cualquier momento puede cancelar esta autorización. Si usted decide cancelar esta autorización, no podrá participar en el Proyecto de Investigación. Los Investigadores podrán usar y compartir la información de salud que ya habían recopilado antes de que usted cancelara la autorización. Para cancelar esta autorización, usted debe hacer la solicitud por escrito a Vickie Henry, 3310 Live Oak, Dallas, TX 75235, (214) 266-1240.

9. Una copia de esta autorización se le proporcionara a usted.

\_\_\_\_\_  
Firma del Participante en Investigación

\_\_\_\_\_  
Fecha

**Para Representantes Legales de los Participantes en Investigación (si se aplica):**

Nombre en letra de molde del Representante Legal: \_\_\_\_\_

Relación con el Participante en Investigación: \_\_\_\_\_

*Certifico que tengo la autoridad legal bajo las leyes correspondientes para dar esta autorización a nombre del Participante en Investigación identificado anteriormente. Esta autoridad legal es a base de:*

\_\_\_\_\_  
(e.g. padre o madre, patria potestad, carta poder, etc.)

\_\_\_\_\_  
Firma del Representante Legal

\_\_\_\_\_  
Fecha

## **Telephone Script (English)**

### **Quantitative Analysis of Barriers to Follow-up after an Abnormal Mammogram**

#### Follow-up after an Abnormal Mammogram Questionnaire Telephone Script

Hello, I'm \_\_\_\_\_, calling from Parkland about the mammogram research study. About 2 weeks ago, you had gotten a letter about the study, and sent back a form saying that you were willing to be a part of the study. I'd like to ask you some questions about things women can do to stay healthy.

My questions will only take about 15 minutes, and, as we told you in the letter, any personal information about you will be kept private. Your name will not be used – we will use an ID (identification number) instead. If there are any questions you don't want to answer, that is OK. If you choose not to stay in our study that will not change the way you are taken care of at Parkland.

If you have any questions about this study, please call the head of the research study, Valerie Copeland at (817) 253-8878, or Dr. Jeffrey Guidry at (979) 845-3109.

Texas A&M University and University of Texas, Southwestern Medical School have looked over this study, and they have approved it. If you have any questions about your rights when you are part of a research study, you can call Dr. Michael W. Buckley, Director of Research Compliance, Office of Vice President for Research at (979) 845-8585 (mwibuckley@tamu.edu).

## **Guión por Teléfono**

### **Análisis Cuantitativo de los Obtáculos al Seguimiento luego de un Mamograma Anormal**

Cuestionario sobre el Seguimiento luego de un Mamograma Anormal  
Guión por Teléfono

Hola, me llamo \_\_\_\_\_, y estoy llamando de Parkland en cuanto al estudio de investigación sobre el mamograma. Hace como unas 2 semanas, usted recibió una carta sobre el estudio, y usted devolvió un formulario en que indicó que usted estaba dispuesta a participar en el estudio. Me gustaría hacerle algunas preguntas sobre las cosas que las mujeres pueden hacer para mantenerse saludable.

Mis preguntas tan sólo tomarán como unos 15 minutos, y, así como se le explicó en la carta, cualquier información personal de usted permanecerá privada. No se usará su nombre – en su lugar usaremos un ID (número de identificación). Si hay alguna pregunta que usted no quiere contestar, está bien, no tiene que contestarla. Si usted decide salirse de nuestro estudio eso no cambiará la manera en que usted recibe atención médica en Parkland.

Si usted tiene cualquier pregunta sobre este estudio, favor de llamar a la dirigente del estudio de investigación, Valerie Copeland al (817) 253-8878, o al Dr. Jeffrey Guidry al (979) 845-3109.

La Universidad de Texas A&M y, la Escuela de Medicina Southwestern de la Universidad de Texas han examinado este estudio, y éstos lo han aprobado. Si usted tiene cualquier pregunta sobre sus derechos por ser un partícipe en un estudio de investigación, puede llamar al Dr. Michael W. Buckley, Director of Research Compliance (Oficina de Acatamiento y Cumplimiento en la Investigación), Office of Vice President for Research (Oficina del Vice Presidente para Investigación) al (979) 845-8585 (mwbuckley@tamu.edu).

## APPENDIX D

ENGLISH QUESTIONNAIRE

SPANISH QUESTIONNAIRE





1. How would you describe your general state of health? Would you say that it is **(READ RESPONSES)**

- 1 Excellent
- 2 Good
- 3 Fair OR
- 4 Poor

2. Is there a particular clinic, health center, doctor's office or other place that you usually go to if you are sick or need a checkup?

- 1 Yes **(skip to question 4)**
- 2 No
- 88 Don't Know
- 99 Refused

3. What is the main reason you do not have a particular place to go?

- 1 Have not needed a doctor
- 2 Previous doctor not available
- 3 Have not been able to find the right doctor
- 4 Recently moved to the area

4. Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMO's of government plans such as Medicare?

- 1 Yes
- 2 No

5. Was there a time in the last 12 months when you needed to see a doctor, but could not because of the cost?

- 1 Yes
- 2 No
- 88 Don't Know
- 99 Refused

6. Was there a time in the last 12 months when you needed prescribed medications, but could not buy them because of the cost?

- 1 Yes
- 2 No
- 88 Don't Know
- 99 Refused

7. How do you normally get to your doctor appointments?

1. Drive myself
2. Family member or friend
3. Taxi
4. Bus
5. Walk
6. Other \_\_\_\_\_

### BREAST CANCER SCREENINGS

A mammogram is an x-ray of each breast to look for cancer.

8. About how old were you when you had your first mammogram?

Age \_\_\_\_\_

9. How long has it been since you had your last mammogram?

**Read only if necessary:**

- 1 Within the past year (1 to 12 months ago)
- 2 Within the past two years (13 months to 24 months (2 years)
- 3 Within the past three years (25 months to 36 months (3 years)
- 4 Within the past five years (37 months to 5 years ago)
- 5 more than 5 years ago
- 88 Don't know/Not sure
- 99 Refused

10. How many mammograms have you had in the last five years?

Number of mammograms \_\_\_\_\_

- 2 None
- 88 Don't know/Not sure
- 99 Refused

11. In the past year has a doctor or other health professional recommended that you have a mammogram?

- 1 Yes
- 2 No
- 88 Don't know/Not sure
- 99 Refused

12. How much did you pay for this mammogram? Was it NONE, PART, or ALL of the cost?

- 1. I paid NONE of the cost
- 2. I paid PART of the cost
- 3. I paid ALL of the cost (**skip to question 14**)
- 88 Don't know/Not sure
- 99 Refused

13. Which of the following sources paid for (some/all) of the cost of this mammogram?

- 1. Private insurance
- 2. Medicare
- 3. Medicaid
- 4. Free clinic
- 5. Other source \_\_\_\_\_

14. What was the main reason you had this mammogram?

- 1. Part of a routine physical exam/screening test
- 2. Because of a specific breast problem
- 3. First mammogram
- 4. Family history
- 5. Other \_\_\_\_\_
- 88 Don't know/Not sure
- 99 Refused

15. Do you know the results of your mammogram?

- 1 Yes
- 2 No
- 88 Don't know/Not sure
- 99 Refused

16. What were the results of this mammogram?

- 1. Normal
- 2. Abnormal/follow-up required
- 3. Didn't remember receiving results

17. After getting your mammogram results, did you receive an appointment for follow-up?

- 1 Yes
- 2 No
- 88 Don't know/Not sure
- 99 Refused

18. Did anyone talk to you about your mammogram results in person?

- 1 Yes
- 2 No
- 88 Don't know/Not sure
- 99 Refused

18a. Did anyone talk to you about your mammogram results on the phone?

- 1 Yes
- 2 No
- 88 Don't know/Not sure
- 99 Refused

19. Did you understand the explanation of your mammogram results?

- 1 Yes
- 2 No
- 88 Don't know/Not sure
- 99 Refused

20. Did anyone tell you that you would need a more tests?

- 1 Yes
- 2 No
- 88 Don't know/Not sure
- 99 Refused

21. Because of these results what additional tests or surgery did you have?

- 1. None (**skip to question 23**)
- 2. Another mammogram
- 3. Ultrasound
- 4. Clinical breast exam
- 5. Needle biopsy
- 6. Tumor/lump removed/ lumpectomy
- 7. Breast removed/mastectomy

22. Did the surgery or additional tests indicate that you had cancer?

- 1 Yes
- 2 No
- 88 Don't know/Not sure
- 99 Refused

23. Did you have problems with any of the following in getting your follow-up exams?

Did you have problems with....(READ RESPONSES)

Receiving mammogram results	Yes	No
Making or receiving a follow-up appointment	Yes	No
The hospital canceling of your follow-up appointment	Yes	No
Your mammogram results being lost or misplaced	Yes	No
The hospital rescheduling your follow-up appointment	Yes	No
Your follow-up appointment being inconvenient for you	Yes	No
Having to take off work for follow-up appointment	Yes	No
Not having transportation to follow-up appointment	Yes	No
Paying for the follow-up exam	Yes	No
Receiving an unexpected bill for the follow-up exam	Yes	No
Insurance covering the follow-up exam	Yes	No
Waiting a long time to receive the follow-up appointment	Yes	No
Waiting a long time to be seen by the doctor at the follow-up appointment	Yes	No

24. Have you ever had an operation to remove a mass or lump from your breast that was not cancer?

1. Yes
2. No (**skip to question 26**)
3. Lump removed was cancerous
- 88 Don't know/Not sure
- 99 Refused

25. How many of these operations have you had?

- \_\_\_\_\_
- 88 Don't know/Not sure
  - 99 Refused

26. Has your mother, sisters, or daughters ever had breast cancer?

- 1 Yes,            Which relative (mother, sister or daughter) \_\_\_\_\_
- 2 No
- 88 Don't Know
- 99 Refused

A clinical breast exam is when the breasts are felt by a doctor or other health care professional to check for lumps or other signs of breast cancer.

27. Have you ever had a clinical breast exam by a doctor or other health professional to check for lumps or other signs of breast cancer?

- 1 Yes
- 2 No **(skip to question 29)**
- 88 Don't know/Not sure
- 99 Refused

28. When did you have your most recent clinical breast exam by a doctor or health care professional?

- 1. Days ago
- 2. Weeks ago
- 3. Months ago
- 4. Years ago
- 88 Don't know/Not sure
- 99 Refused

**Now I would like to ask you about breast self-exams-that is an examination you do yourself of your breast for lumps and other possible signs of cancer**

29. Do you know how to examine your breast for lumps?

- 1 Yes
- 2 No
- 88 Don't know
- 99 Refused

30. How often have you examined your breast?

- 1 Never
- 2 Once every month
- 3 Once every two months
- 4 Other, please specify \_\_\_\_\_

**Please tell me if you agree or disagree with the following statements.**

31. In spite of advances in modern medicine, breast cancer is as serious and dangerous a disease as it was several years ago.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

32. There is a good probability that cancer may now be developing in my breast.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

33. I am more vulnerable to breast cancer than anyone else.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

34. The majority of women who develop breast cancer have serious emotional as well as physical side-effects.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

35. My chances of developing breast cancer are small.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

36. Having regular mammograms is the best, most effective method of detecting breast cancer early.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

37. There are so many ways to get cancer today, its just a matter of time; I might as well just try and accept it.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

38. I am currently at risk for developing breast cancer.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|



39. The prospect of developing breast cancer makes me want to have a mammogram every year.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

40. If I have an abnormal mammogram, I can go to the follow-up exams.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

41. Having a yearly mammogram will not drastically improve my chances of surviving breast cancer.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

42. Only time will tell if I develop breast cancer; nothing can be done anyway but wait.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

43. If I get regular mammograms, my chances of detecting breast cancer are extremely high.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

44. If I have an abnormal mammogram, I believe I can get all the follow-up exams.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

45. If I have an abnormal mammogram, I believe that the cancer will be detected early and I will survive.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

46. If you are destined to die of breast cancer, you will; there is really little you can do about it.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

47. Even with advanced medical procedures, the best treatment for cancer involves radical surgical techniques.

- |                      |             |                              |          |                   |
|----------------------|-------------|------------------------------|----------|-------------------|
| 1. strongly disagree | 2. disagree | 3. neither agree or disagree | 4. agree | 5. strongly agree |
|----------------------|-------------|------------------------------|----------|-------------------|

48. Other women are more capable of going to follow-up appointments than I am.

1. strongly disagree	2. disagree	3. neither agree or disagree	4. agree	5. strongly agree
-------------------------	-------------	---------------------------------	----------	----------------------

49. Going to follow-up exams are easy to do.

1. strongly disagree	2. disagree	3. neither agree or disagree	4. agree	5. strongly agree
-------------------------	-------------	---------------------------------	----------	----------------------

**DEMOGRAPHICS**

50. What is your age?

Age in years \_\_\_\_\_

88 Don't know

99 Refused

51. What is the highest grade or year of school you completed?

1 Never attended school or kindergarten only

2 Grades 1 through 8 (Elementary)

3 Grades 9 through 11 (Some high school)

4 Grades 12 or GED (High school graduate)

5 College 1 year to 3 years (Some college or technical school)

6 College 4 years or more (College graduate)

99 Refused

52. Are you:

1 Married

2 Divorced

3 Widowed

4 Separated

5 Never been married

6 A member of an unmarried couple

99 Refused

53. Are you currently....(**READ RESPONSES**)

1. Employed for wages

2. Self-employed

3. Out of work for more than 1 year

4. Out of work for less than 1 year

5. A Homemaker

6. A Student

7. Retired

99. Refused

54. Which of the following best describes your annual household income from all sources?

1 Less than \$5,000

2 5,000 to 9,999

3 10,000 to 19,999

4 20,000 to 29,999

5 30,000 to 39,999

6 40,000 to 49,999

7 50,000 and over

88 Don't know

99...Refused

**That's my last question. I appreciate you taking the time to complete this important survey.**



En general, ¿cómo describiría usted su estado de salud? Diría usted que es **(LEA LAS RESPUESTAS)**

1. Excelente
2. Buen estado
3. Regular O
4. Pobre

¿Tiene usted en específico, alguna clínica, centro de salud, oficina médica privada o algún otro lugar a donde va usted usualmente si está enfermo/a o de necesitar un examen de rutina?

1. Sí **(De ser Sí, pase a la pregunta 4)**
2. No
- 88 No sé
- 99 Rehusa

¿Cuál es la razón principal por la que usted no tiene un lugar en específico a donde ir?

1. No he necesitado de un doctor
2. Mi anterior doctor no ha estado disponible
3. No he podido encontrar un doctor a mi gusto
4. Recientemente me he mudado al área
5. Tengo uno o más especialistas quienes tratan mis problemas rutinarios en visitas citadas con anticipación (tiene varios doctores de acuerdo a lo que tiene mal)
6. No hay suficiente dinero/demasiado caro
7. No me gustan los doctores
8. No pienso que los doctores me puedan ayudar
9. Otro: \_\_\_\_\_
- 88 No sé/No estoy seguro/a
- 99 Rehusa

4. ¿Tiene usted cualquier tipo de cobertura para el cuidado de la salud, en la se incluye, aseguranza de la salud, planes pre-pagados tales como las HMO (siglas en inglés) o planes del gobierno tales como Medicare?

1. Sí
2. No

5. ¿Hubo alguna vez en los últimos 12 meses en que usted necesitara de consultar con un doctor, pero no pudo hacerlo debido al costo?

1. Sí
2. No
- 88 No sé
- 99 Rehusa

6. ¿Hubo alguna vez en los últimos 12 meses que usted necesitara medicinas por receta, pero no pudo hacerlo debido al costo?

- 1. Sí
- 2. No
- 88 No sé
- 99 Rehusa

7. ¿Cómo se transporta usted por lo usual a sus citas?

- 1. Manejo yo misma
- 2. Un miembro de la familia o amigo
- 3. Taxi
- 4. Autobús
- 5. Camino
- 6. Otro \_\_\_\_\_

## PRUEBAS PARA DETECTAR EL CÁNCER DEL SENO

Un mamograma es un rayos X de cada seno para detectar el cáncer.

8. ¿Qué edad tenía usted más o menos cuando se le hizo el primer mamograma?

Edad \_\_\_\_\_

9. ¿Cuánto tiempo ha pasado desde que se le hizo el último mamografía?

**Lea si fuera necesario:**

- 1. En lo que va del último año (1 a 12 meses)
- 2. En lo que va de los últimos 2 años (13 a 24 meses)
- 3. En lo que va de los últimos 3 años (25 a 36 meses)
- 4. En lo que va de los últimos 5 años (37 meses a 5 años)
- 5. Más de 5 años
- 88 No sé/No estoy seguro/a
- 99 Rehusa

10. ¿Más o menos cuántos mamogramas ha tenido usted en los últimos 5 años?

- 1. Número de mamogramas \_\_\_\_\_
- 2. Ninguno
- 88 No sé/No estoy seguro/a
- 99 Rehusa

11. ¿En el último año, le ha recomendado el doctor u otro profesional de la salud a usted para que se haga un mamograma?

1. Sí

2. No

88 No sé/No estoy seguro/a

99 Rehusa

12. ¿Cuanto pagó usted por este mamograma? ¿NADA, SOLO UNA PARTE, o pagó el TODO EL COSTO?

1. No pagué NADA del costo

2. Pagué UNA PARTE del costo

3. Pagué TODO el costo (**Si ésta es la respuesta dada, pase a la pregunta 14**)

88 No sé/No estoy seguro/a

99 Rehusa

13. ¿Cuál de las siguientes fuentes o medios pagó por el costo (en parte/en total) de este mamograma?

1. Aseguranza médica privada

2. Medicare

3. Medicaid

4. Clínica gratuita

5. Otra fuente \_\_\_\_\_

14. ¿Cuál es la razón principal por la que usted se ha hecho este mamograma?

1. Es parte rutinaria del examen físico/prueba de despistaje

2. Por un problema específico del seno

3. Primer mamograma

4. Historial familiar

5. Otra fuente \_\_\_\_\_

88 No sé/No estoy seguro/a

99 Rehusa

15. ¿Conoce usted los resultados de su mamograma?

1. Sí

2. No

88 No sé/No estoy seguro/a

99 Rehusa

16. ¿Cuáles fueron los resultados de su mamograma?

1. Normal

2. Abnormal/Se requiere re-evaluación o seguimiento

3. No recuerdo haber recibido resultados



17. ¿ Después de haber recibido los resultados de su mamograma, le dieron una cita de re-evaluación o seguimiento?

- 1. Sí
- 2. No
- 88 No sé/No estoy seguro/a
- 99 Rehusa

18. ¿Alguien le habló sobre los resultados de su mamograma en persona?

- 1. Sí
- 2. No
- 88 No sé/No estoy seguro/a
- 99 Rehusa

18a. ¿Alguien le habló sobre los resultados de su mamograma por teléfono?

- 1. Sí
- 2. No
- 88 No sé/No estoy seguro/a
- 99 Rehusa

19. ¿Entendió usted la explicación que le dieron sobre los resultados de su mamograma?

- 1. Sí
- 2. No
- 88 No sé/No estoy seguro/a
- 99 Rehusa

20. ¿Se le mencionó a usted por cualquiera de las personas que necesitaría más pruebas?

- 1. Sí
- 2. No
- 88 No sé/No estoy seguro/a
- 99 Rehusa

21. Debido a dichos resultados, ¿qué otros exámenes o cirugías se le hicieron?

- 1. Ninguno (**Si ésta es la respuesta dada, pase a la pregunta 23**)
- 2. Otro mamograma
- 3. Ultrasonido
- 4. Examen clínico del seno
- 5. Biopsia con aguja
- 6. Tumor/extracción de masa/lumpectomía
- 7. Quitar el seno/mastectomía

22. ¿Fueron las cirugías u otros exámenes adicionales lo que señalaron que usted tenía cáncer?

1. Sí

2. No

88 No sé/No estoy seguro/a

99 Rehusa

23. ¿Tuvo usted algún problema con alguno de los siguientes aspectos para obtener exámenes de re-evaluación o seguimiento?

Tuvo usted un problema con.... (LEA LAS RESPUESTAS)

El recibir los resultados del mamograma	Sí	No
Dificultad en hacer/recibir citas de re-evaluación o seguimiento	Sí	No
Cancelación por parte del hospital de citas de re-evaluación o seguimiento	Sí	No
Pérdida o extravío de los resultados de su mamograma	Sí	No
El hospital le cambia la cita a otra fecha para su re-evaluación o seguimiento	Sí	No
Cita dada de re-evaluación o seguimiento le es inconveniente	Sí	No
Necesita faltar al trabajo para poder asistir a su cita de re-evaluación o seguimiento	Sí	No
Falta de transportación para asistir a su cita	Sí	No
Problema de cubrir el costo de su examen de seguimiento	Sí	No
Recibir una cuenta inesperada de su examen de re-evaluación o seguimiento	Sí	No
Problema con la cobertura de la aseguranza médica para su examen de re-evaluación o seguimiento	Sí	No
Se espera mucho tiempo para obtener una cita de re-evaluación o seguimiento	Sí	No
Se espera mucho tiempo para poder consultar al doctor en su cita de re-evaluación o seguimiento	Sí	No

24. ¿Alguna vez se le ha hecho alguna operación (cirugía) para extirpar o quitar alguna masa o bulto de su seno que no fuera cáncer?

1. Sí

2. No (Si ésta es la respuesta dada, pase a la pregunta 26)

3. La masa removida era cancerosa

88 No sé/No estoy seguro/a

99 Rehusa

25. ¿Cuántas cirugías (operaciones) de este tipo ha tenido usted?

---

88 No sé/No estoy seguro/a

99 Rehusa

26. ¿Alguna vez, han tenido cáncer del seno, su madre, hermanas, o hijas?

1. SíCuál/es (madre, hermanas, hija) \_\_\_\_\_

2. No

88 No sé/No estoy seguro/a

99 Rehusa

Un examen clínico de los senos es un examen por tacto de los senos por un doctor u otro profesional de salud para detectar masas u otras señales del cáncer del seno.

27. ¿Alguna vez le ha hecho (un doctor u otro profesional de salud) un examen clínico del seno para detectar masas u otras señales del cáncer al seno?

1. Sí

2. No **(pase a la pregunta 29)**

88 No sé/No estoy seguro/a

99 Rehusa

28. ¿Cuándo fue su examen clínico de los senos más reciente que le haya hecho un doctor o profesional del cuidado de la salud?

1. Hace algunos días

2. Hace algunas semanas

3. Hace algunos meses

4. Hace algunos años

88 No sé/No estoy seguro/a

99 Rehusa

**Ahora, me gustaría preguntarle sobre exámenes del seno hechos por usted mismo/a — esto es, un examen por tacto de sus senos que usted se hace a sí mismo/a para detectar masas/abultamientos y otras posibles señales del cáncer.**

29. ¿Sabe usted como examinarse sus senos para detectar masas o abultamientos?

1. Sí

2. No

88 No sé

99 Rehusa

30. ¿Qué tan a menudo se examina usted los senos?

1. Nunca

2. Una vez al mes

3. Una vez cada tres meses

4. Otro, especifique \_\_\_\_\_

**Favor de decirme si usted está de acuerdo o en desacuerdo con las siguientes declaraciones:**

31. A pesar de los avances de la medicina moderna, el cáncer del seno es tan serio y peligroso como lo fue hace varios años.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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32. Hay una buena probabilidad de que el cáncer en estos momentos se esté desarrollando en mi seno.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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33. Yo soy más vulnerable al cáncer del seno que cualquier otra persona.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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34. La mayoría de las mujeres que desarrollan cáncer del seno tienen efectos secundarios serios tanto emocionales como físicos.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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35. Las probabilidades de desarrollar cáncer del seno son pocas.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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36. Hacerse mamogramas con regularidad es el mejor método y el más efectivo en la detección temprana del cáncer.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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37. Hay muchas maneras de tener cáncer hoy en día, es una cuestión de tiempo; de una vez por todas, debería resignarme y aceptarlo así.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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38. En estos momentos, corro el riesgo de desarrollar cáncer del seno.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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39. La posibilidad de desarrollar cáncer causa que quiera hacerme un mamograma cada año.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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40. De tener un mamograma anormal, yo puedo ir a los exámenes de seguimiento.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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41. Hacerme un mamograma cada año no va a mejorar por mucho mis probabilidades de sobrevivir cáncer del seno.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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42. Sólo el tiempo dirá si desarrollo cáncer del seno, no se puede hacer nada, tan sólo esperar.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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43. Si me hago mamogramas con regularidad, las probabilidades de que detecten cáncer son extremadamente altas.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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44. De tener un mamograma anormal, yo creo que puedo obtener todos los exámenes de seguimiento.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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45. De tener un mamograma anormal, yo tengo fé de que el cáncer se va a detectar a tiempo y yo sobreviviré.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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46. Si lo que el destino le guarda a uno es morir de cáncer del seno, así será; en realidad, es muy poco lo que usted puede hacer sobre eso.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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47. Apesar de los avances en los procedimientos médicos, el mejor tratamiento para el cáncer son las técnicas radicales de cirugía.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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48. Otras mujeres son más hábiles que yo en asistir a las citas de seguimiento.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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49. Es fácil asistir a las citas de seguimiento.

muy en desacuerdo	en desacuerdo	ni de acuerdo ni en desacuerdo	de acuerdo	muy de acuerdo
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## Datos demográficos

50. ¿Cuántos años tiene usted?

Edad en años \_\_\_\_\_

88 No sé

99 Rehusa contestar

51. ¿Cuál es el grado o año más alto de escuela que completó?

1. Nunca asistí a la escuela o tan sólo jardín de niños
2. Grados 1 hasta 8 (Primaria)
3. Grados 9 hasta 11 (Algo de Secundaria)
4. Grados 12 o GED (Se graduó de la Secundaria)
5. Universidad 1 año hasta 3 años
6. Universidad 4 años o más (Graduado de la Universidad o Título Universitario)
- 99 Rehusa

52. Está usted:

1. Casado/a
2. Divorciado/a
3. Viudo/a
4. Separado/a
5. Nunca ha estado casado
6. Un miembro de una pareja no casada
- 99 Rehusa

53. ¿En estos momentos, está usted... (**LEA LAS RESPUESTAS**)

1. Trabajando a jornal, a sueldo
2. Trabajando por cuenta propia, por sí mismo
3. Sin trabajo por más de un año
4. Sin trabajo por menos de un año
5. Ama de Casa
6. Un/a estudiante
7. Retirado o Jubilado
- 99 Rehusa contestar



54. De las siguientes categorías, ¿cuál describe mejor sus ingresos anuales de la casa de todas las fuentes o medios?

1. Menos de \$5,000
2. 5,000 a 9,999
3. 10,000 a 19,999
4. 20,000 a 29,999
5. 30,000 a 39,999
6. 40,000 a 49,999
7. 50,000 y más
- 88 No sé
- 99 Rehusa

**Esa fue mi última pregunta. Le agradezco el haber tomado de su tiempo para completar esta encuesta importante.**

## VITA

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#### EDUCATION

B.A. Latin American Studies, Mount Holyoke College, S. Hadley, MA, 1983  
 M.P.H. Behavioral Sciences, University of California, Berkeley, CA, 1989  
 M.P.H. Health Education, University of California, Berkeley, CA, 1990  
 Ph.D. Health Education, Texas A&M University, College Station, TX, 2006

#### PROFESSIONAL EXPERIENCE

**Health Education Specialist/Affiliate Trainer**, The Susan G. Komen Breast Cancer Foundation, Dallas, Texas (2000-2005)

**Public Health Educator – COPC**, Parkland Memorial Hospital, Dallas, Texas (1990-2000)

**Research Assistant/ Health Education Internship**, "I HAVE A FUTURE" Program, Nashville, Tennessee (1989-1990)

**Health Education Internship**, The Marin Institute for the Prevention of Alcohol and Other Drug Problems, San Rafael, California (1989)

**Research Assistant**, Oakland Cancer Control Program, Oakland, California (1988-1989)

**Research Assistant**, University of California, Berkeley, California, Minority Enrollment Summer Program (1988-1989)

**Family Community Worker**, St. Margaret's Hospital for Women, Boston, Massachusetts (1985-1987)

#### PUBLICATIONS

Guidry, J. J., Matthews-Juarez, P., & **Copeland, V.** (2003). Barriers to breast cancer control for African-American women. *Cancer*, 97, 318-323.

#### PRESENTATIONS

*The Susan G. Komen Breast Cancer Foundation: An Overview.* Minority Women's Health Summit, 2004.

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