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The proportion of mammograms interpreted as abnormal in large screening programs is as high as 15-20%. Thus, if 15% of the 48 million American women 40 years of age or older have mammograms, there would be more than 7 million abnormal mammography results each year. It has been estimated that 30% or more of women with abnormal mammograms fail to comply with follow-up recommendations. This proportion is disparate across racial groups, such that women from minority populations are less likely to receive follow-up than white women. There is little known about why this disparity exists and a need to find out more in order to decrease the number of black women dying from this disease. This study proposes to look at this existing problem from a new perspective-- that of the African American woman. The goal of this study is to improve the rates of follow-up in African American women after an abnormal mammogram result by understanding the variables that predict follow-up and developing an innovative intervention through community input that overcomes obstacles to follow-up.

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I. Introduction

Although a higher proportion of black women than white women of all ages have reported being screened for breast cancer, mortality rates for black women are higher than those for white women. Even though the proportion of black and white women with invasive disease upon diagnosis is similar, African American women are more likely to die from the disease. Differences in follow-up and treatment are two of many reasons for this disparity. The proportion of mammograms interpreted as abnormal in large screening programs is as high as 15-20%. Thus, if 15% of the 48 million American women 40 years of age or older have mammograms, there would be more than 7 million abnormal mammography results each year. It has been estimated that 30% or more of women with abnormal mammograms fail to comply with follow-up recommendations. It is also the case that many minority women who obtain one mammogram are also more likely than white women to not obtain rescreening as recommended. This proportion is disparate across racial groups, such that women from minority populations are less likely to receive follow-up than white women. There is little known about why this disparity exists and a need to find out more in order to decrease the number of black women dying from this disease. This study proposes to look at this existing problem from a new perspective-- that of the minority woman. The goal of this study is to improve the rates of follow-up in minority women after an abnormal mammogram result and to improve rescreening rates by understanding the variables that predict follow-up and developing an innovative intervention through community input that overcomes obstacles to follow-up.

II. Overview of Progress to Date

During the period of December 1, 2001 thru December 31, 2002, the following accomplishments were achieved:

- Complete literature review of relevant topics (*Appendix A*);
- Submissions and completion of local IRB approvals (*Appendix B*);
- Development of materials to educate state health department and obtain their consent to proceed (*Appendix C*);
- Submissions and completion of Human Subjects Research Review Board (HSRRB) approval (*Appendix D*);

- Initiation of data collection through three local health departments (*Appendix E*).

Each of these key research accomplishments are described below.

a. Key Research Accomplishments

Literature Review:

In preparation for the development of the research protocol to be used for this study, a literature review was completed to obtain information on the work others have done in this area. *Appendix A* includes a chart of the studies that were reviewed. Information from these studies was incorporated into protocol development where relevant.

Submission and completion of local IRB approvals:

Prior to submitting for approval by HSRRB, a package was developed for local IRB approval. Initial approval was obtained in March 2002. This information was shared with Mercy Swatson, RN, MSN, Human Subjects Protection Scientist, along with a draft of the submission to HSRRB for her review and advice on revising the package. A package was later submitted to HSRRB and after several revisions, final approval was received in August 2002. At that point, local IRB approval had to again be obtained, with the revisions made since March, and this was received in August 2002 (*Appendix B*).

Partnership Development with State Health Department:

Obtaining a working partnership with State Health Department (SHD) staff proved to be a major challenge in the implementation of this study. Even though the Principal Investigator (PI) has a long-standing and positive relationship with the SHD, an extensive review and approval process was followed before this study was allowed to proceed. Materials in *Appendix C* were developed to provide an overview of the study in March 2002 and was sharec with management in obtaining approval. Upon approval in May 2002, several meetings were held with the North Carolina Breast and Cervical Early Detection Program and the PI for this study. For each meeting, we reviewed the process for data collection and developed a strategy that was suitable to the SHD and HSRRB. It was then left to the SHD to use the criteria for inclusion in the study

and select 3-4 local health departments that would be asked to participate. Criteria for selection included that they had screened a higher than average number of minority women and had numerous cases that had either failed to follow-up for abnormal results or for re-screening as recommended. In June, the SHD staff selected 4 counties to participate and then wanted to visit each county in person to explain the study and ensure their willingness to participate prior to the PI meeting with each department. After HSRRB approval was obtained in October 2002, the PI went to each local health department (LHD) to discuss the study and explain the procedures to be used in data collection. Ultimately, three of the four LHDs agreed to participate in the study. These include the LHDs located in Robeson, Randolph, and Cabarrus counties.

Obtaining HSRRB Approval:

Obtaining approval from HSRRB proved to be another challenge in the implementation of this study. Initial materials were submitted in February 2002, with final approval not obtained until October. The initial package was submitted in February after obtaining local IRB approval. In May, a second revision was submitted upon receiving instructions, with subsequent revisions occurring through August 2002. As of August, the PI was instructed to obtain local IRB approval again which was immediately completed (*Appendix B*). Upon receiving that approval, the PI again resubmitted to HSRRB and obtained final approval in October. Once that approval was obtained, visits to the LHDs could be conducted so that women could be identified and recruited into the study, per the final study protocol (*Appendix D*).

Initiation of Data Collection:

Site visits with the LHD were scheduled quickly so that visits could be made before the Christmas holidays. Two of the LHDs were visited so that data collection could be initiated in December 2002. The third LHD could not be visited before the holidays and arrangements were made for a visit the first week of January. The protocol followed for the interviews with recruited women appears in *Appendix E*. By the end of December, eight interviews were completed and 21 consent forms received with the hope of completing at least 60 interviews prior to the IRB deadline of March 7, 2003.

b. Reportable Outcomes

The only reportable outcome is the literature review chart created to guide the development of the study protocol (*Appendix A*).

III. Conclusions

This study is still underway and therefore research conclusions are not available at this time. Two major barriers were encountered during this report period that caused delays in study implementation. These barriers included the time required to obtain final approval from both the state health department and HSRRB to proceed with the study. Because of these delays, a no-cost extensions was requested in October, 2002, and was obtained in December. This study will now conclude on or before December 31, 2003.

Now that the primary barriers have been overcome, the study is proceeding as planned. All data collection will cease by March 7, 2003, since that is the deadline for local IRB approval. At that time, data analysis will proceed with a final report of findings submitted to the Department of Defense on or before December 31, 2003. It is hoped that the findings from this study can be used to obtain subsequent funding from the National Cancer Institute to implement a community-based intervention that addresses barriers to rescreening or follow-up identified by the respondents.

APPENDIX A

Source	Purpose	Methods	Results
Aziz H, Hussain F, Sohn C, Mediavillo R, Saitta A, Hussain A, Brandys M, Homel P, Rotman M. Early onset of breast carcinoma in African American women with poor prognostic factors. Am J Clin Oncol. 1999 Oct;22(5):436-40.	Determine significance of age and race at onset of BC	Retrospective study 713 patients w/ BC (327 W and 386 AA) other races excluded 2 NY hospitals from 1983 to 1993	Used MV analysis Found that AA women developed BC 10 years earlier than W women.
Tessaro I, Eng E, Smith J. Breast cancer screening in older African-American women: qualitative research findings. Am J Health Promot. 1994 Mar-Apr;8(4):286-92.	To discover why older AA women perceive and react to BC the way they do	Focus groups (14) from various AA social groups and some sons and husbands	1)BC risk not major concern for AA women over 60. Younger women did consider BC major concern. 2)Age not seen as risk factor but family history was. 3)Believed no difference in risk bn AA and W women 4)believed AA less likely to seek treatment than W Believed BSE and physician exam to be as effective as mammography. 5)Fear may be factor – many practiced BSE but didn't go to Dr. 6)Cost 7) older AA women tend to seek care for specific problem and not for preventive med. 8) Family over self; privacy
REPORTS ON FOLLOW UP OF AB MMG!!!!!!!! Burack RC, Simon MS, Stano M, George J, Coombs J. Follow-up among women with an abnormal mammogram in an HMO: is it complete, timely, and efficient? Am J Manag Care. 2000 Oct;6(10): 1102-13.	Describe follow-up behavior for women with seriously abnormal mammograms.	Retrospective chart review 92 women in HMO 90% AA 40% over 40 80% Medicaid 50%+ income < $20,000	Rate of follow-up within 60 days for seriously abnormal mammograms was 32% Beyond 60 days was another 35% Not completed was 34%
Skinner CS, Arfken CL, Sykes RK. Knowledge, perceptions, and mammography stage of adoption among older urban women. Am J Prev Med. 1998 Jan;14(1):54-63.	Understand older urban women's attitudes and perceptions about breast cancer by stage of mammography adoption	Telephone interviews by female grad students Sample recruited from peer volunteer program Mean age 72.5 88% AA 32% less than 8th grade education	Good sample stats… 42% knew early BC not painful 37% knew BC doesn't=masectomy 59%knew Fam. History = >risk 38% knew risk > w/age <50% knew that physical contact and breast size does not = >risk 18% knew that bumps/bruises don't = BC

			More women were sure that mammogram could find BC early than it's ability to find "before big enough to feel"... More likely to have mammogram w/in previous 2 years if: <75, more education, nonsmokers, rcvd reg. med care @ clinic, saw MD 2X in previous year.
Champion VL, Menon U, McQuillen DH, Scott C. Validity of self-reported mammography in low income African American women. Am J Prev Med. 1998 Feb; 14(2):111-7.	Compare self-reported mammography rates and medical records.	Interviewed participants about last mammogram then checked medical records Volunteers from women waiting to receive social services 286 useable participants mean age= 54.7	Of 219 reporting mammogram w/in past year - only 48.4% verifiable -23.7% verified to be completed 13 to 24 months prior - 15.1% more than 2 years prior
Danigelis NL, Roberson NL, Worden JK, Flynn BS, Dorwaldt AL, Ashley JA, Skelly JM, Mickey RM. Breast screening by African-American women: insights from a household survey and focus groups. Am J Prev Med. 1995 Sep-Oct;11(5):311	Collect information to develop strategy for addressing barriers to breast screening in low and moderate-income AA women	Focus groups and household surveys using social learning theory and HBM. - 2 tracts with total of 333 participants - 84% response rate - results based on 281 AA women - face to face interview by AA interviewer - Focus groups (3) 90min led by 2 AA women - 2 criteria for participants low income and limited education	Survey: - Gives screening stats and opinion stats - 81% heard of mammogram - 63% knew that woman over 50 should get mmg every year - 87% knew CBE should be done every year - 77% believed screening participation mattered to family members - 46% knew women who rcvd reg. breast screening Focus: - knowledge of screening guidelines appeared limited (?no #'s) - most generally believed they had little chance of getting BC Interaction w/ screening behavior and income level for 3 factors: Having heard of mammogram, screening mattered to family, and being shown BSE in MD's office increased behaviors but increase in mod. Income sign. > than low income
Danigelis NL, Worden JK, Mickey RM. The importance of age as a context for understanding African-American women's mammography screening behavior. Am J Prev Med. 1995 Sep-Oct;12(5):358-66.	Examine association of predisposing, reinforcing, and enabling factors for AA women X age groups	Stratified random sample N=648 AA women Ages 40+ divided into 3 age groups (40-49; 60-64; 65+) - Bivariate (X2) Screening X age Factor X age - ageXscreeningXfactor interactions	Ages 40-49: - sign. < likely than either older groups to have recent mammogram (38.3% to 51.3% and 50.4% respectively) - sign. > likely to perceive they would get BC (47.2% to 38% and 34.4%) Ages 65+: - sign > likely to visit MD several times a year and to have health insurance - sign < likely to be taught BSE in MD office

Hedegaard HB, Davidson AJ, Wright RA. Factors associated with screening mammography in low-income women. Am J Prev Med. 1996 Jan-Feb;12(1):51-6.	Looked at factors associated with screening mammography in public health center	N=10982 (n=3521 screened and 7461 unscreened) - 32% W - 23% AA - 40% H - 4% other - 1% unknown	Native American, Asian, and other less <likely to be screened than W, AA, or H. Women on Medicaid 2X as likely as those w/o
Mandelblatt J, Traxler M, Lakin P, Kanetsky P, Thomas L, Chauhan P, Matseoane S, Ramsey E. Breast and cervical cancer screening of poor, elderly, black women: clinical results and implications. Harlem Study Team. Am J Prev Med. 1993 May-Jun;9(3):133-8.	Cross-sectional descriptive study Looked at participation rates when Nurse Practitioner approached women in urban public hospital who are already there for routine visit	491 participants	20.6% refused screening 8.4% claimed recent screening 71% participation
Pearlman DN, Rakowski W, Ehrich B, Clark MA. Breast cancer screening practices among black, Hispanic, and white women: reassessing differences. Am J Prev Med. 1996 Sep-Oct;12(5):327-37.	Examine differences in screening behavior by race (B,W,H) TTM stages Current screening and intention to have mmg	National Database from NHIS-HPDP N=9219 Ages 40-75 Classified according to TTM stages W=80% of sample AA=15% H=5%	AA and H at >risk of underscreened or unscreened - H in south sign more likely to be underscreened or unscreened - Lack of physician recommendation major barrier?
Wagner TH. The effectiveness of mailed patient reminders on mammography screening: A meta-analysis. Am J Prev Med. 1998; 14(1):64-70.	Meta-analysis: Compare effectiveness of mailed patient reminders at increasing mmg screening	Articles using controlled randomized trials N=16 articles In US=12	Women in US receiving reminders are morelikely to get screening Tailored letters associated w/sign > rates of mammography
Weinberg AD, Cooper HP, Lane M, Kripalani S. Screening behaviors and long-term compliance with mammography guidelines in a breast cancer screening program. Am J Prev Med. 1997 Jan-Feb;13(1):29-35	Intervention to increase mmg compliance for all hospital employees (FT and PT who qualified for benefits)	Mean age = 55.8 N=239 49.8% W 29.3% AA 11.7% H 9.2% other employees sent invitations to "in-service" where watched video on CBE and SBE were permitted 1 free mammogram for every year they attended and filled out follow-up questionnaire. Invitations to in-service sent every year. Physician participation allowed women to consult w/MD and required MD referral after 1st screening…not clear of cost on MD visit	Mean number of days in program = 1287.3 - Those requiring fewer invitations, Who were older, who had at least 1 mmg or CBE by T1 stayed in program longer. - time in program not sign related to fam history, having 1 mmg in past year at T1, or performing monthly BSE at T1 not sign. Related to time in program. Of 67.8% who remained active - Greater % of W remained active (81.5%) - H = 67.9%; AA=48.6%; o=54.6% AT T2: - 89.5% reported having mammogram compared to 65.7% at T1 - Mmg use sign. Related to ethnicity - 53.8% W; 46.4% H; 28.6% AA; 22.7% "o"
Merkin SS, Stevenson L, Powe N. Geographic socioeconomic status, race,	Compared AA and W women ages 40+	Examined associations between race, geographical SES, and advanced BC stage	Found similar trends for AA and W with similar SES.

and advanced-stage breast cancer in New York City. Am J Public Health. 2002 Jan;92(1):64-70.	On incidence of BC based on cancer registry info from NY	37921 cases	- adjusting for age and year at diagnosis – lower income and education increased odds of late stage BC (50% AA and 75% W) - AA presented at younger ages - Area SES associated with race - % of unknown and distant stages decreased steadily as income and education increased Methodological problems! Left out some zipcodes for incomplete info. These were mostly low income areas and low income areas tended to have higher % AA pop. Left out hospital for not reporting race
O'Malley MS, Earp JA, Hawley ST, Schell MJ, Mathews HF, Mitchell J. The association of race/ethnicity, socioeconomic status, and physician recommendation for mammography: who gets the message about breast cancer screening? Am J Public Health. 2001 Jan;91(1):49-54.	Investigate association between physician recommendation of mmg and race, SES, and other characteristics	Sample from baseline measure of Program funded by NCI through UNCSpecialized Program of Research Excellence in Breast Cancer Age = 52+ N=1933 45 min questionnaire by trained interviewer self-report of MD recommendation is primary outcome measure	Increasing age, lower educational attainment and lower income were negatively associated with physician recommendation
Wells BL, Horm JW. Targeting the underserved for breast and cervical cancer screening: the utility of ecological analysis using the National Health Interview Survey. Am J Public Health. 1998 Oct;88(10):1484-9.	Compare characteristics of those who have/have not had mmg, CBE, and Pap using NHIS	Ages 18-64 For mmg ages 35-64	Odds of never having mmg increased as education level decreased. Odds of never having mmg also lower in areas 70 to 100% H Lower income areas And for younger women (ages 30 to 44 compared to ages 45 to 59)
McCarthy EP, Burns RB, Coughlin SS, Freund KM, Rice J, Marwill SL, Ash A, Shwartz M, Moskowitz MA. Mammography use helps to explain differences in breast cancer stage at diagnosis between older black and white women. Ann Intern Med. 1998 May 1;128(():729-36.	Examine relationship between previous mmg use and BC stage at diagnosis for older AA and W women.	Retrospective from database Geographically diverse population (Conneticut, Atlanta and Seattle-Puget Sound) N=4005 Age = 67+ and on medicare for 2 years Data on race, marital status, age, SES 4% AA	Previous mmg use significantly contributes to black-white difference in stage at diagnosis. Explained 30% of excess late-stage BC among AA. Black women were overrepresented among nonusers (35% to 22%) and underrepresented among regular users (11% to 19%) Late-stage disease diagnosed more frequently in AA women.
Simon Ms, Gimotty PA, Moncrease A, Dews P, Burack RC. The effect of patient reminders on the use of screening mammography in an urban health department primary care setting. Breast Cancer Res Treat. 2001 Jan;65(1):63-70.	Determine if patient reminders would significantly effect mmg use.	Randomized control trial 3 conditions (1 letter, 2 letter, 0 letter) n=1966 used stratified sampling to send letters no ethnicity data!	Letters had no impact Those with prior mammograms and commercial health insurance were more likely to be rescreened. Age had no significant effect. Low levels of mmg use overall 3 conditions.

Chang SW, Kerlikowske K, Napoles-Springer A, Posner SF, Sickles EA, Perez-Stable EJ. Racial differences in timeliness of follow-up after abnormal screening mammography. Cancer. 1996 Oct 1;78(7):1395-402.	Is race associated with timelines of follow-up care after abnormal mmg?	N=317 Age= 33 to 85 mean=52 48% over 50 With abnormal screening mmg 64% W; 16% H; 12% Asian; 8% AA in SanFrancisco	- Abnormal screening mmg interpretation not sign. diff by race. - Median time to final disposition differed sign. by race (12 days W and 19 days nonW) - Median time to 1st diagnostic test sign. (7days W and 15 days nonW) - Overall difference from 1st diag to final disp. Not sign different (explained by lag to 1st diag.) - Age not found to be sign. predictor of follow-up time
Mayo RM, Ureda JR, Parker VG. Importance of fatalism in understanding mammography screening in rural elderly women. J Women Aging. 2001;13(1):57-72.	Investigate associations bn demographics, fatalism correlates, and the impact of those factors on breast screening. Defined fatalism as individual's belief that BC inevitably leads to death.	4 page self report questionnaire given (demographics, screening behavior, resource variables, fatalism) Powe Fatalism Inventory Convenience sample = 300 from various senir social sites in 6 counties that were predominantly low income minority. Final sample=220 135 AA and 85 W ages 50+ with majority over 70	Initial positive associations bn fatalism and: Age, race Initial negative associations bn education level and MD recommendation 30% of the sample had not participated in mmg in previous 2 years. 13% never had mmg. Bivariate analyses: Sign diff in mean fatalism scores by: Age, race, education, MD recommendation, and insurance X2 for demographics/resource/compliance w screening - older women less likely to be screened in previous 2 years - race and place of residence not associated w screening - Resource var. associated w noncompliance included: MD recommendation, insurance, having service paid by Best Chance Network T-tests compare mean fatalism for compliance and noncompliance: - mean fatalism for AA in compliance was sign lower than for noncompliant AA. - Same difference not found for W! Fatalism did not add to the explanatory model when logistical regression included all variables for noncompliance.

Phillips JM. Breast cancer and African American women: moving beyond fear, fatalism, and silence. Oncol Nurs Forum. 1999 Jul;26(6):1001-7.	Explore beliefs, attitudes and practices related to BC screening for low & mid income AA women.	3 focus groups…all AA women 90 min 8 mid income 8 service workers 10 unemployed ages 40-65 recruiting and snowballing used to get sample moderator and assistant moderator to conduct groups both AA similar settings…$25 payment to all ?'s included "What are primary health concerns of AA women?" and "Compared to other ethnic groups, how would you rate the health status of AA women?"	Demographics: - 7 <HS - 19 at least HS - 13 did BSE monthly - 19 had CBE every 6 to 12 mo. - 6 had no mmg (4 service and 2 unemp.) - 1 unemp. Never had CBE Major feelings associated w/BC: - Panic and Fear (all groups) - Death and amputation - ONLY TEACHERS mentioned mmg and early detection. - Secrecy and silence - Power of prayer - Screening associated with fear and this was a reason not to get screened…didn't matter if early detection best assurance of cure Barriers in Health Care System: - money - racial differences in treatment - only go to doctor if something is wrong - transportation - no guarantees - physician discouragement (?!) - surgery associated with worsening of condition - HMO's
21. Phillips JM, Cohen MZ, Moses G. Breast cancer screening and African American women: fear, fatalism, and silence. Onclo Nurs Forum. 1999 Apr;26(3):561-71.	NO research…mostly discussion of previous Mentions study: EVAXX , INC. study (1981) as 1st to do research on fatalism.		
Lawson HW, Henson R, Janet K, Kaeser, Mary K. Implementing recommendations for the early detection of breast and cervical cancer among low income women.	NO research…this is a review of prevalence rates and information from several sources on cervical and breast cancer screening.		REALLY GOOD STATS FROM ACS ON MORTALITY AND BC! There are some quotes in here that would support the importance for early detection and would be additive to research component of lit review.
Jones BA, Kasl SV, Curnen MG, Owens PH, Dubrow R. Can mammography screening explain the difference in stage at diagnosis of breast cancer? Cancer. 1995 Apr 15;75(8):2103-13.	Investigates the role of screening mmg in stage at diagnosis	N=322, 145 AA and 177 W 22 hospitals in Conneticut interview and access to medical charts (modified version of questionnaire used in NCI Black/White Cancer Surveillance Study)	- AA women with newly diagnosed 1st primary BC were sign. younger than W women. - AA women almost 2X as likelyto be diagnosed before 50. - AA women had lower SES, education, and occupation

		- physicians refused acess to white patients more often than AA patients! - 76% participation rate - Used TNM stage established by American Joint Committee on Cancer.	- AA women were 3X as likely to be obese - Risk of diagnosis at TNM II or > was twice more for AA women than W. - W women 2X as likely to ever have mmg. AA women were sign. more likely to NEVER have mmg or to NOT have mmg in 3 years prior to diagnosis. - Race-mmg association greater in younger women. - Sign. more W women reported physician recommendation for mmg. Prior to illness. - Adjustment for SES, education and occupation did not alter race-mmg association. - **History of screening mmg was protective against later stage of BC only in white women!**
Baquet CR, Commiskey P. Socioeconomic factors and breast carcinoma in multicultural women. Cancer. 2000 Mar 1;88(5 Suppl): 1256-64. Review.	This is a review of literature on SES and ethnicity as it is associated with BC rates.		There are a few blanket statements that relate SES to BC that may be used as "filler" if needed.
Menck HR, Mills PK. The influence of urbanization, age, ethnicity, and income on the early diagnosis of breast carcinoma: opportunity for screening improvement. Cancer. 2001 Sep 1;92(5):1299-304.	Examined relationship of Age, ethnicity, income, and urbanization on BC diagnosis at early stage. In California based on existing data set from California Caner Registry.	N=85, 808 From 1994-1997	Larger % of non-Hispanic white women and younger women were diagnosed at early stage. Larger % were diagnosed in more recent years. 12 % increase in diagnosis of in situ tumors b/n 1994 and 1997. Groups at high risk of later diagnosis were elderly, H, AA, and those living in nonurban areas.
Newman LA, Carolin D, Simon M, Kosir M, Hyrniuk W, Demers R, Schwartz AG, Visscher D, Peters W, & Bouwman D. Impact of Breast Carcinoma on African-American Women: The Detroit Experience. Review. Cancer. 2001 May 1;91(9):1834-43.	Review of literature on AA women with BC.		10-20% higher mortality rate for AA than W. One study on follow-up that we don't have was cited: **McCarthy BD, Yood MU, Boohaker EA, Ward RE, Rebner M, Johnson CC. Inadequate follow-up of abnormal mammograms. AM J Prev Med 1996;12:282-8.** **Found: 34% W with inadequate follow-up compared to 49%AA!**
Lauver, DR, Dane J. A motivational message, external barriers, and mammography utilization. Cancer Detect	Test interaction of motivational message with external barriers on women's mmg use in SES dis	- N=101 51 to 80 yrs. (avg=64) - no mmg in prior 18 mos. - ID'd by chart review at urban	Increased mmg use for women without external barriers but not for those with barriers.

Prev. 1999;23(3)254-64.	advantaged groups. H1: Women who rcvd message and had no barriers would be more likely to obtain mmg.	hospital mmg clinic. - Excluded women under 50 and over 80 and women who couldn't speak English. - 55% W and 45% AA. - Random assignment done for each group separately to control race. - Control received no message and Intervention received message and brochure. - Phase II involved getting consent from control and assessing screening bx and barriers for all participants. At this time nurses discussed rationale and recommentdations for screening w/control. - Measure = whether mmg was rcvd b/n message delivery and PII.	Racial differences: AA used mmg more than W. AA had less education and higher perception of BC risk but these var. unrelated to mmg use.
Barroso J, McMillan S, Casey L, Gibson W, Kaminski G, Meyer J. Comparison between African-American white women in their beliefs about breast cancer and their health locus of control. Cancer Nurs. 2000 Aug;23(4):268-76.	Looked at HBM and HLOC to evaluate differences in knowledge and beliefs about BC between W and AA women.`	Convenience sample from health care facilities in Florida. Heath Screening Questionnaire (psychometrics presented...good internal consistency, construct validity, and T/rT reliability) distributed to participants along with demo. Measure. 374 questionnaires returned (89%) 152 AA and 197 W ages 19-93 with mean=51.6 AA and 54.1 W.	More AA indicated: - Health is matter of luck - They worry about health - Could not or were unsure they could prevent BC. - Were unsure that 50% of those with cancer can be cured - Were unsure of benefits of early diagnosis Internal HLOC was equal for W and AA. BUT... - AA women were sign more likely to believe in chance and depend on powerful others for health. Level of Education was significantly related to beliefs about seriousness of BC for white women but not for AA women. For both AA and W women, level of education was sign. related with belief in Chance and Powerful Other (i.e. better education = less belief in chance)
Moore RJ. African American women and breast cancer: notes from a study of narrative. Cancer Nurs. 2001 Feb;24(1):35-42; quiz	Interviews with breast cancer survivors	Small sample of AA women's perspectives presented	The most mentioned idea that came out of this was the absence of AA survivors in media, absence of AA prosthetics, and the need for more culturally sensitive models of BC presentation and care.

Gulitz E, Bustillo-Hernandez M, Kent EB. Missed cancer screening opportunities among older women: a review. Cancer Pract. 1998 Sep-Oct;6(5):289-95.	Presents analysis of literature and findings from interview/surveys with professionals in BC field. Discusses perceived barriers to BC screening.	218 MD's, 54 DO's, 178NP's, 46 CNM's. n=496 respondents out of 2052 randomly sampled (see next article) Open ended survey's and interviews (telephone and face to face) Qualitative analysis	Patient Barriers: - reasons women did not seek out preventive health services - this is mostly reasons that providers felt that women were not directed to have screening and perceptions of why those women wouldn't follow through - poorer, older women harder to motivate - women with comorbid conditions - if provider suspects woman would not follw through - not wanting to further burden a woman Provider Bariers: - No personal commitment to prevention …focus on treatment of acute conditions - Inexperience in patient education - Not wanting to offend patients - Unsure of clinical skills Practice Barriers: - small practices are overwhelmed with acute cases and may have little time for preventive care. - Lack of personnel - Belief that screening should only be discussed during well visits Access Barriers: - difficulty of referral and same day scheduling - cost - limited screening facilities - location of screening facilities
Gulitz E, Bustillo-Hernandez M, Kent EB. Missed cancer screening opportunities among older women: A provider survey. Cancer Pract. 1998 Nov-Dec;6(6):325-32.	Quantitative survey component of previous	See previous Majority of MD's and Do's were men Nurses were mostly women Majority white Florida 37 item self-admin questionnaire	Older providers in small or rural practices who specialized in geriatrics or adult health were least likely to screen older asymptomatic women. 30% of physians and 43% of nurses concur that mmg is not financially accessible to most of their women patients. 10% of providers were uncertain and 12% agreed with a statement that annual mmg in women over 50 is too frequent! That's 22% who don't

			know!!!!!! And these are the experts
Erwin DO, Spatz TS, Stotts RC, Hollenberg JA. Increasing mammography practice by African American women. Cancer Pract. 1999 Mar-Apr;7(2):78-85.	Looks at effectiveness of Witness Project. Uses cancer survivors to promote screening in rural underserved AA women.	Quasi-experimental pre/post Women in church and community groups in 2 counties in rural Arkansas There was only one potential site in this area to receive screening mmg. Intervention and control group AA role models in intervention group did presentations in local churches and community groups using a model (with appropriate skin tone!) to show how to do BSE, talked about personal experience with cancer and gave out vouchers for free mmg.	Women in intervention reported a significant increase in BSE (49.0 % to 65.4%) and MMG (52.4% to 64.4%) screening behaviors. There were no sign. changes in control.
Blair KA. Cancer screening of older women. Cancer Pract. 1998 Jul-Aug; 6(4);217-222.	Are family practice physicians and residents screening older women for cancers as recommended by ACS, the Guide to Clinical Preventive Services, and Healthy People 2000?	Retrospective chart review Random sample from 660 women seen b/n July 1, 1992 and June 30, 1993 over age 60. N=201 charts Predominantly white (85%)	Younger women more likely to be screened. Family practice physicians and residents varied from 58 to 76% in recommending appropriate screening Only b/n 9 and 46% oif those tests were done. **Table of Barriers to Cancer Screening**
Paskett ED, Tatum CM, Mack DW, Hoen H, Case LD, Velez R. Validation of self-reported breast and cervical cancer screening tests among low-income minority women. Cancer Epidemio Biomarkers Prev. 1996 Sep;5(9):721-6.	Improving screening bx, attitudes, and beliefs of women over 40 in low income housing in NC.	Baseline: - random samples selected for interview - knowledge attitudes, barriers, use of screening - 78% response rate overall with N=125 intervention and N=123 control Follow-up: - only women in communities during intervention period were sampled - 75% response rate N=168 intervention and N=134 Control Intervention: - used baseline data - Precede/proceed, HBM and social learning theories and PENIII for cultural sensitivity	Equivalent baseline characteristics between intervention and control. Intervention: - 31% had mmg at baseline; 56% had mmg at follow-up (sign) - psysician referral effect on screening rates at baseline 38 to 28%; at follow-up 60 to 31% - proportion of women reporting fewer barriers at follow-up 40% Comparison: - 33% had mmg at baseline; 40% had mmg at follow-up (nonsign) - proportion of women reporting fewer barriers at follow-up 10%

		- community events, educational programs, brochures, mass media, monthly classes by lay health educator, birthday cards, targeted mailings and door knob hangers, one-on-one educational sessions. Winston Salem – intervention - 9 housing communities - 908 women; predominatly AA - majority over 65 - final N=125 Greensboro – control - 18 housing communities - 1021 women; predominantly AA - majority over 65 - final N=123 Face to face interviews	
Phillips J, Smith ED. Breast cancer control and African American women: a review. Cancer Invest. 2001;19(3):273-80. Review.	Review of literature on BC in AA women **Same author as Fatalism articles**		Advocates incorporating knowledge of cultural themes, beliefs and attitudes of AA women toward screening, detection, and BC in general. BC=death sentence Injury of breast and blood toxins = BC Limited efficacy of mmg Spiritual and religious beliefs Belief that BC is white woman's disease
Cozier Y, Palmer JR, Rosenberg L, Adams-Campbell LL. Recent mammography use among African American women. Ethn Dis. 2001 Spring-Summer;11(2):188-91.	Large national study to assess mmg use in AA women in 1995 BASIC STATS ON MMG USE	Mail survey of 64, 350 AA women ages 21 to 49 Report based on responses of 27,632 AA women b/n ages 40-69 Asked when last mmg was. Response categories were: never, <1 year ago; 1-2 years ago; 3-4 years ago, and 5 or more years ago.	Mmg <1 year: - 39% age 40-44 - 47.2% age 45-49 - 62% age 50-69 differences in MMG use: not completed HS = 73.7% completed HS= 79.2% HS+1 = 80.1 More education = more mmg Greater mmg use among women with family history and those with cystic disease
Wagner TH, Hu T, Duenas GV, Kaplan CP, Nguyen BH, Pasick RJ. Does willingness to pay vary by race/ethnicity? An analysis using mammography among	Survey on how much low-income women of 5 differenct ethnicities were willing to pay for mmg.	W, H, AA, Filipino, And Chinese women Some information on demographics and screening behaviors	Willingness to pay varied by ethnicity With average overall of $130

low-income women. Health Policy. 2001 Dec;58(3):275-88.			
Schneider TR, Salovey P, Apanovitch AM, Pizarro J, McCarthy D, Zullo J, Rothman AJ. The effects of message framing and ethnic targeting on mammography use among low-income women. Health Psychol. 2001 Jul;20(4):256-66.	Investigates impact of video messages on mmg use and attitudes. Whether differences exist in the way that video message is framed (Gain or loss and multicultural vs. targeted).	Convenience samples from 2 inner-city community health clinics and from public housing developments - 43% AA, 27% W, 25% Latina, 2% AI, 1% Asian, 3%other Flyers invited women 40 years and over to participate Women in clinics were invited to participate and completed questionnaire before and continued experiment after appointment $10 participation incentive Random assignment to 1 of 4 conditions: all watched videos, - loss-framed multicultural - gain-framed multicultural - loss-framed targeted - gain-framed targeted All participants were to answer questionnaire before and after that assessed demographics and screening behavior Measures taken at 6 month and 12 month follow-up	Immediate: - Loss framed messages elicited greater negative affect - Ethnically targeted videos had higher ratings of vido model similarity and were rated as more important to participants families and backgrounds. 6 month: - loss framed multicultural condition participants were more likely (1.81X) to report mmg than gain framed multicultural condition - framing and targeting use differed by ethnicity - AA women's use of mmg not improved by intervention. - W and Latina's more persuaded by loss-framed multicultural message 12 month: effects were not significant Suggestion for more studies using booster to prevent fading
Bernstein J, Mutschler P, Bernstein E. Keeping mammography appointments: motivation, health beliefs, and access barriers experienced by older minority women. J Midwifery Womens Health. 2000 Jul-Aug;45(4)308-13.	Investigates willingness and ability of women over 50 to keep mmg appts. Peer intervention to increase mmg Differences bn English and non-English speaking women	Doesn'tconnect ethnicity and language....????? - the % English speaking is exact same as % AA. Conducted in emergency department of Boston Medical Center Project ASSERT – peer educator based primary care referral program Mmg history and beliefs, general health, prevention bx's and health care resources werew evaluated.	English speaking were less likely to keep appointment – no mention if race was a factor here!!!!!! Identified barriers: Fear 46% Transportation 38% Cost 22% Preference not to know 24% Pain 15% Family responsibilities 14%

		Peer educators did intervention - gave info on importance of mmg - assisted review of pros and cos of making/keeping mmg appt. - aided in development of self-defined plan for breast health maintenance - assessed mmg readiness - set up mmg appt if requested. Follow up telephone survey at 3 months with 66% response rate	
Roetzheim RG, Pal N, Tennant C, Voti L, Ayanian JZ, Schwabe A, Krischer JP. Effects of health insurance and race o early detection of cancer. J Natl Cancer Inst. 1999 Aug 18;91(16);1409-15.	Relationship of time at diagnosis with type of health insurance	Data from 28237 all patients with 4 types of cancer in Florida in 1994 Evaluated stage at diagnosis, race, SES, type of insurance (or no insurance)	Results for BC showed that those insured by Medicaid or uninsured were more likely to be diagnosed with late stage disease. AA or H more likely to be diagnosed late independent of insurance
Breen N, Wagener DK, Brown ML, Davis WW, Ballard-Bash R. Progress in cancer screening over a decade: results of cancer screening from the 1987, 1992, and 1998 National Health Interview Surveys. J Natl Cancer Inst. 2001; 93: 1704-1713.	Examines trends in screening use for cancers across 1987, 1992, and 1998 national surveys.	Evaluation of the National Health Interview Survey	Use of MMG almost doubled bn 1987 and 1992. slower rate of increase up to 1998. - 1998 - 67% of women over 40 received mmg within last 2 years. Racial/ethinc differences in mmg use for AA shown in 1987 disappeared by 1998. H women screened at lower proportion. Low income and uninsured women remain underserved.
Phillips JM, Cohen MZ, Tarzian AJ. African American women's experiences with breast cancer screening. J Nurs Scholarsh. 2001;33(2):135-40. **SAME AUTHOR AS FATALISM**	Describe meaning and breast cancer screening experiences of AA women	Very qualitative with small sample 8 low-income and 15 mid-income AA women unstructured open-ended interview describe experiences with BCscreeening (including self and physician exam and mmg) 60-90 minute interviews included demographics identified universal themes	More low income women expressed problems with lack of access to health care Less than optimal screening rates in both groups Themes Lack of health insurance Relationships Religion Caring and respectful physicians were more important than racial and ethnic attributes in determining trust. Women who were confident in their skills, comfortable with their bodies, and had sense of self-

			esteem were more likely to engage in BCS.
Coleman EA, O'Sullivan P. Racial differences in breast cancer screening among women from 65 to 74 years of age: trends from 1987-1993 and barriers to screening. J Women Aging. 2001;13(3):23-39.	Compare BC screening rates and barriers for AA and W women and identify trends between 1987 and 1983 Reports on 3rd survey wave	N=6061; 16.8% AA and 83.2% W Computer assisted telephone interviews, mailed questionnaires, and field interviews	Medicare funding for MMG resulted in more use of MMG but trends differed for w and AA. W showed more substantial increase 32.6% in 1988 and 59% in 1993. Increase from 1991 to 1993 = 5.4% AA showed less increase 26.2% in 1988 and 47.9% in 1993. Increase from 1991 to 1993 <1%. Physicians recommendation, level of education, and health status were sign associated with mmg use. Physicians were more likely to recommend mmg for W married women with education beyond HS and >$20,000. income.
Douglass M, Bartoluci A, Waterbor J, Sirles A. Breast cancer early detection: differences between African American and white women's health beliefs and detection practices. Oncol Nurs Forum. 1995 Jun;22(5):835-7.	To determine if differences exist between W and AA women with respect to frequency of use, health beliefs about mmg, CBE and BSE. What differences, if any, exist?	3 part descriptive survey - investigator developed Questionnaire consisting of items on frequency of use of mmg, CBE, and BSE according to ACS recommendations. - modified version of Champion's HBM scales (CHBMS). 25 additional items on benefits, barriers, and control to address use of mmg and CBE. - items used to calculate SES using Green's 2 factor formula. Entire study questionnaire evaluated by experts. 117 AA and 157 W avg. age for AA=47.62 and for W=44.71 this is statistically sign. but authors purport it is not clinically sign. **All women were currently employed by school system and over 35!!!!!!!!!!**	No sign. difference found for frequency of mmg use and CBE **THERE WERE NO SIGN. DIFFERENCES IN INCOME OR FAMILY HISTORY OF BC** More AA women practiced monthly BSE W women had sign. higher mean score for perceived barriers to mmg and CBE
Lauver DR, Kane J, Bodden J, McNeel J, Smith L. Engagement in breast cancer screening behaviors. Oncol Nurs Forum. 1999 Apr;26(#):545-54.	What variable distinguish women who engage in recommended breast screening from those who do not?	Cross-sxl Telephone interviews; structured likert scale questions 8 item mood adjective checklist (POMS) with established psychometrics Attitudes Towards MMG Scale to measure beliefs about mmg. Time of last mmg use=1 nonuse=0 in last 13 months	Women of Color were put into one category and compared with Caucasian women. Women of low SES were over represented Single women were more likely to perform monthly BSE and seek yearly MMG. Most women reported few barriers Women who had low negative moods, no barriers, no history of asymptomatic breast problem, had

		Belief in likelihood of developing BC 3?'s on BC knowledge Facilitators / Barriers measured with Melnyk's Barrier Scale (1990) Age range=51-80 Sample from records at mmg clinic or urban hospital Ability to speak English N=119 Protocol not specific	private insurance and were single women of color were more likely to have had a mmg in the past year.
Facione NC. Breast cancer screening in relation to access to health services. Oncol Nurs Forum. 1999 May;26(4):689-96.	Examines perceptions of access to health care and the relationship between perceptions of access and BCscreening bx.	Volunteer sample Work and community settings in northern California (nonhealth settings) N=838 (AA=287; H=316; 235=W) $10 reimbursement all materials in English and Spanish multiple measures: - Perceived Access to Health Services (PAHS); psm given - Habits of Health Services Utilization (HHSU); psm - Perceptions of Prejudice; newly developed - Social desirability response bias accounted for by Peynold's short form of the Marlowe-Crowne; psm given also measured mmg screening history; SES; and availability of health care coverage/money for healthcare	PAHS scores increased significantly for women who had more than a HS education vs. those who did not. 24% of the variance in the PAHS was attributed to family annual income level. - higher income = higher PAHS score 51% of the sample perceived some degree of prejudicial treatment in healthcare services with 22% reporting personal experience Prejudicial treatment : small sign. difference between AA and W with AA experiencing more Small sign difference for poor women Sign. difference for lesbian vs. hetero and bi women. 25% reported little or no healthcare use. Significantly lower HHSU scores for women reporting experiencing prejudicial treatment 57% of the variance in perceived access was attributed to health care habits, Spanish as the spoken language, 3 measures of financial capability Family annual income was only factor to explain unique variance This sample had unusually high rate of mmg adherence. Sign. differences found for perceived access to health services, personal experience of prejudice, annual income.

Champion VL, Skinner CS, Foster JL. The effects of standard care counseling or telephone/in-person counseling on beliefs, knowledge, and behavior related to mammography screening. Oncol Nurs Forum. 2000 Nov-Dec;27(10):1565-71.	Improving MMG screening Beliefs and Knowledge, decreasing perceived barriers using telephone, or in-person counseling.	Test-retest with control and random assignment to condition Used time post intx of 4 weeks to measure compliance with mmg screening. women >50 / no mmg past 15mo. From large HMO and general medicine clinic in Indianapolis Only 39% (1098 of 2815) contacted agreed to participate. Only 696 remained at follow-up. Calculations based on original N. 30% AA 3 groups: no counseling, telephone, in-person measures included perceived susceptibility, benefits, and barriers (5 pt. likert) knowledge scale had 18 MC questions related to screening and BC treatment Stage of mmg adoption was assessed	No sign. differences in stage of mmg adoption pre. Post: 17% of control became compliant 30% of telephone; 33% of in-person post perceived susceptibility scores sign. higher in both intx groups. Perceived benefits for control sign. lower than both intx. Sign difference across all groups for perceived barrier scores but those in the control group were sign. higher than in both intx. Groups Controlling for knowledge pre, post knowledge for both intx. Sign. higher
Burnett CB, Steakley CS, Tefft MC. Barriers to breast and cervical cancer screening in underserved women of the District of Columbia. Oncol Nurs Forum. 1995 Nov-Dec;22(10);1551-7.	Perceptions of perceived barriers of BC and cervical cancer for underserved women in relation to intent to perform screening bx's. Relationship between attitudes and influence of sign. other. Relationship between service site and intentions.	Cross sectional correlational Using Theory of Reasoned Action as basis Investigator created questionnaire with 237 items: 30 min interview by trained RA - Demographics - Attitudes - subjective norms (perceptions of family/friend beliefs about screening) - contextual factors (barriers) - knowledge Subjects 339 uninsured English-speaking > 40 years old. *recruited from 6 cancer screening sites	Mean age =51 90%AA 6% H 60% unemployed mean income $7933. All variables accounted for between 11-36% of variance Intention to have mmg positively related to influence of sign. other Intention to have mmg was negatively related to uncaring healthcare professional, taking too much time. Positive patient-provider relationships were highly associated with intention to have screening. (no direction stated)

		participating in free BC and cervical screening *site coordinators identified potential study subjects (no details)	Because the actual results were only in text (except for demographics), it was difficult to determine direction of some of the "associations"
Frazier EL, Jiles RB, Mayberry R. Use of screening mammography and clinical breast examinations among black, Hispanic, and white women. Prev Med. 1996 Mar-Apr;25(2):118-25.	Examines relationship of race/ethnicity and screening bx's. Age, education, region, marital statud, family income are also evaluated.	Based on data analysis from a large state-based telephone survey. Includes data from 44 states. N=22,657 (9.1%AA, 3.1%H, 87.8%W)	47% AA and H reported having recent mmg 50% W reported recent mmg 68% AA, 59% H, and 66% W reported recent CBE. Lowest screening rates for mmg and CBE were reported by >50 y/o, <HS education, and having routine exam >1 year ago. 35% of all women said they had never had a mmg (8016) no demographics presented of those never having mmg, reasons included: - 33% said they did not need it (33% AA and W, 43% H) - 30% said no physician recommendation (36% AA, 26% H, 30% W) - 8% said it was too expensive or lack of insurance - less than 1% had never heard of mmg. **AA women ages 50-64 were less likely to report having screening mmg than AA women 65+!!!!!** Considering that research reports earlier incidence of BC for AA and higher stage at diagnosis.....*******
Husaini BA, Sherkat DE, Bragg R, Levine R, Emerson JS, Mentes CM, Cain VA. Predictors of breast cancer screening in a panel study of African American women. Women Health. 2001;34(3):35-51.	Examines predictors of breast cancer screening and examines the impact of a church/community based BC education program on AA women.	No random assignment Pre and post with control Control was not equivalent All intervention groups were shown 2 videos and some of the intervention groups received reinforcement from a clinical instructor. Intervention lasted b/n 1 and 1 ½ hours. Measures were questions on mmg status, cancer related beliefs, social support. These appear to be created by experimenters (though this was never directly stated). A 20 item measure of depression scale was used to assess the impact of	N=305; mean age=56.2 Intx. and 51.2 Control There were only 3 differences between control and intx that were not significant. Measure of depression, mmg inpast year at T1, and family history of BC. Those who failed to get screening agter 2nd wave were sign. younger than those who did. Women in low income housing were disproportionately screened. Those who did not get mmg were less confident that BC could be cured

		depression on mmg participation.	
Miller AM, Champion BL. Attitudes about breast cancer and mammography: racial, income, and educational differences. Women Health. 1997;26(1):41-63.	Examines differences between AA and W attitudes toward, and knowledge of BC and mmg.	Cross sectional correlational N=1083 (78% W and 22% AA) Church women Mean age =65.7 Mailed survey (researcher developed) Measures of susceptibility, benefits and control derived from HBM. Initial contact by phone with followup letter. Advertisement in churches to increase participation.	Return rate of surveys = 45% usable. 85% from both races had ever had mmg 22.1% of W and 17.4 % of AA followed mmg guidelines for 3 years . AA women had higher perceived susceptibility than W women Intx bn race and income for perceived benefits: - AA low income women had highest level of perceived benefits - W women perceived more benefits as income increased. Increased education in AA women was associated with steady decrease in perceived barriers W women were 65% less likely to regard radiation as a barrier and 50% less likely to worry about finding BC. Higher barrier scores and greater perceived control for both races were less likely to have mmg.
LA, Kaplan CP, Bastani R, Scrimshaw SC. Determinants of adherence among health department patients referred for a mammogram. Women Health. 1996;24(2):43-64.			

APPENDIX B

North Carolina State University is a land-grant university and a constituent institution of The University of North Carolina

Office of Research and Graduate Studies

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From: Debra A. Paxton, IRB Administrator
North Carolina State University
Institutional Review Board

Date: August 15, 2002

Project Title: Increasing Follow-up Rates Among Minority Women with Abnormal Mammography Results or Delays in Re-Screening

IRB#: 047-02-2

Dear Dr. Holden:

Your addendum to the study named above has been reviewed by the IRB office, and has been approved. This approval does not alter the original expiration date of your project, which is March 7, 2003. Your project must receive continuing review if it will extend beyond that date. If you have any questions please do not hesitate to contact the IRB office at 919.515.4514.

Thank you,

Debra Paxton
NCSU IRB

APPENDIX C

SUMMARY OF THE STUDY ON INCREASING RESCREENING AND FOLLOW-UP RATES AMONG MINORITY WOMEN

Study Goals:

Immediate

- To interview 30 minority women, aged 50 years or older, in 3-4 North Carolina counties who have received mammography re-screening as recommended for at least two of the past three years; and,
- To interview 30 minority women, aged 50 years or older, in 3-4 North Carolina counties, who have not received the recommended mammography re-screening (e.g., have missed at two of the last three years) or follow-up care during any of the past 3 years.

Intermediate

- To develop, in conjunction with NCBCCCP, an innovative, community-based intervention to overcome identified problems and barriers to breast cancer re-screening and follow-up.

Ultimate

- To improve the rates of re-screening and follow-up for breast cancer among minority women by better understanding the variables that predict these behaviors.

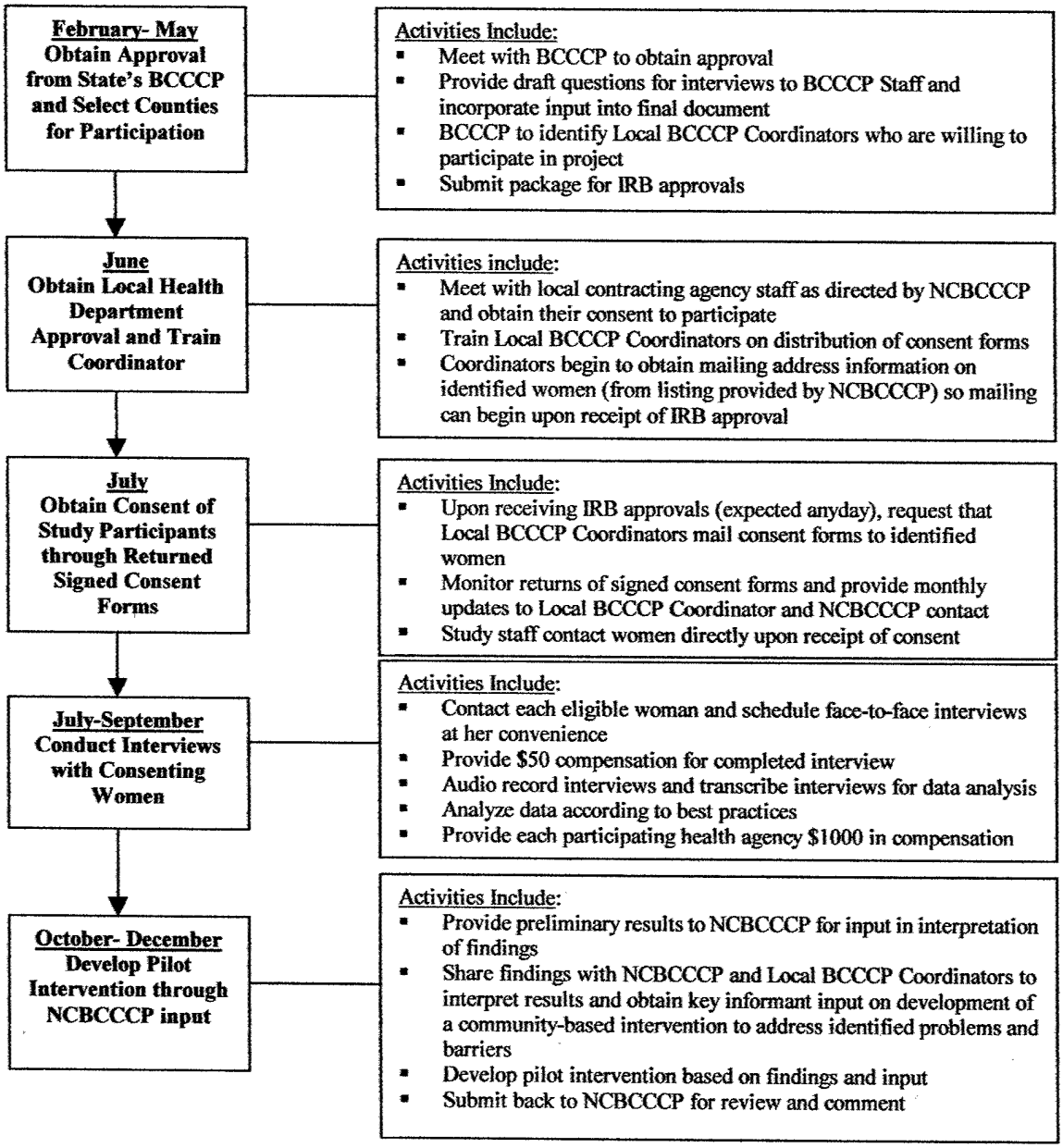
Study Procedures

1. As specified in the Flow Chart (*page 2*), the study will be conducted with ongoing NCBCCCP involvement and feedback.
2. Once appropriate approvals are obtained, the study questions to respondents will be finalized with NCBCCCP input and an IRB package submitted for approval.
3. While waiting on IRB approval, NCBCCCP will provide guidance on the selection of 3-4 local agencies contracting to provide services for NCBCCCP for participation in the study, based on analyses of data for minority women screened within the past 3 years (calendar years 1999, 2000, and 2001).
4. Each of these Coordinators of the chosen agency will be contacted and a face-to-face meeting scheduled with the Study Leaders (Drs. Holden and Martin) at the agency. Funding will be established so that each Local BCCCP Clinic will receive $1000 as compensation for participating. This compensation will be provided to NCBCCCP directly and local participating clinics will be provided a product catalog to choose items to help in the delivery of services (i.e., breast models, educational materials, etc.). Each local clinic will be allowed to order items equal to their level of compensation for assisting in the study.
5. During the meeting in the local agency's office, the purpose of the study will be explained, along with the selection criteria for women who can participate. A listing of the qualifying women will be provided directly from NCBCCCP to the Local BCCCP Coordinator for mailing out consent forms. The consent form, accompanied by a lead letter from the local contracting agency (complete packages will be provided by the Study Staff to the local agency directly), will be mailed by the Local BCCCP Coordinator to each qualifying woman. Signed consent forms will be returned directly to the Study Staff and copies provided to the Local contracting agencies for their records (*if requested*).
6. Once a woman consents to be involved, the Study Staff will contact her directly to arrange for a face-to-face interview. All women who complete at least half of the interview will be provided with $50. Women will be allowed to skip or refuse questions and still receive

compensation. Telephone interviews may be completed with some women who have limited transportation or are home bound.

7. Findings of this study will be provided to NCBCCCP for review and input into the interpretation of results, as well as for planning for development of an intervention to address the identified concerns and problems.

Flow Chart of Activities for Completing Proposed Study



APPENDIX D

REVISED-2 Research Protocol

Submitted to Department of Defense for
Breast Cancer Concept Award (BC995929)

NOTE: Only attachments with required or requested changes are included with this package (Revision-2). Other materials were provided in previous packages. The following is a list of applicable attachments with this revised submission:

Attachment A:	Revised CV of Dr. Debra J. Holden
Attachment B:	Revised Consent Form
Attachment C:	Revised Interview Protocol
Attachment D:	Letters of Collaboration from Participating Local Health Agencies

1. Protocol Title:

Increasing Follow-up Rates among Minority Women with Abnormal Mammography Results or Delays in Re-Screening

2. Phase: N/A

3. Principal Investigator:

Debra J. Holden, Ph.D.
North Carolina State University
Psychology Department
Box 7801
Raleigh, NC 27695-7801
(919) 662-3896 (office phone)
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Dr. Holden's current curriculum vita is Attachment A to this revised package.

Significant Contributor:

Rebecca D. Martin, Ph.D.
Independent Consultant
Cancer Epidemiologist and Researcher

4. Location of Study:

North Carolina Breast and Cervical Cancer Control Program
Dianah Bradshaw, RN, MSHA
Director, Quality Assurance and Patient Services
Breast and Cervical Cancer Control Program
1915 Mail Service Center
Raleigh, NC 27699-1915
Dianah.Bradshaw@ncmail.net

5. **Time Required to Complete:** May 1, 2002- December 31, 2002

6. **Objectives:**

To better understand why minority women are less likely to follow-thru with recommendations to obtain mammography re-screening in a timely manner or to receive diagnostic care for an abnormal mammography result and use the findings from this target group to design an initiative to address this disparity.

Study Objectives:

Immediate—To be completed as part of this study

- To interview 30 minority women, age 50 years or older, in 3-4 North Carolina counties who have received mammography re-screening as recommended for each of the past three years; and,
- To interview 30 minority women, age 50 years or older, in 3-4 North Carolina counties, who have not received the recommended mammography re-screening or follow-up care during any of the past 3 years.

Intermediate—To be completed as part of this study

- To develop, in conjunction with North Carolina Breast and Cervical Cancer Program (NCBCCCP), an innovative, community-based intervention based on findings from this study that will help to overcome identified problems and barriers to breast cancer re-screening and follow-up.

Ultimate—as a long-term outcome for the NCBCCCP

- To improve the rates of re-screening and follow-up for breast cancer among minority women by better understanding the variables that predict these behaviors.

7. **Study Population:**

a. Describe the target population: Minority women (primarily African or Native American women, all English speaking), ages 50 years or older, receiving at least one mammogram during the past 3 calendar years (1999-2001) through any of 3-4 local agencies contracting with the NCBCCCP will be possible study participants. These local agencies will be selected by NCBCCCP based on state-based epidemiological data from the reports generated by the state program from data supplied from local agencies on the women they screen. This data set will be used to identify 3-4 counties within North Carolina that have had a high rate of late-stage diagnosis of breast cancer among minority women. Women who have obtained either screening or follow-up later on in their disease progression are more likely to have their cancer identified at a late stage. Studies have shown that a disproportionate number of these women are African American or from other minority groups. Through collaboration with the NCBCCCP, the local public health agencies in these

selected areas of high need will be contacted. The focus of the study will be on two groups of women: those who have obtained a mammogram at least 2 of the past 3 years, as recommended for their age group, and those who have not obtained a mammogram all 3 years, or have not returned to receive diagnostic care after receiving an abnormal mammogram result.

b. Describe the methods for obtaining sample: Based on state epidemiologic data, local agencies will be recruited for participation in this study. Sampling of the women to recruit is not random but is stratified by age, race, and mammography utilization over the past 3 years (1999-2001 calendar years). Only women who are 50 years or older and non-white will be selected for study participation As mentioned above, their mammogram utilization either has to be high (having had a mammogram for at least 2 of the past 3 years) or low (having had a mammogram for only 1 of past 3 years), or failing to return for follow-up after receiving an abnormal mammogram result. The most accurate description of the sampling strategy is convenience. Using a list of participant identifiers (coded as numbers, not names) supplied directly from the NCBCCCP to the local clinic staff, participating local agency staff will verify that women meet one of these two criteria and mail the study's consent form to the woman, with the lead letter on agency letterhead, requesting she return it to the researchers. Women who are not representatives of a minority population will not be included since they are more likely to obtain re-screening or diagnostic care as recommended.

c. Inclusion of pregnant subjects: Study participants will all be 50 years or older, past child-bearing years so determining pregnancy status is not relevant to this study.

d. Sample size for study: Study includes a total of 60 completed interviews. The target for the study is to complete 30 interviews with women who have received screening as recommended and with 30 women who have not. However, since the health agencies are not able to provide the researchers with the results of each woman's test, we will not know how many women in each group we have obtained until completing each interview (we ask questions related to this in the interview). Therefore, we plan to recruit up to 75 total women in order to complete 60 interviews that meet the criteria of half the women receiving screening regularly, and half who have not. This sample size was not calculated statistically since this is a pilot project to determine the issues that should be addressed in developing a local intervention. This sample size was also negotiated with NCBCCCP as what seemed feasible to them in terms of the women who would meet the criteria for this study AND agree to participate, given the time frame for conducting this study.

e. Survey instrument: The interview items were developed for this study (Attachment C) through a thorough and systematic review of the literature on relevant topics. Using peer-reviewed data as a guide, the PI then utilized items created on previous studies she has led that have been tested and validated. For many items however, the information has to be obtained through open-ended questions that are rarely standardized and certainly not psychometrically tested. Drafts of the instrument were then reviewed by the researchers for this project and the NCBCCCP staff. The finalized instrument will be used for conducting interviews for this study.

f. Data Analysis Plans include preparing a thorough set of written notes, enhanced by the transcription of audio tapes, from each of the interviews completed. Once these notes have been prepared, current and rigorous methods for analyzing qualitative data will be utilized to identify themes across the respondents and prepare findings for the study (Miles & Huberman, 1987). Some of the findings will be summarized quantitatively, such as the questions in Sections I, II, and V. In these sections, an interviewee is asked to provide answers to mostly close-ended questions. The following provides a sample table of how these findings may be presented:

Sample Table ____. When did you last see a doctor or nurse for your breast health?

Responses	#	%
Within the past year		
1-2 years ago		
More than 2 years ago		

Other findings will need to be analyzed qualitatively, such as the majority of questions in Sections III-IV. For these, all interview data will be coded for themes, based on the domains of questions asked in the interview setting. For example, one area of questioning includes an understanding of their experiences in getting mammograms (Section IV, Questions 1-2). Codes will be developed to capture all types of responses. Two people will review each set of interview responses. One person will be responsible for coding the responses and the other will be responsible for checking the codes against their own results in order to determine reliability of findings. Where possible, quantitative findings of the data will be provided. For example, the questions noted may appear in a summary table such as the following:

Sample Table ____. Positive aspects or reasons for obtaining mammograms

Response Provided	Number of Interviewees providing response
It helps me take care of myself	
My family thinks it's important	
It helps me not worry about my health	

8. **Protocol Design: The following outlines the proposed methodology in sufficient detail to show a clear course of action, followed by an explanation of each item specified in the protocol guidelines.**

Local public health agencies contracting with the NCBCCCP will be eligible for participation in the study. They are required by NCBCCCP to provide monthly data on the women they provide mammograms to and various characteristics of her screening experience (such as test results, demographics, etc.). The researchers for this study do not have access to this data set. However, NCBCCCP has agreed to analyze their mammogram screening data for minority women 50 years of age or older to identify areas of the state that seem to be the most prone to have women who do not return for screenings as recommended. Based on this analysis, NCBCCCP will notify us of which 3-4 local agencies they suggest we work with in recruiting women. The researchers will then meet individually with the staff at the local agency (i.e., the clinic nurse and possibly the local health department director) to explain the study and procedures for recruiting women. NCBCCCP will provide a list directly to the local clinic nurse of the patient identifiers (data are coded by identifiers, not names) for women qualifying for this study. The researchers will not be permitted to see this list or know the results of the women since the agencies do not have the consent of the women to provide this information. The nurse will then access each patient's medical record to ensure that the data recorded matches her chart and verify that she hasn't left the area.

Once the nurse verifies the women who are eligible for in the study, they will mail consent forms provided by the researchers (Attachment B) to women who qualify for inclusion in the study. Study selection criteria will be explained to the agency staff, including: 1) women representing a minority population; AND 2) women who have obtained re-screening mammograms as recommended for at least 2 of the past 3 years OR have NOT obtained regular re-screening and/or diagnostic care as recommended within the past 3 years. Once these women are identified

by the local agency, their staff will mail the consent form to each woman to be returned directly to the PI (Attachment B). Two copies of the consent form will be mailed by the local agency to the woman and accompanied by a lead letter on agency letterhead and a stamped, self-addressed envelope for returning a signed consent directly to the researcher. The women will be directed to keep a copy of the consent form for herself. A witness form will also be enclosed in each envelope so that the woman can consent to participate in the study even if she isn't able to read the consent form. Each consenting woman will then be contacted by phone to schedule a face-to-face interview at her convenience.

Participation will be completely voluntary and confidential and it will be explained to her that her involvement (or not) will not impact any future care provided by the local agency. Once they agree to be interviewed, the researcher will arrange for a 1-hour face-to-face interview to be conducted at a conveniently located public building in her area, such as a library, the health department, or a senior health center. Efforts will be made to provide a location that respects her privacy in providing responses (such as a private room in the local library). Each of the women completing at least half of the interview will receive a $50 compensation. Part of the $50 compensation can be used by the woman to cover her transportation costs to the interview site. For women who are not able to travel to a convenient location (such as she is disabled or has limited access to transportation), but she consents to participate in the study, she will be provided the option of completing the interview over the phone. This option will be provided only as a last resort to obtaining information from women who might otherwise drop out of the study.

Face-to-face interviews for this study are considered to be the best methodology, but telephone interviews could be substituted if necessary. The purpose of the interview will be to talk to the women about their understanding of the results they received, what they have done to obtain care since receiving their abnormal results, barriers they had to overcome to obtain any care that they have, or reasons she has or has not obtained care (Attachment C). The notes from this interview will be written by the interviewer and audio recorded. After the interview, the interviewer will use the audio recorded tapes to complete the written notes so that the data collected from each individual woman will be thorough. Once the tapes have been used to provide more details to the written notes, they will be labelled according to the date the interview was conducted and the number of respondents for that date (i.e., the woman interviewed on June 15, who was the 3rd person interviewed that day, would be coded as 3-6.15, etc.). The written notes and tapes will be coded so that they are linked to each other but not to the individual woman who is interviewed. Once the tapes have been used to enhance the written notes, they will be maintained in a locked file that the PI only has access to until the conclusion of this study. At that point, their contents will be erased or the tapes otherwise destroyed. The contact information is used strictly to locate the women and invite their participation and maintained in a log to determine if she has been

reached for scheduling an interview. This log will be maintained in a locked secure file cabinet with access only by the research team. Upon completion of the interviews, the log will be destroyed.

a. Subject Identification: Once a woman consents to the study by returning a signed form, her contact information will be entered into a log that helps the researchers keep track of where she is in the process of data collection. The log will track information on how to reach her, attempts that have been made to reach her, and dates of when the interview is scheduled. This log will be kept in a locked, secured file that is only accessible to the research staff. Once all of the interviews have been completed, this log will be maintained in a locked file for a minimum of two years after the completion of the study. All data collected and entered for analysis from the interviews will be coded using unique identification codes in order to protect confidentiality and will contain only the woman's age and race, and other demographic information collected at the end of the interview. Identifier codes will be used to link the audio tapes to the written notes but individual responses cannot be linked back to respondents.

b. Description of recruitment process: Explained above. There will be no advertising or recruitment materials used other than a mailing to each qualifying woman that includes the lead letter , two copies of the consent form that includes a 'short form' for women who are illiterate (Attachment B), and a stamped, self-addressed envelope to the PI, Dr. Holden.

c. Description of the Informed Consent process: This process is described above in detail and supporting documents are included as attachments.

d. Subject assignment: Randomization is not possible and will not be utilized for this study.

e. Evaluations prior to entry: Selection for participation will be based on results of former mammograms received through the NCBCCCP. However, these mammograms are not provided as part of this study and are only a mechanism for identifying women who meet the study criteria.

f. Evaluations to be made during the conduct of the study: N/A.

g. Clinical assessments: N/A.

h. Describe the research intervention or activity that the subject will experience: Women are consenting to participate in a face-to-face interview to discuss her understanding of the abnormal results or the need for re-screening and her rationale for the health practices she has followed. The interviews will require approximately one hour of her time. For their time and input, the women will

be provided a $50 reimbursement for participating in the interviews. Women who complete at least 1/2 of the interview but refuse to answer some of the questions will be provided the $50 compensation.

9. Risks/Benefits Assessment:

a. Risk from participation in this study is minimal and is no risk for the majority of women involved. The only risk is that a few of the women will be contacted because they have received abnormal mammography results. The interviewers are highly trained on this issue and the woman will be allowed to skip or refuse to answer questions that make her feel uncomfortable.
b. As specified in the informed consent (Attachment B), the participating women will not benefit directly from participation in this study.
c. Compensation provided is described in the protocol design section of this document.

10. Reporting of serious or unexpected adverse events.

It is possible that by participating in the face-to-face interview a woman will be more willing to face the consequences of an abnormal result (for women that this is applicable, which will only be approximately 5-10 women). It is possible that some of the women will have been in denial about the need for follow-up and that, just by talking about this issue, will be more likely to face it and realize the potential risk to their health from these results. Both lead interviewers have extensive psychological or social work counseling experience and will conclude each interview with questions about how the women feel about their interview. The researchers will inform the women that they can return to the local health department for more specific information on next steps to take and will be provided with a sheet listing resources in their area for discussing this issue.

Adverse experiences that are both serious and unexpected will be immediately reported by telephone to the USAMRMC Deputy Chief of Staff for Regulatory Compliance and Quality (301-619-2165) (non-duty hours call 301-619-2165 and send information by facsimile to 301-619-7803). A written report will follow the initial telephone call within 3 working days. Address the written report to the U.S. Army Medical Research and Materiel Command, ATTN: MCMR-RCQ, 504 Scott Street, Fort Detrick, Maryland 21702-5012.

11. Description of Protocol Drugs or Devices: N/A

12. Disposition of Data:

As previously described, a log will be maintained of contact information for each woman. Throughout the study, this log will be maintained in a locked, secured file that the research staff only have access to. At the conclusion of the study, this

information will be destroyed. The interview data will not be linked to the personal contact information of each women. During the interview, the responses will be audio recorded and notes taken for use in analysis. The written notes from each interview will be linked to the audio recording through a coding system indicating the date of the interview and the number of the person responding (for example, the 3rd person on June 15 will be coded as 3-6.15 on both the written notes and audio tapes). The tapes will be used to enhance the written notes and ensure that the information each woman provided is complete and thorough. The tapes will then be stored in a locked file that only the research staff has access to. The data used in the analysis (i.e., the complete interview notes) will not be linked to the women themselves.

13. Modification of the Protocol:

Should any study procedures need to be changed, both the local IRB and all relevant contacts at HSRRB will be contacted and guidance requested on procedures to follow.

14. Departure from the Protocol:

Local IRB and HSRRB will be notified if protocol is to be changed. No departure from the protocol will be permitted for conducting interviews with individual subjects that has not already been addressed elsewhere.

15. Roles and Responsibilities of Study Personnel

Principal Investigator: (15%) Obtain cooperation with all study partners, including the North Carolina Breast and Cervical Cancer Control Program and the local agencies selected to participate. Create research protocol and study questions. Train study staff on their roles and responsibilities and supervise all activities. Conduct ½ of study interviews and oversee data analysis and reporting. Oversee budget monitoring and overall conduct of study.

Consultant (Dr. Martin, 200-240 hours total). Assist in establishing collaborative relationship with all study partners, attend meetings to negotiate study protocol, and provide input into accomplishing study goals within the study's context. Provide guidance and input into IRB package, study protocols, consent forms, etc. Conduct ½ of the face-to-face interviews. Assist in data analysis and report writing.

Graduate Student Research Assistant (25%). Conduct literature review to inform protocol development. Coordinate study activities including contacting consenting women to participate in the study (once consent is received via mail). Schedule interviews and coordinate sessions. Assist Dr. Holden in interview

sessions by being present for note-taking and audio-taping interview. Lead data entry and assist in data analysis and report writing.

Consultant (Ms. Ladner, MPH—75-80 hours). Assist Dr. Martin in conducting interviews by being note-taker and audio-taping interviews. Assist RA with data entry and provide input into review of final report of results.

Study Partner (Ms. Bradshaw, RN, MSHA, at NCBCCCP). Obtain listing of women meeting study criteria and work with local agencies to identify women and direct mailing of consents to qualifying women. Provide input into study design, interview questions, and interpretation of results.

Study Recruiters (Clinical staff from 3-4 local agencies contracting with NCBCCCP, all staff will be at least at the registered nurse (RN) level and are responsible for the operation of the local public health adult clinic that administers NCBCCCP). Meet with PI to discuss study and agree to work to mail consent forms to qualifying women. Obtain list of cases with patient identifiers (coded in numbers, not names and provided directly from the state health department to this agency for the women screened in their clinic) and review charts to ensure information is accurate and women are eligible for participation. Mail consent forms with lead letters to each woman. Answer questions from women who call about the study as possible, or refer questions to PI if needed.

16. This study is not greater than minimal risk to the participants.

APPENDIX E

Department of Defense Study Entitled:
"Increasing Follow-up Rates Among Minority Women with Abnormal Mammography Results or Delays in Re-Screening"

Prior to interview, record the following information for each interview:

Date of interview _____
ID code of subject _____
Name of person conducting interview _____
Signature of person conducting interview _____

Script and Questions for Face-To-Face Interviews

Hello, my name is _____. I wanted to come meet with you today to talk about your experiences in obtaining care for a mammogram that you received from the _____ BCCEDP contracting agency on _____. A couple of weeks ago, I called and scheduled this meeting with you to talk about this experience.

RE-READ components of consent related to confidentiality, use of information, and purpose of research.

Section I

To get started, I'd like to ask you a few questions about your general health care.

1. Do you have a doctor or nurse that you see on a regular basis?
   _____ Yes
   _____ No

2. When did you last see a doctor or nurse for your breast health?
   _____ Within the past year
   _____ 1-2 years ago
   _____ More than 2 years ago

3. What was the reason for this last visit?

4. Where was this doctor or nurse located?
   _____ In a private practice
   _____ In a hospital setting
   _____ In the local BCCEDP contracting agency →
   (*if this is the response, skip to Item 6*)
   _____ Some other place, please specify _____

5. When was the last time you went to the _____ BCCEDP contracting agency for your breast health?
   _____ Have not returned since receiving the mammogram

_____ Within the past year
_____ 1-2 years ago
_____ More than 2 years ago

If she has not returned to the BCCEDP contracting agency:
Do you plan to ever return for breast health care at your local BCCEDP contracting agency? Why or why not?

6. Would you say you've been very satisfied, somewhat satisfied, or not at all satisfied with the breast health care you received at your local BCCEDP contracting agency during your last visit?

_____ Very satisfied
_____ Somewhat satisfied
_____ Not at all satisfied

What are the reasons for the response you just gave?

7. How did you know you could get a mammogram through your local BCCEDP agency?

8. Have family members or friends of yours received a mammogram through this (or another) local BCCEDP contracting agency?

9. What was your primary reason for getting a mammogram at the ____ BCCEDP contracting agency?

10. The mammogram you received then was provided through a state program called the Breast and Cervical Cancer Early Detection Program. Have you ever heard of this program?

_____ Yes
_____ No

If yes, how did you hear about it?

Section II

Now I'd like to ask you some more specific questions about any care you've received for your breast health.

1. A clinical breast examination is when a doctor or nurse examines the breast for lumps. When did you have your most recent clinical breast examination?

2. Has your doctor or nurse ever told you that you had a lump in your breast?

_____ Yes
_____ No

If yes, when was this? Date or year lump was found _____

Did he or she ask you to complete any tests to find out what it was?

_____ Yes
_____ No

If yes, what was the result of these test(s)?

3. Do you currently have any breast problems, such as lumps, unusual pain, soreness, or discharge?

_____ Yes
_____ No

If yes, do you know what is causing this breast problem?

_____ Yes
_____ No

Have you told your doctor or nurse about this problem?

_____ Yes
_____ No

If yes, what did s/he tell you to do about it?
If no, do you plan to talk about it with your doctor or nurse during your next visit? (if yes, when do you plan to go the next time?)

Section III

As you remember, you had a mammogram through the ____ BCCEDP contracting agency at sometime during the past three years. The following questions are about mammograms and any additional tests you've received since then.

1. When did you receive your last mammogram?

2. Who referred you for your last mammogram? (Probe: who told you to go get your last mammogram?)

____ your local doctor or nurse
____ your local BCCEDP contracting agency
____ a doctor or nurse at another facility (*if so, where?*)

[*If not at the localBCCEDP contracting agency]* what were your reasons for not getting another mammogram at your local BCCEDP contracting agency?

3. What do you remember was the result of that last mammogram?

Carefully follow these criteria for determining next set of questions:

If she has received a mammogram within the past year AND her results were 'normal', go to Item C on page 5

If she has NOT received a mammogram within the past year but the last one was 'normal', go to Item A below.

If she has NOT received a mammogram within the past year, but the last one was 'positive' or 'abnormal', go to Item B below.

A. For those needing re-screening:

What are your primary reasons for not returning to get another mammogram within a year after your last one?

Has a doctor or nurse ever told you that you should receive a mammogram at least once a year?

_____ Yes
_____ No

If yes, when was the last time you were told this?

Do you agree with what they said? If not, what are your reasons for disagreeing?

Do you plan to get another mammogram?

_____ Yes
_____ No

If yes, when do you think you will get another mammogram?

_____ Within the next 6 months
_____ Within the next year (but more than 6 months from now)
_____ Within the next 2 years (but more than 1 year from now)
_____ More than 2 years from now

If 1 year or more from now before getting another mammogram, what are your primary reasons for not getting a mammogram within the next year?

For those completing Item A above (have not received mammogram in past year AND had normal results on last one), continue now to Section IV

B. For those needing diagnostic care:

What does that result mean to you?

What did your doctor or nurse tell you to do about it?

How did you feel about getting this result?

With this result, what did you think you should do about it, if anything?

You mentioned that for the results, the recommendations given to you by your doctor or nurse were (*from answer above*), did you obtain this care?

_____ Yes
_____ No

If no, have you received any care from a doctor or nurse about this result?

_____ Yes
_____ No

If yes *to any care*, when did you receive this care? Date or Years since care received _____

What was the care you received? (Probes: do you remember the names of any other breast tests you received? What were the results of these tests?)

If no *to any care*, what are your primary reasons for not receiving any more care for this mammogram result? What do you think will happen to you since you haven't received any care?

For those completing Item B above (received 'abnormal' results on last mammogram), continue now with Section IV

C. For those who have received screenings as recommended

How often do you typically receive mammograms? (*every year, every other year,* etc.)

What are your reasons for getting a mammogram on this schedule?

How important is it to you to get mammograms on a regular basis? What are the main reasons this is important to you?

What barriers have you ever experienced in getting a mammogram on a regular (or yearly) basis?

Section IV

Now I would like to ask you some questions about your impressions and opinions on things related to getting regular breast health care. Please feel free to be open and honest with your responses and let me know what you really think.

1. Tell me about your overall experiences in getting mammograms. What would you say was positive about your experience of getting this test? What was negative about this experience?

2. When you think about scheduling an appointment for getting a mammogram, what are some reasons that you think about for postponing getting one or deciding not to get one? What are some reasons for not putting it off?

3. How often do you think you need to receive a mammogram?

4. Do you think women 50 years or older should get mammograms every year?
   _____ Yes
   _____ No

5. What does the word 'cancer' mean to you? (Probe: tell me what you think of when you hear the word 'cancer')

6. What kind of treatment do you think that a woman would have to have if she found out she had breast cancer? (Probe: Do you think that every woman who has breast cancer has to have one or more breasts removed?)

7. What do you think makes a woman your age more likely to have breast cancer? (Probe: Do you think that a woman who's relatives have had breast cancer will probably get it too? What do you think are the characteristics of women who are most likely to have breast cancer?)

8. How likely do you think it is that a woman diagnosed with breast cancer will survive and live a good life for at least 10 more years?

9. Would you say your family is supportive of you getting regular check-ups for your breast health?
   _____ Yes
   _____ No

   What do members of your family say or do to let you know they support you getting this care?

   What do members of your family say or do to discourage you from getting this care?

10. Would you say that all, almost all, a few, or none of your closest friends get regular mammograms (that is, at least once a year if they're over 50 years of age)?
   _____ All
   _____ Almost all

_____ A few
_____ None

What do your closest friends say or do to let you know they support you getting this care?

What do your closest friends say or do to discourage you from getting this care?

11. Do you know anyone who has ever been diagnosed with breast cancer? What is your relationship to this person? What happened to them? Do you think their experience has influenced what you have done with regards to receiving care for breast health? If yes, in what ways?

Section V

I just have a few more questions to ask about your background. We should be finished in about 5 minutes and I appreciate your help with this study.

1. What is your date of birth?

2. What is the total number of years of schooling you have completed?

3. Has any of your immediate family (including grandparents, parents, and siblings) been diagnosed with cancer? If yes, what is their relationship to you?

4. What is your primary occupation? If retired, what job or occupation did you work in the most during your working years?

   If currently working, does your work place allow for you to have time off to obtain screening, like mammograms, in order to maintain good health?

6. What is your current marital status?

Thank you so much for your help in answering these questions. The information you provided will be used to develop a program that better meets the needs of women in getting regular and timely breast health care. Should you think of anything else you would like to share with me, please feel free to contact me (give respondent contact information and provide with $50 incentive before leaving).