GRANT NUMBER DAMD17-96-1-6277

TITLE: Breast Cancer Screening in a Low Income Managed Care Population

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REPORT DATE: October 1997

TYPE OF REPORT: Annual

PREPARED FOR: Commander
U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

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Abstract

Low income women experience more morbidity and a shorter survival compared to more affluent women. Yet these women are least likely to avail themselves of screening and early detection testing which has been previously demonstrated to be associated with prolongation of survival for women subsequently diagnosed with breast cancer.

The goal of this project is to increase screening and early detection practices in low income women, forty years and older, who are enrolled in a statewide HMO. It compares the relative effectiveness of two interventions (a simple one using a letter of invitation and a more intensive “step-wise” intervention of two sequential letters and follow-up counseling and home visits). Both interventions are compared with a control group of women who continue to receive their “usual care”.

This report gives an account of program planning and process evaluation. The results of the baseline survey across groups are presented. A most significant finding was the difficulty of locating and contacting subjects who were literally “hard-to-reach”. Detailed data are provided illustrating the scope of this problem. Baseline survey data analysis is in process and intervention among groups is being initiated.
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Robert E. Hardie
PI - Signature
Date
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Nature of the Problem

Breast cancer is the leading cause of non-skin cancer affecting American women, with a life time expectancy of about 12% for all US women. More than 180,000 cases are expected to develop in 1997 and 46,000 deaths will occur (1). Recently breast cancer has shown a decline in mortality for US women, but while this trend is evident among white women, evidence of a decline is not yet evident for African American females (2). Evidence suggests that this trend is the result of both earlier detection and earlier treatment when localized, and adjunctive treatment of women at high risk for recurrence of their cancer and metastasis after primary treatment.

A number of studies have indicated the usefulness of adjunctive systemic chemo and hormonal therapy for women at risk for breast cancer recurrence (3,4,5). A review of historical cohort trends in breast cancer survival for British Columbia women treated before and after the advent of this type of treatment demonstrated a subsequently decline in breast cancer mortality (6). More recently several studies have documented the further increase in survival of women with breast cancer who are treated with systemic chemotherapy plus radiation therapy above that of adjunctive chemotherapy alone (7,8).

It is estimated that much of the reduction in breast cancer is also due to early detection as evidenced by an increase in minimal and non-invasive to invasive breast cancer ratio, a pattern previously demonstrated for cervical cancer (9). This decline in the ratio of invasive to non-invasive breast cancer has occurred during a period when there has been increased public emphasis upon the use of screening and early detection methods.

Mortality from breast cancer is most preventable when diagnosed at its earliest stages, when it is non-invasive or in the absence of regional spread.

Mammography is the only screening test to be demonstrated by prospective clinical trial to decrease cancer mortality (11-13). Its efficiency and relative safety is well accepted and barriers to its use such as cost and availability are gradually being overcome (14). Although there has been a significant increase in the utilization of mammography in conjunction with clinical breast exam, the technology continues to be underutilized, especially among certain hard-to-reach groups (minority, the poor and elderly women), who consistently participate at lower rates than more affluent white women (15-17).

A lack of adherence to breast cancer screening guidelines is a serious problem for these women because of barriers which seem to relate to their socioeconomic and age status. As a result a number of approaches have been tried in order to overcome related barriers. One strategy recently reported has been to reach women through their health maintenance organization (18,19). In both studies the screening mammography rates increased by using simple interventions. With the advent of health care reform a larger proportion of the American population is expected to be covered by Managed Care Organizations (Health Maintenance Organizations - {HMO}). These organizations offer a unique opportunity to develop novel approaches to the prevention and early detection and treatment of breast cancer. Their advent offers a number of advantages such as: (1) access to large numbers of patients and their records; (2) access to HMO providers health care related databases; and (3) resources for screening and
other preventive health services. The purpose of this project is to demonstrate that the screening behavior of low income women enrolled in a managed care organization can be positively impacted and screening mammography rates can be significantly increased if simple interventions are employed.
Purpose of Research

Our research is to ultimately reduce the morbidity and mortality of breast cancer among the population of low income women who have incomes less than 200% of the national poverty level. Our strategy is to compare the effectiveness of a relatively simple technique to a more complex intervention to reach and effect a significant change in the behavior of the subjects. We hope that this approach will become a model for similar groups elsewhere.

The goals of this project are twofold:

(a) To increase breast cancer screening and early detection by mammography in low income women, forty years of age and above, who are enrolled in a statewide HMO-using a culturally sensitive “step-wise” approach; and

(b) To increase the number of early breast cancers detected - at a time when they are most curable - and to reduce the number of advanced cancers detected so as ultimately decrease Beast Cancer morbidity and mortality.

Technical Objectives

1. To institute a culturally sensitive stepwise intervention to overcome barriers to screening in low income women.

2. To compare the stepwise intervention to a more simple intervention.

3. To document and evaluate the process and outcome results of various screening approaches used to reach this population.

Hypothesis

The study seeks to test three hypotheses:

a. \( H_1 \) A culturally appropriate, step-wise, in-reach intervention which addresses knowledge, attitudinal and logistical barriers will increase mammography utilization in a low-income managed care organization at least 20% over a usual care group from the same HMO.

b. \( H_2 \) An intervention involving a simple reminder letter will increase mammography utilization 10% over a usual care group.

c. \( H_3 \) A culturally appropriate, step-wise, in-reach intervention which addresses knowledge, attitudinal and logistical barriers will increase mammography utilization in a low income managed care organization at least 10% over a simple reminder letter.
Methodological Approach

The purpose of this methodologic approach's to overcome screening barriers experienced by low income women. Our research is based upon a useful model of diagnostic, intervention, and evaluation to influence change and enhance health status. This model developed by Michileutie identifies predisposing, enabling and reinforcing factors to primarily influence process outcomes (reaching high risk women, increasing their knowledge, and skills necessary to participate in screening, sensitizing physicians, institutionalizing screening policies, changing negative and neutral attitudes about screening). The project provides knowledge through the interventions thus predisposing them to positive change (intermediate outcome). It is enabling through the provision of increased access by the HMO which provides coverage for the procedure, physician follow-up and transportation. Finally, reinforcement is insured by the provision of counseling and organizational literature for participants (Figure 1).

1. Project Design

This study builds upon two interventions recently reported in the literature using HMO populations. In one study a randomized trial was conducted to evaluate the combined impact of a reminder letter from a personal physician and a telephone contact on the use of Pap-tests and mammograms in low income managed care organization (16). The second study evaluated a stepped intervention involving two reminder letters, a letter from their primary care physician and a telephone counseling session from a health educator (17). The study also builds upon ongoing work by the Meharry investigators who previously demonstrated the effectiveness of a simple intervention of news letters to providers and HMO-signed letters to member-clients (19). The proposed study will use a culturally sensitive intervention providing personal contacts through trained lay health (peer) workers in home visits and small group interactive sessions. The project utilizes a randomized trial.

Evaluation will consist of comparing the comprehensive intervention with the usual care and the simple intervention groups. Comparisons will also be made with results from the previous studies.

2. Study Population

The study population consists of women 40 years and older who are enrolled in the Tennessee Managed Care Network (TMCN) in Nashville Davidson County, Tennessee. TMCN is the second largest of the twelve managed care organizations (MCO) that have contracted with the state of Tennessee to serve as HMO’s for the former Medicaid population and the working poor. The state obtained a waiver from the federal government (DHHS) in December 1993 to create TennCare as a demonstration project for five years from January 1, 1994.

The population of women in this age group in Nashville, Davidson County, enrolled in TMCN was found to be 1400 women. Based on numbers from claims records - only 26 percent have had mammograms for all reasons (diagnostic and screening). Therefore, more than 1,000 women are eligible for study (i.e. within the past year for those 50 years and older and within the past 2 years for those 40-49 years old) (14). Screening mammograms are covered benefits under this managed care organization.
3. Research Design

From the medical claims database, have been accessed from the organization's home office in Nashville, computerized medical claims data have been reviewed to identify female enrollees 40 years and older who are eligible for inclusion in the study. Those without a claim for a mammogram in the previous year (for those 50 years old or older) or the previous 2 years (for those 40 to 49 years old) have been randomly assigned into one of three groups. Thus the research design is a randomized trial with three groups (a control group and two intervention groups). Women in one group (control) will receive the usual care only; women in a second group will receive a written reminder, while women in the last group will receive an intensive step-wise intervention designed to overcome real and perceived barriers to screening (See Table 4, illustrations).

Patients are randomized by placing the first three names on the list of enrollees in one of the three groups randomly by the use of random number tables. Thereafter every third name will be added to the corresponding group. For example the first, fourth, and seventh and so on will belong to the same group.

4. Intervention Design

a. Experimental Groups: The three experimental groups are characterized as follows:

(i) Group 1
(Usual Care): Visits physician for health care needs only, does not participate in interventions initiated by this project.

(ii) Group 2
(Simple Intervention): Receives usual care plus a prompter letter stating the need for annual mammograms.

(iii) Group 3
(Comprehensive-Step-Wise Intervention): Receives usual care plus a prompter letter followed by a reminder letter followed by phone calls, then interactive group sessions, then home visits.

b. Intervention Procedures

All experimental groups will have barriers removed to differing extents. All groups will benefit from the resources provided by the MCO. Barriers will be addressed by the intervention program as outlined in Chart 2. How barriers are handled within each experimental group is described below.

(i) Barriers Removed by Usual Care from TMCN
Lack of Knowledge: TMCN distributes a newsletter every month to providers and members. The newsletter features different awareness campaigns at the discretion of the editor.
Access to Services: TMCN provides transportation to members for services, as needed. TMCN also has special training for lay health outreach workers within low income housing projects.

Availability of Services: TMCN stresses to its provider membership that breast cancer prevention and control procedures be instituted for all clients as a part of physical assessment. Lay health outreach workers will facilitate follow-up visits as scheduled by primary care physicians or as needed.

Cost of Services: TMCN reimburses up to $50 for mammograms.

Culture: TMCN Lay health workers are former welfare recipients recruited from low income projects and undergo a 5-month training program.

Physician Attitudes: These will be affected via TMCN newsletter awareness campaigns.

(ii) Barriers Removed by First Level Experimental Intervention Groups 2 & 3
Lack of Knowledge:
Brochures beyond Newsletter (physician offices, mail out)
Reminder letter
All other barriers addressed by Usual Care (i) above

(iii) Barriers Removed by Intensive Intervention (Group 3)
Lack of Knowledge: Interactive small group sessions

Access to Services:
Distribution of transportation vouchers routinely for visit to providers and for mammograms;
Priority Appointments;
Reminder letters and telephone counseling

Availability of Services: A tracking system to facilitate follow-up visits; combined with reminder letters, telephone calls and home visits.

Culture:
Training lay health outreach workers intensively on cultural sensitivity;
Using familiar sites for special program activities e.g. churches, clinic sites;
Developing culturally-sensitive information at the appropriate literacy levels to overcome culturally-induced attitudes of fear, inertia, self medication, hopelessness;
Apply individually - appropriate counseling.

Physician Attitudes:
Design special education sessions to improve attitudes
Designing a reminder system for physicians
All other barriers addressed by (ii) above
**Results (Interim)**

**Administrative Process**

The project began on schedule with the hiring of research personnel, development of the research planning committee, meeting with officials and technical personnel of Access Med-Plus, the HMO providing subjects.

By the fifth month of the project letters had to be sent to subjects in groups II and III and baseline questionnaires of breast knowledge, attitudes and practices had been submitted to the MCO and State’s Board of Tenn Care for their approval.

By month 8 of the program community outreach health workers had been trained to assist in administering questionnaires to a sample of each of the three groups. This was necessitated by the fact that two-thirds of targeted women did not have telephones (telephone numbers were provided to the Tenn Care bureau or the MCO).

The administration of the questionnaire began in month 9 and was planned to continue for two months. However, contacting the subjects has proven to be difficult in a majority of the cases.

We are in the process of completing the baseline survey of a sample of each randomized group of women. The intervention phase will begin in December of 1997.

**Problems Encountered**

A number of unexpected problems have been encountered in carrying out this project including the following:

1. **A smaller study population** - the number of subjects available for randomization (1400) was less than one-half of the expected 3,500 population which was planned to be studied. To overcome this problem the broader boundaries of the metropolitan Nashville statistical area encompassing five additional counties were included in order to increase eligible TMNC members.

2. **Claims data reliability** - claims data showed that nearly all claims paid had diagnoses for various medical breast conditions rather than “screening”. Access Med Plus staff are in the process of verifying the true nature of the tests through follow-up with individual physicians.

3. **Contact and follow-up difficulties** - most frustrating is the fact that this population is indeed extremely “hard-to-reach”. Problems arise from the fact that only one-third (36%) of member-subjects have telephones listed with the MCO (Table 5). Of these, 20-30 percent have had those phones disconnected and two thirds of the remaining phones were not answered when called (Table 4). To overcome this problem, community Health Outreach Workers were sent to the homes to make contact and complete questionnaires. Even with much effort only
sixty percent of women were contacted by the two methods (telephone and home visits).

**Lack of Telephones**

As can be seen from Table 5, only 36% of this population of targeted women have telephones listed with their Managed Care Organization (MCO) or with the Tenn Care Bureau. Of these women, only 46% could be reached after three repeat calls. Twenty percent of the telephones had been disconnected. Of the women reached by interviewers, often the proprietor of the phone was a relative, neighbor or a place of employment. Thus only 16% of the targeted population could be reached by telephone.

**Home Visits**

One hundred and twenty women residing within Davidson County were contacted. Only 28% of subjects were successfully contacted with a questionnaire completed (Table 1). Women who were contacted were usually contacted on the first attempt (Table 2). Domiciles were visited three times before the contact attempt was deemed a failure. In most such instances repeat visits were not useful. Considerable effort was put forth by the interviewers who made a total of 418 visit efforts. The reasons for the failure to make contacts are listed in Table 1 and include: (a) not being at home; (b) moved from the premises; (c) refusal to participate; (d) language barriers, and (e) there was no physical structure at the address in 10 percent of the cases (Tables 1,3,4).

**In Summary**

From our experience, it is obvious that this population is hard to reach. They move much of the time. Most do not have telephones and some of the addresses are those of relatives, friends and neighbors. In a few instances addresses may even be Post Office Boxes. In spite of the fact that many are at poverty level (Medicaid eligible) socioeconomically, a considerable proportion of these women go out to participate in some gainful activity during week days. To reach these individuals will require special efforts such as staff who will visit at night or on weekends.

**Analysis of Surveys**

This aspect of the study is presently in progress. Baseline questionnaire measuring knowledge, attitudes and practices across all groups are being analyzed. This will be followed by the intervention phase to begin December 1997.
References


2. Presentation of National Center for Health Statistics at the NCI - Meeting on “Screen Mammography for Minority Women 40-49 years of Age” March 1996.


### Appendices

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<tbody>
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</tr>
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<td>Table 1</td>
<td>Survey Effort Summary</td>
</tr>
<tr>
<td>Table 2</td>
<td>Total Completed Surveys</td>
</tr>
<tr>
<td>Table 3</td>
<td>Total Unsuccessful Attempts</td>
</tr>
<tr>
<td>Table 4</td>
<td>Survey Activity / Effort Per Woman</td>
</tr>
<tr>
<td>Table 5</td>
<td>Telephone Contacts</td>
</tr>
</tbody>
</table>
Figure 1

Disease Prevention, Health Promotion Intervention Model

PREDISPOSING FACTORS
Knowledge
Beliefs; value

ENABLING FACTORS
Access to care, skills; decision-making authority at personal and community levels.

PROCESS OUTCOMES:
Accessing target population; increased use of appropriate services, increasing knowledge skills and beliefs important for health promotion & disease prevention.

INTERMEDIARY OUTCOMES:
HEALTH BEHAVIORS:
Smoking cessation; saturated fat intake; weight control; compliance with treatment.

HEALTH OUTCOME
Decreased cardiovascular mortality, decreased deaths from cancer.

REINFORCING FACTORS
Incentives & rewards for health promotion behaviors; social support from provider, family, peer feedback; environmental support for health behaviors.
Figure 2

Research Process Activities Accomplished

- Hiring Research Support Staff
- Organizing Research Planning Committee
- Meeting with Access Med Plus Officials and Staff
- Obtaining a File of Eligible Women Members
- Obtaining Claims Data File on Screening Mammograms Performed on Access Med Plus Women ≥ 40 Years Old within the Previous 12 Months
- Focus Group Discussion of Low Income Women as Baseline for Knowledge and Attitudes about Breast Cancer Screening
- Training Sessions with Community Outreach Health Workers
- Implementation of Baseline Survey
- Analysis of the Survey Process
- Analysis of the Survey Results
Table 1

SURVEY EFFORT SUMMARY

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<tr>
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<th>Group II</th>
<th>Group III</th>
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<td>1. Total Attempts</td>
<td>155</td>
<td>114</td>
<td>149</td>
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<td>2. Total Completed Surveys</td>
<td>37</td>
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<td>3. Total Unsuccessful Attempts</td>
<td>118</td>
<td>84</td>
<td>97</td>
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Reasons:

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<td>49</td>
<td>144</td>
</tr>
<tr>
<td>b. Moved</td>
<td>29</td>
<td>24</td>
<td>19</td>
<td>72</td>
</tr>
<tr>
<td>c. Refused</td>
<td>8</td>
<td>14</td>
<td>16</td>
<td>38</td>
</tr>
<tr>
<td>d. No Physical Address</td>
<td>16</td>
<td>5</td>
<td>9</td>
<td>30</td>
</tr>
<tr>
<td>e. Language Barriers</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>f. Miscellaneous/Other</td>
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<td>84</td>
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### TOTAL COMPLETED SURVEYS

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<td><strong>Group III</strong></td>
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<tr>
<td><strong>Total</strong></td>
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<td>63</td>
</tr>
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</table>

**Group I:** It took 37 attempts to reach 37 people.

**Group II:** It took 32 attempts to reach 30 people.

**Group III:** It took 63 attempts to reach 52 people.
## TOTAL UNSUCCESSFUL ATTEMPTS

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## SURVEY REPORT

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<td><strong>a. Successful Surveys</strong></td>
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<td>63</td>
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<tr>
<td><strong>b. Unsuccessful Surveys</strong></td>
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<td>118</td>
<td>49</td>
<td>84</td>
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<tr>
<td><strong>Total (a+b)</strong></td>
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<td>155</td>
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<td><strong>No One At Home</strong></td>
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<tr>
<td><strong>Refused</strong></td>
<td>6</td>
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<td>5</td>
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<tr>
<td><strong>Language Barriers</strong></td>
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<td>5</td>
<td>9</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total Unsuccessful</strong></td>
<td>60</td>
<td>118</td>
<td>49</td>
<td>84</td>
<td>61</td>
<td>97</td>
</tr>
</tbody>
</table>
# Table 5

## Members having Telephone

<table>
<thead>
<tr>
<th></th>
<th>Davidson County</th>
<th>Others counties</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Size</td>
<td># Listed</td>
</tr>
<tr>
<td>Group I</td>
<td>190</td>
<td>67</td>
</tr>
<tr>
<td>Group II</td>
<td>182</td>
<td>68</td>
</tr>
<tr>
<td>Group III</td>
<td>195</td>
<td>65</td>
</tr>
<tr>
<td>Total</td>
<td>567</td>
<td>200</td>
</tr>
</tbody>
</table>
Questionnaires
Breast Cancer Screening in A Managed Care Population

A Survey of Knowledge, Attitudes and Practices (KAP)

Questionnaire

Meharry Medical College

1996
Breast Cancer Screening in A Managed Care Population
A Survey of Knowledge, Attitudes and Practices (KAP)

Code Number: ____________________________________________________________

Date of Interview (MM/DD/YY): __________________________________________

Name: _________________________________________________________________

Address: __________________________________________________________________________

Telephone number (Day time): _____________________________________________

(Evening time): ___________________________________________________________
A. General Information

First, I would like to ask you some general questions.

A1. What month, day and year were you born?

<table>
<thead>
<tr>
<th>MM</th>
<th>DD</th>
<th>YY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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<tr>
<td>97</td>
<td>97</td>
<td>97</td>
</tr>
<tr>
<td>99</td>
<td>99</td>
<td>99</td>
</tr>
</tbody>
</table>

A2. How many people in your family (household)?

| Number
| In your family, how many adults age 18 or older? |
|----------------------------------|----------------------------------|
|                                  |                                  |

A3. Do you consider yourself white, black or other?

<table>
<thead>
<tr>
<th>White</th>
<th>Black</th>
<th>Other(Specify)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

A4. What was the highest grade of school you completed?

| Highest grade completed
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>------------------------</td>
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</tbody>
</table>

A5. Are you?

<table>
<thead>
<tr>
<th>Married</th>
<th>Single</th>
<th>Divorced</th>
<th>Widow</th>
<th>Separated</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

A6. What is your family's total annual income?

<table>
<thead>
<tr>
<th>Less than $5,000</th>
<th>$5,000--$10,000</th>
<th>$10,001--$15,000</th>
<th>$15,001--$25,000</th>
<th>More than $25,000</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>RF</td>
<td></td>
<td></td>
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</tbody>
</table>
B. Health Knowledge, Attitudes and Exams

Now, I am asking you some questions about your health knowledge, attitudes and exams.

B1. How would you say your health is in general?  
   - Poor................................................1  
   - Fair...............................................2  
   - Good.............................................3  
   - Excellent.......................................4  
   - RF................................................9

B2. How would you say your health is compared to other women who are close to you in age?  
   - Much worse....................................1  
   - Worse............................................2  
   - Same.............................................3  
   - Better..........................................4  
   - Much better.................................5  
   - RF..............................................9

B3. How serious do you think breast cancer is as a health problem for women?  
   - Not so serious.................................1  
   - Somewhat serious............................2  
   - Very serious.................................3  
   - RF..............................................9

B4. Have you had a general physical exam in the past three years (check up) ?  
   - Yes.............................................1  
   - No..............................................2  
   - RF..............................................9

B5. Do you smoke?  
   - Yes.............................................1  
   - No..............................................2  
   - RF..............................................9
### C. Breast Cancer History

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>DK</th>
<th>RF</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1</td>
<td>Is there anyone in your family who has had any type of cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>What type?</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>C2</td>
<td>Are there any female relatives of yours who ever had breast cancer?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Female relatives include your mother, sisters, daughters, grandmother</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>and aunts.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C3</td>
<td>Have you ever had breast cancer?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C4</td>
<td>Have you ever been told by a doctor that you had some kind of breast</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>condition, but that it was not breast cancer?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### D. Breast Cancer Screening Knowledge and Attitudes

**D1. In your opinion, how likely is it that you will get breast cancer in your lifetime?**

- Very likely .............................................. 1
- Somewhat likely ........................................ 2
- Somewhat unlikely ................................... 3
- Very unlikely ......................................... 4
- DK ............................................................. 7
- RF ............................................................. 9

**D2. Can you name any examinations that can be done to find breast cancer in its very early stage? (DO NOT READ. CHECK ALL MENTIONED. AFTER RESPONDENTS GIVE THEIR ANSWERS, ASK, "ANY OTHERS?")**

- Women examine their own breasts... 1
- Doctors or nurses do the exam .... 2
- Chest X-ray ............................................. 3
- Mammography ........................................... 4
- DK ............................................................. 7
- RF ............................................................. 9

**D3. What do you think are some warning signs or symptoms of breast cancer? (DO NOT READ. CHECK ALL MENTIONED. AFTER RESPONDENTS GIVE THEIR ANSWERS, ASK, "ANY OTHERS?")**

- Lumps in breast ...................................... 1
- Shortness of breath ................................. 2
- Pain, soreness, burning in the breast .... 3
- Nausea ..................................................... 4
- Discharge from nipple ............................. 5
- Swelling or enlargement of breast ......... 6
- Changes in shape of breast or nipple .... 7
- Discoloration ......................................... 8
- DK ............................................................. 97
- RF ............................................................. 99

**D4. Do you know how to examine (to check) your breasts for lumps? (If "NO", SKIP TO D7) or TO D6**

- Yes ................................................................ 1
- No .................................................................. 2
- RF .................................................................. 9

**D5. Who taught you how to exam your breasts? (CHECK ALL MENTIONED)**

- Doctor......................................................... 1
- Nurse .......................................................... 2
- Other health professional ....................... 3
- Mother ........................................................ 4
- Friend .......................................................... 5
- Sister or other relative .............................. 6
- Learned in class or meeting ...................... 7
- Read in a book, magazine, etc ............... 8
- Television .................................................. 9
- Other (Specify) .............................................
D6. How often do you think
a woman should examine her breasts?
(RECORD THE CLOSEST CHOICE)
Whenever she thinks about it............1
Yearly........................................2
Monthly......................................3
Weekly......................................4
Daily........................................5
RF.............................................9

D7. Women have many reasons for not
examining their breasts.
What would you say are the reasons
they do not examine (check) theirs?
(DO NOT READ. CHECK ALL MENTIONED.
AFTER RESPONDENTS GIVE THEIR
ANSWERS, ASK, "ANY OTHERS?")
Doctor or nurse does it..................1
Husband or partner does it................2
No cancer in the family....................3
Afraid of what I might find...............4
Doctor said not necessary................5
I couldn't find anything...................6
Can't remember to do it...................7
Just don't do it............................8
Don't know how to do it...................9
Other (Specify) _______________________
RF.............................................99

D8. How much have you heard about
current treatment allowing the doctor
to remove only the part of the breast
that has the cancer if it is detected very early?
Nothing at all.............................1
Very little..................................2
Fair amount................................3
Great deal..................................4
RF.............................................9

D9. How much have you heard about
a clinical breast exam which is
when the breast is felt for lumps
by a doctor, nurse or medical assistant?
Nothing at all.............................1
Very little..................................2
Fair amount................................3
Great deal..................................4
RF.............................................9

D10. About how often should a woman
at your age have a clinical breast exam?
(RECORD THE CLOSEST CHOICE)
Weekly........................................1
Monthly......................................2
Yearly........................................3
Less than once a year......................4
Only when there is a problem............5
Only when a doctor/nurse
recommends...............................6
DK............................................7
RF.............................................9
D11. How much have you heard about
a mammogram which is when an X-ray is taken
only of the breast by a machine that
presses the breast while the picture is taken?)

Nothing at all........................1
Very little............................2
Fair Amount..........................3
Great Deal...........................4
RF......................................9

D12. Women have many reasons for
not having mammogram.
What would you say are their reasons
for not examining (check) their breasts?
(DO NOT READ. CHECK ALL MENTIONED.
AFTER RESPONDENTS GIVE THEIR
ANSWERS, ASK, "ANY OTHERS?")

Procrastination........................1
Don't know I should...................2
Not needed...........................3
Cost too much........................4
No insurance coverage...............5
Don't go to the doctor's office.......6
Don't have a doctor..................7
Not recommended....................8
Too embarrassing....................9
Haven't had any problems...........10
Fear of pain.........................11
Other (Specify) .......................99

D13. About how often should a woman
at your age have a mammogram?
(RECORD THE CLOSEST CHOICE)

Weekly...............................1
Monthly..............................2
Yearly...............................3
Less than once a year..............4
Only when there is a problem.....5
Only when a doctor/nurse
recommends.......................6
DK....................................7
RF....................................9
### E. Clinical Breast Exam

**E1.** When did you have your last clinical breast exam?

- Within the last year
- Between 1 and 2 years ago
- Between 2 and 5 years ago
- More than 5 years ago
- Never
- DK
- RF

**IF NEVER SKIP TO F1**

**E2.** Have you ever had a breast exam where the results were not normal?

- Yes
- No
- RF

"Not normal" means positive problems found in the breast exam.

**E3.** Did your doctor ask you to have additional tests because your results were not normal?

- Yes
- No
- RF

(If NO, skip to F1)

**E4.** Did you have any additional tests?

- Yes
- No
- RF

**E5.** Did you have any surgery or other treatment?

- Yes
- No
- RF

**E6.** Did the breast exam, additional tests, surgery or other treatment indicate that you had breast cancer?

- Yes
- No
- RF

If yes, in which year?

If yes, in which hospital?
## F. Mammogram

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
</tr>
</thead>
</table>
| F1. Has a doctor or nurse ever recommended that you have a mammogram? (IF NO, SKIP TO G1) | Yes.................................1  
No.................................2  
RF.................................9 |
| F2. Have you ever had a mammogram? (IF NO, SKIP TO G1) | Yes.................................1  
No.................................2  
RF.................................9 |
| F3. When did you have your last mammogram? | Within the last year ..............1  
Between 1 and 2 years ago........2  
Between 2 and 5 years ago........3  
More than 5 years ago.............4  
DK.................................7  
RF.................................9 |
| F4. Have you ever had a mammogram where the results were not normal? "Not normal" means positive problems found in the breast exam. (If NO, skip to G1) | Yes.................................1  
No.................................2  
RF.................................9 |
| F5. Did your doctor ask you to have additional tests because your results were not normal? | Yes.................................1  
No.................................2  
RF.................................9 |
| F6. Did you have any additional tests? | Yes.................................1  
No.................................2  
RF.................................9 |
| F7. Did you have any surgery or other treatment? | Yes.................................1  
No.................................2  
RF.................................9 |
| F8. Did the mammogram, additional tests, surgery or other treatment indicate that you had breast cancer? If yes, in which year? and in which hospital? | Yes.................................1  
No.................................2  
RF.................................9  
Year___________________________  
Hospital________________________
### G. Knowledge About Breast Cancer

I am going to read a series of statements about breast cancer. Please tell me whether you strongly agree, agree, disagree, strongly disagree or undecided with each statement.

<table>
<thead>
<tr>
<th>G1.</th>
<th>Many women are concerned about the possibility of getting breast cancer.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly agree............................................................................... 1</td>
</tr>
<tr>
<td></td>
<td>Agree......................................................................................... 2</td>
</tr>
<tr>
<td></td>
<td>Disagree...................................................................................... 3</td>
</tr>
<tr>
<td></td>
<td>Strongly disagree......................................................................... 4</td>
</tr>
<tr>
<td></td>
<td>Undecided..................................................................................... 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>G2.</th>
<th>Women over 50 are more likely to get breast cancer.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly agree....................................................... 1</td>
</tr>
<tr>
<td></td>
<td>Agree.............................................................................. 2</td>
</tr>
<tr>
<td></td>
<td>Disagree......................................................................... 3</td>
</tr>
<tr>
<td></td>
<td>Strongly disagree..................................................... 4</td>
</tr>
<tr>
<td></td>
<td>Undecided........................................................................ 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>G3.</th>
<th>Women whose mothers or sisters have had breast cancer are most likely to get breast cancer.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly agree....................................................... 1</td>
</tr>
<tr>
<td></td>
<td>Agree.............................................................................. 2</td>
</tr>
<tr>
<td></td>
<td>Disagree......................................................................... 3</td>
</tr>
<tr>
<td></td>
<td>Strongly disagree..................................................... 4</td>
</tr>
<tr>
<td></td>
<td>Undecided........................................................................ 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>G4.</th>
<th>Women under 50 are more likely to get breast cancer.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly agree....................................................... 1</td>
</tr>
<tr>
<td></td>
<td>Agree.............................................................................. 2</td>
</tr>
<tr>
<td></td>
<td>Disagree......................................................................... 3</td>
</tr>
<tr>
<td></td>
<td>Strongly disagree..................................................... 4</td>
</tr>
<tr>
<td></td>
<td>Undecided........................................................................ 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>G5.</th>
<th>Any woman is likely to get breast cancer.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly agree....................................................... 1</td>
</tr>
<tr>
<td></td>
<td>Agree.............................................................................. 2</td>
</tr>
<tr>
<td></td>
<td>Disagree......................................................................... 3</td>
</tr>
<tr>
<td></td>
<td>Strongly disagree..................................................... 4</td>
</tr>
<tr>
<td></td>
<td>Undecided........................................................................ 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>G6.</th>
<th>If breast cancer is found and treated early it can be cured.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly agree....................................................... 1</td>
</tr>
<tr>
<td></td>
<td>Agree.............................................................................. 2</td>
</tr>
<tr>
<td></td>
<td>Disagree......................................................................... 3</td>
</tr>
<tr>
<td></td>
<td>Strongly disagree..................................................... 4</td>
</tr>
<tr>
<td></td>
<td>Undecided........................................................................ 5</td>
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<tr>
<td>G7.</td>
<td>Women who have their first child after age of 30 are more likely to get breast cancer.</td>
</tr>
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<tr>
<td>G8.</td>
<td>If a woman has a lump in her breast, it is almost always breast cancer.</td>
</tr>
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<tr>
<td>G9.</td>
<td>I worry about getting breast cancer.</td>
</tr>
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<tr>
<td>G10.</td>
<td>By doing a self breast exam often, it is possible to find breast cancer in time to cure it.</td>
</tr>
<tr>
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<tr>
<td>G11.</td>
<td>Women who do not have children are more likely to get breast cancer.</td>
</tr>
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</tbody>
</table>
### H. Barriers to Cancer Screening

For each statement, check the one answer that comes closest to the way you feel

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Cancer treatment would be worth going through if there was a small chance that it would save my life</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>2.</td>
<td>There is very little a person can do to reduce his/her chances of getting cancer.</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>3.</td>
<td>Having a check-up once a year is worth the time and effort.</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>4.</td>
<td>I have doubts about some of the things doctors say they can do for you.</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>5.</td>
<td>I am aware of the health services in my community.</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>6.</td>
<td>I would have a mammogram (breast x-ray) only if my doctor recommended it.</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>7.</td>
<td>I would seek more medical services if they were not expensive.</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>8.</td>
<td>I am usually afraid of what the doctor will find.</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>9.</td>
<td>Breast exams embarrass me.</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>10.</td>
<td>Exposure to radiation during a mammogram concerns me.</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>11.</td>
<td>I appreciate reminders about my medical appointments.</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Disagree</td>
</tr>
<tr>
<td>---</td>
<td>----------------------------------------------------------------------------</td>
<td>----------------</td>
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</tr>
<tr>
<td>12</td>
<td>Not having transportation makes it difficult for me to keep medical appointments.</td>
<td><strong>4</strong></td>
<td><strong>3</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>13</td>
<td>The cost of medical care keeps me from going to the doctor.</td>
<td><strong>4</strong></td>
<td><strong>3</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>14</td>
<td>It takes a long time to get an appointment to see a doctor.</td>
<td><strong>4</strong></td>
<td><strong>3</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>15</td>
<td>Doctors make me feel uncomfortable.</td>
<td><strong>4</strong></td>
<td><strong>3</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>16</td>
<td>Getting the time off work makes it difficult for me to go to the doctor.</td>
<td><strong>4</strong></td>
<td><strong>3</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>17</td>
<td>The chance of finding something wrong keeps me from asking for medical advice.</td>
<td><strong>4</strong></td>
<td><strong>3</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>18</td>
<td>Doctors take their time when explaining medical procedure to me to make sure I understand.</td>
<td><strong>4</strong></td>
<td><strong>3</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>19</td>
<td>Instead of going to the doctor when I do not feel well, I just take it easy for a while.</td>
<td><strong>4</strong></td>
<td><strong>3</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>20</td>
<td>Privacy is important to me during my visit to health care facilities.</td>
<td><strong>4</strong></td>
<td><strong>3</strong></td>
<td><strong>2</strong></td>
</tr>
<tr>
<td>21</td>
<td>I am afraid of the pain I may feel when I visit a health care facility.</td>
<td><strong>4</strong></td>
<td><strong>3</strong></td>
<td><strong>2</strong></td>
</tr>
</tbody>
</table>
A. THANK RESPONDENT FOR PARTICIPATING.

B. ASK RESPONDENT TO SIGN PERMISSION TO ABSTRACT MEDICAL RECORDS FORMS.