# A COMPARISON BETWEEN US AND AUSTRALIAN HEALTHCARE DELIVERY 

by

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Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Health and Human Services in the

Bitonte College of Health and Human Services

Screening Mammography: A Comparison between US and Australia Healthcare Delivery
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#### Abstract

US and Australian women's experiences with screening mammography were studied with regard to healthcare delivery systems: the Australian government provides free screening; the US does not. Methods: Self-report surveys concerning mammography experience were administered to 402 Australian and 381 US women having mammograms on mobile facilities. Results: There were no differences in compliance with mammography guidelines. US women had significantly more knowledge about breast cancer risks. Seeing the mobile facility and receiving a reminder were important cues to action for Australians, having a doctor's recommendation was more important for US women. Most Australian women would continue screening if they had to pay for it; most US women said they would be more likely to be compliant if mammography were free.


## TABLE OF CONTENTS

Abstract ..... iii
List of Tables ..... vi
List of Figures ..... vii
Acknowledgements ..... vii
Chapter 1: Introduction and Statement of Problem ..... 1
Breast Cancer in the United States and Australia. ..... 1
Methodology in Brief ..... 3
Statement of the Problem and Research Questions ..... 3
Significance of the Study ..... 4
Delimitations ..... 4
Limitations ..... 5
Basic Assumptions ..... 5
Definitions ..... 6
Chapter 2: Review of the Literature ..... 10
Breast Cancer Incidence and Risk Factors ..... 10
Mammography Screening ..... 11
The Health Belief Model. ..... 13
Differences in Healthcare Delivery in the US and Australia. ..... 16
United States: Healthcare Delivery for Mammography Screening ..... 17
Australia: Healthcare Delivery for Mammography Screening ..... 25
Chapter 3: Procedures ..... 32
Subjects ..... 32
Pilot Studies ..... 35
Administration of Instruments ..... 36
Development of the Instrument ..... 39
Chapter 4: Analysis of the Data ..... 45
Profile of the Subjects ..... 45
Elements of the Problem ..... 49
Results: Compliance with Guidelines for Mammography ..... 49
Results: Knowledge of Breast Cancer Risk ..... 51
Results: Cues to Action ..... 54
Results: Attitudes of Australian and US Women Concerning Payment ..... 56
Chapter 5 ..... 61
Summary ..... 61
Conclusions ..... 65
Discussion and Implications ..... 65
Recommendations for Further Study ..... 72
Bibliography ..... 74
Appendix A: Approval from Human Subjects Review Committee ..... 79
Appendix B: Approval from MammoVan, Inc ..... 80
Appendix C: Approval from BreastScreen NSW Northcoast ..... 81
Appendix D: Protocol for Instrument Administration ..... 82
Appendix E: Survey Instruments ..... 84

## LIST OF TABLES

Table 1. Subject profiles: US and Australian Samples, 2000 ..... 48
Table 2. Summary of Compliance Rates for US, Australia, and US Groups, 2000 ..... 50
Table 3. Comparison of Correct Identification of Risk Factors for Breast Cancer by US and Australian Participants, 2000 ..... 53
Table 4. Comparison of Cues to Action Encouraging Women to Engage in Mammography Screening in US and Australia, 2000 ..... 54
Table 5. US: Would You Be More Likely to Get Regular Mammography if It Were Always Free? 2000 ..... 57
Table 6. US: "Have You Ever Decided Not to Get a Mammogram Because It Cost Too Much?" 2000 ..... 58
Table 7. US: Would You Be as Likely to Have Regular Mammography if You Always Had to Pay More Than $\$ 20$ for a Mammogram? 2000 ..... 59

## LIST OF FIGURES

Figure 1. Health Belief Model relating to mammography
$\qquad$
behavior14

Figure 2. Maps of US and Australia including identifying
location of each research site34

## ACKNOWLEDGEMENTS

- I could not have completed this thesis without the patience and support of my husband, Lloyd, who fed me, encouraged me and put up with being a "single" husband for the duration of my master's program.
- The help of my best friend, Anita Lee, B.S.R.T, and Beth Trevan, director of BreastScreen NSW Northcoast, was invaluable. Without their help, and the help of the staff on the Breast Screen mobile unit, I could not have collected the Australian data. Thanks to all of you!
- The cooperation of the staff on the Mammovan in collecting the information from the US sample was truly appreciated. Thanks, ladies!
- A very special thanks to my thesis advisor, Carol Mikanowicz, who patiently proofread my thesis numerous times during its development and suggested ways for me to improve it. Thanks so much for your encouragement during my Master's studies!
- Another special thanks to Gordon Frissora, Ph.D., who patiently helped me with the statistical analyses.


## CHAPTER 1

## INTRODUCTION

## Chapter Overview

This chapter outlines the background of the study. It addresses the problem of breast cancer and the importance of mammography screening in the United States (US) and Australia, using the Health Belief Model as the theoretical basis for the study. The components of this chapter are the statement of the research questions and significance of the study, along with a discussion of the limitations and delimitations of the study. Additionally, the basic assumptions underlying this topic are stated, and definitions of terms necessary for understanding the study are provided.

## Breast Cancer in the United States and Australia

Breast cancer morbidity and mortality is a major health issue for women. In the US, it is the most commonly diagnosed cancer among women, and the second leading cause of cancer death. The age adjusted incidence rate for breast cancer in the United States in 1998 was $110 / 100,000$ women, and the rate of death was 28/100,000 (Centers for Disease Control and Prevention [CDC], 2000a). In Ohio, the US location of this study, the mortality rate for breast cancer in 1998 was 31.2/100, 000 women (Ohio Department of Health, 1998). In Australia, breast cancer is the most commonly diagnosed cancer in women aged 35 and older, and the leading cause of cancer death, as well. In 1998, the age-adjusted incidence rate in Australia for breast cancer was $98.5 / 100,000$ women, and the death rate was $23 / 100,000$ (Australian Institute of Health and Welfare [AIHW], 1999). In New South Wales (NSW), the Australian location of this study, the mortality rate for breast cancer was $24 / 100,000$ women in 1995 , just slightly higher than the national rate (Kricker A., Farac K, Smith D, Sweeny A, McCredie M, \& Armstrong B, 1999).

Currently, the most promising means of reducing deaths from breast cancer is early detection of malignancies while they are quite small and have not yet metastasized outside the
breast tissue. Three methods are used to screen for breast cancer: clinical breast examination (CBE), breast self-examination (BSE), and mammography screening. Of these, only mammography is able to find very tiny lesions before either the woman or healthcare provider can physically palpate them. Technological improvements in mammography in the late 1980s and the institution of strict quality assurance programs have made mammography the most valuable tool for detecting small breast lesions through mass screening efforts.

Among the major risk factors for breast cancer are being female and getting older, having a family history of breast cancer, early menarche and late menopause, reproductive history of women, and the absence of breastfeeding. The two greatest risk factors for the disease are being female and aging, with 70-85 percent of breast cancer being diagnosed in women fifty years of age and older (BreastScreen Australia, 2000a, ACS, 2000a). Since none of these risk factors may be mitigated by personal health habits, early detection by mammography screening is seen as the best way to improve mortality rates for breast cancer.

The healthcare delivery and promotion for mammography screening is very different for each country. In the US, a woman must find a way to pay for her mammogram by one of three means: (a) by securing private or public insurance coverage, (b) by attending a private or government funded community agency that offers free mammography to low income women, or (c) by paying out-of-pocket for the full cost of the mammogram. US federal, state, and community agencies and individuals all work toward providing mammography screening for all US women, but the effort is uncoordinated. In Australia, a government-administered program, BreastScreen Australia, offers mammography to women 40 years and older at no expense to participants. This program acts as a national registry for mammography screening and insures that cost is not a barrier to any eligible woman who wishes to receive a mammogram.

## Methodology in Brief

The Health Belief Model is used as the theoretical basis of this study. This theory has been used as the conceptual framework in many studies to explain people's health related behaviors.

Self-report surveys are administered to an Australian sample and a US sample of women receiving mammography from mobile mammography providers in each country. MammoVan Inc. (Boardman, Ohio) provides mammography screening to six counties in northern Ohio, and BreastScreen NSW Northcoast provides screening in the southern part of NSW. Survey instruments are designed to elicit information about participant demographics, as well as mammography experience, knowledge about breast cancer risk, and information about factors influencing mammography, and attitudes toward the cost of mammography. This study compares and contrasts the responses of the samples.

## Statement of the Problem and Research Questions

The US and Australia have differing methods of healthcare delivery for mammography screening: the Australian government provides mammography screening free to eligible women; the US government does not provide free screening. The purpose of this study is to compare the effects of different healthcare delivery systems on mammography screening utilization in the US and Australia.

- Does the difference in healthcare delivery systems-fragmented and complex in the US, and government supported and coordinated in Australia-affect the compliance rates for mammography?
- Is there a difference in knowledge levels of breast cancer risk between the two samples?
- What are the most effective cues to action in each country that influence women to seek mammography screening?
- What are the attitudes toward different methods of payment for mammography screening in the US and Australia?


## Significance of the Study

The comparison between the US and Australia demonstrates the strengths and weaknesses in each country's screening efforts, and allows each country to learn from the other. This knowledge can be used to increase mammography screening behavior in both countries.

## Delimitations

- Because of the researcher's access to the resources of mobile mammogram facilities in northeastern Ohio (MammoVan, Inc., Boardman, Ohio) and the north coast of New South Wales (NSW) (BreastScreen NSW Northcoast), the study was limited to women 40 years of age and older who were utilizing the services of these facilities. Use of these mobile facilities limited the geographical area of the study, as well as restricting the study only to women who were having mammograms. This condition excludes the inclusion of women who do not get regular mammograms, and having information from this group of women would have permitted evaluation of barriers to mammography that did not apply to women receiving mammography.
- The choice of purposive sampling limited the study only to women having mammograms on MammoVan or BreastScreen mobile facilities. The use of a non-random sampling technique resulted in samples that may not be representative of the populations to which the participants belong. This limitation does not permit generalization of the findings to the entire populations of women receiving mammography screening.
- Men were excluded from consideration because breast cancer is not a significant problem for men: only 0.22 percent of breast cancer deaths are in men.
- Self-report nature of the instrument may lead to biased responses.
- Even though the purpose of the study was to compare the two samples on the basis of free versus payment for mammography, information about barriers other than cost would have added more depth and meaning to the findings.


## Limitations

The following were limitations of the study:

- There was missing data from some of the instruments. This consequence was unavoidable because of the successive nature of the question, "is this your first mammogram". Women who answered "yes" to this question were asked to pass over several of the following questions because these questions only applied to women who had previously had mammograms. In addition, some questions about ethnicity and age were not answered in both samples. It was particularly notable in the Australian sample, as questions about age and ethnic background are considered socially sensitive and possibly inappropriate.
- Lack of funding did not permit the researcher to personally instruct instrument administrators or collect data in Australia.


## Basic Assumptions

Using Comte's positivist paradigm as a basic guide, the researcher assumed there is an objective reality to be observed (Babbie, 2001). These assumptions include:

- The researcher remains objective and does not influence the participants. In this study, self-report instruments are used that protect the participants' anonymity.
- The researcher uses a fixed research design emphasizing the gathering of measurable, quantitative data.
- The researcher assumes that phenomena are not random events; rather there is a preceding cause for any event. This assumption allows a greater understanding of mammography screening practices in the US and Australia.
- The researcher seeks generalizations that may be applied to the population of women ages 40 and older.

Some of the basic assumptions concerning utilization of mammography screening used in this study are as follows:

- Women are aware of the morbidity and death associated with breast cancer.
- Women want to avoid having breast cancer and the negative outcomes associated with it.
- Mammography screening is currently the best way to detect breast cancer when it is in its earliest and most curable stage.
- In order to detect breast cancer at an earlier and more curable stage, women are willing to obtain mammography screening.
- If women are not getting regular mammograms an explanation must be sought.


## Definitions

The following terms are defined as used in this study:
Prevention-any action that protects and promotes health and healthy behaviors
Risk factors-biological, psychosocial, or behavioral conditions that might influence a person's likelihood of susceptibility to an illness (Healthy People 2010, 2000b) Cancer (malignancy) -disease in which uncontrolled cell division in an organ or organ system causes harmful effects on the body's functioning and can spread and affect other parts of the body (Healthy People 2010, 2000b)

Breast cancer-a malignant growth in the tissues of the breast
Metastasis-occurs when cancer cells spread beyond the original tumor to other parts of the body Clinical breast examination (CBE)-manual palpation of the breast by a trained health practitioner in order to detect breast masses

Breast self-examination (BSE)-manual palpation by a woman of her own breasts for the purpose of becoming familiar with her breasts in order to detect any change that might occur

Mammography-an X-ray procedure using very low doses of radiation to visualize internal breast structures.

Screening mammography, mammography screening-mammography used to detect breast cancer in asymptomatic women, as distinguished from diagnostic mammography, which is used to evaluate the breasts of women with symptoms such as lumps, thickening, discharge, or a previous history of breast cancer surgery.

Asymptomatic-without symptoms of disease, in this case, no breast masses, tenderness, or other breast changes associated with breast cancer.

Film/screen systems-used in mammography screening. Film/screen systems consists of very high resolution x-ray film sandwiched between two layers of intensifying screens which serve to greatly reduce the radiation exposure to the patient and enhance the resulting image quality. Radiographer-a specially trained technologist who performs x-rays examinations, including mammograms.

Incidence rate--the number of new cases that occur in a given population in a given time period. It is usually presented as the number of new cases per 100,000 of the population at risk; also called the morbidity rate (Healthy People 2010, 2000b). All rates cited in this study are ageadjusted.

Mortality rate-the frequency of deaths in a specific population within a specified period of time (Healthy People 2010, 2000b). All rates cited in this study are age-adjusted.

Ductal carcinoma in situ (DCIS)_a very early stage of breast cancer in which the cancer cells are confined within the milk ducts in the breast and have not spread past the duct's membranes. This form of breast cancer can only be detected by mammography screening because it cannot be manually detected by CBE or BSE. One of the signs of DCIS is abnormally shaped calcifications in the breast tissue that appear as tiny densities on a mammogram.

Calcification-deposits of calcium salts in body tissues that may be visualized on a mammogram

Health Belief Model (HBM)-describes the theoretical relationship between an individuals' beliefs about health and their actual health behavior. The beliefs consist of: (a) perceived threat which include the person's perceived susceptibility or vulnerability to the disease and the perceived seriousness of the disease (b) perceived benefits of the health behavior (c) perceived barriers or obstacles preventing the health behavior. (d) cues to action, environmental triggers that influence a person's likelihood to engage in health behavior (Becker, et. al., 1977). Social marketing-using the theory and principles of marketing to persuade individuals to adopt healthy behaviors for the benefit of the individual and society as a whole.

Lymph node (lymph gland)_-part of the lymphatic system and act as a filter. Lymph nodes collect white blood cells and cancer cells. If, when removed during breast surgery, the axillary (underarm) nodes contain cancer cells, a breast malignancy has spread beyond the confines of the breast.

Fee-for-service-a system of payment for healthcare services in which a payment is rendered to the provider of the health service

Health maintenance organization-a legal corporation which offers health insurance and medical care. It usually offers a wide range of preventive and medical services at a fixed price. Free mammograms-US women who do not have insurance coverage and receive free mammograms from their employer or from a community agency are considered to be the recipients of a free mammogram

Insurance mammograms-women whose insurance policy paid or partially paid for their mammograms are considered to be the recipients of an insurance mammogram Self-pay mammograms-women who had no insurance coverage and had to pay for their mammograms out-of-pocket are considered to be recipients of a self-pay mammogram. Recommended guidelines for mammography screening-In the US, current recommendations suggest annual or biannual mammography for women who are 40-49 years of age, and annually for women 50 and older. BreastScreen Australia's recommendations target women from ages 50
to 69 , suggesting a mammogram every 2 years. However, any woman older than 40 is welcome to participate and follow the screening guidelines.

Compliance in the Australia and US. For simplicity, compliance is measured by having had a mammogram within the previous two years.

Knowledge of breast cancer risks-measured by choosing the answer "very important" for the risk factors of being a woman, growing older, and family history of breast cancer. In addition, having knowledge of breast cancer risks will be measured by US participants selecting "one in eight women" as the lifetime risk for breast cancer, and Australian participants choosing "one in eleven women."

## Summary

This chapter provided background information concerning breast cancer in the US and Australia, and how early detection of small breast cancers by mammography screening can save lives. It introduced the theoretical construct used in this study, and the research questions to be addressed. Then the research was justified, the methodology was briefly introduced, definitions of terms used in this study were provided, and limitations and delimitations of the study were outlined. On the basis of these foundations, this report can proceed with a detailed description of the research.

In the following chapters, a review of the literature will be provided and procedures for the study will be addressed, followed by analyses of the data. Lastly, the summary and conclusions of the study will be presented.

## CHAPTER 2

## REVIEW OF THE LITERATURE

## Chapter Overview

The purpose of the study is to examine how the difference in healthcare delivery in the US and Australia affects mammography screening behavior. The review of the literature consists of:

- A background of breast cancer incidence and risk factors
- The development of mammography as a screening tool
- Differences between US and Australia in terms of their healthcare delivery of mammography screening
- Use of the Health Belief Model (HBM) as the theoretical basis for the research
- The components of the HBM: barriers to mammography, the perceived vulnerability to breast cancer, cues to receiving mammography screening. These features of the HBM will be discussed separately for each country.


## Breast Cancer Incidence and Risk Factors

Breast cancer incidence and mortality is of great concern both in Australia and the United States. It is the most commonly diagnosed cancer in the US, and it is the most frequently diagnosed cancer in women aged 35 and older in Australia (American Cancer Society [ACS], 2000a, [AIHW], 1999). Breast cancer is the most common cause of cancer death of women in Australia (AIHW, 1998), and the second most common in the US, exceeded only by lung cancer (ACS, 2000a). In Ohio, the mortality rate for breast cancer in 1998 was $31.2 / 100,000$ women (compared to the national mortality rate of $28 / 100,000$ women), surpassed only by deaths from cardiovascular disease and lung cancer (Ohio Department of Health, 1998). In NSW, the mortality rate for breast cancer was $24 / 100,000$ women in 1995 , just slightly higher than the national rate of $23 / 100,000$ women (Kricker A., Farac K, Smith D, Sweeny A, McCredie M, \& Armstrong B, 1999). Among the major risk factors for breast cancer are being female and getting
older, having a family history of breast cancer, early menarche and late menopause, reproductive history of women, and the absence of breastfeeding. The two greatest risk factors for the disease are being female and aging, with 70-85 percent of breast cancer being diagnosed in women fifty years of age and older (BreastScreen Australia, 2000a, ACS, 2000a). Since none of these risk factors may be mitigated by personal health habits, early detection by mammography screening is seen as the best way to improve mortality rates for breast cancer.

Women over the age of fifty are at highest risk for breast cancer, and regular mammography screening in this target population will reduce the death rate and associated disability by about 20 to 30 percent (Healthy People 2010, 2000a; AIHW, 1999). Reduction in cancer rates can decrease the rising cost of health care, especially in the rapidly aging population, allowing limited healthcare dollars to be spent on other ailments; and reduce the devastating effects of breast cancer on individuals and their families.

It is the aim of screening programs to reduce mortality in this population by detecting breast cancer in its earliest, most curable stage. When breast cancer is diagnosed at an early stage in which there is no lymph node involvement, the survival rate is 96 percent (ACS, 2000b). Since mammography screening is the most effective way to detect early breast cancers, increased utilization of screening will result in lower mortality rates and a higher number of cures for breast cancer.

## Mammography Screening

There are three methods of breast cancer screening currently utilized: clinical breast examination (CBE) done by trained healthcare providers, breast self-examination (BSE) performed by the woman herself, and mammography. Of these three, only mammography can find very small tumors before either the clinician or the woman can palpate them. Mammography screening in both countries consists of two views of each breast, using X-ray film/screen combinations that are designed to reduce radiation exposure and optimize image quality. Of particular importance is the ability of mammography to detect ductal carcinoma in situ (ACS,

2000b). This cancer is characterized by the presence of cancer cells in the milk ducts of the breast that have not yet moved beyond the walls of the duct. This type of malignancy does not form a palpable mass, and the only way to detect this pre-invasive form of breast cancer is by the presence of minute abnormal calcifications on the mammogram. Mammography, while not a perfect screening method, will recognize about 90 percent of breast cancers, and is somewhat more accurate in post-menopausal women than in pre-menopausal women because of internal changes in breast structure that occur with age (ACS, 2000b). Fortunately, the accuracy of mammography increases as the age-related risk for breast cancer increases.

The wide use of mammography screening has become feasible because of international technological advances occurring in the late 1980s that increased image resolution of the mammograms and decreased the radiation dose to patients (Harris \& Vogel, 1997). During this time, improvements were made in film/screen technology, allowing for better images and a reduction in the number of sub-optimal, blurry films due to patient motion. In addition, enhancements of the x-ray instruments used for mammography contributed to the increased resolution of the resulting films. One of the greatest advancements was the development of dedicated mammography equipment that is specifically designed for imaging breast tissue. Together, these technological advances allowed for imaging of smaller, more subtle pathology, and mammography became a very useful screening tool for the detection of tiny, more curable breast cancers.

In addition to universally available improvements in x-ray film and equipment, both the US and Australia have quality assurance programs in place to monitor and evaluate the images, $x$ ray equipment, and film processors. These procedures are discussed in the sections on each country.

## Expectations of Screening

If there is to be a major reduction in breast cancer mortality in the populations at risk in both countries, a high number of women from the population must be screened and remain
adherent to a schedule of regular mammography. If breast malignancies are found in their earliest stages, before the cancer has spread to neighboring lymph nodes, it is estimated there will be a 20 to 30 percent reduction in breast cancer mortality for women aged $50-74$ years and 17 percent reduction in women aged 40-49 years (Healthy People 2010, 2000b; AIHW, 1999). In order for this decline in breast cancer morbidity to occur, a large segment, at least 70 percent, of the target populations must be screened regularly for at least seven years. It will take this length of time because when a screening program first begins, many new cancers are detected in later, less treatable stages. At this point in time, there will be an increased incidence rate because of the discovery of breast cancers that had remained undetected due to lack of screening. After screening has taken place for about 7 years, the incidence rates should fall, and most new cancers will be very small (AIHW, 1999). Because these tiny malignancies have a greater cure potential, the mortality rates should decrease.

## The Health Belief Model

Using the Health Belief Model (HBM) as a theoretical basis, the researcher examined the differences in mammography screening the US and Australia (Becker, Haefner, Kasl, Kirscht, Maiman, \& Rosenstock, 1977). HBM has often been used as the theoretical foundation to explain health related behaviors, including women's participation in mammography screening (Thomas, Fox, Leake, \& Roetzheim, 1996; Holm, Frank, \& Curtin, 1996). According to Becker, the probability that a person will engage in preventive health behavior depends on a number of factors. These factors include perceived susceptibility to the disease and seriousness of the health problem, cues which prompt women to take precautionary action (e.g. media, social network, health practitioner's recommendation, etc.), perceived personal threat of the disease, and the perceived benefits of and barriers to taking preventive action. All of these factors interact to determine the likelihood of health behavior occurring, but this study will focus on three aspects: perceived susceptibility, perceived barriers, perceived susceptibility, and cues to action. Figure 1 illustrates the relationships of these variables as they pertain to mammography screening.


Figure 1. Health Belief Model relating to mammography behavior

## HBM: Barriers

Differences in the delivery of mammogram screening in Australia and the US provided a basis to address how cost is perceived as a barrier to mammography in the US. One of the most commonly mentioned barriers to mammography screening is the expense associated with the examination. In Australia, a government-administered program, BreastScreen Australia, offers mammography to women 40 years and older at no expense to participants. This program insures that cost is not a barrier to any eligible woman who wishes to receive a mammogram. However, in the US, a woman must find a way to pay for her mammogram by one of three means: (a) by securing private or public insurance coverage, (b) by attending a private or government funded community agency that offers free mammography to low income women, or (c) by paying out-ofpocket for the full cost of the mammogram. Numerous studies have shown that cost is a significant barrier to mammography in the US (US Department of Health and Human Services [DHHS], 1998; Miller \& Champion, 1997; Schillinger, Mosbaek, Austin, Jack, Heumann, Moore, Bussman, Osdal, \& Fleming, 2000; Bush \& Langer, 1998).

## HBM: Perceived Susceptibility As a Barrier To Mammography

In keeping with the HBM, a woman must believe that she is at risk for breast cancer before she will be motivated to seek preventive care. In both the US and Australia, programs are in place that communicate information concerning breast cancer, breast cancer risks, and mammography screening. In Australia, since the inception in 1991 of the national breast screening program, there has been a massive media campaign and continuing research-driven efforts by BreastScreen Australia to educate women about breast cancer and to encourage their utilization of free mammogram screening.

In the US, Healthy People 2000 set forth its mission to increase the quality and years of life of US citizens, and to reduce health inequities within the racially, ethnically, and economically diverse segments of society (Healthy People 2010, 2000a). Since that time, there has been an increase in health promotion programs sponsored by government, private and community health sources aimed at increasing women's awareness of breast cancer. Particular
attention has been given to raising women's awareness of the risk factors associated with breast cancer and mammography as the primary screening tool. However, unlike Australia's focused effort to increase women's understanding of the importance of mammography screening, the informational effort in the US has not been overseen and continually reevaluated due to the fragmented approach to health promotion and health delivery in the US. This uncoordinated approach has resulted in many government and community agencies providing an abundance of mammography and breast cancer information through social marketing endeavors.

## HBM: Cues to Action

Cues to action, as described by the HBM, identify prompts from the environment that may encourage a person to seek preventive care. These cues may be something as simple as two friends talking about breast cancer and mammography. It might be having a friend or family member with breast cancer. Social marketing techniques have been used in both the US and Australia to raise awareness of breast cancer and mammography screening, with the purpose encouraging as many woman as possible to obtain regular mammograms. Cues to action that may be effective in the US may not be as useful in Australia.

## Differences in Healthcare Delivery in the US and Australia

Both countries have programs in place to encourage breast cancer screening with mammography, but each country uses a very different approach due to variations in healthcare system structure. In Australia, mammograms are provided at no cost to all women over the age of 40 ; however, the target age group for screening is women who are $50-69$ years of age (Cockburn \& Pit, 1998). In the US, however, a woman must find her own financial coverage for mammography services, which includes mammography being covered by her private health insurance plan, Medicare, or Medicaid. If a woman in the US does not have access to these insurance benefits, mammography may be provided free of charge by various community health services through government and private funding, or by personally paying for the exam. Each
country's approach to the management of breast cancer and screening will be discussed separately.

## United States: Healthcare Delivery for Mammography Screening

In the US, breast cancer is the most commonly diagnosed cancer in women and the second leading cause of cancer death, and a woman has a one in eight chance of developing breast cancer during her lifetime (National Cancer Institute [NCI], 2000). Prior to 1990, there was no focused effort to increase participation in breast screening by mammography. Again, this situation was due to the inability of x-ray technology to reliably and consistently detect small, subtle breast cancers. In the early 1990s, however, the US government was prepared to begin screening efforts. A description of health service delivery for mammography follows to supply background for the discussion of screening in the US.

US: Insurance coverage for mammography screening. The delivery of health services in the US is extremely complex due to the many different kinds of insurance coverage and the lack of insurance for a segment of the population. In the US, a woman either has variable coverage by health insurance policies (full or partial payment for screening mammograms), or does not have health insurance at all. Approximately 16 percent of the population in the US was uninsured in 1998, although this rate was only 11 percent in Ohio (Ohio Department of Health, 1999).

There are three insurance payment conditions in the US:

1. Medicare provides insurance coverage for annual mammography for women over the age of 65 , and since 1998 the patient does not have to meet a deductible in order to have annual mammography. This complete mammography coverage is particularly important because the incidence of cancer increases significantly for older women.
2. Medicaid provides insurance for eligible low-income women, and provides for annual mammography screening in most states. Ohio law mandates that Medicaid recipients receive coverage for routine mammography (CDC, 2000b).
3. The remaining women with health insurance have private coverage. In Ohio, state law mandates reimbursement for mammography for all women covered by health insurance policies (CDC, 2000b). However, because of the variety of health plans available, including HMOs or fee-for-service plans, a woman's policy may pay none of the cost due to out-of-pocket deductable, or for only part of the cost of the mammogram and may limit her choices of mammogram providers. Incomplete coverage for mammography may be a deterrent for underinsured and low income women.

US: Mammography coverage for women without insurance. The remaining women have no insurance. In the US in 1998-1997, the uninsured rate was about 16 percent, while in Ohio, the rate was significantly lower, at 11 percent Ohio Department of Health, 1999). For the most part, these are low income women who cannot afford the expense of a mammogram, and uninsured women use preventive healthcare less than those with insurance (Makuc, Freid, Freid, \& Parsons, 1994). In order to provide mammography screening to these medically underserved women, the CDC in 1990 initiated the National Breast and Cervical Cancer Early Detection Program (NBCCEDP, 2000). This program provides breast cancer education, health promotion, and mammography services to low income and underinsured women through partnerships with community health centers in all 50 states. In Ohio, these include Women's Health Advantage in Youngstown, Women's Preventive Health Services in Cleveland, and Women's Health Screening Network in Akron. Funding from the NBCCEDP is granted to these organizations, which then contract with other community agencies to provide screening mammograms to this segment of the population.

Other funding from federal institutions, such as the Health Care Financing Administration (HFCA), NCI, and the Food and Drug Administration (FDA); and from private institutions such as the Susan B. Komen Breast Cancer Foundation and Avon Products, Inc. also assists local community health organizations in providing mammography screening for underserved women.

However, despite the efforts of these agencies, in 1997 the proportion of women without
insurance who had a recent mammogram was 46.2 percent, compared to 71 percent of women with insurance who had recent mammography (CDC, 1998).

In addition to the CDC's NBCCEDP which provides mammography screening and breast cancer education to low income women, in 1990, the US introduced a national health promotion plan: Healthy People 2000 (Healthy People 2010, 2000a). This program was designed to engage federal, state, and local agencies, along with non-profit, voluntary, and professional organizations to promote health and prevent disease in all Americans. Local businesses, communities, and caring individuals were also invited to participate in activities to improve community well-being. These diverse groups of preventive health promoters use social marketing techniques to encourage breast cancer awareness and promote mammography screening as a tool to reduce breast cancer mortality. The fundamental goals of this strategic plan were to increase the quality and years of life of US citizens, and to reduce health disparities within the different segments of the diverse US population. As the decade ended, a new and updated version, Healthy People 2010 , is continuing to work toward restructured goals and expanding on the progress made by its predecessor.

One of the 28 focus area goals of Healthy People 2010 (2000a) is to reduce the new cases of cancer and the disability and death associated with them in all segments of society. Within this are the specific objectives for reducing the number of cancer deaths and increasing the utilization of mammography screening.

The first objective is to reduce the number of breast cancer deaths in the population of women of all ages to an age related rate of $22.2 / 100,1000$ women (Healthy People 2000a). The baseline rate of cancer deaths in 1998 was $27.7 / 100,000$ US women, and this rate is much higher in Ohio: $31.2 / 100,000$ women. This goal will be achieved only if a large majority of the women at risk are getting mammography on a regular basis. Improvements in the total breast cancer death rates are expected to become evident after seven years of regular mammography in this large majority of the target population.

Increasing the number of women getting mammography screening is the next objective, and increased participation in screening has been and will continue to be the way to fulfill the first objective. The Healthy People 2010 target rate for mammography screening for women 40 years of age and older is 70 percent. In 1998, the rate was 68 percent, both nationally and in Ohio, so that objective is close to being met (Healthy People, 2010, 2000b). However, there is disparity among different segments of the population regarding mammography. In 1998, 67 percent of women with middle or high incomes had mammograms within the past two years. In contrast, only 43 to 48 percent of women who were classified as being poor or near poor had been adherent to suggested mammography guidelines.

US: quality assurance for mammography. Prior to 1996, no program was in place to ensure the standards necessary to provide consistently high quality mammography. In 1997, HCFA sponsored the Mammography Quality Standards Act (MQSA) that provides for the strict regulation of the mammography screening process (FDA, 1992). Under these rules, there is mandatory annual inspection of all facilities that provide mammography to government sponsored insurance programs, such as Medicaid and Medicare. This inspection includes annual evaluation of x-ray equipment and film processing units, and verifies the certification and continuing educational status of the radiographers.

MQSA also requires that physicians interpreting the mammograms must meet specific training and mammography experience criteria, read at least 40 mammograms per month over a 2 year period, and accrue five continuing education hours in breast imaging techniques each year. These requirements are in place to improve the interpretation quality of mammograms.

In addition, MQSA requires accreditation by the American College of Radiology (ACR). This accrediting body stipulates that each facility submit sample mammograms that meet stringent quality standards that allow for the detection of small breast cancers. These quality assurance provisions help to assure the quality of mammography on a national basis.

Unfortunately, since the delivery of mammography screening is fragmented, there is no direct compilation of mammography data as is the case in Australia. Most information gathered about screening in the US is from the government sponsored programs that provide mammography, and from self-reports on surveys of US women.

## US: Perceived Vulnerability to Breast Cancer and Barriers to Mammography

US: Cost as a primary barrier. There are many barriers to mammography screening mentioned in the literature, but one of the greatest barriers is the cost associated with the examination. As expected, lack of healthcare insurance decreases the likelihood that a woman will receive mammography screening, despite the availability of government-funded mammography screening to women without health coverage. Currently, the National Center for Health Statistics (NCHS) states that approximately 10 percent of women between the ages of 40 and 65 are uninsured by either private or government health insurance (CDC, 1998). According to this research, which used the data from the 1991-1992 and 1996-1997 Behavioral Risk Factor Surveillance System (BRFSS), the mammography rates for women with insurance were 65.2 percent in 1991-1992, and 70.9 percent in 1996-1997. However the rates for women without insurance ( 9 percent of the sample) were substantially lower: 39.6 percent in 1991-1992 and 46.2 percent in 1996-1997. Even though programs are in place to provide uninsured women with mammography screening, many of these women did not receive mammograms. Previous research points out various barriers to mammography, but none specifically look at why women are not aware that screening services are available.

Another study concurs that cost remains an important barrier to mammography. A study by Miller and Champion (1997) used a convenience sample of 1083 women church members ( 78 percent Caucasian and 22 percent African American), who answered mailed surveys concerning knowledge and perceptions of breast cancer and mammography. The results of this study also suggest that cost is a barrier to mammography, especially for Caucasian women and low-income women of either racial background.

Other studies related to cost barriers to mammography examined screening between women of low and higher income levels. According to a study conducted by the NCHS, as the amount of out-of-pocket spending increased, the use of preventive medical services decreased (Makuc et al., 1994). According to NCHS (2000) in 1998, women with high incomes were about 60-70 percent more likely to get mammograms than the poorest women, regardless of the race or ethnic group to which they belonged. In addition, in 1998, 53 percent of women living below the poverty level were receiving regular mammography, compared to 72 percent of women at or above poverty level (CDC, 1998).

In other research, Facione (1999) interviewed a convenience sample of 838 women in non-healthcare settings about their use of mammography, in order to determine perceived access to health services and barriers to breast screening. This sample included women of various socioeconomic status (SES) and racial/ethnic backgrounds. Lack of money to pay for this service was the most commonly cited reason for not taking advantage of mammography screening. Also mentioned as an important deciding factor was whether or not the women perceived demeaning or prejudicial treatment during previous screening experiences.

US: other barriers. On the other hand, Bush and Langer (1998) found that having a medical provider was significantly associated with women having a mammogram in the previous 2-year period. A convenience sample of 2453 women ages 50 to 79 was recruited during screening at a Woman's Health Initiative site in San Diego. In this study, cost was suggestive as a barrier to mammography, but did not meet the significance cut-off of $\underline{p}=0.006$. Not having health insurance or a medical provider, less than 12 years of education, and having an income of less than $\$ 20,000$ per year were factors associated with non-participation in mammography screening. In another study, Valdini and Cargill (1997) explored the barriers to and frequency of mammography among women receiving healthcare at community health centers in six New England States. Even though subsidized mammography screening was offered at a low cost, the researchers found that only 55 percent of women 50 and older had mammography in the past two
years, and the rates were even lower in women aged 40-49 (45 percent). Valdini and Cargill found that the most common reason cited by a racially/ethnically diverse group of 3176 women 40 years of age and older was that the women did not think the exam was important for them. However, the second most common reason was the cost of the exam and/or lack of medical insurance.

Disparities in coverage for mammography exist between fee-for-service insurance plans and health maintenance organizations (HMOs). Fee-for-service insurance plans vary with regard to the amount of the mammography expense they cover (NCHS, 1994). Often, mammography is not a covered service, or the woman incurs a substantial out-of-pocket expense. Unlike many fee-for-service plans, HMOs generally cover the cost of preventive care. In this study of 1171 racially/ethnically diverse women, 62 percent of women enrolled in HMOs had mammography within the past year. Between 50 and 64 percent of women enrolled in fee-for service plans had recent mammography, depending on their educational level: a higher educational level was associated with greater usage among these women, but educational level did not affect mammography adherence by the HMO participants. The researchers suggest that comprehensive health coverage that includes screening exams may encourage greater use of mammography screening by all women.

In another study, researchers assessed the psychological barriers to regular mammography use, with the indicators of SES, fear of radiation, embarrassment, pain, anxiety, and cost being measured (Stein, Fox, \& Murata, 1991). Participants in a convenience sample of 586 Caucasian, 227 Black, and 150 Hispanic women were interviewed. Once again, cost was an important barrier to mammography screening. The results demonstrated a strong relationship between cost concerns and the use of mammography screening by African American and Caucasian women, and fear of pain by Hispanic and African American women.

US: health delivery experiment: the Oregon Health Plan. Very few states have offered comprehensive health plans to its uninsured residents; among them are Hawaii and

Oregon. What happens when mammography is provided to women who previously had no coverage for the screening exam? In 1994, the Oregon Health Plan (OHP) provided health insurance to all uninsured residents of Oregon (Schillinger, et al., 2000). Even though there were some limitations on covered services due to limited funding, mammography screening was extended to low-income women who did not previously participate consistently in screening. In this study, a random sample of 666 women was selected from the enrollment database of OHP. At the time of enrollment, only 34 percent of the women were being screened regularly, and 66 percent had not had a mammogram in the past two years. Cost was cited by 55 percent of the participants as the principal reason for their lack of mammography adherence. At the end of the second year of enrollment in OHP, 57 percent of women were up-to-date with screening, representing an increase of 23 percent. The researchers were also concerned with why more women did not receive screening exams. The study suggested that not receiving a recommendation for mammography from their healthcare provider, not believing in the importance of mammography, and not receiving regular medical care may negatively influence women's adherence rates, and may explain why some of the women did not take advantage of free screening.

This study is particularly interesting. Although mammography participation increased when previously uninsured women were enrolled in a comprehensive health insurance program that provided free mammography, some barriers still remain. This finding is important and may help to explain why some women in the US are not participating in regular mammography.

US: cues to action. Health promotion experts have an acute interest in discovering sources of motivation for women regarding regular utilization of mammography screening. Many studies mention the importance of a health provider's recommendation for screening. In one study, researchers observed that a physician's recommendation was one of the strongest predictors for mammography utilization (Friedman, Woodruff, Lane, Weinberg, Cooper, \& Webb, 1995). In another study, it was demonstrated that a physician's advice was again a key
motivator, and also mentioned mailed reminder letters as being effective social marketing tools to encourage mammography screening (Taplin, Barlow, Ludman, \& MacLehos, 2000).

Other cues to action have been explored, as well. Taplin's (2000) group also demonstrated that motivational and reminder telephone calls which included scheduling opportunities also increased mammography screening behaviors. A woman's social network has been shown to encourage women to seek mammography, as well. McCance, Mooney, Field, and Smith (1996) found that a woman's family and friends, as well as the influence of knowing someone with breast cancer increases mammography utilization. In their study of female church attendees, Miller and Champion (1997) noted that knowledge of breast cancer risk was a major predictor of mammography utilization.

## Australia: Healthcare Delivery for Mammography Screening

As mentioned earlier, Australian women die more often from breast cancer than from any other form of cancer. A woman living in Australia has a one in eleven chance of developing the disease in her lifetime (BreastScreen Australia, 2000b). Prior to 1991, no concerted efforts were made to reduce the climbing mortality rates from breast cancer, partly because of the lack of effective screening technologies (McGinness, 1999). However, once the improved x-ray instruments and ancillary equipment became available, Australia was ready to address the growing problem of breast cancer.

Australia has a two-tiered healthcare system, which, together, provide for most of the medical needs of its citizens. Medicare, a system funded by the federal government, is designed to provide access to healthcare services to all Australians. The private sector healthcare system is subsidized by the government and provides more choice and a wider availability of services for those women who choose to purchase private health insurance. Although Medicare was in place before the introduction of BreastScreen Australia, most screening procedures, including mammography screening, were not covered services (McGinness, 1999).

In 1991, representatives of the states, territories and the commonwealth governments agreed to jointly fund a nationwide breast cancer screening program out of concern for the rising rates of breast cancer. Current advances in mammography screening technologies now made mass screening an effective tool for detecting breast cancer. This decision was in line with the health delivery philosophy in Australia: equal access to all medical services. In this plan, mammography would be provided at no cost for all Australian women between the ages of 50 and 69 years at two-year intervals (BreastScreen Australia, 2000a). The goal was to decrease the morbidity and mortality associated with breast cancer. The plan, now known as BreastScreen Australia, was initiated in 1991 and was fully implemented in NSW and all other states and territories by 1994 (AIHW, 1998).

BreastScreen Australia. A short-term goal of the BreastScreen Australia program is to achieve a screening rate of 70 percent by the year 2000. This rate was chosen because it is essential that a high proportion of the female population be screened in order to realize the ultimate goal of a 30 percent reduction in breast cancer mortality rates (Scott, \& Bowen, 1995). Initial recruitment for participation in BreastScreen Australia was relatively simple. In Australia, every citizen must register to vote, and direct mailings to women in the target group from the electoral polls encouraged their participation in the new screening program (AIHW, 1998). The referral of a physician is not required for screening. Prior to the introduction of the national screening program, only about 20 percent of the population were being screened. Participation rates in the program during 1997-1998 were 54.3 percent of the target population, representing a 34 percent increase since the beginning of the program (AIHW, 1999). It is estimated that a seven year time frame of regular screening is necessary to achieve a reduction in breast cancer mortality rates (AIHW, 1998). Because BreastScreen programs were implemented in the states and territories at various times from 1991 to 1994, the full impact of the screening program is not yet apparent. While the current screening rate of 54 percent continues to fall short of the 70 percent objective, there has been steady progress toward this goal over time, and it is expected
that national mortality rates will begin to decrease by 2001 when all states' BreastScreen programs have been in operation for at least seven years.

BreastScreen Australia maintains its high standards by focusing on program management, monitoring, evaluation and accountability (AIHW, 1998). One of the ways this is accomplished is by collecting and analyzing data from all BreastScreen sites in order to monitor the program's effectiveness. The information gathered provides the basis for the direction of future policy and program development.

Australia: quality assurance for mammography. In order to ensure that mammograms are of the highest, most diagnostic quality, BreastScreen Australia's equipment must meet National Accreditation Requirements (BreastScreen NSW, 1999). This includes periodic scientific evaluation of all x-ray and film-processing devices to ensure they are operating at optimum levels.

In addition, the administrators of BreastScreen Australia realize that even the best equipment cannot produce the superior films necessary for the detection of breast cancer. The radiographers employed by BreastScreen Australia are highly skilled and attend several in-house continuing education programs per year. These training sessions involve topics such as quality assurance, processor chemical handling, and mammogram positioning techniques. This training serves to heighten the skill of the radiographers so that patient recalls and retake films due to technical errors are kept to a minimum and film quality is of the highest standard.

Another factor influencing the quality and success of the mammography screening program is the professional interpretation of the examination. Two specially trained physicians independently interpret each mammogram taken by the radiographers. This practice serves to reduce the number of false positive and false negative exams, minimize the number of unnecessary follow-up procedures, and maximize the number of small, curable cancers detected.

Australia: perceived barriers to mammography and perceived vulnerability to breast
cancer. While cost is not a barrier to mammography screening, Australia has its own barriers to
recruitment and adherence to the two year screening schedule recommended by BreastScreen Australia. The geography of the country creates difficulties. Excluding the large metropolitan areas, most of the population lives in small rural towns, many of which are isolated by great distances. Mobile BreastScreen units are utilized to provide service to the outlying regions, and transportation to the screening site is provided, if necessary. However, many women still have to travel great distances, and the availability of mobile services to these remote areas may be very limited.

Like the United States, Australia is culturally and ethnically diverse, and participation of people with low levels of education, women of non-English speaking backgrounds, and minority women (primarily Aboriginals and Torres Strait Islanders), is decreased compared to the majority Anglo-Saxon population (AIHW, 1998). To reach these women, special strategies are needed. Printed materials are prepared for non-English speaking women in their native languages. Scheduling the BreastScreen Van with Aboriginal communities requires working with local Aboriginal health workers, medical services, and health practitioners. Offering screening without appointments, assisting women to complete paperwork, and providing transportation to the BreastScreen site have all been found to be useful ways to encourage participation by Aboriginal women. Efforts are made on a continuing basis to encourage participation of these underserved women.

Other barriers also remain after cost is no longer of concern. Another study demonstrates perceived barriers to screening. Prior to the advent of BreastScreen Australia, but while free mammography was being offered to women living in Sydney, a random sample of women from this large metropolitan area was interviewed by telephone concerning attitudes and knowledge about mammography (Irwig, Cockburn, Turnbull, Simpson, \& Mock, 1991). All were aware that mammograms saved lives, but many did not understand the concept of screening as a preventive measure to be taken when healthy. The main barriers mentioned were concern about radiation ( 25 percent) and fear of the results ( 25 percent).

Early in the implementation stage of BreastScreen Australia, researchers were interested in the remaining barriers so that they might be able to address them and increase participation in the screening program. A purposive sample of ethnically diverse women from Central Sydney were interviewed by Adelson, Irwig, and Turnbull (1992) after the BreastScreen mobile unit had visited the area four times in a two year period. The results were that older, non-English speaking women were less likely to participate in screening, as were those with less than a high school education.

Munn (1993) surveyed a random sample of 167 women between the ages of 40 and 65 to determine why they had not attended the screening program during the 22 months it had been in operation. Apathy, lack of concern, and lack of perceived vulnerability to breast cancer were reasons noted for non-attendance by nearly 50 percent of the participants. Other barriers mentioned were fear of a positive mammogram result ( 39 percent), and non-referral by health provider (19 percent). Interestingly, since this BreastScreen program was less than two years old at the time of the study, many women cited cost as a barrier, even though no cost was involved and only 28 percent said that they would be willing to pay more than $\$ 55$ for a mammogram. The researcher suggested social marketing strategies to encourage non-attendees to begin mammography screening.

Cockburn, Sutherland, Cappielo, and Hevern (1997) conducted a study of 180 rural women to determine what factors were associated with attendance at the mobile screening service. Fifty percent of the sample did not attend screening in the ten-week period of its operation in the area. Compared with non-attendees, women were more likely to have screening if they perceived at least some personal risk of breast cancer. Contrary to the findings of other studies, there did not appear to be any difference in knowledge levels about mammography in the two groups, nor was there any difference in perceptions of pain, fear of the result, embarrassment, or radiation risk.

Since the inception of BreastScreen Australia, education of women concerning breast cancer has been a priority. According to one study, researchers found that many Australian women remain unknowledgeable about most risk factors for breast cancer despite vigorous educational and informational campaigns (Paul, Barratt,, Redman, Cockburn, \& Lowe, 1999). A stratified, quota system was used to select the sample. Three thousand women aged $30-69$ years from each state and territory in Australia were surveyed by telephone. They were asked questions about their knowledge and perceptions of breast cancer. Only five percent recognized age as a risk factor, and only about one third were able to correctly estimate the lifetime risk for beast cancer among Australian women, with most women underestimating their risk. Family history was correctly chosen as a risk factor by two-thirds of the sample. These results have implications in planning community education for breast cancer. In order to increase the screening rates of older women, more emphasis must be consistently placed on age rather than family history of breast cancer as a more global risk factor.

Australia: cues to action. Because BreastScreen Australia is a coordinated effort to enroll women in mammography screening, there is an acute interest in discovering the most effective methods for motivation. As mentioned previously, initial recruitment was made by mailed invitations to women in the target group from the mandatory election poll register. In the initial stages of the BreastScreen program, researchers noted cues to action mentioned most often by participants, including seeing the BreastScreen mobile van, recommendation from health practitioner, articles in the newspaper and other print media about mammography screening, and the influence of personal social networks (Adelson, et al., 1992). The researchers suggest that future focused social marketing efforts should be made to discover the barriers that discourage these women from attending breast cancer screening.

BreastScreen frequently polls its mammography participants to assess the current most effective ways to reach women. The most commonly methods at this time are reminder letters,
friend's or relative's prompting, and seeing the BreastScreen mobile unit (BreastScreen NSW Northcoast, 1999).


#### Abstract

Summary The incidence of and risk factors for breast cancer were reviewed. The development of mammography as the most useful tool for detecting breast cancer in its early stages was discussed. A comparison of the healthcare delivery systems and health promotion practices of Australia and the US was presented, outlining BreastScreen Australia's coordinated program providing breast health education and free mammography to all women over the age of forty. In contrast, the fragmented approach to healthcare delivery in the US creates many difficulties for women seeking mammography. In the US, there are no coordinated health promotion programs in place for breast health; however, federal and state governments, community agencies, and concerned individuals in the community work together to increase awareness of breast cancer and mammography screening.

The HBM provided a framework to analyze the mammography screening behavior in the US and Australia. A review of the literature demonstrated similarities and differences in perceived barriers to screening, perceived susceptibility to breast cancer, and cues to action motivating mammography behavior in the US and Australia.

No studies have been done that examine the effect of different healthcare systems on mammography screening. This study compares Australia's government supported and directed Breast Screen program with the uncoordinated health provider and promotion partnerships among government, community and individuals in the US.

The next chapters will provide information concerning the procedures used in this study, followed by analyses of the data. The final chapter presents the summary and conclusion of the research.


## CHAPTER 3

## PROCEDURES

## Chapter Overview

The purpose of the study was to examine the effects of two different health delivery systems on participation in mammography screening in these countries. In this chapter, the various measures and procedures used in this study are explained. The first section describes the components of the participant selection process. The next section concerns pilot testing of the instrument and revisions made to the survey after examining the pilot results. The development of the instrument is discussed in the subsequent section, including the differences between the US and Australian instruments. Administration of the instrument is presented in the following section, together with the protocol for the administrators of the survey, and the data collection procedure. The final section provides an overview of the plan for data analysis.

## Subjects

Purposive samples of the populations of women 40 years of age and older receiving mammography in each country were recruited for the study. The procedures for selection in the US and Australia will be discussed separately.

## US Sample

Prior to beginning the study, the proposed research was presented to the researcher's thesis committee. After this discussion, revisions were made, and a thorough description of the proposed research plan was submitted to Youngstown State University's (YSU) Human Subjects Research Committee (Appendix A).

Women from northern Ohio having mammography screening on the mobile unit of MammoVan Inc. were asked to voluntarily participate in the study. Three hundred eighty one women were included in the study, a sample size similar to that of Australia's. The medical director of MammoVan, Inc., located in Boardman, Ohio, gave permission to distribute surveys to women obtaining mammography on the MammoVan (Appendix B). During this study,

MammoVan, Inc. provided free, insurance, and self-pay mammography screening to various sites, both rural and urban, in Cuyahoga, Geauga, Ashtabula, Mahoning, Summit, Portage, and Van Wert counties in northern Ohio (see Figure 2). For this study, the choice was made to use women having mammograms on the MammoVan because this mobile type of service is also used by the Australian sample. According to ACS guidelines, the MammoVan offers mammography screening only to asymptomatic women age 40 and older, so that was the age criteria for inclusion in the study.

## Australian Sample

Before commencing with the research, information about the proposed study was forwarded to the director of BreastScreen NSW-Northcoast, along with a faxed copy of the HSRC approval document from YSU. In turn, the director passed this information to the ethics review board of the Mid North Coast Area Health Service (Appendix C).

This sample was comprised of 401 women from the rural northeast area of NSW. This region is about 250 miles north of Sydney on Australia's eastern coast. These women were receiving screening mammograms from one of the mobile units of BreastScreen Australia and were asked to voluntarily participate in the study. According the BreastScreen Australia guidelines, mammography screening is offered to women 40 years of age and older; consequently, this became the age criteria for acceptance into the study. Access to BreastScreen NSW-Northcoast was possible because the researcher had personal contact with one of the radiographers, who in turn, introduced the researcher to BreastScreen NSW Northcoast's director. The director generously supplied pilot survey copies, final survey copies, stamped return envelopes, and secretarial help in tabulation of the pilot results.


Figure 1. Maps of US and Australia including identifying location of each research site

## Pilot Studies

Pilot studies were carried out in the US and Australia beginning on July 27, 2000, prior to the beginning of this study. The Australian pilot surveys and instructions for administration were sent as an e-mail attachment to the director of BreastScreen Australia NSW-Northcoast. She provided 50 copies of the instrument, which were distributed to pilot participants who were members of the target population on July 31, 2000. In the US, the researcher gave 40 copies to MammoVan personnel to distribute during the week of July 31, 2000. All pilot surveys were returned by August 4, and the results were tabulated and evaluated.

Administration of the pilot surveys was similar in both countries. In the US, the researcher provided the secretaries and radiographers on the MammoVan with pilot studies and instructions for administration. In Australia, the researcher sent detailed administration instructions (explained in the section concerning the administration of the instruments) to the associate radiographer at BreastScreen NSW, who in turn, instructed the secretaries and other radiographers in the protocol for administering the instruments. The surveys were distributed to women 40 years of age and older who were receiving mammograms. In the US, the researcher collected the completed surveys on August 5, 2000. In Australia, the pilot surveys were collected on August 5, 2000, and the results were sent via email on August 8 .

The pilot instruments consisted of the surveys in their initial form, and the participants were asked to write comments on the questionnaire to improve readability, clarity, and format of the surveys:

- "Was this questionnaire easy to understand?"
- "Were there any questions that were unclear or confusing to you?"
- "Do you have any suggestions about any of the questions that would make this survey easier to understand?"

There were no negative comments concerning the comprehensibility or clarity of the instrument, but several suggestions for improvement were offered and incorporated into the final
documents. The font size was increased from 10 to 11 in response to a request that the print size should be larger. A "not sure" response selection category was added to the Likert-type scales concerning risk factors for breast cancer because several Australian participants said they thought this extra category would help them complete the section. Another suggestion from the Australian sample prompted the addition of "a friend or family member has had breast cancer" to the "cues to action" section. It was decided to add "white" following the "Caucasian" choice in the US demographic section, noting that several participants chose the category "other" and wrote in "white."

No questions were deleted as a result of this pilot, but an additional question was added to the US section concerning mammography experience. Several more questions were also added relating to the influence of the US healthcare delivery system on compliance or non-compliance with recommended guidelines for mammography.

When the data from the pilot studies were tabulated into SPSS statistical software (SPSS, Inc., 1997), analysis was made of the Knowledge of Risk Factors scale to evaluate the scale's reliability. Inter-item correlation for the nine-item scale ranged from .2932 to .5070 , indicating moderately strong positive correlation. The score for Cronbach's alpha was .6917 , which is supportive of the scale's internal consistency.

## Administration of Instruments

The following description of the training of personnel to administer the surveys was the same in each country. Following this section, administration procedures specific to the US and Australia will be addressed.

In order to ensure consistent administration of the instrument, the researcher developed a protocol for administering the surveys (Appendix D). Meetings were held for the staffs of the mobile units in both countries. The researcher in the US and the researcher's associate radiographer in Australia asked the radiographers and secretarial staff for support and cooperation
in helping with the study. Directives about the collection of completed questionnaires were also discussed. In addition, the following instructions for administration were reviewed and instituted:

- Ask each women having a mammogram if she would be willing to take part in a survey that would take about 5 minutes to complete.
- Advise them of the purpose of the study and that participation is entirely voluntary and anonymous.
- Inform the participants that they may stop completing the survey at any time.
- Make the participants aware that by completing the survey, they are giving consent to participate.
- Direct participants to detach the survey's coversheet in order to retain important information about the study.

As reinforcement to the information given to each participant, each survey included a coversheet that provided contact information about the researcher. In addition, the remainder of the page reiterated the information given by the survey's administrator concerning why the study was being conducted, voluntary participation, anonymity, the estimated time necessary to complete it, and consent for participation. The participant was instructed to detach the coversheet for future reference. In the US, if participants accepted a questionnaire, they were asked to place it in a special envelope on the desk. In Australia, the women were given the option to either place the survey in a particular envelope or complete the survey at home and return it by mail using the addressed and stamped envelope provided by BreastScreen. When collected, only completed surveys were included in the study; incomplete surveys were not used.

The following sections detail the instrument administration procedures in each country.

## US: Administration of Instruments

In the US, 400 surveys were administered beginning on August 28, 2000, and completed on October 30. Three hundred ninety one questionnaires were returned for a response rate of 98
percent. Of these, ten surveys were not sufficiently complete to be included in the study, resulting in 381 usable surveys. On the MammoVan, patient information is collected at the time of a woman's mammogram appointment, so there is a usually a short waiting period before mammography takes place. At the time this information was collected, the secretaries asked the women if they would like to participate in the study. Most patients completed the survey at this time. Stamped return envelopes were not provided to US participants because of cost constraints and because there was adequate time for participants to complete the surveys on-site. Participants were asked to place their surveys in a large enveloped provided by the secretary. At the end of each day, the secretaries and radiographers of Mammovan Inc. transported the completed questionnaires to the Mammovan home base in Boardman, Ohio.

## Australia: Administration of Instruments

Four hundred five surveys were administered in Australia from August 28, 2000 through September 11,2000. Four hundred two were returned, for a response rate of 99 percent. With BreastScreen Australia, women are scheduled in advance for mammography appointments, and all necessary paperwork for each person is prepared beforehand so that there is no delay when a woman arrives for her appointment. Since the woman is actually only at the facility for the exact amount of time necessary to have a mammogram, with no waiting time for the woman, BreastScreen's director and the researcher's associate radiographer saw this as a potential problem in recruiting participants. The director offered to supply participants with pre-addressed, stamped envelopes in which to return completed questionnaires to BreastScreen NSW-Northcoast headquarters. The researcher expressed concern that this could result in a reduced response rate, but was assured by the director that, in her experience, the response rate was actually very high for mailed responses to surveys. It was decided to accept the director's suggestion and generosity, and participants were given the option to complete a survey on-site or mail it in.

Returned questionnaires were collected by the associate radiographer from BreastScreen headquarters and tabulated by her. The resulting data were forwarded to the researcher via an email attachment on September 18, 2000.

## Development of the Instrument

Following a description of the portions of the US and Australian surveys that differ, a description of the elements that both surveys shared will be presented.

## US Instrument

The US survey instrument is available in Appendix E. There were 5 sections:

- Demographic information
- Mammography experience
- Knowledge about risk factors for breast cancer
- Cues to action
- Open-ended questions concerning attitudes toward payment for mammography and amount of breast cancer information available

Questions one through three in the demographic section include requests for information about age, years of education completed, and race.

The next section of questions concerned the US participants' mammography experience
Questions in the mammography experience section were as follows:
4. Is this your first mammogram? (if YES, go to question 9)
5. How old were you when you had your first mammogram?
6. When was your last mammogram?
7. How often do you have a mammogram?
8. Did you receive a reminder letter in the mail telling you that it was time for another mammogram?
9. Does your medical insurance pay or partially pay for the mammogram?
10. How much is your out-of-pocket expense for the mammogram?
11. If you always had to pay or partially pay more than $\$ 20$ out-of-pocket expense, would you be as likely to get regular mammograms?
12. Have you ever decided NOT to get a mammogram because it cost too much?
13. If mammography were always available at NO COST to you, would you be as likely to have regular mammography?
14. Is your mammogram being provided at no cost to you through a community agency (e.g. Planned Parenthood, YWCA?) or your place of employment?

The open-ended question section at the end of the US instrument included the following questions:

- Do you think it would be a good idea for the US and/or Ohio state government to pay for screening mammograms for all women over the age of 40 ? Why or why not?
- Do you feel that you have as much information about breast cancer and mammography as you need to make decisions about your health? In your opinion, what would be the most effective way for women to get this information?


## Australian Instrument

The complete Australian instrument is available in Appendix E. The initial section of the Australian instrument contained questions one through three concerning age, years of education completed, and ethnicity. The response choices offered in the Australian demographic section reflected social sensitivity to ethnicity. Because questions concerning race are considered rude by the majority Caucasian population and minority groups, the researcher was advised to offer culturally accepted choices, Aboriginal, Torres Strait Islander, Other, for ethnicity questions. The category "other" referred to the majority Caucasian population.

The next section concerned the Australian participants' mammography experience:
4. Is this your first mammogram? (If YES, go to question 9)
5. How old were you when you had your first mammogram?
6. When was your last mammogram?
7. How often do you have a mammogram?
8. Did you receive a reminder in the mail telling you that it was time for another mammogram?
9. If you had to pay for your mammogram, would you be as likely to have regular mammography?

Open ended questions at the end of the Australian instrument were as follows:

- If BreastScreen Australia did not offer FREE mammograms, do you think you would be as likely to get regular mammograms? Why or why not?
- Do you feel that you have as much information about breast cancer and mammography as you need to make decisions about your health? In your opinion, what would be the most effective way for women to get this information?


## Elements Common to US and Australian Instruments

The following section concerning risk factors for breast cancer was the same for both instruments:

- On average, how many US (or Australian) women do you think might get breast cancer in their lifetimes?
- What do you think are your personal chances for getting breast cancer in your lifetime?
- The following is list of Likert-type scales in which the participants are asked to choose "very important," "somewhat important," "not sure," not very important," or "not important" for the items in the list.

There are many risk factors that influence your chances of getting breast cancer. The following is a list of items that may or may not be risk factors for breast
cancer. In your opinion, how important is each of these items? Please indicate your answers with a check.

- Being a woman
- Growing older
- Smoking cigarettes
- Family history of breast cancer
- Family history of cancer of any kind
- Having lumpy breasts
- Having previous surgery for a benign (non-cancerous) breast lump

The section concerning cues to action are the same in the US and Australian instruments.

- Which of the following factors made you aware of your need to get a mammogram?
- Television advertisements
- I received a reminder letter about my mammogram
- Radio advertisements
- Magazine articles about mammography or breast cancer
- My doctor or other healthcare practitioner suggested that I get a mammogram.
- Posters or brochures about breast cancer
- My friends or family urged me to get a mammogram
- Saw the mobile mammography unit was here today
- A friend or family member has had breast cancer
- Other-please specify


## Profile of the subjects.

Both the US and Australian samples were comprised of women 40 years of age and older who were receiving mammography. The US sample was composed of 381 participants in northern Ohio using the services of MammoVan, Inc. In Australia, 402 women in NSW having mammograms provided by BreastScreen Australia were included in the sample.

## Elements of the Problem and Relationship of the Elements

This analysis is designed to investigate the differences in compliance with mammography guidelines and knowledge of risk factors for breast cancer between the US and Australian samples. Because mammography is provided free in Australia to all women 40 years of age and older, and free mammograms are not available to women in the US, there were many bases for comparison between the samples. Attitudes of women from the US and Australia concerning payment options for mammography were also explored. Comparisons were made within the context of the four research questions of this study: compliance to recommended guidelines in the US and Australia, assessment of knowledge of risks for breast cancer, cues to action, and attitudes of women from US and Australia about payment for mammograms. Each are listed with a brief description followed by an overview of the relationships between the elements of the study.

## Compliance To Recommended Guidelines in the US and Australia

As noted in previous sections, compliance is defined as having a mammogram annually or biannually. Both the independent $t$-test and Chi Square were used to examine the relationship between the US and Australian samples concerning compliance to mammography guidelines. In addition to comparisons between the entire samples, subsets of the US sample, including the compliance rates of women receiving free mammograms and women whose insurance covered the exam were compared.

The Chi Square test was used to examine the effects of the different healthcare delivery systems on mammography. In this section, there are questions concerning whether Australian participants would be willing to pay for mammography, and whether US participants thought that
they would be more likely to have regular mammography if it were always free. The relationship of the responses to these questions and categories such as age, compliance and whether or not this was the participant's first mammogram were explored.

## Assessment of Knowledge of Risks for Breast Cancer

"Having knowledge" has been defined as having answered "very important" to the breast factors "being a woman," "getting older," and "family history of breast cancer." A fourth component of "having knowledge" was identifying the correct lifetime risk for breast cancer in the sample country. The independent t-test and Chi Square test was used to make comparisons of knowledge between samples, and the relationships of knowledge to age, education and compliance.

## Cues to Action

The most influential factors influencing women to have mammography were identified, and the independent $t$-test was used to compare the differences between samples. The Chi Square test was used to demonstrate relationships between different cues to action (as shown in Australian instrumentation section) and compliance.

## Attitudes of Women From US and Australia About Payment for Mammograms

Responses to these questions (as shown in the US and Australian instrumentation sections) were examined, and relationships concerning age, education, ethnicity and other variables were investigated using the Chi Square test.

## Summary

This chapter described the Australian and US samples of women who participated in this study. The results of the pilot study were discussed, including subsequent revisions to the survey instruments. A discussion of the administration of the surveys in each country followed, ending with a description of the instruments used in the US and Australia. The last section outlined the treatment of the data collected from the samples. The following chapters present the analyses of the data and the summary and conclusions of the study.

## CHAPTER 4

## ANALYSIS OF THE DATA

## Chapter Overview

The purpose of this study is to compare the effects of the healthcare delivery systems of the US and Australia on mammography screening. Since mammography screening is always free to Australian women over 40 years of age, and it is not always free to US women, comparisons of compliance with screening guidelines, attitudes toward the availability of pay versus free mammograms, knowledge of risk factors for breast cancer, and factors influencing regular mammography were explored.

In this chapter, a profile of the subjects is presented. Next, findings in each of the four major aspects of the study will be presented. These four areas of research are (a) compliance to mammography guidelines in and between the samples and subgroups of the samples, (b) knowledge of breast cancer risks between and within samples, and (c) how different cues to action to have mammograms influenced women in both samples. (d) attitudes of Australians and US women concerning payment for mammography. All statistical analyses were conducted using SPSS software (1997). The significance level was set at $\mathrm{p}=.05$.

Profile of the Subjects

## US Sample

In this sample, 68.5 percent $(\mathrm{n}=261)$ of the women were between 40 and 50 years old, $21.5(\mathrm{n}=78)$ percent were between 51 and 59 , and 10 percent $(\mathrm{n}=38)$ were 60 years of age and older. The ethnicity of the sample was 87 percent Caucasian $(n=331), 12$ percent were African American $(n=45)$, and less than 1 percent each Hispanic $(n=3)$ and Asian ( $n=2$ ). The educational levels for the US sample were as follows: 36 percent ( $\mathrm{n}=136$ ) completed high school, 36 percent $(\mathrm{n}=135)$ attended a university or technical school, and 29 ( $\mathrm{n}=110$ ) percent had college or technical degrees (Table 1).

In addition to demographic variations in the US sample, methods of payment for a mammogram differed as well. Sixty-two percent $(\mathrm{n}=223)$ of the sample had insurance coverage for their mammograms, whereas three percent ( $\mathrm{n}=12$ ) had no insurance for mammography and paid out-of pocket for the exam. In this sample, mammograms were provided at no cost to 38 percent $(\mathrm{n}=146)$ of the US participants.

## Australian Sample

In this sample, 24 percent $(\mathrm{n}=96)$ of the women were between the ages of 40 and 50,31 percent ( $n=124$ ) were between 51 and 59 years, and 45 percent $(\mathrm{n}=179)$ were 60 years of age or older. The ethnicity mix of the sample was as follows: Aboriginal, 2.5 percent ( $\mathrm{n}=10$ ), Torres Strait Islander, 1 percent ( $\mathrm{n}=4$ ), and the portion of the sample who were neither Aboriginal or Torres Strait Islander and presumed to be of the Caucasian majority was 89.5 percent ( $n=360$ ). Twenty eight participants did not respond to the question concerning ethnicity. In Australia, asking questions about ethnicity is not considered to be politically correct, and this is most likely the reason why some women did not respond to the query. It is also likely that some minority women did not feel comfortable answering the question because of perceived racial prejudice.

Educational levels of the participants were as follows: 71 percent ( $n=287$ ) completed at least 12 years of formal education (high school), 11 percent ( $\mathrm{n}=45$ ) had some university or technical education, and 13 percent ( $\mathrm{n}=51$ ) had a technical or university degree (Table 1 ). However, 20 participants did not answer this question, perhaps because the researcher did not offer a choice for "up to 11 years of school." The omission of an option concerning education of less than 12 years was an oversight on the part of the researcher.

Statistically significant differences emerged between the US and Australian samples. Variations in education levels became apparent: 65 percent of the US sample had university or technical school experience, versus 42 percent of Australian women. These results may be a consequence of the rural settings of the Australian sample. Rural women have limited access to
urban-located universities, and this circumstance may be especially true in Northeastern NSW, because there are no large urban areas in that region.

Regarding age differences, Australian women in the sample were older than their US counterparts, with most of them being older than 60 years, while most of the US women were between 40 and 50 years old. This finding is reasonable: BreastScreen Australia has targeted older women between 50 and 69 for screening. As previously noted, all women over 40 are invited, but not necessarily encouraged, to participate. However, in the US, health authorities recommend that women begin screening at age 40 , which accounts for the increased numbers of younger women in the US sample.

Another notable difference was in the number of ethnic minorities included in the samples. Only 3.7 percent of the Australian sample were Aborigines or Torres Strait Islanders, while 13 percent of the US women were African-American, Hispanic, or Asian. The number of minority women in Australia may have been underestimated due to 7 percent $(\mathrm{n}=28)$ non-response rate to the question about ethnic background. Summaries of both samples can be found in Table 1.

Table 1
Subject Profiles: US and Australian Samples, 2000

| Variable | US |  |  |  | Australia |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Age | 40-50 yrs | 51-59 yrs. | $\geq 60 \mathrm{yrs}$. | $N R$ | 40-50 yrs. | 51-59 yrs. | $\geq 60 \mathrm{yrs}$. | $N R$ |
|  | 68.5\% | 21.5\% | 10\% |  | 24\% | 31\% | 44.9\% | .1\% |
| Ethnicity | Asian | Hispanic | Afr-Amer. | Саис. | Aborig. | Torres <br> Strait Is. | Other | $N R$ |
|  | .05\% | 0.8\% | 12\% | 87\% | 2.5\% | 1\% | 89.5\% | 7\% |
| Education | High School | Some univ/tech | Degree <br> Univ/tech | $N R$ | High <br> School | Some univ/tech | Degree <br> Univ/tech | $N R$ |
|  | 3\%6 | $36 \%$ | 29\% |  | 71\% | 11\% | 13\% | 5\% |

Note. US sample: $\mathrm{n}=381$, Australian sample: $\mathrm{n}=402$.

## Elements of the Problem

## Results: Compliance With Recommended Guidelines for Mammography

Compliance is defined as having mammography every year or every other year. In the US, 52.9 percent $(\mathrm{n}=336)$ were found to be compliant compared with 47.1 percent $(\mathrm{n}=299)$ in Australian sample. Although compliance rates were slightly higher in the US sample, the results of the significance tests $(t=1.551, d f=692, p=0.121, n=694)$ indicated that there was no significant difference in compliance between samples in the two countries.

Thirty-eight percent of the US sample that had no insurance coverage were provided with free mammography. Of the remaining participants, 58 percent had private or public insurance that fully or partially paid for their mammograms, and three percent had paid for their own mammograms due to lack of insurance coverage. In Table 3, compliance to mammography guidelines by the Australian and US sample is shown, as well as compliance of the US subgroups.

Table 2
Summary of Compliance Rates for US, Australia, and US Groups With Various
Methods of Payment for Mammography, 2000

| Variable |  | Percentage |  |
| :--- | :--- | :--- | :--- |
|  | Compliant | Not <br> Compliant | N |
| US | 89.8 | 10.2 | 333 |
| Australia | 93.1 | 6.9 | 361 |
| $\quad$ US free mammogram group | 90.5 | 9.5 | 126 |
| US insurance mammogram group | 90.3 | 9.7 | 195 |
| US elf-pay mammograms | 75 | 25 | 12 |

The rates for compliance with recommended guidelines for screening are similar across the US, Australian, and the US groups in the US sample. Only one group, the small sample of women with self-pay mammograms $(\mathrm{n}=12)$ appeared to differ in compliance: $75(\mathrm{n}=9)$ percent of the women were compliant, compared with about 90 percent of the remaining samples. However, the sample size of uninsured women was very small $(\mathrm{n}=12)$, and small changes in numbers make large differences in percentage points. The lower rate of compliance in this group suggests, but is not significant, that having to pay out-of-pocket for mammography might be a barrier to screening compliance $\left(X^{2}=2.970, d f=1, p=0.085, n=333\right)$ for uninsured women.

Effects of age, education, and personal risk assessment on compliance. When comparing compliance and age, there was no statistical significance between the US and Australian samples. In addition, no significant differences in terms of age and compliance were found within each sample, either. The two samples were also very similar with regards to compliance and participants' estimates of personal risk for breast cancer. However, regarding education and compliance to mammography guidelines within the Australian sample, a weak negative relationship was found $(\mathrm{r}=-.117, \mathrm{p}=.031)$ : as educational level increased, compliance decreased. Further analysis revealed a weak positive relationship between the level of education and adherence to mammography guidelines within the US sample $(\mathrm{r}=.144, \mathrm{p}=.008)$. Therefore, in the US, as education level increases, a woman has a tendency to have regular mammography.

There was no significant relationship between compliance with mammography standards and a woman's estimation of her personal risk for breast cancer. In the Australian sample, 70 percent $(\mathrm{n}=249)$ of the women assessed their risks as "average," and of these, 94 percent were compliant. Similarly, 71 percent $(\mathrm{n}=238)$ of the women in the US sample estimated that they had an average risk for breast cancer, and 90 percent of these women followed mammography guidelines.

## Results: Knowledge of Breast Cancer Risks

Important risk factors. In terms of relative importance, three items on the Likert-type scales concerning risk factors for breast cancer, the following were considered to be most important: being female, getting older and having a family history of breast cancer (Healthy People 2010, 2000b; AIHW, 1999). In order to determine if participants were discerning between actual risk factors and other selections that were not actual risk factors, other items were included and rated as "not important." "Having had any other cancer," "having a non-cancerous lump removed," "smoking," and "having lumpy breasts" are not risk factors for breast cancer.

Using the guidelines mentioned above, the researcher measured knowledge using four criteria: answering "very important" to considerations of the three risk factor "being a woman,"
"getting older," and "family history of breast cancer;" and answering the question about lifetime risk for breast cancer correctly ("one in eight" for the US sample, "one in eleven" for the Australian sample). If a participant identified the three risk factors as "very important" and correctly recognized the lifetime risk for breast cancer for her country, she was considered to have knowledge of important breast cancer risks.

As shown in Table 4, 36 percent of the Australian participants ( $n=45$ ) had knowledge of risk factors, and 64 percent of the US sample $(\mathrm{n}=80)$ were determined to have knowledge. Tests of significance reveal that knowledge of the important risks for breast cancer was significantly greater in the US sample $(\mathrm{t}=-3.479, \mathrm{df}=729, \mathrm{p}<.001, \mathrm{n}=731)$. However, no significant relationship between having knowledge and compliance to mammography guidelines was observed, either between or within samples.

Unimportant factors. Not all items listed in the "risk factor" section of the survey were actually risk factors. Items that are not risk factors for breast cancer include: "having had any other cancer," "having a non-cancerous lump removed," "smoking," and "having lumpy breasts." Table 3 shows proportions of US and Australian women who correctly identified both the important risk factors and who recognized that the rest of the items listed are not risk factors.

Table 3
Comparison of Correct Identification of Risk Factors for
Breast Cancer by US and Australian Participants, 2000

| Risk Factor | US $\%$ | AUS $\%$ |
| :--- | :--- | :--- |
| being a woman | 48.5 | 51.5 |
| getting older | 50.5 | 49.5 |
| family history of breast cancer | 50.3 | 49.7 |
| having had any other cancer | 50 | 50 |
| having a benign lumpectomy | 51.1 | 48.9 |
| smoking | 55.3 | 44.7 |
| lumpy breasts | 50 | 50 |

Note: US: $\mathrm{n}=381$, Australia, $\mathrm{n}=402$

Lifetime risk. Concerning participants estimates of lifetime risk of breast cancer in their respective countries, significantly more US women were able to identify the correct answer than Australian women $(t=-4.835, \mathrm{df}=729, \mathrm{p}=.001, \mathrm{n}=731)$. Forty-six percent $(\mathrm{n}=168)$ of women in the US correctly recognized that the lifetime risk, "one in eight" for breast cancer in the US, in contrast to 29 percent of Australian women who selected "one in eleven" as the lifetime risk for breast cancer in their country. However, knowing these facts had no effect on compliance levels either between or within samples.

## Results: Cues to Action

This section of the instrument listed ten factors that may prompt women to seek mammography. Table 4 illustrates the frequency with which each item was chosen by Australian and US women.

Table 4
Comparison of Cues to Action Encouraging Women to Engage in Mammography
Screening in US and Australia, 2000

| Cues to action | US \% | AUS \% | t | df | p |
| :--- | :--- | :--- | :--- | :--- | :--- |
| TV | 31 | 42.8 | 3.443 | 781 | $<.01^{*}$ |
| Radio | 14.7 | 12.7 | -.818 | 781 | .41 |
| Newspaper ads | 15.7 | 17.9 | .807 | 781 | .42 |
| posters/brochures | 33.3 | 27.6 | -1.741 | 781 | .08 |
| seeing mobile mammogram unit | 18.6 | 50.5 | 9.900 | 871 | $<.01^{* *}$ |
| reminder letter | 38.8 | 61.2 | 6.405 | 781 | $<.01^{* *}$ |
| magazine article | 27.6 | 18.7 | -2.972 | 781 | $<.01^{* *}$ |
| doctor's recommendation | 69 | 31 | -11.191 | 781 | $<.01^{* *}$ |
| friends/family recommended | 19.9 | 17.2 | -1.001 | 871 | .32 |
| friend or family with breast | 24.4 | 19.2 | -1.784 | 781 | .08 |
| cancer |  |  |  |  |  |

Note: Australia, $\mathrm{n}=402$, US: $\mathrm{n}=381$;
${ }^{*} \mathrm{p}<.05,{ }^{* *} \mathrm{p}<.001$

As shown in Table 4, numerous significant differences existed when comparing the cues to action chosen by women from each country. More Australian participants than their US counterparts reported that seeing the mobile unit influenced them to have a mammogram ( $\mathrm{t}=$ $9.900, \mathrm{df}=781, \mathrm{p}=<.001, \mathrm{n}=783$ ). This finding is not surprising, due to the differences in the mobile services offering mammography in the US and Australia. In the US, the MammoVan is not generally open to the public for mammography; instead, it is scheduled at a particular location to provide mammograms for a health agency, place of employment, or other community location. Usually the van is there only as long as it takes to complete mammography screening at the site. In contrast, BreastScreen's mobile units generally arrive at a town and stay there for a week or two, scheduling and providing mammograms for any woman 40 years of age or older. In this scenario, seeing the mobile unit is an important cue to action for residents of the Australian town, unlike the situation of the MammoVan in the US.

Additionally, Australian women were more likely than US participants to have received a letter reminding them to schedule a mammogram $(\mathrm{t}=6.405, \mathrm{df}=781, \mathrm{p}=<.001, \mathrm{n}=783)$. This result is understandable: Part of BreastScreen's program is to mail reminder letters to women who have used their services in the past. However, this is not the case in the US, since there is no national registry for mammography. MammoVan, Inc. is a private mammography facility and its staff mails reminders to women who have previously utilized the service. However, if MammoVan is providing mammography at a new location, reminders are not possible.

Seeing information about breast cancer or mammography on television was a more important cue to action for the Australian participants than those in the $(t=3.443, \mathrm{df}=781, \mathrm{p}$ $=<.001, \mathrm{n}=783$ ), and articles in magazines were more influential prompts for mammography in the US than in Australia $(\mathrm{t}=-2.972, \mathrm{df}=781, \mathrm{p}=<.001, \mathrm{n}=783$ ). Higher educational levels in the US sample compared to the Australian sample may account for this difference.

A significantly greater number of US women had received recommendations for mammography from their healthcare providers than had Australian women $(\mathrm{t}=-11.191, \mathrm{df}=781$,
$\mathrm{p}=<.001, \mathrm{n}=783$ ). This finding is interesting, given that health care is provided by the national government in Australia. A possible explanation might be that most women are familiar with the BreastScreen program, and since a physician's order is not necessary for having a screening mammogram, they do not consult with their healthcare provider prior to mammography. It is also possible that Australian physicians see no need to discuss the subject of mammography with their patients since the government is managing this aspect of women's health.

## Results: Attitudes of Australians and US Women Concerning Payment for Mammography

US attitudes. Because of the complex US healthcare delivery system, US women were asked three questions concerning how the current system has affected their mammography experience in the past, and if different delivery systems for mammography would influence them to have mammography on a more regular basis. These three questions are addressed individually.

1. "Would you be more likely to get regular mammography if it were always free?" Overall, 88 percent of participants acknowledged that free mammograms would increase compliance levels. A summary of the responses is shown in Table 5.

Table 5
US: Would You Be More Likely to Get Regular Mammography if It Were
Always Free? 2000

| Variable | Yes | No | N |
| :--- | :--- | :--- | :--- |
| US | $\%$ | $\%$ | $\%$ |
|  | 88 | 12 | 381 |
|  | 89.7 | 10.3 | 146 |
| $\quad$ self-pay mammograms | 91.7 | 8.3 | 12 |

Note: No significant differences found between groups
2. Answers to the question "Have you ever decided not to get a mammogram because it cost too much?" are found in Table 6. In response to this item, 14 percent of US women said that cost had never prevented them from having mammography. Similar findings were found in the free and insurance subgroups, as well. However, for the small group of women who had to pay out-of-pocket for their screening, a significant proportion ( 58.3 percent) said that they had deferred mammography in the past due to cost constraints.

Table 6
US: "Have You Ever Decided Not to Get a Mammogram Because It Cost Too
Much?" 2000

| Variable | No | Yes | N |
| :---: | :---: | :---: | :---: |
|  | \% | \% |  |
| US | 85.6 | 14.4 | 381 |
| free mammogram group | 83.6 | 16.4 | 146 |
| insurance mammogram group | 89 | 11 | 223 |
| self-pay mammograms ${ }^{\text {a }}$ | 41 | 58.3 | 12 |

$$
{ }^{\mathrm{a}} \mathrm{X}^{2}=19.330, \mathrm{df}=1, \mathrm{p}=<.001, \mathrm{n}=12
$$

3. Table 7 displays the responses to the question "Would you be as likely to have regular mammography if you always had to pay more than $\$ 20$ for a mammogram?" Answers to this item reveal that 60 percent of the US women would be willing to pay this amount, and the findings were similar for the three insurance condition subgroups.

Table 7
US: Would You Be as Likely to Have Regular Mammography if You Always
Had to Pay More Than $\$ 20$ for a Mammogram? 2000

| Variable | Yes | No | Unsure | N |
| :--- | :--- | :--- | :--- | :--- |
| US | $\%$ | $\%$ | $\%$ |  |
|  | 60.4 | 31.9 | 7.7 | 381 |
| $\quad$ insurance mammogram group | 54 | 39 | 6.2 | 146 |
| $\quad$ self-pay mammograms | 58.3 | 27.1 | 8.6 | 223 |
|  |  |  | 8.3 | 12 |

Note: No significant differences found between groups

In addition, no significant differences in responses were found with regards to age, education or ethnicity for any of the three questions described above.

Australian attitudes. Since Australian women are provided with free mammography, the question was asked, "If you had to pay for your mammogram, would you be as likely to have regular mammography?" Seventy-six percent affirmed that they would continue with screening even if they had to pay for the exams. There were no significant relationships between willingness to pay and assessment of personal risk for breast cancer, education, ethnic background, or whether or not this mammogram was the participant's first screening. A
suggestive, but not significant, association was found between age and willingness to pay for mammography. Eighty-seven percent of women between the ages of 40 and 50 were slightly more disposed to pay, in contrast to 75 percent of women older than 51 years.

Summary
The content of this chapter provided the results of the statistical analysis of the data collected in the study. The attributes of the US and Australian sample were discussed. Results of measures of compliance and knowledge of risk factors of breast cancer were measured and compared between and among samples. Factors that motivate women to seek mammography were presented, noting the importance of cues to action that varied in importance between countries. The last sections dealt with question concerning possible alternate payment strategies for each sample. In the last and final chapter, the summary and conclusions drawn from the findings will be discussed.

## CHAPTER 5

## SUMMARY AND CONCLUSIONS

## Chapter Overview

This chapter provides a summary of the background of the study, a summary of the procedures used to carry out this study, as well as a summary of the findings and general conclusions based on these findings. The results are discussed and directions for future study are suggested.

## Summary

The purpose of this study was to explore the effect of the different healthcare delivery systems on mammography screening in Australia and the US. Regular mammography screening is the most important tool for reducing cancer mortality because it is able to detect breast cancer at a very early and curable stage. The Health Belief Model was used as the theoretical basis for the study (Becker, et al., 1977), to assess perceived vulnerability to and seriousness of breast cancer, barriers to screening, and cues to action that predict mammography behavior.

The US health delivery system is fragmented into many complex segments. Women seeking mammography have either private or public insurance, depending on employment and economic status, or they have no insurance coverage at all. In addition, health promotion, and healthcare delivery are loosely coordinated or independent undertakings provided by a diverse mix of government and private agencies and private individuals. Because mammography information cannot be collected from a single source such as occurs with BreastScreen Australia, precise data collection concerning breast cancer incidence and mammography is are not possible.

In contrast, in Australia, a government-funded intervention, BreastScreen Australia, provides mammography screening at no cost to all women forty years of age and older. This program is a well-controlled and coordinated endeavor in which Breast Screen Australia directs breast cancer education and screening, as well ensures quality control and tracking of incidence and mortality rates for all participants in the program.

The study examines the effect of these differing healthcare structures with regard to participants' compliance with recommended guidelines for mammography screening, knowledge of breast cancer risks, factors influencing mammography adherence, and women's attitudes toward alternate payment options in each country.

## Summary of Procedures

The sample for this study was comprised of 402 Australian women and 381 US women who were having mammograms. Prior to distribution of the survey, a pilot study was conducted to determine the clarity and understandability of the instrument. Minor changes were made based on feedback from the pilot participants.

During the study, mammography was being provided to participants in both countries by mobile mammography services, and trained radiographers or secretaries administered a three page self-report instrument. The staff used an administration protocol and asked each woman if she would participate in a voluntary, anonymous study concerning their mammography experiences. The survey instruments included close-ended questions concerning demographics, previous mammography experience, knowledge of breast cancer risks, and factors that promote mammography utilization. Women were provided with the opportunity to answer open-ended questions to express their ideas and opinions on topics presented in the initial portion of the questionnaire.

The instruments were collected and data were analyzed using SPSS (1997) statistical software. Tests of significance employed were the t -test for independent groups and Chi-Square.

## Summary of the Findings

Assessment of compliance. Compliance to mammography guidelines was defined as having had a mammogram in the previous one or two years. There were no significant differences in compliance between the US and Australian samples. There were also no differences in compliance rates within the three segments of the US sample: women who had insurance, free, or self-pay mammograms were all similar in compliance to recommended
screening guidelines. Ninety-three percent of Australian women and 90 percent of US women, regardless of insurance status, reported having a mammogram within the past two years. Age, ethnicity and perceived personal threat of breast cancer had no effect on compliance levels in the US and Australian samples.

There was a tendency for women with higher educational levels in the US to be more compliant, a finding that agrees with the results of other researchers (Miller, et al. 1997; Makuc, et al., 1994; \& Faccione, 1999). However, in Australia, there was a slight inclination for women with more education to be less compliant. Personal communication with the director of BreastScreen NSW Northcoast suggests a possible explanation for these findings: "Many women who have higher education levels prefer to use the 'private' sector for their mammograms because they (mistakenly) believe that the service is better in a fixed private radiology practice than in a public health service facility provided on a mobile unit. However, we routinely screen women with all income levels" (November 28, 2000).

## Assessment of knowledge of risk factors for breast cancer. "Having knowledge" of

 breast cancer risks was operationally defined as (a) having identified that being a woman, getting older, and having a family history of breast cancer as very important risk factors, and (b) having correctly recognized the lifetime risk for breast cancer in the country of residence. Results of tests of significance revealed that US women are more likely to have greater knowledge of risk factors for breast cancer. These findings reflect similar findings by Paul et al. (1999) who stated that Australian women in their study had low perceptions of breast cancer risks, and most underestimated their personal risks for breast cancer. However, since the compliance to screening guidelines was not significantly different between the US and Australian samples, dissimilar levels of knowledge did not affect compliance rates. Australian women were compliant to mammography recommendation despite the fact that they had less knowledge of breast cancer risk. It could be that the visual stimulus and convenience of having the BreastScreen mobile unit set up in their town for one or two weeks, and receiving reminder lettersfrom BreastScreen Australia are strong enough cues to action that knowledge about breast cancer risk need not be a motivating factor in the decision to seek mammography.

Cues to action-prompts promoting mammography behavior. There were significant differences between the US and Australian samples in regard to most influential cues to action. Australians were three times more likely than US women to report seeing the mobile screening unit and nearly twice as likely to receive a reminder letter from the screening service. Television was also a significantly more effective prompt in Australia than in the US. More than twice as many US women indicated that a physician's recommendation encouraged them to have mammograms. Reading a magazine article about breast cancer was a more important trigger to seek mammography for women in the US.

Adelson et al. (1992) concurred that seeing a mobile screening unit was an important cue to action in Australia, however the finding that a physician's recommendation for mammography was also important was not corroborated in this study. However, BreastScreen NSW Northcoast's report that seeing the mobile unit and receiving a reminder were conducive to screening agrees with the findings in this study. In the US, the findings of numerous studies agreed that receiving a health provider's recommendation was an important cue to action for women (Friedman, et al., 1995; Taplin, et al. 2000; Schillinger, et al. 2000).

Attitudes toward payment by US and Australian women. Both US and Australian women were asked questions concerning continued compliance with mammography screening if their payment conditions were altered. US participants expressed that they would be more likely to get regular mammography screening if it were provided free. The US women also said that they would still be as likely to have regular mammograms if they always had to pay more than $\$ 20$ for the exam, regardless of insurance status, age, education level, or ethnicity. Overall, 85.6 percent of the US women had never deferred mammography due to the cost involved. Findings were similar in the subgroups who had free or insurance mammograms, but significantly more women ( 58.3 percent) who had no insurance and paid out-of-pocket for their exams said that cost
constraints had prevented them from having mammograms in the past. This outcome agrees with similar findings that indicate as out-of-pocket spending increases, screening behavior has a tendency to decrease (Makuc, et al., 1994).

Australian women were asked if they would continue to have mammography if they had to pay for it themselves, and three quarters said that they would. There was no effect of age, education, personal risk assessment, or ethnicity on willingness to pay for screening.

## Conclusions

Based on the findings and limitations of this study:

- There are more similarities than dissimilarities between US and Australian women in regard to mammography behaviors.
- Despite the notable differences in healthcare delivery in the US and Australia, participants in the study had comparable compliance rates for mammography screening, which is the most important indicator for the detection of early breast cancers and the resulting decrease in breast cancer mortality.
- While there were variations in knowledge of risk factors and cues to seeking mammography services, these differences did not affect compliance rates.
- Women in both countries agreed that mammography was important to them, whether it was provided free or they had to pay for the exam out-of pocket.


## Discussion and Implications

## Compliance Concerns

Compliance to recommended guidelines for mammography screening is the most effective way to prevent cancer deaths. If a woman has a mammogram annually or biannually, her chances of having breast cancer found at a very early stage increase. If breast cancer is detected while the malignancy is very small and has not spread beyond the breast tissue, a woman's probability for cure is 96 percent (ACS, 2000b).

In spite of the very different healthcare delivery structures in the US and Australia, the compliance rates were very similar across countries and insurance status of US participants. It would seem a remarkable finding that women in the US who have many different payment conditions had compliance rates similar to Australian women. However, having regular mammograms may not always be easy for US women. Participants were given the opportunity to express their thoughts about cost barriers to mammography. Though the number of US women who had self-pay mammograms in this study was small $(\mathrm{n}=12)$, more than half of them said that they had decided not to have mammograms in the past due to the expense involved. One participant commented, "The cost of $\$ 90$ is a lot for a single person who has a high deductible and no medical problems. I try to take care of myself, but sometimes bills pile up and I take care of those first." Another woman believed that "most single or divorced moms cannot fit the cost of a mammogram into their budgets. It's not one of those priority items."

In the US, the current national rate for having had a mammogram within the past two years is about 68 percent, just two percent short of the 70 percent Healthy People 2010 target rate for mammography screening. However, low income women are still not having mammograms as often as they should. Women who are at or below poverty level (currently set at about $\$ 17,000$ for a family of four) have screening rates about 25 percent lower than those women above poverty level (CDC, 1998). In this study, more than one third of the US women had no insurance and were provided with free mammograms. However, it is not always easy to learn where free screenings are offered and the financial eligibility requirements of the agency. Many women are not even aware that mammography may be available to them from community agencies, and it is important that this information is disseminated to the women who need it.

## Knowledge concerns

An interesting finding was that US women have more knowledge of breast cancer risks than their Australian counterparts. This favorable finding may be partially due to the uncoordinated health promotion efforts in the US. With many government and private agencies
pointing out the importance of mammography in detecting breast cancer, women appear to be getting the message. It is possible that the budget constraints of BreastScreen Australia prevent massive media exposure to breast cancer information. Another factor influencing US women's higher rate of knowledge of breast cancer risks was that many US women cited that their healthcare provider had recommended mammography. This personal interaction with their providers concerning mammography allows women to ask questions they may have about breast cancer and breast cancer detection from a source they respect and trust.

It is important to recognize, however, that in this study, knowledge levels of breast cancer did not affect compliance rates. Perhaps it is enough to know that mammography screening is the best way to detect breast cancer earlier. This incentive alone may be enough to help women remain adherent to regular screening. However, social marketing efforts should continue. It seems likely that educational programs about breast cancer and mammography may function as cues to action for women not yet having mammograms, who are not attending screening on a regular basis, or who simply need to be reminded about the importance of screening in order to remain compliant.

Even though knowledge levels did not influence the compliance rate of the participants, not being knowledgeable about breast cancer risks or not understanding the reasons for screening might influence women's decisions to continue screening if the service were no longer offered free. Australian women were asked if they would continue to have mammography screening if it were no longer free. Many women said that they would still have mammograms, but not as often. One woman commented, "I would still have a mammogram if I had to pay for it myself, and if everything were fine, then I would probably have one in about five years." Another woman said she would "stretch it to three years." It is important that health education programs communicate the necessity of and reasons for having a mammogram at two-year intervals. It would appear that many women are not aware that the two-year mammography schedule is essential in order to find
very small, curable breast cancers. Extending this time interval would not permit detection of these cancers in their earliest stages.

Several other Australian women also said that they would continue to seek mammography if it were no longer free, but "less often, maybe every three/four years, because I don't think $x$ rays are good for you." Fear of radiation exposure is another topic that should be addressed in social marketing efforts in Australia and the US. Due to improvements in film/screen technology, the amount of radiation from one mammogram is minimal: about equal to the amount a person is exposed to during common dental x-rays or an airline flight from New York to Los Angeles (Feig, 1996). Since most women are not concerned about radiation from these sources, fear of radiation exposure during screening should not be a barrier to regular mammography.

Many Australian and US women commented that they were interested in getting more information about breast cancer. One woman suggested that placing information in women's hygiene products might be a way to reach more women. "How about enlisting ministers to distribute brochures about mammography to church members-maybe even mention it from the pulpit," one woman recommended. Another woman thought that posters in the toiletries and women's hygiene aisles of the drugstore or supermarket, or in the women's restrooms at work or in department stores would also spread the word about breast cancer and mammography.

On the other hand, many women felt that there was enough information available to everyone to be able to make sound decisions about their breast health. One Australian woman observed, "I think there is an abundance of information available. Unfortunately, some people will tend to put their head in the sand." This sentiment is echoed by a US woman who stated, "I think information is pretty well available to all. It is the individual who has to want to pay attention to it and take care of herself."

## Cues to Action Concerns

Different cues to action were more important in one country than in the other. In the US, having a health provider's recommendation was a significantly more influential motivational
factor for seeking mammography than in Australia. A possible explanation for this finding is that the BreastScreen program has taken over this aspect of women's health, and women no longer consult with their provider prior to mammography screening, especially since a provider does not have to order the exam. Perhaps also, the provider does not feel responsible for this aspect of women's health because it is supplied by BreastScreen. However, in the US, a health provider's order is often necessary to have mammography screening, and women rely on this recommendation as a reminder to have mammography.

Unlike the US, getting reminder letters from BreastScreen and seeing the BreastScreen mobile facility are the most important cues to have mammography screening for Australian women. Reminder letters are possible because BreastScreen is a national registry for screening, and every two years, a woman receives a reminder that it is time for mammography. These letters are sent to women prior to the arrival of the mobile unit in their locale. Since there is no single provider of mammography in the US, it is not possible to remind women about their screening exams. Another reason that seeing the mobile unit was not an important cue to action in the US is that the MammoVan is usually scheduled at a particular facility for a day, and is not open to the public. Often, the BreastScreen Mobile unit is in the same location for one or two weeks-long enough for women to see the unit and make an appointment for mammography screening.

Australian women appreciate the reminder letters. When asked to comment on whether or not they would continue to have mammography even if they had to pay for it, many women were not concerned about the cost-only about not receiving a reminder. One woman said, "Probably not as much, as I wouldn't think of it. The van is a good reminder as are the letters. Busy people often need prompting to make the time." Another woman concurred, "No I wouldn't - the reminder is what I need - time goes so quickly you tend to forget."

There were also differences between the two countries concerning other cues to action. Seeing breast cancer and mammography screening information on television was a significantly
more important influencing factor for Australian women than for their US counterparts. However, for US women, reading a magazine article pertaining to breast cancer or mammography was a significantly more important prompt than for Australian women. Possibly the higher educational status of the US women in this study influenced them to get their breast health information from printed sources rather than television. It is also possible that the rural Australian areas do not have as great access to women's magazines, and women living in these isolated areas relied on television as an important source of breast health information.

## Attitudes Toward Alternate Payment Options for Mammography screening

The majority of US women expressed that they would be willing to pay more than $\$ 20$ for a mammogram. Most women had never deferred having mammography due to cost constraints, and the vast majority said they would be more likely to have regular mammography if it were always free.

US women responded to a question that asked, "Do you think it would be a good idea for the US or Ohio state government to pay for screening mammograms for all women over the age of 40 ?" The majority of women who replied to this thought that government involvement in providing mammography would help to ensure that those who could not afford mammograms would have them. Other women qualified their answers, "Maybe the government should cover part of the cost-if someone didn't have a lot of money, she could just pay a portion of the cost." Another woman expanded on this topic, "The government shouldn't have to pay for everyone. People who can afford to pay should do so-more left over for those who are financially deprived." A large minority of women did not want the government to get involved at all with mammography. "Taxpayers would end up paying the cost," commented one woman. Another responded, "I don't want to see the government involved. Individuals should take responsibility for their own health-not depend on the government!"

Diverse opinions such as these from US participants are representative of a nation that has always been known for its rugged individualism. However, it appears that many US women who
have health insurance are becoming aware that healthcare that they may have taken for granted is not available to all women, and they would like to see mammograms be made available to every woman who wants one, regardless of her insurance status.

Australians answered a similar question, "If BreastScreen Australia did not offer free mammography, do you think you would be as likely to get regular mammograms?" In contrast to some of the "keep the government out of it" comments from US participants, one Australian woman shared, "No, I would not, because the average person, particularly older or on pension could not afford it. I think it is vital that the Australian government should continue to offer this service to women." Another woman agreed, "Cost could stop some people from getting a mammogram." Even though willing to pay for a mammogram, one woman expressed appreciation for the free quality mammograms provided by BreastScreen, "This program here in NSW is an excellent one and I commend the government for their initiative." This level of social consciousness and responsibility is not surprising. The Australian healthcare system covers all citizens, and the prevailing feeling is that "good people take care of their own."

Most Australian women said that they would continue mammography screening even if it were no longer free. "Yes I would. I love life, and if I should get breast cancer, my life as a naturalist would be no more!" However, others were aware that cost could be a barrier to continuing mammography screening. Although continuing compliance with guidelines "is important, I would not be able to keep up, considering the financial pressure from all aspects of living today." Several older women on pension also said that they would no longer have mammograms due to the cost of the exam.

Another barrier often mentioned by Australian women was geographical isolation from mammography services. The sites where BreastScreen distributed the survey instruments were rural, separated from other areas by great distances. Several women explained that potential cost for mammography was not their concern, but that lack of access to services would be a problem for them. These women lived in remote country locations with no access to mammography
services, and said they probably would not continue with biannual mammography due to this barrier if BreastScreen no longer visited their towns.

## Recommendations for Further Study

This study brings to light several areas for future research. The first concerns the education of women about the reasons for annual or biannual mammography. Women need to know that early detection of breast cancer is possible only with mammography on a regular basis. Women appear to be aware that mammography screening is an important part of their healthcare, but may not understand the reason for an annual or biannual schedule for screening. Health promotion programs might make that a focus of educational campaigns, and evaluate subsequent changes in compliance rates.

Many Australian women said that they would be willing to pay for mammography screening; others said that cost would be an important barrier for them. Perhaps the Australian government could have a trial screening period in an area typical of the majority of sites visited by BreastScreen, in which women were asked for a small co-pay to help defray the costs of the program. This co-pay could be waived for women who could not afford the expense. It may be that this small co-pay would allow BreastScreen to allocate the savings to expand service to more women.

Further studies should continue to explore why some women have mammography screening according to recommended guidelines, and why other women do not. In Australia, cost is not a barrier, yet some women, even those with access to mobile mammography screening, choose not to participate in screening. In the US, more research should be done to examine the barriers that non-compliant women perceive.

There are many women in the US for whom the cost of mammography remains a barrier to screening. These are women who do not have insurance coverage, or whose insurance coverage entails high out-of pocket expense and who are not getting regular mammograms. These women may not be aware of the availability of mammography from community agencies.

Future studies should attempt to discover if low-income women who do not have public or private insurance have the information necessary to obtain free or low-cost mammograms from community agencies. Research should also try to determine the best methods for transmitting this information to these women. Outcomes from such research could be used to plan for health promotion programs for these underserved women.

Factors associated with compliance and non-compliance to mammography guidelines deserve further scrutiny. Once women begin mammography screening, what influences continuing compliance to recommended guidelines? What factors influence women who either stop having mammograms or stop having them annually or biannually? Information derived from this research would be helpful in analyzing ways to encourage continued compliance and planning future educational efforts.

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## Appendix A

Approval from Human Subjects Review Committee

July 25,2000

Dr. Carol Mikanowicz, Principal Investigator
Mís. Alice I Scherl-Siusher, Co-Investigator
Health Professions
Youngstown State University
Campus

## RE: HSRC Protocol \#01-2001

Dear Dr. Mikanowicz and Ms. Slusher:
Based on an administrative review of this protocol, including the follow-on correspondence on file, I am writing to inform you that the proposed activity has been determined to be exempt from full committee review under DHHS Category 1 exemption and has been approved as a study involving no risk to subjects. This determination will remain in effect for three years, subject to annual review and approval, as of the date of this notice.

Please accept the best wishes of the Human Subjects Research Committee for the success of your study.

Sincerely,


Eric C. Lewandowski, CRA
Administrative Co-chair
Human Subjects Research Committee

ECL/

## Appendix B

Approval from MammoVan, Inc.

July 6, 2000

## Dear Alice,

You may certainly distribute surveys to our patients on the MammoVan. Please meet with Ann and the staff on the MammoVan to give instructions.

Good luck with your thesis.

Sincerely,
Floyd E. Slate mo
Lloyd E. Slasher, M.D.
President

Appendix C
Approval from BreastScreen Australia NSW NorthCoast

Tephore 623 662 1822


## TO WHOM IT MAY CONCERN

This is to confirm that Alice Slusher has my permission to use Breast Screen NSW North Coast mobile unit facilitics in order to administer instruments and collect data from women who attend the units for routine screening for breast cancer.



## BETH TREVAN

Director
22.11 .00

Appendix D
Protocol for Instrument Administration

## ADMINISTRATION PROTOCOL FOR MAMMOVAN, INC.

Please ask each patient if she would be willing to take part in a survey study. Participation is entirely voluntary.

Please give the patients the following information:

1) Researchers from Youngstown State University are conducting a study to compare the mammography experience of women in Australia and the United States. The information gathered may help influence public policy concerning mammography. The purpose of the study is to gather and compare information on a woman's opinion on mammography and knowledge of breast cancer risk.
2)The questionnaire is anonymous since your name will not appear on it. This questionnaire will take between 5 and 10 minutes to complete.
2) You may stop at any time during your participation without negative consequences.
3) There is a sheet attached to the questionnaire that provides contact information and other facts about the study. Please tear this page off the survey and keep it in case you want to contact the investigators."

By completing this questionnaire, you are giving your consent to participate in the study."

If they are willing to participate:
5) "After removing the information page and completing the survey, please place your questionnaires in the envelope marked "Surveys.

## Thanks so much for your help!

Note to secretaries and mammotechs-Please return the completed surveys to the box in the Mammovan office. I'll be picking them up every couple days. This is a very important project for me. I can't tell you how much your help with this means to me!!

## ADMINISTRATION PROTOCOL FOR BREASTSCREEN

Please ask each patient if she would be willing to take part in a survey study. Participation is entirely voluntary.

Please give the patients the following information:

1) Researchers from Youngstown State University in the US are conducting a study to compare the mammography experience of women in Australia and the United States. The information gathered may help influence public policy concerning mammography. The purpose of the study is to gather and compare information on a woman's opinion on mammography and knowledge of breast cancer risk.
2)The questionnaire is anonymous since your name will not appear on it. This questionnaire will take between 5 and 10 minutes to complete.
2) You may stop at any time during your participation without negative consequences.
3) There is a sheet attached to the questionnaire that provides contact information and other facts about the study. Please tear this page off the survey and keep it in case you want to contact the investigators."

By completing this questionnaire, you are giving your consent to participate in the study."

If they are willing to participate:
5) "After removing the information page and completing the survey, please place your questionnaires in the envelope marked "Surveys", or return by mail in the envelope we have provided.

## Thanks so much for your help!"

## Appendix E

## Survey Instruments

# PLEASE DETACH THIS PAGE FROM THE QUESTIONNAIRE AND KEFP FOR FITTIIRF RF.FFRENCE 

Information About This Survey Study

## Primary Investigator: Carol Mikanowicz, PhD

Co-Investigator:

Alice I. Scherl-Slusher, B.S., R.D.M.S.

| Affiliation: | Youngstown State University <br> One University Plaza <br> Youngstown, OH 44512-3327 <br> USA |
| :--- | :--- |
| Telephone: | 330.742 .3327 <br> or 330.726 .9087 |
| Email: | alslush@hotmail.com |

You are being asked to take part in a survey study we are conducting. Your participation is entirely voluntary.

The purpose of this study is to compare the mammography experience of women in Australia and the United States. The information gathered may help influence public policy concerning mammography.

The questionnaire is anonymous since your name will not appear on it. This questionnaire will take between 5 and 10 minutes to complete.

You may stop at any time during your participation without negative consequences.
By completing this questionnaire, you are giving your consent to participate in the study.
Please tear this page off the survey and keep it in case you want to contact the investigators.

If you would like further information about breast disease, please contact the your branch of the American Cancer Society in the business white pages of your phone directory. Another good source of information can be found on the ACS's website at http://www.cancer.org/ Select "breast" from the drop-down list on the upper left of the page.

## Please circle the most correct answer

1. What is your age? : 40-45 46-50 51-55 56-59 60 or older
2. How many years of education have you completed?

High school some college/technical college degree/technical certificate
3. What is your race?

African American Caucasian (white) Hispanic Other____
B. Please tell us about your mammography experience

## Please circle the most correct answer

4 Is this your first mammogram? yes no

## (If YES, go to question 9)

5. How old were you when you had your first

35-39 $\quad 40-49$ mammogram?
6. When was your last mammogram?
7. How often do you have a mammogram?
8. Did you receive a reminder in the mail telling you that

| $1-2$ years ago | $3-5$ years ago | more than <br> 5 yrs. ago <br> longer than <br> 2 years |
| :--- | :--- | :--- |
| every year | $1-2$ years |  | it was time for another mammogram?

9. Does your medical insurance pay or partially pay for
10. How much is your out-of-pocket expense for the mammogram?
11. If you always had to pay or partially pay more than
yes
yes
no
12. Have you ever decided NOT to get a mammogram because it cost too much?

13 If mammography were ALWAYS available at NO
yes no COST at all to you, would you be more likely to have regular mammography?
14. Is your mammogram being provided at no cost to yes
no

Parenthood, YWCA?) or your place of employment?
C. What do you know about breast cancer risk?:
15. On average, how many US women do you think might get breast cancer in their lifetimes?

One in 5 women One in 8 women one in 23 women
16. What do you think are YOUR personal chances of getting breast cancer in your lifetime?

I'll probably never get breast cancer
I think I have about an average risk of getting breast cancer
I think I am at higher than average risk for getting breast cancer
D. There are many risk factors that influence your chances of getting breast cancer. The following is a list of items that may or not be risk factors for breast cancer. In your opinion, how important are each of these items? Please indicate your answers with a check $\square$.

| Very <br> imporant |  |  |  | Somewhat <br> important |  |
| :--- | :--- | :--- | :--- | :--- | :--- |
| 17. Being a woman |  |  |  |  |  |
| 18. Growing older |  |  |  | Not very <br> important |  |
| 19. Smoking cigarettes |  |  |  |  |  |
| 20. Famportant history of breast cancer |  |  |  |  |  |
| 21. Family history of cancer of any kind |  |  |  |  |  |
| 22. Having lumpy breasts |  |  |  |  |  |
| 23. Having previous surgery for a benign |  |  |  |  |  |
| (non-cancerous) breast lump |  |  |  |  |  |

E. Which of the following factors made you aware of your need to get a mammogram?

Please mark all that apply:

Television advertisements

Radio advertisementsNewspaper advertisements

Posters or brochures about breast cancer

Saw that the Mammovan was here today
$\square$ I received a reminder letter about my mammogram
$\square$ Magazine article about mammography or breast cancer

My doctor or other healthcare practitioner suggested that I get a mammogram
$\square$ My friends or family urged me to get a mammogram
$\square$ A friend or family member has had breast cancer

1. If you have ever had a mammogram in a hospital or private office, what are the reasons that you have chosen to have your mammogram on the MammoVan today?
2. Do you think it would be a good idea for the US and/or Ohio state government to pay for screening mammograms for all women over the age of 40 ? Why or why not?
3. Do you feel that you have as much information about breast cancer and mammography as you need to make decisions about your health? In your opinion, what would be the most effective way for women to get this information?

## THANKS SO MUCH FOR PARTICIPATING IN THIS SURVEY!!

## PLEASE DETACH THIS PAGE FROM THE QUESTIONNAIRE AND KFEP FOR FI/TIIRF RFFFRFNCF.

Primary Investigator: Co-Investigator:<br>Carol Mikanowicz, PhD<br>Alice I. Scherl-Slusher, B.S., R.D.M.S.

# Affiliation: Youngstown State University One University Plaza Youngstown, OH 44512-3327 USA 

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or 330.726.9087
Email: alslush@hotmail.com

You are being asked to take part in a survey study we are conducting. Your participation is entirely voluntary.

The purpose of this study is to compare the mammography experience of women in Australia and the United States. The information gathered may help influence public policy concerning mammography.

The questionnaire is anonymous since your name will not appear on it. This questionnaire will take between 5 and 10 minutes to complete.

You may stop at any time during your participation without negative consequences.

By completing this questionnaire, you are giving your consent to participate in the study.
Please detach this page and keep it in case you want to contact the investigators.

If you have any questions, please feel free to contact Alice Slusher at the following e-mail address: alslush@hotmail.com.

Please circle the most correct answer

1. What is your age? : 40-45 $46-50 \quad 51-55 \quad 56-59 \quad 60$ and older
2. How many years of education have you completed?

High school some university/technical university degree/technical certificate
3. Are you

Aboriginal Torres Strait Islander neither

## B. Please tell us about your mammography experience

Please circle the most correct answer
4. Is this your first mammogram?
yes no
(If YES, go to question 9)
5. How old were you when you had your first

35-39
40-49
mammogram?
6. When was your last mammogram?
$1-2$ years ago $\quad 3-5$ years ago $\quad \begin{aligned} & \text { more than } \\ & 5 \text { yrs. ago }\end{aligned}$
7. How often do you have a mammogram?
every year 1-2 years
8. Did you receive a reminder in the mail telling you
yes no that it was time for another mammogram?
9. If you had to pay for your mammogram, would you
yes no
50 or older be as likely to have regular mammography?

## C. What do you know about breast cancer ?: (Please circle your answer)

11. How many Australian women do you think might get breast cancer in their lifetimes?
one in 5 women one in 11women one in 23 women
12. What do you think are YOUR personal chances of getting breast cancer in your lifetime?

I'll probably never get breast cancer
I think I have about an average risk of getting breast cancer
I think I am at higher than average risk for getting breast cancer
D. There are many risk factors that influence your chances of getting breast cancer. The following is a list of items that may or not be risk factors for breast cancer. In your opinion, how important are each of these items? Please indicate your answers with a check $\quad$.

|  | VERY important | Somewhat important | Not Sure | Not very important | NOT important |
| :---: | :---: | :---: | :---: | :---: | :---: |
| 13. Being a woman |  |  |  |  |  |
| 14. Getting older |  |  |  |  |  |
| 15. Smoking cigarettes |  |  |  |  |  |
| 16. Family history of breast cancer |  |  |  |  |  |
| 17. Family history of cancer of any kind |  |  |  |  |  |
| 18. Having lumpy breasts |  |  |  |  |  |
| 19. Having previous surgery for a benign (non-cancerous) breast lump |  |  |  |  |  |

E. Which of the following factors made you aware of your need to get a mammogram?

Please mark all that apply:Television advertisements
$\square$
Radio advertisements


Newspaper advertisements

Posters or brochures about breast cancer

Saw that the Mammovan was here today

I received a reminder letter about my mammogram

Magazine article about mammography or breast cancer

My doctor or other healthcare practitioner suggested that I get a mammogramMy friends or family urged me to get a mammogram

A friend or family member has had breast cancer

Other factor? Please specify: $\qquad$

This section is optional, but it would be very helpful if you could give short answers to the following questions.

1. If BreastScreen Australia did not offer FREE mammograms, do you think you would be as likely to get regular mammograms? Why or why not?
2. Do you feel that you have as much information about breast cancer and mammography as you need to make decisions about your health? In your opinion, what would be the most effective way for women to get this information?

## THANKS SO MUCH FOR PARTICIPATING IN THIS SURVEY!!

